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END-OF-LIFE DECISION-MAKING IN PATIENTS WITH A CARDIAC DEVICE

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Digital Object Identifier: https://doi.org/10.13023/etd.2019.214

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Recommended Citation
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END-OF-LIFE DECISION-MAKING IN PATIENTS WITH A CARDIAC DEVICE

Dissertation

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
in the College of Nursing at the University of Kentucky

By

Jessica Harman Thompson

Lexington, Kentucky

Director: Dr. Debra K. Moser, Professor of Nursing

Lexington, Kentucky

2019

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ABSTRACT OF DISSERTATION

END-OF-LIFE DECISION-MAKING IN PATIENTS WITH A CARDIAC DEVICE

Heart failure (HF) is one of the top causes of mortality in the United States and globally. In order to combat the high mortality rates of this disease, medical technology, including internal cardioverter defibrillators (ICD) and left ventricular assist devices (LVAD), have become one of the most common treatments. Over the past 10 years the utilization of these cardiac devices has increased exponentially, which has created a new phenomenon of how we discuss death with patients who have one of these devices. The purpose of this dissertation is to increase understanding of the end-of-life decision making processes and current experiences that patients with a cardiac device are having.

This dissertation includes four original manuscripts that focus on patients with a cardiac device and their experiences with decision-making at the end-of-life. The first paper is a data-based paper that examines experiences of patients with an ICD and what factors are associated with having a conversation with their providers about end-of-life. The second paper is an integrative review of the literature regarding what is currently known about end-of-life with an LVAD. The third paper is a psychometric evaluation of the Control Attitudes Scale-Revised (CAS-R) for patients with an LVAD. The fourth paper is a data-based manuscript that looks at patients with an LVAD and their attitudes and experiences with end-of-life conversations with providers and next-of-kin and the impact of cognition on these attitudes and experiences. The findings of this dissertation will hopefully inform providers of patients with cardiac devices about their patients end-of-life decision making processes. It will also demonstrate the gaps that are currently in practice, and ideally be able expand on how to assist patients and providers on improving communication about end-of-life decision making.

KEYWORDS: end-of-life, LVAD, ICD, decision-making, heart failure, perceived control

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April 12th, 2019

Date

END-OF-LIFE DECISION-MAKING IN PATIENTS WITH A CARDIAC DEVICE

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Director of Dissertation

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DEDICATION

To Jeffrey and my parents, thank you for all your love and support.
To J.K. Rowling and Harry Potter, thank you for instilling in me a love to read that hasn't tarnished since the first book I read cover to cover, Harry Potter and the Sorcerer's Stone. Without this love, I wouldn't be the student and person I am today.

ACKNOWLEDGMENTS

I would first like to thank my husband, who has supported me and loved me through the fastest three years in my life. I couldn't have gotten through this dissertation process without your unending love and support. I would also like to thank my parents, I wouldn't be the person I am today without their guidance, they are the best parents in the world. Thank you to Tara and Devan, you both gave me confidence and love that spurred me to get my PhD, and I wouldn't have had the fun I was able to have during this grueling time without you. Thank you to Katie Voigts for being a constant voice of encouragement and for reading countless drafts of these manuscripts.

Thank you to the UK LVAD program, especially Tamra Halcomb and Miriam Ross; without their help, this project would not have gotten done. Thank you to the University of Kentucky College of Nursing, I would not be the nurse I am today without their guidance, and would not have thought to get a PhD without the opportunities they gave me throughout my undergraduate and graduate career. Thank you to the Robert Wood Johnson Future of Nursing Scholar Program, their support was crucial to completing this dissertation. I would like to thank my teachers in the PhD program, without their guidance and persistence I would never have been able to complete these manuscripts. Last, I would like to thank Dr. Moser, throughout her own personal battles, she was always available for guidance and support and this dissertation could not have been completed without her.

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CHAPTER 1. INTRODUCTION

Heart disease continues to be the leading cause of death in the United States, accounting for 23% of all deaths, and killing more than 630,000 people in 2016.[1] By the year 2030, it is estimated that 44% of American adults will have some type of cardiovascular disease.[2] Cardiovascular disease is also the leading killer globally, estimated to have been the primary cause of death for over 17.3 million people in 2013.[2] One of the deadliest types of cardiovascular disease is cardiomyopathy, also referred to as heart failure (HF).

In the United States, one in eight deaths is attributed to HF.[3] In 2012, the total economic burden of HF was $30.7 billion, and by 2030 it is projected that this burden will increase by 127%.[3] Despite these staggering statistics, there have been improvements in both 1-year and 5-year survival rates. This is primarily attributed to improvement in guideline-directed medical therapy.[1]

Several notable advances in HF medical therapy over the last decade have been linked to longer survival, including improved drug therapy, coronary revascularization therapies, and advanced medical devices, including implantable cardioverter defibrillators (ICD) and left ventricular assist devices (LVAD).[4] Implantable cardioverter defibrillator and LVAD treatment are estimated to have saved hundreds of thousands of lives since their development.[2]

An ICD is a palm sized internal device that senses heart rhythms and can electrically convert an inappropriate rhythm to normal sinus rhythm. The primary indication for ICD therapy is to prevent sudden cardiac death in those who are high risk

for abnormal life-threatening rhythms, such as those with advanced heart failure, or after a myocardial infarction.[5] Compared to optimized drug therapy, implantation of an ICD decreased mortality of sudden cardiac death by almost 30%.[6] It is estimated that there are over 1.7 million Americans eligible for ICD treatment and over 12,000 lives are saved each year due to ICD therapy.[7,8]

An LVAD is a mechanical pump that functions as the patient's left ventricle. Left ventricular assist device therapy is targeted at patients with advanced heart failure, who have exhausted all other guideline-directed therapy and can either no longer wait for a heart transplant due to HF severity, or are not a candidate for heart transplantation. The first LVAD was developed in 1994 for in-hospital use only and had extremely high mortality rates.[9] The device that is most similar to what we use today, the HeartMate II, was approved in the mid 2000's with the well-known REMATCH trial.[10] Data from this randomized clinical trial demonstrated that LVAD therapy was superior to optimized medical management for patients with advanced HF; LVAD therapy increased survival for patients and also demonstrated an improved quality of life.[11] In the early post-REMATCH era before 2009, there were less than 500 people with an LVAD. As of 2016, over 17,000 patients have received an LVAD.[12,13]

Although it is known that ICD and LVAD therapies save lives, it is inevitable that most of these patients will face death with the device in place. Implantable cardioverter defibrillator and LVAD devices, in the majority of cases, do not reverse HF or its effects on the human body, therefore, patients with these devices need information and guidance on how to incorporate their device into end-of-life planning.

Over the past several years professional organizations have developed guidance for communicating with patients who have an ICD or LVAD in relation to the end-of-life. For providers of patients with an ICD, guidelines from the Heart Rhythm Society, in conjunction with other professional organizations, state that providers need to advise patients, prior to ICD implantation, about the potential for deactivation .[14] For providers of patients with an LVAD, the Centers for Medicaid and Medicare Services mandate that a palliative care team must be involved in the care of LVAD patients, to ensure that goals of care are discussed, however, the guidelines are vague and do not explicitly state that deactivation of the LVAD or end-of-life be included in these discussions.[15] Other professional organizations, such as the International Institute for Heart and Lung Transplantation, urge providers to incorporate end-of-life discussions into the care of patients with an LVAD, however, these guidelines are also vague and do not directly address deactivation or involvement of palliative care teams throughout LVAD therapy.[16]

Despite guidelines from professional organizations, patients with a cardiac device, their caregivers, and their health care providers do not seem to be equipped to deal with end-of-life situations that may arise with these devices. Results from numerous studies of patients with an ICD have shown that many experience inappropriate and unnecessary shocks toward the end-of-life, even within minutes before death.[17-19] Even though professional guidelines urge providers of patients with an ICD to initiate discussions about ICD deactivation, researchers have demonstrated that these types of conversations happen infrequently, if at all, with patients and their families.[19-21] These gaps in care can leave patients and their families in frustrating and confusing situations in a time that is already very difficult.

There has been very little research about end-of-life experiences or deactivation of the LVAD device. This is most likely related to the relative newness of the technology. Several editorials have been written regarding the lack of shared decision-making in the end-of-life processes associated with LVAD deactivation. These authors proposed that this problem may be related to a lack of understanding of the ethical permissibility of deactivation.[22-25] In 3 qualitative studies examining LVAD patients and their caregivers, a common theme related to end-of-life with an LVAD emerged: confusion. The participants in these studies consistently voiced a lack of understanding of end-of-life processes with an LVAD, difficulty receiving information from providers about deactivation, and questions of whether it is ethical to turn the device off at all.[26-28] Providers of patients with LVADs also seem to have similar uncertainty about end-of-life with an LVAD. In a web-based survey of different specialties who take care of patients with LVADs, there were vastly different opinions regarding whether deactivation of the LVAD is considered active euthanasia or physician assisted suicide, as well as confusion how to integrate hospice and palliative medicine for patients who wish to deactivate their LVAD towards the end of their lives.[29-31]

Therefore, the purpose of this dissertation was to examine patient attitudes and experiences related to end-of-life conversations involving their LVAD or ICD and factors involved in end-of-life decision making. The chapters of this dissertation demonstrate the development of my initial program of research. First, I did a secondary data analysis of a national cohort study of patients with an ICD to determine the factors associated with having a conversation about end-of-life with their providers. Second, I conducted an integrative review of the literature to examine what is currently known about end-of-life

with an LVAD related to providers', patients', and caregivers' experiences of end-of-life with this device. Third, is an analysis of the psychometric properties of the Control Attitudes Scale-Revised in a population of patients with an LVAD. Last, I did an observational study of a cohort of patients with an LVAD and an exploration of their attitudes and experiences related to end-of-life decision-making and pump exchange of patients with an LVAD and the impact of cognition on these attitudes and experiences.

1.1 Summary of Subsequent Chapters

In order to understand of predictors of end-of-life discussions and decision making in patients with an ICD, Chapter Two presents a secondary data analysis of a national cohort study comparing experiences, attitudes, and knowledge about the ICD at the end-of-life between ICD recipients with and without HF. A total of 3,067 ICD recipients participated, and 52% of the cohort had HF. End-of-life experiences, attitudes, and knowledge were measured using an end-of-life questionnaire, demographic and medical history information were self-reported, and information regarding ICD indication and shock history were gathered using a national Swedish ICD registry. Experiences, attitudes and knowledge were compared between the HF and non-HF groups and a logistic regression analysis was conducted to identify significant predictors of having a discussion with a health-care provider about end-of-life scenarios. The questionnaire and study design from this analysis were used to guide the study conducted and described in Chapter Five of this dissertation.

For a more comprehensive understanding of what the LVAD population experiences towards the end-of-life, Chapter Three is an integrative review of the literature regarding processes and content of end-of-life discussions, and end-of-life

experiences of individuals, families, and health-care providers of patients with an LVAD. Several electronic databases were searched from earliest available through November 2018, with keywords including 'LVAD' and 'end-of-life'. Articles were included if they met the following criteria: were research studies that focused on the perspective about end-of-life of provider, caregiver, or patient with an LVAD, focused on adults 18 and older, and were published in English. Articles were excluded if the primary research focus was testing palliative care interventions in patients with an LVAD. Six articles met the inclusion criteria and were included in the integrative review. Three focused on provider knowledge and opinions of end-of-life for patients with an LVAD and three studies examined patient and caregiver experiences related to end-of-life processes associated with the LVAD.

To ensure there is a validated instrument to measure perceived control, Chapter Four reports on the psychometric properties of the Control Attitudes Scale-Revise (CAS-R) in an LVAD population. The CAS-R is a measure of perceived control, which is a variable that is often targeted in interventions to improve quality of life because of the ability to modify and improve perceived control. This was a secondary data analysis of 89 LVAD patients from a larger prospective research study described elsewhere.[32] The purpose of this study was to evaluate the internal consistency reliability and convergent validity of the CAS-R in an LVAD population. Reliability was assessed with Cronbach's alpha, inter-item and item-total correlations to assess for homogeneity of the scale. Convergent validity was assessed using factor analysis and hypothesis testing.

Last, in culmination of the research from the prior chapters, Chapter Five presents the findings of cross-sectional, correlational study of 30 patients with an LVAD focused

on end-of-life attitudes and experiences and the impact of cognition on those attitudes and experiences. Patients were eligible to participate if they had an LVAD device for the treatment of end-stage HF, had the device for at least 30 days, were able to complete a three-question cognitive assessment, and were able to speak and write English. Participants were excluded if they were less than 18 years of age or resided in an extended care nursing facility. Participants completed a cognitive screening tool and an end-of-life questionnaire focused on experiences related to end-of-life decision making and attitudes towards end-of-life decision making and pump exchanges.

Chapter Six is an integrated discussion synthesizing the prior chapters of this dissertation and discusses how these studies contribute and advance what is already known regarding end-of-life decision making and care for patients with a cardiac device. There are also recommendations for future research and practice regarding end-of-life decision making in these populations.

CHAPTER 2. SHARED DECISION-MAKING ABOUT END-OF-LIFE CARE SCENARIOS COMPARED AMONG IMPLANTABLE CARDIOVERTER DEFIBRILLATOR PATIENTS WITH AND WITHOUT HEART FAILURE: A NATIONAL COHORT STUDY

2.1 Introduction

Heart failure (HF) affects over 6.5 million people in the US every year, and the trajectory of a patient's life is shortened once a HF diagnosis has been made.[1] Over 42% of people diagnosed with HF will die in less than five years after diagnosis.[1] Many of these HF patients require the placement of an implantable cardioverter defibrillator (ICD) to prevent sudden cardiac death, a major cause of death in HF. There are about 800,000

patients with HF who have an ICD in the US, and an additional 800,000 HF patients who qualify for ICD treatment but do not have one.[2]

Approximately 30% of ICD recipients experience a shock in the minutes before death.[3] Many of these shocks are not in the context of sudden cardiac death, but in the context of death from a terminal illness such as cancer.[4] According to guidelines developed by the Heart Rhythm Society, in conjunction with multiple professional organizations, providers are advised to discuss the potential for deactivation of ICDs in certain situations such as a terminal illness, prior to implantation of the ICD.[5] Despite these guidelines, in multiple studies of patients with and without HF, these discussions did not occur, or occurred very infrequently.[3,6,7] One of the consequences of failure to have end-of-life (EOL) discussions throughout the illness trajectory is potentially decreased quality of life (and quality of death experience) at the EOL. Thus, the purpose of this study was to compare experiences, attitudes and knowledge about the ICD at EOL between ICD recipients with and without HF to determine how well patients with HF could participate in EOL decisions. We hypothesized that given the poor prognosis in HF compared to other patients with an ICD, clinicians would have had discussions about the ICD at the EOL with HF patients more commonly.

2.2 Methods

2.2.1 Sample, Study Design, and Data Collection

This study was a cross-sectional and correlational design. All data were self-reported and participants were recruited from the national database of all Swedish ICD and pacemaker recipients. This registry has been active since 1989 and included 5,535

adult ICD recipients as of 2012. All ICD recipients were sent an invitation to participate in the study, and if a signed consent form was returned, a questionnaire was mailed. If the questionnaire was not returned in two weeks, one reminder was sent out. This study was sanctioned by the Regional Ethics Committee for Human Research at the University of Linköping, Sweden and followed the principles outlined by the Declaration of Helsinki.

2.2.2 Demographic and Clinical data

Demographic data and information on participants' co-morbidities, including HF, medications, and ICD shock history were collected using self-report. Data regarding indications for ICD placement, implantation and generator replacement history, and device types (ICD versus ICD with a cardiac resynchronization pacemaker/CRT-D) were collected using the Swedish ICD and Pacemaker Registry.

2.2.3 End-of-life information

The questionnaire used to collect data on EOL knowledge, perceptions, and attitudes is titled "Experiences, Attitudes, and Knowledge of End-of-Life Issues in ICD Patients" (EOL-ICD). It is a self-rated questionnaire that includes three domains related to EOL in patients with an ICD. The domains included are, experiences (10 items), attitudes (18 items), and knowledge (11 items). This questionnaire was developed and tested for construct validity, content, homogeneity and reliability in a Swedish setting; these properties were considered sufficient after evaluation.[8] In the current sample of 2,566 participants with an ICD the Cronbach's alpha was 0.719.

The experience domain included items about discussions with either providers or family about EOL care and experiences. An example of an item in this domain was, "I

have told my next of kin (either in writing or orally) my wishes regarding the defibrillator shocks in my ICD, if I become seriously ill with some fatal disease". The knowledge domain was concerned with the patient knowledge about ICD deactivation. An example of a question in this domain was, "An ICD always gives defibrillator shocks in connection with end-of-life". Lastly, the attitudes domain included items about the patient's feelings, emotions, and attitudes about potential discussions related to ICD deactivation and future events related to the ICD. An example in this domain was "I want to have the defibrillator shocks in my ICD even if I'm dying of cancer or another serious disease". Patients listed their answers to these questions as "agree/don't agree", "true/false", "I don't know", "yes/no", or "no opinion".

2.2.4 Implantable Cardioverter Defibrillator Concerns Scale

The Internal Defibrillator Concerns Scale (ICDC) short version is an 8-item scale that assesses patient related concerns regarding the ICD. This instrument helps identify patients who are at risk for adverse outcomes related to the ICD by identifying how worried various aspects related to the ICD the patient is concerned with.[9,10] Patients rate the items on a 5-point Likert scale with 0 being not worried at all, to 4 being very much worried.[10] The items are scored and totaled with a range from 0-32, with 0 being not worried at all about the ICD, to 32 being extremely concerned about the ICD.[10] This has been shown to have excellent reliability and validity in various ICD populations.[9,10] In the current sample of 3,003 participants with an ICD, the Cronbach's alpha was 0.944, also indicating excellent reliability. The median total score from the sample was used as a cut-point for low ICD concerns, and higher ICD level of concerns.

2.2.5 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) is a brief self-report instrument used to detect symptoms of anxiety and depression in multiple populations..[11,12] It is divided into anxiety and depressive subscales that have also been validated and have demonstrated good reliability.[11,13] The anxiety and depression subscales each have 7 items, scored on a 4-point Likert scale; each item score on the subscale are summed and can have a total score from 0-21.[11] Based on clinical presentations of generalized anxiety and depressive disorders, cut points of greater than or equal to 8 on the HADS anxiety and depression subscales were considered acceptable cut-points.[11]

2.2.6 Data analysis

For data analysis, we used SPSS version 24. We used means ± standard deviations, and frequencies and proportions to describe patient characteristics. Comparison of demographic and clinical characteristics, and experiences, attitudes, and knowledge between HF and non-HF groups was accomplished using X^2 and independent t-tests. Hierarchal binary logistic regression was used to determine predictors of whether or not participants had deactivation discussions with their providers. The assumptions for logistic regression were tested and were not violated. The outcome was participant responses to the question "Have you discussed what turning off shocks/deactivating the ICD involves with a doctor?" Four blocks were entered, in block one sociodemographic information was entered, block two included co-morbidities, block three included ICD related information, and block four was anxiety and depression. A probability values of less than 0.05 was considered to be statistically significant.

2.3 Results

2.3.1 Sample Characteristics

There was a total of 3,067 participants who responded to the questionnaire and were included in the analysis (Table 2.1). Of these, 1,461 (47%) stated they had HF. The average age of the participants with HF were older than those without HF (p-value <0.001). The HF cohort was more likely to have higher levels of depressive and anxiety symptoms compared with the non-HF (p-value <0.001). The HF cohort was more likely to suffer from comorbidities including history of myocardial infarction, diabetes and history of stroke (p-values all less than 0.001). It was also evident that those participants without HF were more likely to have experienced a shock than those with HF (p-value 0.012), and those without HF were more likely to have received an ICD related to secondary prevention compared to those with HF (p-value <0.001). See Table 2.1.

2.3.2 EOL-ICDQ Results

To determine whether there were differences in understanding of EOL situations between those with and without HF, we compared responses to the EOL-ICD questionnaire between HF and non-HF cohorts (Table 2.2). There was little variation between the cohorts in the majority of the domains indicating that in general, they had the same attitudes and equivalent knowledge about ICD deactivation, EOL care, and patient control. However, some differences were observed between the cohorts in the experiences domain (Table 2.2). Those without HF were more likely to have discussed battery replacement with their provider and next-of-kin than those with HF. Additionally,

a larger percentage of those without HF had more thoughts and questions concerning EOL compared to those with HF.

Tables 2.3A and 2.3B show the results of the attitudes portion of the EOL-ICDQ. Among these 18 questions, there were only significant differences between cohorts for two questions. Question 13, would you want the ICD battery replaced, even at an advanced age. A higher percentage of patients with HF replied "yes" than those without HF. The other difference in the attitudes portion of the questionnaire was regarding the desire for the doctor to decide if ICD shocks should be turned off at the EOL. More patients with HF replied "yes" they would prefer this option compared to those without HF.

Last, in Table 2.4, the percentage of each cohort that got the questions correct, as well as the total knowledge score of the EOL-ICDQ are presented. While there was no difference in the overall scores between the cohorts, there were three questions that the non-HF cohort picked the correct response more than the HF cohort. Question 12 was the only question that the HF cohort picked the correct response more frequently that the non-HF cohort.

2.3.3 Hierarchal Logistic Regression Results

Because we found that HF was not related to more comprehensive understanding of EOL with an ICD, we sought to understand what predictors were associated with having discussions with providers regarding EOL with an ICD. To determine these predictors a hierarchal logistic regression was performed. Block one with age, gender, education, and living alone was non-significant. Block two was significant with HF, atrial

fibrillation, and history of myocardial infarction were entered in the model (p =0.003); the Hosmer and Lemeshow goodness-of-fit coefficient was 0.296, indicating acceptable model fit. In block three, ICD variables were entered, including whether patients had a high level of ICD concerns, whether they had been shocked in the past, and whether their ICD was implanted for secondary prevention. This model block had a p-value of less than 0.001 and the Hosmer and Lemeshow test showed a coefficient of 0.601, indicating good model fit. In block four, whether or not patients had symptoms of anxiety and depression were added to the model. The model remained significant with highest Hosmer and Lemeshow coefficient of 0.958, indicating good model fit. In the final model with all potential predictors, the significant predictors of having a discussion with the provider were having high levels of ICD concerns ($p<0.01$), having had a shock in the past ($p<0.001$), and having a high level of anxiety ($p=0.027$; Table 2.5).

2.4 Discussion

Our hypothesis that participants with HF would have a better understanding of EOL with an ICD because of their shortened life expectancy was not supported.[1] Results from the EOL-ICDQ indicated that participants with and without HF had similar responses. However, we also saw that the participants with HF had more symptoms of anxiety and depression compared to those without. Despite the shortened life expectancy, and higher levels of symptoms of anxiety and depression, those with HF did not want to initiate discussions regarding EOL any more frequently than those without.

Our results are congruent with other research in the ICD and HF communities. It has been shown that patients are reluctant to have their ICD deactivated at the EOL, despite recommendations from providers.[14-16] It is also uncommon to have information

regarding ICD deactivation in an advanced directive or living will.[17] This is consistent with our findings which demonstrate that over 40% state they never wanted to have a discussion about deactivation of the ICD at the EOL with their provider, and only 11% of those with HF had ever had any EOL conversation with their next-of-kin. It also important to note that both those with and without HF had poor knowledge regarding what EOL with an ICD entailed. In the same cohort of Swedish participants, only 3% of participants scored correctly on all the knowledge questions and over 25% were considered to have inadequate knowledge.[18] This prior study also demonstrated that those with poor knowledge were more likely to have a stressful and potentially painful EOL.[18] Poor knowledge and lack of desire to have a discussion regarding EOL with an ICD are strong barriers to shared decision making regarding the EOL.

Shared decision making, an established concept, is becoming a more crucial component of modern healthcare. This concept is succinctly described as "helping patients understand the importance of their values and preferences in making decisions that are the best for them".[19] It is ideally used in individualizing the plan of care for patients and ensuring that they are receiving medical treatment that is cohesive with patients' goals for life, or in our scenario, the goals for EOL care. Initially we hypothesized that those with HF would have a higher level of shared decision making because of their shortened life expectancy and complications of their chronic disease, however, through our analysis we saw that in general, their experiences and preferences were identical to those without HF.

We found factors associated with having a deactivation discussion were primarily ICD related, including a history of an ICD shock and having high levels of ICD concerns.

The other factor was anxiety symptom, which has a significant relationship with shared decision making and how patients interact with their providers.[20] These associations may indicate when there is a potential for interventions regarding education on EOL scenarios. If we know patients are more open to having conversations about EOL after they have been shocked, or have high levels of anxiety and concerns about their ICD, we can prompt these types of discussions and ideally increase patients' awareness about how an ICD can impact EOL. In a recent systematic review of the literature, a key point of shared decision making revolved around whether a patient is willing to take action.[21] In this sample we saw that when patients had received an ICD shock, or when they had levels of concern about their ICD, they were more willing to take action regarding creating a plan for their EOL that included their ICD.

By having a more thorough understanding of which patients are willing to participate in EOL education, we may be able to address misconceptions and improve quality of death in this population. Having a HF diagnosis may not be sufficient to overcome the barrier of not wanting to discuss EOL with providers, but other clinical scenarios, such as being shocked or having high levels of symptoms of anxiety, do provide this kind of opportunity, and as providers it is crucial to capture them at these times. Additionally, shared-decision making regarding EOL can help alleviate some of the problems that frequently occur at the end of life, such as being shocked inappropriately, or forcing the next-of-kin to make a decision about deactivation when they have never had this type of discussion with their loved one.

Moving forward it will be important to understand how to educate patients with HF about EOL scenarios with an ICD. Despite the guidelines that suggest providers have

these discussions prior to implantation and regularly after implant, our study shows that this ongoing discussion did not occur in the majority of participants. Additional studies should focus on ways to reach patients with and without HF who are reluctant to discuss EOL scenarios with providers ever, because we saw this was almost half of our sample. These patients may need additional education prior to implantation to ensure they understand the implications that cardiac devices may place on their lives and their deaths, and make sure the care team understands their wishes.

2.5 Limitations

There were several limitations to this study, including that all the respondents were from the same geographical location, which limits generalizability. Also, because this information was self-reported through survey, some portions of the population may not have been able to respond, also limiting generalizability.

2.6 Conclusions

While HF diagnosis was not associated with increased likelihood of having discussions about EOL with a provider, several other factors were identified, including high ICD concern level, high levels of symptoms of anxiety, and having an ICD shock. Future studies should focus on ways to better reach patients who are reluctant to have discussions regarding EOL. More education and guidance is also needed for providers regarding having discussions about EOL with patients an ICD to better improve patient quality of life and quality of death.

Table 2.1. Patient Characteristics and Comparison of Characteristics by Heart Failure and Non-Heart Failure Status (N=3067)				
	Total N=3067 Mean ± SD or n (%)	With HF N=1606	Without HF N=1461	P-value
Sociodemographics	Mean ± SD or n (%)			
Age	66 ± 12	67 0.101 10	64 ± 13	<0.001
Female	629 (21)	309 (19)	320 (22)	0.073
Living Alone	648 (21)	352 (22)	296 (20)	0.240
Education: 9 years or less	1009 (33)	533 (34)	476 (33)	0.700
Works outside the home	705 (23)	280 (18)	425 (30)	<0.001
Pensioner	2074 (68)	1162 (76)	912 (65)	<0.001
Other Employment Type	156 (5)	91 (6)	65 (5)	<0.001
Time since implant: years	5 ± 4	4 ± 4	5 ± 4	<0.001
CRT-D	2346 (77)	578 (36)	139 (10)	<0.001
Etiology: cardiomyopathies	2428 (79)	1422 (90)	1006 (70)	<0.001
Myocardial Infarction	1037 (34)	677 (42)	360 (25)	<0.001

Diabetes	612 (20)	376 (23)	236 (16)	<0.001
Hypertension	1072 (35)	581 (36)	491 (34)	0.139
Stroke	272 (9)	186 (12)	86 (6)	<0.001
Depression: ≥HADS 8	263 (9)	173 (11)	90 (6)	<0.001
Anxiety: ≥HADS 8	485 (16)	299 (19)	186 (13)	<0.001
Has received a shock	1056 (35)	519 (33)	537 (37)	0.012
Received ICD for secondary prevention	1957 (64)	828(52)	1129(77)	<0.001
Legend: CRT-D- Cardiac resynchronization therapy-defibrillator; HADS- Hospital anxiety and depression scale				

Table 2.2: Comparison of Implantable Cardioverter Defibrillator Experiences Between Heart Failure and Non-Heart Failure Patients

	Heart Failure n= 1606 n (%)	Non-Heart Failure n=1461 n (%)	P-Value
Question 1: Discussed Battery Replacement with Doctor/Nurse, Yes	636 (40)	674 (47)	<0.001

Question 2: Discussed battery replacement with next-of-kin, Yes	468 (29)	518 (36)	<0.001
Question 3: Discussed what turning off shocks with a doctor involves, Yes	216 (14)	222 (15)	0.148
Question 4: Discussed what turning off shocks means with next-of-kin, Yes	171 (11)	163 (11)	0.642
Question 5: Informed next-of-kin wishes related to defibrillator shocks if seriously ill, Yes	123 (8)	86 (6)	0.062
Question 6: Considered asking doctor to turn off shocks, Yes	46 (3)	71 (5)	0.004
Question 7: Discussed heart disease development with doctor	624 (39)	502 (35)	0.014
Question 8: Discussed heart disease development with next-of-kin	665 (42)	470 (33)	<0.001
Question 9: Has a religious faith/outlook on life, helps manage daily life, Yes	1317 (83)	1209 (84)	0.403
Question 10: Often think about questions concerning End-of-life, Yes	1296 (82)	1233 (86)	0.003

Table 2.3A: Implantable Cardioverter Defibrillator Attitudes When would you like healthcare staff to broach the question of what it involves to turn off the defibrillation shocks in your ICD – Heart Failure vs. Non-Heart Failure			
	Heart Failure n= 1606 n (%)	Non-Heart Failure n=1461 n (%)	P-Value
Question 1: Pt does not wish to have such conversation, Agree	633 (40)	571 (40)	0.911
Question 2: Pt will themselves broach the question when they feel they need to, Agree	1326 (84)	1203 (84)	1.000
Question 3: In connection with ICD surgery, Agree	759 (49)	707 (51)	0.377
Question 4: If pt receives a defibrillator shock, Agree	815 (52)	687 (49)	0.091
Question 5: If pt has repeated defibrillator shocks, Agree	1022 (66)	916 (65)	0.644
Question 6: Upon repeatedly being hospitalized because of	981 (63)	889 (63)	1.000

recurring heart problems, Agree			
Question 7: If pt should suffer from disease with poor prognosis, Agree	1007 (64)	925 (65)	0.619
Question 8: Routinely when pt visits the ICD clinic	670 (43)	579 (41)	0.354
Question 9: If heart disease deteriorates, Agree	1015 (65)	920 (65)	0.818
Question 10: Towards end-of-life, during last days, Agree	1077 (69)	966 (69)	0.691
Legend: Pt- patient; ICD- Implantable cardioverter defibrillator			

Table 2.3B: Implantable Cardioverter Defibrillator Attitudes

"In time your general state of health or heart disease may deteriorate. Try to imagine how you (the patient), at this moment, feel about your (the patient) ICD treatment in the future…"

	Heart Failure n= 1606	Non-Heart Failure n=1461 n (%)	P- Value

	n (%)		
Question 11: Pt wants to have the battery in ICD replaced even if they never received defibrillator shocks: Yes No No opinion	 1251 (80) 72 (5) 244 (16)	 1130 (79) 69 (5) 229 (16)	 0.888
Question 12: PT wants to have battery replaced, even if seriously ill suffering from another disease: Yes No No opinion	 861 (55) 167 (11) 540 (34)	 773 (54) 162 (11) 491 (34)	 0.815
Question 13: Pt wants to have battery replaced even if reached an advanced age: Yes	 1017 (65) 143 (9)	 859 (60) 162 (11)	 0.022

No No opinion	410 (26)	405 (28)	
Question 14: Pt wants to have defibrillator shocks even if pt dying of cancer or other serious disease: Yes No No opinion	 375 (24) 596 (38) 595 (38)	 296 (21) 556 (39) 575 (40)	0.101
Question 15: Pt wants to have defibrillator shocks even if receiving shocks daily: Yes No No opinion	 288 (18) 472 (30) 808 (52)	 271 (19) 437 (31) 715 (50)	0.773
Question 16: Pt wishes to decide themselves if shocks are to be turned off when finding themselves at end-of-life Yes	 1009 (65)	 923 (65)	0.966

No No opinion	98 (6) 458 (29)	87 (6) 412 (29)	
Question 17: Pt wants the doctor to decide if the shocks be turned off at the end-of-life: Yes No No opinion	 602 (39) 516 (33) 442 (28)	 475 (34) 500 (35) 442 (31)	0.015
Question 18: Pt wants next-of-kin to decide if the shocks be turned off when pt at the end-of-life: Yes No No opinion	 513 (33) 530 (34) 513 (33)	 458 (32) 472 (33) 486 (34)	0.738

Table 2.4: Implantable Cardioverter Defibrillator (ICD) Knowledge Questions

Each statement had a correct answer, participants could choose either true or false based on their own knowledge about their ICD.

	Heart Failure n= 1533 n (%)	Non-Heart Failure n=1371 n (%)	P-Value
Question 1: Correct	1161 (74)	1100 (77)	0.038
Question 2: Correct	1074 (68)	1036 (73)	0.009
Question 3: Correct	1326 (84)	1224 (86)	0.218
Question 4: Correct	982 (63)	914 (64)	0.343
Question 5: Correct	1147 (73)	1051 (74)	0.508
Question 7: Correct	671 (43)	600 (42)	0.795
Question 8: Correct	1107 (70)	990 (70)	0.689
Question 9: Correct	570 (36)	587 (41)	0.005
Question 10: Correct	451 (29)	433 (31)	0.316
Question 11: Correct	1015 (65)	941 (66)	0.420
Question 12: Correct	774 (49)	632 (44)	0.007
Total Score (mean ± SD)	6.6±2.7	6.7±2.8	0.251

Table 2.5: Independent predictors of having an end-of-life discussion with a provider; N= 2,840					
	Odds Ratio	95% Confidence Interval	B	SE	P
Age	0.994	0.984-1.003	-0.006	0.005	0.200
Gender: Female	1.056	0.808-1.380	0.054	0.137	0.691
Living Alone	1.079	0.832-1.398	0.076	0.132	0.567
More than 9 years of education	0.893	0.705-1.131	-0.113	0.120	0.347
Has heart failure	0.895	0.712-1.127	-0.111	0.117	0.346
Has atrial fibrillation	1.206	0.962-1.512	0.187	0.115	0.104
History of MI	0.797	0.625-1.016	-0.227	0.124	0.067
High Level of ICD concerns (score on ICDC $\geq$7)	1.526	1.217-1.915	0.423	0.116	<0.001

Having had an ICD shock in the past	2.049	1.637-2.564	0.717	0.114	<0.001
ICD for secondary prevention	1.147	0.897-1.467	0.137	0.126	0.275
High anxiety symptoms (HADS score ≥8)	1.411	1.040-1.915	0.344	0.156	0.027
High depressive symptoms (HADS score ≥8)	1.038	0.701-1.537	0.038	0.200	0.851

Legend: Overall model p-value <0.001; ICD: internal cardioverter defibrillator; ICDC: internal cardioverter defibrillator concerns scale; HADS: hospital anxiety and depression scale; MI: myocardial infarction

CHAPTER 3. LEFT VENTRICULAR ASSIST DEVICES AT THE END-OF-LIFE: AN INTEGRATIVE REVIEW

3.1 Introduction

Heart failure (HF) is a growing epidemic in the United States. By the year 2030 over 8 million Americans will have a HF diagnosis.[1] Despite the increasing prevalence of the condition, and improved guideline directed medical therapy, the five-year mortality rate of HF is still extremely high at 80%. [2] Since the Food and Drug Administration first approved left ventricular assist devices (LVADs) for use as bridge to heart transplantation in 1994, the science and rapid utilization of these devices has grown exponentially.[3] Between 2008 and 2016, over 17,000 LVADs were implanted in the United States and that number will continue to grow due to the lack of available donor hearts and the growing number of Americans with HF.[4] While scientific advancements such as LVADs do increase life expectancy compared to optimized medical management, the mortality rate at one year is 19%.[4,5] While many patients experience improvements in their quality of life after implantation, around 20% of LVAD patients experience a poorer quality of life post-implant.[6]

Despite the life-prolonging capacity of LVADs, there are significant risks associated with the device that can ultimately lead to death. The most common causes of death in the LVAD population are neurologic complications, primarily stroke, which is the primary cause of death in 20% of patients. Multi-system organ failure is responsible for death in 14% of LVAD patients, and major infection is the cause of death in 7.6% of patients.[7] Investigators have also demonstrated that compared to other chronic illnesses, patients with an LVAD overwhelmingly die in an intensive care unit rather than in the

comfort of their own home or other location of their choice.[8,9] Because of these factors, it is critical that patients who have been implanted with an LVAD, their healthcare providers, and their next-of-kin discuss end-of-life situations and are prepared for when the inevitable occurs.

Professional organizations that advise providers who care for patients with an LVAD have acknowledged that end-of-life is an important area and have created guidelines for providers. The Centers for Medicaid and Medicare Services have mandated that a palliative care team be involved in the care of LVAD patients to ensure that goals of care be discussed, but these guidelines are vague and do not discuss the extent to which palliative care must be involved, the composition of the palliative care team, or if end-of-life discussions must occur.[10] The International Society for Heart and Lung Transplantation also recommends that a palliative care team be involved prior to LVAD implantation to help facilitate discussion of end-of-life and establish an advanced directive; however, there is no recommendation about the continuation of palliative care involvement, or what content should be discussed in these consultations other than advanced directives.[11]

Authors of several editorials have also discussed end-of-life with an LVAD and determined that there is a strong need for increased shared decision-making among LVAD patients, caregivers, and their providers.[12,13] These experts proposed that a lack of shared-decision-making has created confusion for patients, families, and clinicians involved in end-of-life discussions.[12,13] Phan et al., discussed how death can be hard to determine in patients with an LVAD due to the technical aspects of the device, which can still be functioning despite neurological or pulmonary system failure.[14] This difficulty can

cause extreme confusion and frustration, especially for families who are often deemed the decision-maker at the EOL.[14] In an attempt to deliver a consensus on the ethical permissibility of LVAD deactivation, Rady and Verheijide evaluated the legality of deactivation. They determined after consultation with physicians and legal representatives, that in a new onset lethal condition only, such as new diagnosis of cancer, it is ethically permissible to deactivate an LVAD.[15]

High mortality rates, vague guidelines about end-of-life care, and a demand of further understanding by providers seen in published editorials, clearly demonstrate a need for a more thorough understanding about end-of-life care for patients with an LVAD. Despite a few pilot studies that examined the effectiveness of preparedness planning for dyads including patients with an LVAD and their caregivers,[16-18] there is no established understanding of end-of-life decision making in the literature. This includes understanding current practice with the various participants in the LVAD community including providers/clinicians, caregivers, and patients with an LVAD. Therefore, the purpose of this integrative review was to systematically evaluate research studies that focused on the process and content of end-of-life discussions, attitudes towards these discussions, and end-of-life experiences of individuals, families, and health care providers of patients with an LVAD.

3.2 Methods

3.2.1 Search Strategies

We performed a literature search of the PubMed, PsychINFO, and CINAHL databases. The keywords searched included: “LVAD” or “left ventricular assist device”,

and “end of life”. Secondary search terms utilized were “provider”, “caregiver”, “physician”, and “coordinator”. Databases were searched from earliest available to November 1st, 2018; no time restriction was used as the use of the LVAD is a recent innovation. References from the thirteen articles selected for full analysis for inclusion were evaluated, but revealed no new studies for review.

3.2.2 Inclusion and Exclusion Criteria

Studies were included in this review when they: 1) were research studies that focused on the perspective about end-of-life of provider, caregiver, or patient with an LVAD 2) focused on adults (≥18 or older); and 3) were published in English. Articles were excluded when the primary research focus was testing palliative care interventions for preparedness planning.

3.2.3 Quality Assessment

Multiple study designs were included in this integrative review; thus, an instrument designed to assess multiple types of studies was needed. Pluye et al,[19] developed an instrument that incorporates multiple types of assessments for the various study types, including mixed-methods, quantitative, and qualitative studies. This instrument is known as the Mixed Methods Appraisal Tool (MMAT), version 2018.[20] The MMAT has two screening questions that apply to each type of study, and then depending on the specific study type, there is a range of 3-5 items appraising the quality of the various studies. The developers of this instrument suggest not scoring the quality, but rather assessing whether each study has addressed the various appraisal items with an answer of ‘yes’, ‘no’, or ‘cannot tell’, and an explanation for the choice by the reviewer.

The authors then suggest judging over-all quality by reviewing the explanations of the criterion and comparing results of the common studies to make an over-all conclusion.[20]

3.3 Results

The initial search strategy resulted in 68 articles, and after abstract review and application of inclusion and exclusion criteria, 13 studies were evaluated for full review (see Figure 3.1 for flow-chart). After full review, six studies were included in the integrative review based on inclusion and exclusion criteria. Three were qualitative studies focused on end-of-life discussions and experiences of caregivers and patients with an LVAD, two quantitative studies focused on provider opinions about LVAD deactivation or withdrawal of an LVAD, and one mixed-methods study focused on provider opinions of LVAD withdrawal and deactivation.

The qualitative studies included in this review used grounded theory and qualitative descriptive methodology. Investigators for all studies used convenience sampling, and for two out of the three, investigators used open-ended, semi-structured interviews;[21,22] researchers for the remaining study used a structured, three-question open-ended interview style.[23] All interviews focused on patients and caregivers experiences with end-of-life discussions, or the experiences of caregivers related to the processes associated with end-of-life with an LVAD. The qualitative studies included in this review had a total of 70 caregivers and 39 patients with an LVAD. The caregivers in these studies were predominantly female, white, and either married or cohabitating partners of patients with an LVAD. The 39 patients with an LVAD interviewed in these qualitative analyses were predominantly white, males, and over 50 years of age; this is consistent with the LVAD population as a whole.[7]

Investigators for the two quantitative studies and the mixed-methods study, used cross-sectional designs. The investigators for the two quantitative studies, and the mixed-method study all used a 41-item web-based survey entitled, "Characterization of Physician Attitudes Towards Deactivation of Left Ventricular Assist Devices as Destination Therapy at Life's End", which focused on attitudes and practices of clinicians who cared for patients with an LVAD at the end-of-life. In addition to the web-based survey, investigators for the mixed-methods study used a convergent parallel study design, indicating that the researchers collected the quantitative and qualitative data at the same time, where they asked the participants to elaborate on why they chose certain answers.[24] In all three studies, a total of 865 clinicians who provided care to patients with an LVAD completed the web-based survey, most were physicians, male, and in the cardiology field.[24-26]

3.3.1 Qualitative Studies about End-of-Life

The qualitative evaluation of patient and caregiver end-of-life experiences or discussions were examined in three studies,[21-23] with similar themes emerging in all. Caregivers of patients with an LVAD were interviewed in all three studies; however, in one study caregivers as well as patients were interviewed.[22] Investigators for only one of the studies recruited participants at multiple institutions,[22] while investigators for the other two studies recruited participants from a single institution.[21,23]

3.3.1.1 Difficulty Receiving Information

The most common theme identified by investigators in all three qualitative analyses was expressed by both patients and caregivers and was the difficulty in

receiving information from healthcare providers about the end-of-life experience. One participant stated, "In fact, I did ask them one time and I didn't get an answer…" regarding what the end-of-life with an LVAD would be like.[22] There was a strong desire from caregivers to understand what would occur at the end-of-life, and unfortunately many providers, especially those with hospice and palliative care, could not answer their questions, because the providers lacked the knowledge to respond.[21,23] The inability of providers to inform patients and their caregivers about what happens at the end-of-life led to confusion and frustration for patients and their caregivers about end-of-life experiences. Thus, investigators concluded that patients had difficulty getting the information because providers did not have adequate knowledge or experience to be able to answer their questions. The statement below is an example of this theme:

> "*They don't know what they're gonna do… Do you leave the mechanism running or do you turn it off? They don't know.*"[22]

3.3.1.2 Processes of End-of-Life with an LVAD

Another common theme identified by investigators for all three studies was a desire by patients and caregivers to understand how an LVAD would affect the process of end-of-life. A number of caregivers discussed the need for a detailed plan that described how the pump would be turned off when the end-of-life was near.[23] Caregivers also expressed confusion about whether death could even occur with the LVAD in place.[21] This lack of understanding by the patients and the caregivers regarding what end-of-life would be like was central throughout the qualitative interviews, and was compounded by the lack of answers from providers. Investigators from all three studies concluded that there is a desire from patients and caregivers for a detailed outline of the process of end-

of-life and deactivation of the device once the time comes close. Below is an example of caregiver quote related to this theme:

> *"But it just seemed that the rug got pulled out from under us. And we kinda didn't understand what was going on, and to what extent it all meant."*[21]

Patients and caregivers also expressed frustration related to the integration of hospice and palliative care resources during the end-of-life processes. Some patients and families felt like they were abandoned by their LVAD team when they were transferred to hospice team, and wanted their primary LVAD team to guide them through the end-of-life, rather than a team full of strangers.[23] Caregivers in a different study also voiced a similar concern; they felt that the hospice and palliative care teams did not know how to take care of the LVAD, and therefore did not feel comfortable taking care of the patient.[21] They also voiced that when they had to call emergency personnel because their loved one with an LVAD had collapsed, the emergency personnel had to no idea how to take care of the patient and the caregiver was too upset to try to explain what to do to help.[21] These interactions with other teams, outside the LVAD team, demonstrate a lack of education of other personnel who may come into contact with LVAD patients and their families during the emotional time of end-of-life, and the detrimental effects it can have.

3.3.1.3 Ethical Issues of Deactivation of the LVAD

A third common theme focused on the ethical issues associated with the appropriateness of deactivation of the LVAD at the end-of-life. McIlvennan et al. found that six of the eight caregivers viewed deactivation of the LVAD as suicide, and one participant described the deactivation as "not their decision" and "the Lord's decision".[21]

This question of ethical permissibility of deactivation can negatively affect patients' and caregivers' decisions at end-of-life and make it much more difficult for them to make a decision.

3.3.2 Provider Opinion Studies

Three descriptive, web-based, studies were conducted with clinicians as participants. In these studies, investigators studied physicians, advanced practice nurses and physician assistants, and their opinions related to end-of-life care of patients with an LVAD and their experiences with LVAD deactivation.[24-26] Clinicians who provided data for these studies included American cardiology clinicians,[24] American hospice/palliative medicine clinicians,[24,25] and European cardiologists.[26] Investigators for these three studies used the same 41-item web based survey; however, investigators for only one study included qualitative free-responses related to questions chosen by the investigator.[24] None of the investigators discussed validity or reliability of the survey instrument, or details related to development of the instrument. One investigator did describe domains in the survey, which included, "LVAD as a life-sustaining therapy", "Complexities of the process of LVAD deactivation", "Ethical and legal considerations of LVAD deactivation", "Honoring requests for turning off an LVAD in a patient who is not nearing death", and "Believe the underlying disease- heart failure- is the cause of death in a patient who dies after their LVAD is turned off".[24]

Overall, comparison among the various specialties and geographic locations revealed few similarities. Geographically, a greater proportion of Europeans physicians described death post-deactivation of the LVAD as "euthanasia or physician-assisted suicide (European 27%, American 4%, $p < 0.001$)".[26] American physicians were more

likely to report that they had deactivated an LVAD at the request of a patient compared with European physicians (European 50%, American 82%, $p < 0.004$).[26] Investigators concluded that cultural, ethical, legal, historical, and socio-psychological variations can be based on geographical differences, and these differences are evident in clinicians opinions regarding end-of-life care with an LVAD.[26]

In the studies that examined hospice and palliative medicine providers and cardiology providers, significant differences between the two groups, and individually within the groups, can be seen.[24,25] Hospice and palliative care medicine providers demonstrated a very high rate of involvement with deactivation or end-of-life discussions and experiences, with around 96% of clinicians involved with a deactivation of an LVAD.[25] This involvement in care was much smaller in cardiology providers, with only 42% being involved in the deactivation of an LVAD.[26] Along with personal experiences of deactivation, a difference of opinion about the ethical permissibility of deactivation was also seen between the various clinician specialties. Hospice and palliative medicine providers believed that deactivation was a patient and caregiver decision, with 72% and 88% in the various studies believing that a patient did not need to be "dying" to decide to deactivate their LVAD,[24,25] while only 57% of cardiology providers believed that it would be acceptable to deactivate the LVAD if the patient is not actively dying.[24]

The qualitative portion of the web-based survey allowed participants to elaborate on their survey answers in an open-ended way.[24] When answering the question of whether heart failure is the cause of death when an LVAD is deactivated, a cardiology clinician, specifically a cardiothoracic surgeon, stated that, "Turning off an LVAD from a completely conscious patient amounts to euthanasia".[24] However, a hospice and palliative

care physician responded to the same questions by stating, “The act of turning off the machine is not the cause of death; the disease is the cause of death”, these dichotomous responses between the participants demonstrate the complex issues related to end-of-life decision making among providers of patients with an LVAD.[24]

3.3.3 Quality Evaluation Results

In Tables 3.2, 3.3, and 3.4 quality evaluation of the various studies included in this review using the MMAT tool are presented. Overall, the majority of the articles had a low-quality rating, due to lack of information provided by authors related to methodology. The qualitative studies had slightly better overall quality compared to the quantitative studies, however, all three articles could have benefited from more descriptive quotes from the interviews to corroborate the conclusions made by the authors. The quantitative descriptive studies completed by Swetz et. al,[25,26] needed much more explanation of the survey used, including reliability and validity statistics. These studies also lacked explanation for the low response rates, which could have led to biased conclusions. The mixed-methods study also lacked a description of exactly how the qualitative portion was integrated within the quantitative study, and how the results of the various methods agreed or disagreed with one another.[21]

3.4 Discussion

Despite the high mortality rate of patients with an LVAD, there are still large gaps in our understanding of the various aspects of end-of-life care for patients, caregivers, and their clinicians. Investigators using qualitative methods determined that patients with an LVAD and their caregivers reported high levels of confusion and frustration when the

end-of-life approached, and often had unanswered questions about what the end-of-life would be for them. This suggested that there was a lack of preparation and guidance of patients and their caregivers regarding end-of-life from health care providers. However, end-of-life care and decisions should be a point of emphasis for this population due to the nature of the underlying pathology, the high-risk of the LVAD surgery, and the potential for complications following implantation, including stroke and infection.[7]

Despite the lower quality of the qualitative research, the conclusions reached by the investigators were all similar; providers of patients with an LVAD must do a better job educating their patients about end-of-life. Several investigators are currently involved in this kind of work; researchers are developing preparedness planning tools for LVAD patients and their families to ensure that before and after implantation, they know what to expect regarding deactivation and death, as well as incorporating teaching on advanced directives.[16-18,27] These types of interventions could meet the needs voiced by many patients and caregivers in these studies, and create a more cohesive decision-making process at the end-of-life.

Results from the provider opinion studies may explain the frustration and confusion experienced by caregivers and patients with an LVAD. While addressing the needs of patients and caregivers through preparedness planning, we are missing a crucial stakeholder involved in the end-of-life decision making processes. Providers of patients with an LVAD also need more guidance about how to handle end-of-life decision making processes. To date, there have been no studies focused on provider education related to end-of-life with an LVAD, and this review demonstrates this is a major gap in this area. Clinicians in the palliative care field seem to be proactive in trying to educate their

field,[28] however, it does not seem that providers in other fields are changing their practices to ensure they are meeting the needs of this unique group of patients and their families. This provider gap could be attributed to the vague guidance provided by the professional organizations of their fields. There needs to be more guidance from professional organizations that advise providers about the ethical implications of deactivation, as well as in-depth guidance on the role of providers in educating patients and their families about end-of-life with an LVAD.

There is also a disconnect between patient and provider opinions on end-of-life discussions. Participants in the qualitative study expressed that they felt unprepared, and many say that had never had these types of end-of-life care discussions with their providers. However, providers in the quantitative studies often said they had experiences with these types of discussions with their patients and families. This could be due to a lack of conversation had between providers and their patients and families. Providers feel as though the subject has been broached by bringing up an area such as end-of-life, but patients and families may not have fully grasped what the providers were saying or did not feel that their needs were fully met. This could be an example of the lack of shared-decision making.

As discussed before, researchers in the field who have discussed end-of-life in published editorials acknowledge the lack of shared decision-making in these processes.[12,13] This is seen in the confusion and frustration voiced by all shareholders in the area of end-of-life decision making for patients with an LVAD. More research emphasis needs to be placed on interventions that can increase and improve communication between providers and LVAD patients and their families focusing on

end-of-life discussions. This type of research could aim to identify gaps between what providers feel they are discussing with their patients versus what patients feel has been discussed, then interventions can focus on filling this gap. This type of shared decision-making could also alleviate some of the ethical concerns that have arisen by having more open lines of communication between the various groups involved.

While the literature review demonstrates several gaps regarding end-of-life care for patients with an LVAD, the ultimate gap is the lack of credible studies on the subject itself. Multiple types of studies, including quantitative, qualitative, and mixed-methods were included because there were not enough of any one type to create a comprehensive review. Moving forward, research must focus on creating high-quality studies that examine end-of-life with an LVAD for all the stake-holders, both through quantitative and qualitative methods, and examine the various system level factors associated with these decision-making processes.

3.5 Limitations

There were several limitations of this review. Only articles published in English were included, so some studies with important conclusions may not have been evaluated. Second, due to the relative limited availability of studies, multiple different types of studies were included, which limited the ability of the reviewers to compare the studies to one another directly, therefore we used the MMAT tool to compare them. A primary limitation is the lack of investigations of end-of-life care, and the lack of high quality studies related to end-of-life care in patients with an LVAD, which leads to decreased ability to draw conclusions about the research.

3.6 Conclusion

Based on the review of these six studies, providers, caregivers, and patients with an LVAD are struggling with end-of-life issues and care. There is a lack of provider education about end-of-life with an LVAD, and patients and their caregivers are experiencing high levels of confusion and frustration about what to expect at the end-of-life. Further research is needed to create more comprehensive guidelines for end-of-life care for patients with an LVAD. Future studies should focus on patients with an LVAD experiences regarding end-of-life discussions with their provider and caregivers. Research is needed on providers' experiences, attitudes, and knowledge about end-of-life discussions with their patients who have an LVAD, and quantitative analysis regarding factors that impact patients' comprehension of end-of-life discussions with their providers.

Table 3.1 Studies Included in Integrative Review			
First Author (Year) Type of Study Location	N/Sample	Methods/ Measurements	Findings
Qualitative Studies			
Barg (2017) Qualitative-Grounded Theory Multi-site	n= 39 patients n= 42 caregivers	Open-ended, semi-structured interviews with caregivers and patients	Potential to save or "being saved"- created a sense of moral obligation to undergo procedure "Living in liminal state"- patients describe uncertainty of what death with an LVAD would be like, lots of unanswerable questions to providers
Brush (2010)	n=20 caregivers of recently deceased	3 open-ended questions of caregivers (completed within	Most patients did not think about death very

Qualitative Descriptive Single-site	patients with an LVAD as DT	2 weeks of death of patient with an LVAD as DT)	often when QOL was acceptable Open discussion with the LVAD team crucial All expressed relief when detailed plan for withdrawal was outlined Ongoing communication with LVAD team "in concert" with hospice teams very important to patient and family members
McIlvennan (2016) Qualitative Descriptive Single-site	n= 8 bereaved caregivers of patients with an LVAD	In-depth semi-structured interviews with caregivers of patients who died with an LVAD	3 main themes: 1) overwhelmed with process of death with an LVAD, 2) different beliefs about the legal and ethical principles related to deactivation of the LVAD, and 3) lack of integration of resources at

			the EOL, was a major source of confusion and abandonment for caregivers.
Provider Opinion Studies			
McIlvennan (2017) Mixed-methods Multi-site	n= 440 survey respondents, n=269 cardiology clinicians n= 122 hospice/palliative medicine clinicians	41-item web-based survey along with free response section on some items to allow for qualitative analysis about deactivation of the LVAD and other LVAD EOL concerns	Comparison of HPM and cardiology clinicians' views on aspects of LVAD deactivation and EOL. Quantitative and qualitative evaluation demonstrated lack of consensus between providers. Authors concluded that this extreme difference in opinion could lead to confusions for patients, loved ones and other health care providers.

Swetz (2013) Cross-sectional correlational study Multi-site	n=303 clinicians who care for patients with an LVAD. Comparison of European versus North American clinician opinions on LVAD deactivation and EOL	41 item web-based survey regarding deactivation of the LVAD and other LVAD EOL concerns	There were several significant differences between European and North American clinicians. Europeans physicians were less likely to endorse the permissibility of deactivating the LVAD, as well as considering deactivation of the LVAD as physician-assisted suicide/euthanasia ($p<.05$). The researchers concluded that more consensus and guidance is needed to help clinicians regarding education of patients with an LVAD and their caregivers.

Swetz (2015) Cross-sectional correlational study Multi-site	n= 122 hospice/ palliative care medicine clinicians	41 item web-based survey regarding deactivation of the LVAD and other LVAD EOL concerns	Descriptive statistics described the results related to HPM clinicians' experiences and opinions regarding varying aspects of LVAD deactivation. The researchers concluded that compared to other physician groups HPM clinicians support the ethicality of LVAD deactivation and support patient autonomy.

Legend: DT- destination therapy, EOL-end-of-life, HPM- hospice/palliative care medicine, LVAD- left ventricular assist device

Table 3.2 Quality Evaluation of Qualitative Studies					
First Author (Year)	Qualitative approach appropriat	Qualitative data collection methods	Findings adequately derived	Interpretatio n of results sufficiently	Coherence between qualitative

Type of Study Location	e to answer research question	adequate to address research question	from the data	substantiated by data	data sources, collection, analysis, and interpretation
Barg (2017) Qualitative - Grounded Theory Multi-site	Yes	Yes, coding and data management discussed	Yes, however, some quotes did not seem to be completely coherent with the theme	Yes, authors corroborated extensively with other research done in the field and discussed how this was an extension of prior work	Yes, however, some quotes seemed to be linked to a different theme that the authors did not include, however, interpretation / conclusion seemed coherent and appropriate
Brush (2010)	Yes	Cannot tell, coding	Cannot tell,	No, very little actual	Cannot tell, authors used

Qualitative Descriptive Single-site		methods were not discussed	patient quotes were not used in the results section	data from the interviews is seen, so interpretation is somewhat difficult to agree with	very few data sources when drawing conclusions, and their data was not shown in depth
McIlvenna n (2016) Qualitative Descriptive Single-site	Yes	Yes, authors discussed framework for data collection, coding extensively discussed, and qualitative data trustworthiness was detailed	Yes, quotes used extensively to elaborate on thematic discoveries	Yes, extensive quotes from interviews were used and corroborate findings from the authors	Yes, authors used outside sources to connect with their conclusions from the data, and interpretation was cohesive

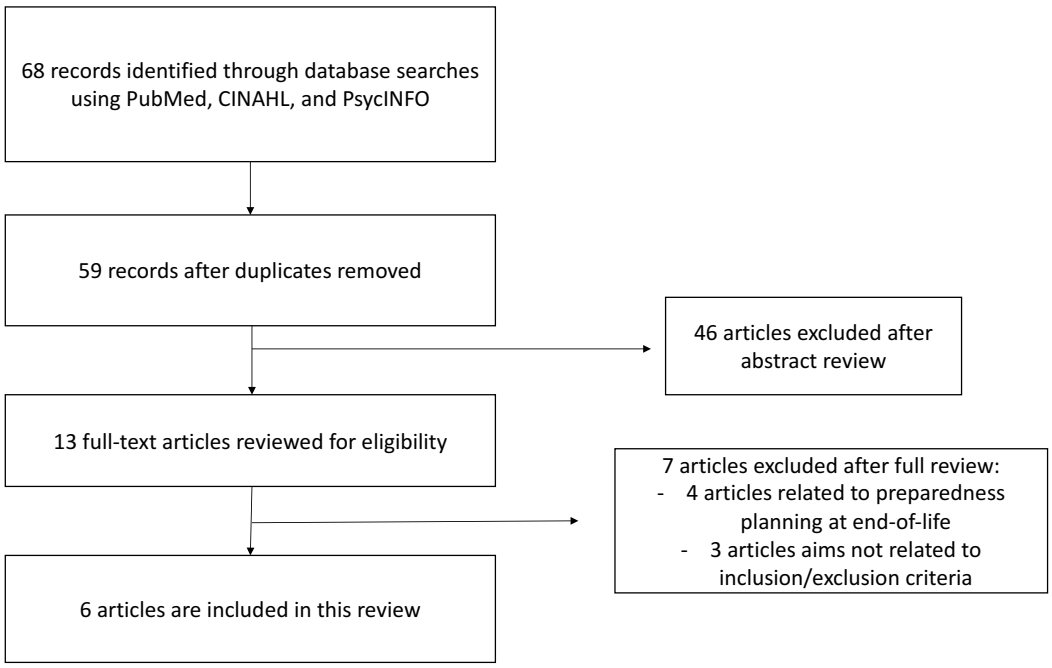
Table 3.3 Quality Evaluation of Quantitative Descriptive Studies					
First Author (Year) Type of Study Location	Sampling strategy relevant to address research questions	Sample representative of target population	Measurements appropriate	Risk of nonresponse bias low	Statistical analysis appropriate to answer the research questions
Swetz (2013) Cross-sectional Quantitative Descriptive	Yes	No—only 4% response rate	Cannot tell-very little reliability/validity information explained regarding the survey; does discuss that it was pilot-tested with heart failure and	Cannot tell-authors did not discuss whether they sent the survey multiple times, how long participants had to complete the survey, or if	Yes

			palliative medicine physicians	they sent reminders	
Swetz (2015) Cross-sectional Quantitative Descriptive	Yes	Cannot tell- reported response rate of 'less than 10%'	Cannot tell- very little information on the survey used	Cannot tell- due to 'crowdsourcing' and using a roster from a national organization authors acknowledge difficulty in this area	Yes

Table 3.4 Quality Evaluation of the Mixed Methods Study					
First Author (Year) Type of Study	Adequate Rational for mixed-methods design to	Different components of the study effectively integrated to answer	Outputs of the integration of qualitative and	Divergences and inconsistencies between quantitative and qualitative	Do the different components of the study adhere to the quality

Location	address research questions	research question	quantitative components adequately interpreted	results adequately addressed	criteria of each tradition of the methods involved
McIlvennan (2017) Mixed-methods Multi-site	Yes	Cannot tell—it is unclear whether each of the 41 questions in the survey had a qualitative component or just a selected few from the researchers	Yes- authors grouped results into domains and integrated both qualitative and quantitative results into the various domains	Cannot tell- the divergences between the comparison groups is adequately discussed, however, it is not discussed whether there were any between the qualitative and quantitative data	Cannot tell- very little is described regarding the qualitative portion of data collection, and the quantitative portion is of relatively low quality

Figure 3.1 Flow Chart of Articles Included in Integrative Review



CHAPTER FOUR. PSYCHOMETRIC TESTING OF THE CONTROL-ATTITUDES SCALE-REVISE FOR PATIENTS WITH A LEFT VENTRICULAR ASSIST DEVICE

4.1 Introduction

Perceived control is a broadly studied construct that primarily focuses on an individual's perception that they can positively influence outcomes related to stressful situations.[1] In healthcare, perceived control is often linked with the ability to positively cope with a diagnosis and management of chronic disease, particularly heart failure (HF).[2-4] As of 2018, HF affected approximately 6.5 million Americans.[5] To treat end-stage HF, many patients receive a left ventricular assist device (LVAD); since the development of these devices, over 17,000 people have received an LVAD and the indications for implantation are increasing.[6]

Patients with an LVAD face much of the same disease burden as those with medically managed HF, however, patients with an LVAD have extremely unique needs related to life with a device. Health related quality of life (HRQOL) is an evolving concept in the LVAD literature; researchers have shown that HRQOL is associated with anxiety and depression in patients with an LVAD, similar to other cardiac populations. [7] It has been shown in the HF population that poor perceived control is related to decreased HRQOL, as well as strongly correlated with anxiety and depressive symptoms.[2,8] In patients with an internal cardioverter defibrillator (ICD) a qualitative analysis revealed that perceived control was the core theme related to psychological adjustment to living with a device.[9] Perceived control is often one of the main targets of nursing interventions, as it is considered modifiable factor. Despite understanding the critical role that perceived control plays in similar patient populations, perceived control has never been examined in the LVAD population.

To more thoroughly understand the role perceived control plays, it is critical to have a validated measure to assess it. Currently, the Control Attitudes Scale-Revised (CAS-R) is the primary perceived control assessment scale used in cardiac populations.[8] The purpose of this study was to evaluate the reliability and validity of the CAS-R in the LVAD population. The specific aims were to: 1) assess internal consistency and homogeneity of the CAS-R; and 2) provide evidence of construct validity with factor analysis and hypothesis testing using the following hypotheses:

- Hypothesis 1a: Patients with higher levels of perceived control will have less depressive symptoms

- Hypothesis 1b: Higher levels of perceived control will be independently associated with lower levels of depressive symptoms in a multivariate regression analysis
- Hypothesis 2a: Patients with higher levels of perceived control will have lower levels of anxiety
- Hypothesis 2b: Higher levels of perceived control will be independently associated with lower levels of anxiety symptoms in a multivariate regression analysis

4.2 Background

The initial Control Attitudes Scale was created in 1995 by Moser and Dracup due to lack of a validated measure of perceived control in cardiac patients, and the relevance that perceived control had shown to possess in clinical practice.[10] The initial four-item scale demonstrated good validity and reliability in several studies of cardiac patients,[10,11] however, the authors found that when a participant did not have a significant support person in their life, the scale had poor reliability.[8] To address this phenomenon, the authors revised the initial four-item scale and added components from the Rheumatology Attitudes Scale;[12] this revision and addition resulted in a 19-item Cardiac Attitudes Index.[8] After extensive psychometric evaluations of the 19-item scale, the authors deleted 11 items, leaving the 8-item CAS-R most commonly used in research today.[8]

The 8-item CAS-R was validated in a large cohort over 4,000 participants with various cardiac diseases and shown to have excellent reliability and validity.[8] The Cronbach's alpha of the sample was greater than 0.7, indicating good reliability.[8] Construct validity of the CAS-R, using convergent validity, was tested by examining the

relationship of perceived control to anxiety and depression. In prior studies, those with lower anxiety and depression symptoms had higher levels perceived control.[10,11,13] Validity was confirmed using hypothesis testing of these prior findings, showing in the sample of 4,000 cardiac participants that higher perceived control was associated of lower levels of anxiety and depressive symptoms.[8]

To our knowledge, perceived control has not been measured and reported in the LVAD population. As the LVAD population continues to increase in number, it is crucial to understand the role that perceived control plays in the QOL of these patients. In a systematic review of the literature related to quality of life with an LVAD, authors found that QOL is not well understood due to limitations of our current instruments to measure this concept.[14] One finding that was consistent in this review was that adaptation to device management was a difficult process and that this process takes significant emotional and physical adaptation.[14] Additionally in the LVAD population, levels of depression and anxiety are higher than in the general population, similar to that of other chronic disease states.[15] However, we do not know the role perceived control may play or if it is valid measure of this concept in this population.

4.3 Methods

In this secondary analysis of perceived control, depressive symptoms and anxiety symptoms in 89 patients with an LVAD. This sample was drawn from a larger prospective research study described in more detail elsewhere.[16] Sociodemographic data were collected through self-report and inspection of the medical record. Institutional review board approval was obtained, and all participants gave written informed consent.

4.3.1 Measures

4.3.1.1 Control Attitudes Scale-Revised

The 8-item instrument (Table 4.2) was completed by each participant individually. The total score ranges from 8-40, with lower scores indicating lower levels of perceived control.[8] Each scale item is rated on a 5-point Likert scale, with 1 being *totally disagree,* and 5 being *totally agree*. Item numbers 5 and 8 are reverse coded. The instrument is typically completed in less than 2 minutes and is between a fourth and fifth grade reading level.[8]

4.3.1.2 Patient Health Questionnaire-9

Depressive symptoms were measured using the Patient Health Questionnaire-9 (PHQ-9), which consists of nine items. Each item corresponds to one of the nine symptoms of the major depressive disorder criteria of the Diagnostic and Statistical Manual of Mental Disorders-IV. Patients rated items based on how often they experienced these symptoms over two weeks on a 4-point Likert scale ranging from 0 (not at all) to 3 (nearly every day). The scores are totaled with a range of 0 to 27. Higher scores on the PHQ-9 indicate higher levels of depressive symptoms. The reliability and validity of the PHQ-9 has been demonstrated extensively in a number of populations as a screening instrument for depression and a measure of depressive symptoms among those at risk for or with cardiac disease.[17-19] The PHQ-9 had demonstrated high specificity and predictive value in relationship with other clinical measures of depression.[17-19] In this sample of LVAD patients the Cronbach's alpha was 0.845, indicating good internal consistency.

4.3.1.3 Brief Symptom Inventory Anxiety Subscale

Anxiety symptoms were measured using the Brief Symptom Inventory (BSI) anxiety subscale. This is a 6-item subscale is used to measure the intensity of anxiety symptoms over the past 7 days.[20] The items are scored on a 5-point Likert scale from 0 (not at all distressed) to 4 (extremely distressed). The total sum of scores range from 0 to 24, with higher scores indicating higher levels of anxiety symptoms. In this sample of LVAD patients the Cronbach's alpha was 0.840, indicating good internal consistency.

4.3.2 Data Analysis

All statistical analyses were conducted using SPSS version 24. Frequencies and percentages or mean and standard deviations were used to describe the sample. The sample was divided into high and low perceived control groups by the median score of the sample, due to the skewness of the data and recommendation of the initial author of the scale. Independent t-tests and chi-square tests were used to test for differences between the high versus low perceived control groups. A probability value of less than 0.05 was considered to be statistically significant.

4.3.2.1 Reliability

Internal consistency reliability was assessed using Cronbach's alpha. A coefficient of greater than 0.7 is considered acceptable internal consistency reliability, a score of 0.8 is considered good internal consistency.[21] Further reliability analyses were conducted using inter-item and item-total correlations to assess for homogeneity of the scale. Inter-item correlation coefficients greater than 0.2 and less than 0.7 demonstrate that the individual items uniquely contribute to the scale and are not redundant.[21] Item-

total correlations greater than 0.2 indicated that the scale items make an individual contribution to the scale.[21]

4.3.2.2 Validity

Factor analysis was completed to test construct validity. We used exploratory factor analysis to examine the number of factors this scale measured in the LVAD population. Principal component analysis was utilized, and if more than one factor loaded, varimax rotation was used to provide a more complete understanding of the variance each item explained per factor. In order to ensure that factor analysis was appropriate, we evaluated the Kaiser-Meyer-Olkin statistic; higher values indicated that the sample would be appropriate for factor analysis.[21] Bartlett's test of sphericity was also examined to ensure that the correlation matrix of the items was not an identity matrix, which would indicate that factor analysis would not be appropriate.[21] In Bartlett's test, a p-value of less than 0.05 is indicative that the sample is appropriate for factor analysis.[21] In principal component analysis, Eigenvalues of one and above were retained. In the scree plot analysis, we will look for a point where the shape of the curve changes, this indicates that the factors above the curve change account for the most significant amount of variance.

Convergent validity was verified using hypothesis testing. Two hypotheses were tested in which we examined the relationship of perceived control with depressive and anxiety symptoms. Prior research has shown that high levels of perceived control were related to lower levels of depressive symptoms and lower levels of anxiety symptoms;[8,10,11] therefore, an instrument that is psychometrically established in the population should also demonstrate the same relationships.[8] In this sample, hypothesized

relationships between high levels of perceived control and lower levels of depressive and anxiety symptoms were tested.

To test Hypothesis 1a, that higher levels of perceived control are associated with lower levels of depressive symptoms in LVAD patients, a two group, t-test analysis was utilized. High and low groupings of perceived control were used as the independent grouping variable, and total score on the PHQ-9 was used as the dependent variable. To test Hypothesis 1b, a multivariate linear regression analysis was used, with total score on the PHQ-9 as the dependent variable, and total score on the CAS-R, after controlling for age, gender, education level, and whether the participant lived alone.

To test Hypothesis 2a, that higher levels of perceived control are associated with lower levels of anxiety symptoms in LVAD patients, a two group, t-test analysis was used. High and low groupings of perceived control were used as the independent grouping variable, and total score on the BSI anxiety subscale was used as the dependent variable. To test Hypothesis 2b, a multivariate linear regression analysis was used, with total score on the BSI anxiety subscale as the dependent variable, and total score on the CAS-R, after controlling for age, gender, education level, and whether the participant lived alone.

4.4 Results

Baseline demographic information was collected prior to LVAD implantation, and other measures were collected 1-month post LVAD implant. Summary statistics for the sample are presented in Table 1. The CAS-R scores were slightly negatively skewed, as assessed by normality plots and histograms. The median score of the CAS-R (30) was

used to divide the sample into two groups, high perceived control (46% of the sample) and low perceived control (54% of the sample). The sample was 80% male, which is consistent with the LVAD population in the United States currently.[6] When comparing the high versus low perceived control groups, there were three significant differences between the groups (Table 4.1). Those with higher perceived control had significantly higher scores of the CAS-R, with a mean score of 34 ± 2.6, compared to those with lower perceived control whose mean scores were 25 ± 4.8. Those with higher perceived control also had on average lower scores on the PHQ-9 compared with those with lower perceived control. Lastly, those with higher perceived control had lower scores on the BSI Anxiety subscale compared to the lower perceived control group.

4.4.1 Reliability

Cronbach's alpha of the CAS-R was 0.867, indicating good internal consistency. Overall, the inter-item correlation coefficients were less than 0.8 indicating little to no redundancy among the items. All correlation coefficients were greater than 0.2, indicating that the items were related to one another (Table 4.3). Item-total correlations were all greater than 0.3, indicating that each item made a unique contribution to the scale (Table 4.4). There were also no items from that scale that if removed would make the Cronbach's alpha increase (Table 4.4), another indicator of good reliability of the scale.

4.4.2 Validity

Construct validity was tested using exploratory factor analysis. To test that factor analysis was appropriate the Kaiser-Meyer-Olkin statistic was run, with a result of 0.828. The Bartlett's test p-value was less than 0.001, indicating that factor analysis was

appropriate to conduct in this sample. Through exploratory factor analysis, one factor loaded with an Eigenvalue of 4.183. This indicates that the CAS-R in the LVAD population is only measuring one construct. The factor explained 52% of the variance in the responses. Table 4.5 demonstrates the loadings of each individual items under the one factor.

In testing Hypothesis 1a, a two-group t-test demonstrated that the relationship of perceived control on depressive symptoms was significant (Table 4.6). When testing Hypothesis 1b, perceived control was independently associated with depressive symptoms in a multivariate linear regression analysis, including age, gender, education, and whether they lived with someone, as well as perceived control was the only significant predictor of depressive symptoms (Table 4.7).

In Hypothesis 2a, a two-group t-test demonstrated that the relationship of perceived control on anxiety symptoms was significant (Table 4.8). A multivariate linear regression analysis to test Hypothesis 2b included age, gender, education, whether they lived with someone, and perceived control and showed that perceived control was the only variable independently associated with anxiety symptoms in the model (Table 4.9).

4.5 Discussion

The results of this study provide evidence that the 8-tem CAS-R is a reliable and valid measure of perceived control in the LVAD population. Reliability testing evidence from Cronbach's alpha coefficient, inter-item correlations, and item-total correlations, indicate that the CAS-R had good internal consistency. Evidence of validity was also provided through construct validity testing and convergent validity hypothesis testing.

The CAS-R loaded on only one factor, indicating that the scale was only measuring one construct, that of perceived control. This is similar to other factor analyses done of the CAS-R.[8] We were also able to observe that patients with LVAD who had higher levels of perceived control, had lower levels of anxiety and depressive symptoms, similar to other cardiac populations.[8,13]

It is critical to have a validated instrument of perceived control in this population because of our lack of understanding of predictors of good quality of life with an LVAD.[14,15] In other populations, especially populations with a cardiac device, there is evidence of the important role that perceived control plays in positive outcomes,[4,9,10,13] however, this had not been demonstrated in the LVAD population. A reliable and valid scale will help clinicians and researchers to accurately identify the role perceived control plays in patients with an LVAD. Improving perceived control would ideally be a target for interventions that can improve quality of life and broaden our understanding of what life with a device truly entails.

4.6 Conclusion

This study demonstrates that the CAS-R is a reliable and valid instrument to use in the LVAD population to measure perceived control. Clinicians and researchers can use the instrument to identify the role perceived control plays in outcomes of patients with an LVAD and target ways to improve perceived control among these patients.

Table 4.1 Participant Characteristics, N= 89				
	All Participants, Mean±SD or n (%)	Higher Perceived Control n= 41 (46)	Lower Perceived Control n=48 (54)	p-value
Age (years)	53 ± 14	53 ± 16	53 ± 12	0.844
Gender (male)	81 (80.2)	55 (57)	41 (43)	0.538
CAS-R	29.1 ± 6	34 ± 2.6	25 ± 4.8	<0.001
PHQ-9	6.4 ± 5.3	4.3 ± 3.7	8.1 ± 6	<0.001
BSI Anxiety Subscale	3 ± 3.6	1.9 ± 2.9	3.9 ± 3.9	0.005
Legend CAS-R: Control Attitudes Scale-Revised; PHQ-9: Patient Health Questionnaire-9; BSI: Brief Symptom Inventory				

Table 4.2. The Control Attitudes Scale-Revised Items
1. If I do all the right things, I can successfully manage my heart condition
2. I can do a lot of things myself to cope with my heart conditions
3. When I mange my personal life well, my heart condition does not bother me as much
4. I have considerable ability to control my symptoms
5. No matter what I do, or how hard I try, I just can't seem to get relief from my symptoms*
6. I am coping effectively with my heart condition
7. Regarding my heart problems, I feel lots of control
8. Regarding my heart problems, I feel helpless*
Legend: * reverse coded

Table 4.3 Inter-Item Correlation of the CAS-R, overall Cronbach's Alpha 0.867								
	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8
Item 1	1.00							
Item 2	0.516	1.00						
Item 3	0.546	0.563	1.00					
Item 4	0.459	0.523	0.544	1.00				
Item 5	0.536	0.318	0.416	0.264	1.00			
Item 6	0.440	0.524	0.297	0.346	0.272	1.00		
Item 7	0.506	0.445	0.603	0.696	0.414	0.437	1.00	
Item 8	0.471	0.338	0.368	0.326	0.539	0.446	0.484	1.00
Legend: CAS-R: Control Attitudes Scale-Revised								

Table 4.4. Item-Total Statistics for the CAS-R		
	Item-Total Correlation	Cronbach's Alpha if item deleted
Item 1	0.687	0.844
Item 2	0.629	0.850
Item 3	0.667	0.846
Item 4	0.626	0.851
Item 5	0.532	0.860
Item 6	0.531	0.860
Item 7	0.725	0.838
Item 8	0.574	0.856
Legend: CAS-R: Control Attitudes Scale-Revised		

Table 4.5 Factor Loadings for the CAS-R	
	Loadings for Factor 1
Item 1	0.779
Item 2	0.735
Item 3	0.762
Item 4	0.731
Item 5	0.639
Item 6	0.639
Item 7	0.804
Item 8	0.676

Table 4.6 Differences in depressive symptoms based on high versus low levels of perceived control (N=89)			
	Low Perceived Control (n=48)	High Perceived Control (n=41)	P-value
PHQ-9 Total Score	8 ± 6	4.4 ± 3.7	0.001
Legend: F statistic 11.915, Brown-Forsyth p-value 0.001 (Levene p-value 0.002); PHQ-9-patient health questionnaire-9			

Table 4.7 Multivariate Linear Regression Model: Perceived control as an independent predictor of depressive symptoms (N=89)					
	Beta	95% Confidence Interval	β	SE	P-value
CAS-R total score	-0.392	-0.563- -0.222	-0.446	0.086	<0.001
Age	0.013	-0.063-0.088	0.033	0.038	0.740
Gender (male)	1.295	-1.163-3.753	0.102	1.236	0.298
Education Level	0.378	-0.395- 2.915	0.96	0.389	0.334
Living Alone (check about this) 0=alone, 1= with someone	-0.372	-3.658- 2.915	-0.022	1.652	0.823
Legend: overall p-value 0.001; B: standardized beta coefficient; SE: standard error; overall adjusted r-square 0.177					

Table 4.8 Differences in anxiety symptoms based on high versus low levels of perceived control (N=89)			
	Low Perceived Control (n=48)	High Perceived Control (n=41)	P-value
BSI Anxiety Subscale Total Score	3.9 ± 3.9	1.9 ± 2.9	0.005
Legend: F statistic 8.127, Brown-Forsyth p-value 0.005 (Levene p-value 0.035); BSI- Brief Symptom Inventory Anxiety Subscale			

Table 4.9 Multivariate Linear Regression Model: Perceived control as an independent predictor of anxiety symptoms (N=89)					
	Beta	95% Confidence Interval	β	SE	P-value
CAS-R total score	-0.186	-0.308--0.065	-0.317	0.061	0.003
Age	0.002	-0.052-0.056	0.007	0.027	0.947
Gender (male)	1.338	-0.410- 3.086	0.157	1.236	0.132
Education Level	0.053	-0.497-0.603	0.020	0.389	0.849
Living Alone (check about this) 0=alone, 1= with someone	-0.317	-2.653- 2.020	-0.028	1.652	0.788
Legend: overall p-value 0.047; B: standardized beta coefficient; SE: standard error; overall adjusted r-square 0.071					

CHAPTER FIVE. END-OF-LIFE ATTITUDES AND EXPERIENCES OF PATIENTS WITH A LEFT VENTRICULAR ASSIST DEVICE

5.1 Introduction

Patients with advanced heart failure (HF) were historically treated with medical management only; however, in the last 10 years the use of advanced surgical treatment options, such as a left ventricular assist device (LVAD), have become viable treatment options. Since the Food and Drug Administration (FDA) first approved LVADs for use as bridge to heart transplantation in 1994, the science and rapid utilization of these devices has grown exponentially.[1] Between 2008 and 2017, over 17,000 LVAD's were implanted in the United States,[2] and that number will continue to grow due to the lack of available donor hearts and the growing number of Americans with HF.[3,4]

While scientific advancements such as LVADs increase life expectancy in some individuals compared to optimal medical management,[5] most recent data show that the there is still a high mortality rate at one year of about 19%,[2] and at times, poorer quality of life than without an LVAD.[6] The most common causes of death in the LVAD population are neurologic complications, multi-system organ failure, and infection.[7] There is also a possibility of pump thrombosis, which occurs when a large clot obstructs flow through the device, causing the device to malfunction. When this occurs, a pump exchange usually is required; however, patients who have a pump exchange exhibit much higher rates of mortality compared to patients who have only one pump in their lifetime.[7] Pump exchanges related to thrombus occur in about 7% of patients in the first year, and up to 18% at year two.[8] Thus, despite the life-prolonging capacity of LVADs, there are still significant risks associated with the device that can ultimately lead to death.

Because of the high mortality rates, and increased morbidity and mortality associated with pump exchanges,[8] it is critical that patients who have been implanted with an LVAD and their healthcare providers discuss end-of-life (EOL) situations and

care. However, many LVAD providers have limited experience with deactivation, with only 42% of American cardiologists having been involved in the care of a patient who had their device deactivated.[9] There are differing opinions among providers on how to approach EOL discussions with patients who have an LVAD, and whether deactivation is an ethical option.[9-11] As a result of lack of provider consistency and knowledge on broaching EOL discussions with this population, patients and caregivers often express confusion and uncertainty about options for EOL with an LVAD, and report frustration when attempting to get information from providers.[11,12]

The high incidence of cognitive impairment in patients with HF compounds difficulties in shared decision making among patients, caregivers and providers.[13] Cognitive impairment leads to blunted responses of HF patients, difficulty responding in conversations, or slower responses to physiologic symptoms that indicate the need for intervention.[14] Mild cognitive impairment in the HF population is associated with higher rates of readmissions and death,[15] thus necessitating more urgent and thorough EOL conversations.

To provide support and education for patients with an LVAD, an exploration of experiences and attitudes about EOL issues is needed. Specifically, there is a need to focus on patients' feelings about living with their LVAD within the context of another terminal illness or worsening of current illnesses, while also considering the impact of cognitive function. This will help clinicians understand how experiences and attitudes about the LVAD influence patient preferences when nearing EOL. The purpose of this study was to explore patients' attitudes and experiences about EOL related to LVAD

deactivation and pump exchange and examine the impact of cognitive status on these attitudes and experiences. The specific aims of this study were to:

Specific Aim 1: Describe patients' attitudes and experiences of discussions with their healthcare about pump exchange and LVAD deactivation at EOL.

Specific Aim 2: Determine the association of cognitive function with patients' attitudes and experiences toward pump exchange and LVAD deactivation.

5.2 Methods

5.2.1 Sample, Study Design, and Data Collection

This study was a cross-sectional correlational design. Patients with an LVAD invited to participate met the following inclusion criteria: 1) had an implanted LVAD for the treatment of end-stage heart failure; 2) LVAD was implanted for at least 30 days prior to enrollment in the study; 3) able to complete a three-question cognition assessment and; 4) able to speak and write English. Exclusion criteria were: 1) less than 18 years of age and 2) institutionalized or resided in an extended care nursing facility. Participants were screened by a recruiter for eligibility. Those who met inclusion criteria and agreed to participant were referred to the project directors who met with the participants to obtain informed consent. Participants were asked to complete a questionnaire packet and received $20 compensation for their time. Data collection took place between November 2018 and February 2019. This study was approved by the Institutional Review Board at the University of Kentucky.

5.2.2 Demographic and Clinical Data

Demographic data and health history were self-reported. Lab values, information about LVAD therapy, such as pump exchange history, and implantable cardioverter defibrillator (ICD) implantation were obtained through review of patients' medical record. Information regarding implant indication (destination therapy versus bridge to transplant), date of implantation, pre-operative New York Hospital Association (NYHA) class, and Intermacs profile (a clinical profile of health status at time of LVAD implantation) were collected using the Intermacs database.

5.2.3 End-of-life with an LVAD Questionnaire

Patients' experiences and attitudes about EOL were collected using a survey initially created for patients with an implantable cardioverter defibrillator that was modified to reflect the LVAD patient perspective.[16] The End-of-Life with an ICD Questionnaire (EOLICDQ) was modified with the assistance of the developer and the modified instrument was called the End-of-Life with an LVAD Questionnaire (EOL-LVADQ). The EOL-LVADQ is a 22-question survey that focuses on patients' attitudes and experiences about decision making surrounding EOL, specifically deactivation of the LVAD and pump exchanges. Participants responded to the statements with either agree/disagree, yes/no, or cannot take a stand. The items on this survey are not scored, and therefore are not totaled; the items should be evaluated individually and responses can be compared. The last six questions on the survey allowed participants to respond with agree/disagree or 'can't take a stand'. Because, very few participants chose the 'can't take a stand' response, those who chose this response were not included in the analysis.

5.2.4 Cognition Assessment

Cognition was evaluated in this study using the Montreal Cognitive Assessment (MoCA), which is a brief cognitive screening tool, widely used in multiple populations to identify mild cognitive impairment (MCI).[17] Mild cognitive impairment is commonly understood as a decline in one or more cognitive functions, which is not attributed to other neuro-cognitive diseases such as dementia or Alzheimer's.[17,18] The MoCA has been validated in the heart failure population as a reliable measurement of cognition and MCI.[19] The range of scores on the MoCA is 0-30. The cut-point recommended by the authors was used in this study. Thus, a score of 0-25 was considered to meet the criteria for MCI and scores 26 and above were categorized as normal cognition.[18,20]

5.2.5 Data Analysis

SPSS version 24 was used for data analysis. Frequencies and proportions, means ± standard deviations, and median, 25th, and 75th percentiles were used to describe demographic and clinical characteristics. Comparison of demographic and clinical characteristics, as well as experiences and attitudes about EOL decision making between normal cognition and MCI groups was completed using X^2 and independent t-tests. Logistic regression analysis was used to determine whether MoCA score was an independent predictor of whether participants had discussed end-of-life scenarios or pump exchange with their providers. A p-value of less than 0.05 was considered statistically significant.

5.3 Results

5.3.1 Sample Characteristics

A total of 30 participants completed the questionnaire (Table 5.1), but one was unable to complete the MoCA and was excluded from subsequent analyses. The majority of the sample was male (76.7%), white (90%), and married (50%). Most were NYHA class IV (70%) prior to implant, and had an Intermacs profile score of 2 or 3 (76.7%), indicating progressive or acute decline of health status requiring inotropic support. Most participants at the time of their interview had an LVAD implanted for destination therapy (63.3%), indicating they were not currently a candidate for heart transplantation. The mean number of days with LVAD therapy was 702, with a range of 34 days to 2,472 days. Most participants had an implantable cardioverter defibrillator (83.3%), and had not had a pump exchange (90%). There was a high incidence of comorbidity burden in the population. A total of 46.7% of the total sample had diabetes, 53.3% reported hypertension, 20% had kidney failure, 60% reported either a history or current atrial fibrillation, and 33.3% reported some type of lung disease, either chronic obstructive pulmonary disorder or asthma. Four (13.3%) participants also reported a history of a stroke in the past, and 12 (40%) reported they had a myocardial infarction prior to LVAD implantation.

5.3.2 Cognitive Assessment

In the final sample of 29 participants, the average MoCA score was 23 ± 4, with 23 of the 29 participants (79%), scoring less than a 26 indicating MCI. The average score of those participants with MCI was 22 ± 3, and the average score of those with normal cognition was 28 ± 1 ($p<0.001$). Demographically, both groups were very similar, however, one significant difference was that the group with normal cognition were more

likely to be bridge to transplant patients (83.3%), compared to those with MCI (26.1%, p-value 0.010; Table 5.1).

5.3.3 End-of-Life with an LVAD Questionnaire

To describe patients' experiences and attitudes related to EOL decision-making, responses from the EOL-LVADQ were evaluated. Overall, 69% of the participants responded that they had discussed a pump exchange with their provider, and 58.6% said they had discussed what turning off the LVAD involves with their provider. Only 3.4% of the participants had ever considered asking their provider to turn off the LVAD at some point. Over 80% of participants said they would want to have a pump exchange even if their quality of life had not improved with their first pump, and 73% said they would want to have a pump exchange even if they were seriously ill and suffering from another disease besides HF. Only 48.3% of participants said they had discussed their wishes regarding EOL and their LVAD with the next-of-kin, despite 75.9% stating they had discussed their illness trajectory with their next-of-kin. When discussing when providers should bring up questions regarding deactivation, 44.8% of the participants said they would prefer to never have a deactivation discussion. A total of 86.2% thought that toward the EOL, during the final days, deactivation should be discussed, but only 51.7% said they felt it should be discussed if they were suffering from a different disease with a poor prognosis, such as cancer.

To determine if cognition was associated with EOL decision making, we compared the responses of participants who had a MoCA score of 0-25 (MCI) and those with MoCA scores 26 and greater (Table 5.2). In general, there was very little variation in the experiences and attitudes of the two cohorts. The only significant difference between

the two cohorts was that those who had MCI were more likely to report that they would like to decide themselves if their LVAD was deactivated towards the EOL ($p = 0.017$). Otherwise, the cohorts responded similarly.

5.3.3.1 Logistic Regression Analysis

Although a sample of 30 LVAD patients is considered relatively large in the LVAD arena (only about 2500 LVADs are implanted each year), statistically it is small and, we were unable to generate a stable regression model to evaluate the relationship between cognition and EOL decision-making, controlling for other relevant covariates. In bivariate analysis, total MoCA score was not a predictor of having a conversation with provider or next-of-kin regarding discussions related to deactivating the LVAD or pump exchange.

5.4 Discussion

The analysis we conducted provides initial insight for researchers and clinicians to have a more thorough understanding of what patients with an LVAD have experienced and feel about EOL decision making. Due to the high rates of mortality and life-threatening complications associated with LVAD implantation, EOL conversations and decision making are imperative. In order to be prepared for adverse events that may occur, guidelines provided by professional organizations urge LVAD teams to discuss EOL care, and integrate palliative care with patients and their families, even prior to any EOL scenario.[21,22] Over 40% of our sample did not discuss deactivation of the LVAD device and or pump exchange with their providers and their next-of-kin even though the majority had their LVAD for almost 2 years. This indicates that less than 50% of the

participants had discussed their wishes about EOL care with their next-of-kin, who would be their primary decision maker if they became incapacitated toward the EOL.

The recent Intermacs analysis showed over 75% of LVAD patients die in the hospital.[23] This finding is important because in a large systematic review, researchers found that dying at home is the primary preference of most patients and an indicator of better EOL care.[24] Shared decision making regarding preferences and plan for EOL care among patients, next-of-kin, and providers, may increase the possibility for patient preferences to be honored at the EOL and decrease frustration and confusion that often occurs for patients with an LVAD and their caregivers.[25]

We saw no differences between our participants with normal cognition and those with MCI. In the future, we may need to consider whether a higher threshold for MCI affects EOL decision making in a larger sample. Further analysis may want to focus on whether there are specific areas of cognition that are related to EOL decision making, such as language, abstraction, or memory, which may individually be more impactful than cognition as a whole. It would also be important to analyze whether depression or anxiety are associated with these relationships, as people with MCI have higher rates of depression and anxiety than those without MCI, which may have confounded our results.[15]

It is also important to recognize that many of our patients did not want to have an EOL conversation. As providers and researchers, it is imperative to find ways to integrate these crucial conversations into standard care, and promote the benefit of decreased confusion and make the EOL process less stressful. Many national organizations across the country recognize this need across different populations and created initiatives such

as The Conversation Project and Caring Connections which aim to inform the general public about the importance of discussing the EOL with loved ones.[26] Through open conversations between stake-holders in EOL decision-making, painful and confusing scenarios could be avoided, such as being shocked inappropriately by an implantable cardioverter defibrillator, or being unaware of the ability to deactivate the LVAD device in the setting of a terminal illness. The additional layers added to EOL care created by having a cardiac device necessitate the need and importance of communicating about EOL scenarios prior to an EOL situation.

In addition to EOL discussions, it is crucial the providers continue to educate patients and their families regarding the purpose of the LVAD and the limitation of pump exchanges. In this study, over 25% of the population said they would want a pump exchange even if they were suffering from another terminal illness such as cancer, and 81% said they would want a pump exchange despite their quality of life not improving with the first pump. Providers need to ensure patients are aware of the risks that pump exchange can create, and if scenarios arise what situations might prompt a discussion related to end-of-life versus a pump exchange surgery. It seems there are many misconceptions related to when a pump exchange would be an acceptable treatment option, especially in the setting of another terminal disease besides HF, and with more guidance and education from providers, these misconceptions could decrease. However, these notions of persevering, despite life-threatening obstacles, are supported by findings that although most people say they want higher quality of life, compared to quantity of life,[27] when EOL situations occur, many individuals change their minds and choose life at all costs.

Misunderstandings about LVADs and lack of EOL discussions with providers may also be related to lack of provider knowledge about EOL decision making. Providers of patients with LVADs also struggle to know what their role is and how to educate patients and family members about the decision making processes.[28] In an analysis of cardiologists and palliative care physicians who routinely take care of patients with an LVAD, researchers found that there are several different perspectives among providers, and that this may lead to increased confusion for patients and their caregivers due to varying opinions or lack of opinions voiced by the physicians who take care of them.[28] In the future, more emphasis is needed on the role that providers play in informing patients and families regarding EOL scenarios, and ensure that they have adequate understanding of how the device functions in various EOL scenarios.

In a recent qualitative study, patients with an LVAD and their caregivers had a mind set about 'being saved' and feeling a moral obligation to continue fighting no matter the obstacles.[29] This sense of moral obligation to continue fighting, and a sense that this expensive and complex device saved their lives, so patients' feel a need to continue fighting and persevering, despite threats of mortality, may be related to patients not wanting to discuss EOL with their providers, as well as a mentality to continue with treatments despite life-threatening diagnoses.

Moving forward, more emphasis is needed to ensure patients and their families have a realistic expectation of life with an LVAD and that EOL discussions are had prior to implantation and continued throughout care. We also need to ensure that providers are equipped with the skills and knowledge to discuss EOL decision making throughout the care continuum of patients with an LVAD. By continuing to research and educate EOL

decision making, we could prevent confusing, painful, and frustrating situations that may arise at the EOL for family members and patients with an LVAD.

5.5 Limitations

The sample was from a single-center, thus limiting generalizability. The end-of-life questionnaire was based on hypothetical scenarios which can be problematic for applicability and generalizability, however, to get data about this type of information, self-report is the only way. The sample size was small, and may not have been powered strong enough to conclude there was no differences between groups, however, in the LVAD literature, 30 LVAD patients is quite large and thus may be an adequate sample size.

5.6 Conclusions

End-of-life decision making for patients with chronic illness is a complex process, and adding advanced medical technology to that process can increase complexity. Approximately half of our population had discussed EOL decisions with their providers or their next of kin, indicating a large gap in care. Patients who had MCI, which was around 80% of our sample, did not have different experience and attitudes regarding EOL decision making. More emphasis needs to be placed on educating patients and their families about these difficult decisions made at the EOL, as well as educating providers about ways to discuss EOL scenarios with patients. By improving these conversations and understanding what may influence EOL decision making, we can hopefully improve decision making processes for patients with an LVAD and their families when they reach the EOL.

Table 5.1 Participant characteristics for the total sample and compared between those with and without mild cognitive impairment				
	Full Sample (N=30)	MoCa Score 25 and below (n=23)	MoCa Score 26-30 (n=6)	P-value
Age (years)	57 ± 16, range 21-79	60 ± 14	45 ± 19	0.135
Sex: male, n (%)	23 (76.7)	17 (73.9)	5 (83.3)	0.620
Race n (%)				
White	27 (90)	20 (87)	6 (100)	0.224
Black or other minority	3 (10)	3 (13)	0 (0)	0.224
Marital status n (%)				
Single	7 (23.3)	4 (17.5)	3 (50)	0.141
Married	15 (50)	11 (47.8)	3 (50)	
Divorced/Separated/Widowed	8 (267)	8 (34.8)	0 (0)	
NYHA classification, n (%)				
III	8 (26.7)	5 (22.7)	2 (33.3)	0.603

IV	21 (70)	17 (77.3)	4 (66.7)	
Intermacs Profile, n (%)				
1	4 (13.3)	3 (13.6)	1 (16.7)	0.754
2	6 (20)	5 (22.7)	1 (16.7)	
3	17 (56.7)	12 (54.5)	4 (66.7)	
4	2 (6.7)	2 (9.7)	0 (0)	
Indication, n (%)				
Destination Therapy	19 (63.3)	17 (73.9)	1 (16.7)	0.010
Bridge to Transplant	11 (36.7)	6 (26.1)	5 (83.3)	
ICD Therapy, n (%)	25 (83.3)	19 (86.4)	5 (83.3)	0.853
Days with LVAD Therapy	702 ± 589, range 34 - 2472	702 ± 408	408 ± 478	0.218
Pump Exchange, n (%)	3 (10)	2 (9.1)	1 (16.7)	0.612
Diabetes, n (%)	14 (46.7)	11 (47.8)	2 (33.3)	0.525
High Blood Pressure, n (%)	16 (53.3)	12 (52.2)	4 (66.7)	0.525
Kidney Failure, n (%)	6 (20)	5 (22.7)	0 (0)	0.198
Lung Problems, n (%)	10 (33.3)	8 (36.4)	2 (33.3)	0.891

Stroke, n (%) (n=28)	4 (13.3)	4 (18.2)	0 (0)	0.302
Atrial Fibrillation, n (%) (n=26)	18 (60)	13 (68.4)	4 (66.7)	0.936
History of Myocardial Infarction, n (%) (n=27)	12 (40)	8 (42.9)	2 (40)	0.907
MoCA total score	23 ± 4, range 14 - 29	22 ± 3	28 ± 1	<0.001
BUN, median [25th,75th]				
Pre-implantation (n=28)	19 [17,30.25]	22 [18,34]	16 [11.25,21.25]	0.030*
3 months post-implant (n=27)	19 [15,21]	20 [15.5,24,5]	16 [15,19.5]	0.253*
Creatinine, median [25th,75th]				
Pre-implantation (n=28)	1.16 [0.91,1.29]	1.37 [0.9, 1.75]	1.07 [0.89,1.41]	0.307*
3 months post-implant (n=27)	1.2 [0.88,1.51]	1.16 [0.87,1.58]	1.20 [1.06,1.36]	0.795*
NT-ProBNP, median [25th,75th]				
Pre-implantation (n=23)	3065 [1131,4347]	3065 [1053,4156]	3177 [1289,6017]	0.529*

3 months post-implant (n=25)	677 [502,1815]	859 [542,1970]	495 [368,1916]	0.118*
BMI, median [25th,75th]				
Pre-implantation (n=28)	31.9 [25.0,37.5]	33.3 [24.7,38.7]	29.4 [24.9,33.6]	0.351*
3 months post-implant (n=27)	30.4 [23.7,36.5]	27.3 [23.6,37.7]	31.6 [25.5,34.1]	0.871*

Legend: Data are shown as mean±SD, except as noted. BUN- Blood urea nitrogen, ICD- Implantable cardioverter defibrillator, LVAD- left ventricular assist device, MoCA- Montreal cognitive assessment, NT-ProBNP- NT-proB-type Natriuretic peptide, NYHA- New York Hospital Association Class. All comparisons for normally distributed were conducted using X^2 likelihood ratios for nominal and ordinal level variables, independent sample paired t-test for continuous level variables, and ANOVA for more than two group comparison variables, for non-normally distributed continuous data a Mann-Whitney U test was conducted as denoted by *. A p-value of 0.05 was considered significant.

Table 5.2 End-of-Life Questionnaire responses compared between those with and without mild cognitive impairment				
End-of-Life Questions	Total Sample (N=29)	MoCa Score 25 and below (n=23)	MoCa Score 26-30 (n=6)	P-value
Experiences Domain; n (%)				
Q.1 Discussed Pump Exchange with provider: yes	20 (69)	15 (65.2)	5 (83.3)	0.372
Q.2 Discussed pump exchange with next-of-kin: yes	19 (65.5)	15 (65.2)	4 (66.7)	0.947
Q. 3 Discussed what turning off LVAD involves with provider: yes	17 (58.6)	14 (60.9)	3 (50)	0.632

Q.4 Discussed what turning off LVAD involves with next-of-kin: yes	16 (55.2)	13 (56.5)	3 (50)	0.775
Q.5 I have discussed illness trajectory of my heart disease with my provider: yes	23 (79.3)	17 (73.9)	6 (100)	0.075
Q.6 I have discussed illness trajectory of my heart disease with my next-of-kin: yes	22 (75.9)	16 (69.6)	6 (100)	0.052
Q. 7 I have told my next-of-kin my wishes regarding my	14 (48.3)	10 (43.5)	4 (66.7)	0.308

LVAD at the end-of-life				
Q.8 I have at some point considered asking my provider to turn off my LVAD	1 (3.4)	1 (4.2)	0 (0)	0.492
Q.9 I have a religious faith or outlook which helps me manage my daily life as an LVAD patient	19 (65.5)	15 (65.2)	4 (66.7)	0.947
Q. 10 I often think about questions concerning the end-of-life	9 (31)	8 (34.8)	1 (16.7)	0.372
Attitudes Domain; n (%)				

Each question began with the phrase: When should providers raise question of what turning off the LVAD involves?				
Q. 11 I never wish to have such a conversation: agree	13 (44.8)	9 (39.1)	4 (66.7)	0.226
Q.12 I myself will raise the question when I feel the need to: agree	22 (75.9)	19 (82.6)	3 (50)	0.115
Q. 13 If I am suffering from a disease with a poor prognosis other than HF: agree	15 (51.7)	12 (52.2)	3 (50)	0.924
Q. 14 Routinely upon visits to	13 (44.8)	9 (39.1)	4 (66.7)	0.226

my LVAD provider: agree				
Q. 15 Towards the end-of-life, during the last days: agree	25 (86.2)	21 (91.3)	4 (66.7)	0.153
Q.16 If my LVAD has a mechanical malfunction or has a clot in it: agree	18 (62.1)	14 (60.9)	4 (66.7)	0.793
Attitudes domain cont. n (%) Each of the following questions began with the phrase: I want to have a pump exchange…				
Q.17* Even if my quality of life has not benefitted: yes	21 (80.8)	17 (85)	4 (66.7)	0.340
Q.18* Even I am seriously ill	19 (73.1)	14 (70)	5 (83.3)	0.503

and suffering from another disease: yes				
Q. 19* Even if I have reached an advanced age: yes	15 (57.7)	10 (50)	5 (83.3)	0.130
Attitudes domain cont. n (%) Each of the following questions began with the phrase: When I find myself at the end-of-life…				
Q.20** I wish to decide myself if the LVAD is turned off or not: yes	22 (81.5)	20 (90.9)	2 (40)	0.017
Q.21^ I want the doctor to decide if the LVAD is turned off or not	11 (45.8)	10 (52.6)	1 (20)	0.178

Q.22**I want my next-of-kin to decide if the LVAD is turned off or not	18 (66.7)		3 (50)	0.336

Legend: LVAD- left ventricular assist device; MoCA- Montreal Cognitive Assessment; Samples that were not n=29 denoted by the following: *n=26, **n=27, ^n=24- this is related to patients who chose 'I cannot take a stand' and were considered missing data. All comparisons were conducted using X^2 likelihood ratios. A p-value of 0.05 was considered significant.

CHAPTER SIX. Conclusion

6.1 Background and Purpose

The overall purpose of this dissertation was to examine patients' attitudes and experiences related to end-of-life conversations involving their left ventricular assist device (LVAD) or implantable cardioverter defibrillator (ICD), and factors associated with end-of-life decision making. The following manuscripts were included in this dissertation: 1) a secondary data analysis of a national cohort of patients with an ICD in Sweden to identify factors associated with having a conversation about end-of-life with their providers, 2) an integrative review of the literature focused on end-of-life with an LVAD from the various stakeholders involved in end-of-life processes, 3) an evaluation of the psychometric properties of the Control Attitudes Scale-Revised (CAS-R) in secondary data analysis of patients with an LVAD, and lastly 4) a cross-sectional correlational study examining experiences and attitudes related to end-of-life and the relationship of cognition in patients with an LVAD.

With heart disease being the leading cause of death in the United States, end-of-life decision making is crucial for those affected by cardiac disease.[1] To treat the high rates of mortality, cardiac devices have become common, with close to 1.8 million Americans having either an LVAD or ICD.[2,3] However, despite the increased use of these devices, healthcare providers have done a poor job of informing patients about the involvement of these devices at the end-of-life. Results from numerous studies demonstrate patients with an ICD experience inappropriate shocks towards the end-of-life, even in the minutes before death, leading to unnecessary pain and suffering.[4-6] Patients with an LVAD, and their caregivers, experience frustration and confusion at the

end-of-life due to a lack of planning and discussion related to end-of-life care, and in particular how to integrate the LVAD into end-of-life plans.[7,8]

The purpose of this chapter is to summarize and synthesize the findings of the manuscripts presented in this dissertation. It will examine how the outcomes of these findings will impact and further the state of the science regarding end-of-life decision making in patients with a cardiac device. Lastly, it will recommend changes regarding practice and recommendations for research related to end-of-life care and decision making in cardiac populations.

6.2 Summary of Findings

Chapter Two is a secondary data analysis of a national cohort study of Swedish patients with an ICD, with and without heart failure, comparing end-of-life attitudes, experiences, knowledge, and factors associated with having a discussion about ICD deactivation with a healthcare provider. This study included 3,067 people with an ICD, and 1,461 (47%) stated they had heart failure. Despite our hypothesis that participants with HF would have a more comprehensive understanding of end-of-life due to their higher risk of mortality, we found no differences between the cohorts in their responses to the end-of-life with an ICD questionnaire. Subsequently, we conducted a hierarchal logistic regression analysis to identify independent predictors of having a discussion with their healthcare provider regarding end-of-life scenarios. In the final model, the significant predictors were having high level of ICD concerns, having had an ICD shock in the past, and having a high level of anxiety ($p<0.001$). In this analysis, we found that our cohort had consistent results with other studies which have demonstrated patients are reluctant to have end-of-life conversations with their providers,[9-11] with over 40% of our

participants stating they never wished to have an end-of-life discussion with their providers. These findings suggest more research is needed to assess willingness to participate in end-of-life discussions and evaluate the best ways to incorporate shared-decision making into end-of-life decision making in patients with an ICD.

Chapter Three is an integrative systematic review of the literature on the current evidence related to the process and content of end-of-life discussions with an LVAD and end of life discussion experiences of individuals, families, and healthcare providers of patients with an LVAD. Overall, there was very little evidence regarding decision making and end-of-life processes with an LVAD; only six articles were included in this review. Patients with an LVAD and their caregivers expressed frustration and confusion related to end-of-life processes associated with dying with an LVAD, and many stated they felt completely unprepared for the decisions they would have to make towards the end-of-life. The opinions of healthcare providers of patients with an LVAD suggested that there is controversy related to the ethical permissibility of deactivation of the LVAD, as well as a divide regarding practices at the end-of-life for patients with an LVAD. The evidence suggests more research is needed to understand the current healthcare practices related to end-of-life care for patients with an LVAD, as well as increased education for providers about end-of-life processes and the ethics surrounding deactivation of the LVAD in order to develop a consensus about these topics.

Chapter Four is an evaluation of the validity and reliability of the CAS-R in a cohort of patients with an LVAD. This was a secondary analysis of a longitudinal study of 89 patients with an LVAD. Cronbach's alpha in this examination was 0.867 indicating adequate internal consistency of the CAS-R instrument. Corrected item-total correlations

were all greater than 0.4 and less than 0.8, indicating homogeneity of responses and lack of redundancy among the items in the instrument. To examine convergent validity, hypothesis testing was used. We confirmed associations between lower depressive symptoms and lower anxiety symptoms, and higher levels of perceived control, correlating with other studies that have demonstrated prior relationships among these concepts.[12] Overall, the results of this psychometric evaluation support the use of the CAS-R in the LVAD population, and can be utilized to in future studies as a target for interventions which aim to improve decision making processes for patients.

Chapter Five is a primary data analysis of a cross-sectional, correlational study of 30 patients with an LVAD, examining end-of-life attitudes and experiences and the impact of cognition on these processes. Of the 29 participants able to complete cognitive testing, 23 (79%) had scores indicative of mild cognitive impairment (MCI). There were no differences in the attitudes or experiences related to end-of-life between the participants who had MCI and those with normal cognition. Overall, 41% of the cohort had never discussed end-of-life with their provider, and 30% had never discussed what an LVAD pump exchange would involve. Forty four percent of the participants said they never wanted to have a discussion with their provider regarding end-of-life situations involving their LVAD. There were also several alarming attitudes regarding LVAD pump exchanges, with 73% saying they would want to have a pump exchange even if they were seriously ill and suffering from a terminal disease other than heart failure. Despite patients with MCI having higher mortality rates in the heart failure population,[13] those with cognitive impairment in this study had similar end-of-life attitudes and experiences. There are several alarming attitudes and experiences related to decision-making at the

end-of-life and pump exchanges in the LVAD population and future research should continue to focus on identifying factors associated with these processes.

6.3 Impact of Dissertation on the State of the Science

Despite the increasing prevalence of cardiac devices to treat cardiac disease, especially end-stage heart failure,[3] there is still a gap in that providers are not fully preparing patients for end-of-life scenarios they may face with a device in place. In patients with an ICD, it is common for patients to be shocked inappropriately toward the end-of-life.[6] Further, despite recommendations from providers about device deactivation and the role of the ICD at the end-of-life, many patients are still reluctant to deactivate their device,[10,11] and do not include information about the device in their advanced directives.[9,14] In patients with an LVAD and their caregivers, frustration and confusion is the overarching theme related to end-of-life care and discussions.[7,8] This is further compounded by the fact that among providers of patients with an LVAD, there is a lack of consensus on how to handle end-of-life scenarios and questions of ethical permissibility of deactivation of the device.[15,16] In both cohorts of patients, there is a lack of guidance from professional organizations about topics that need to be addressed end-of-life scenarios, and scenarios in which it is acceptable to deactivate a device.[17-19]

Through this dissertation, I have advanced the state of the science of end-of-life decision making in patients with a cardiac device by: 1) identifying factors related to having a discussion with your provider in regards to deactivation of an ICD, 2) identifying overarching themes related to end-of-life opinions and experiences of the shareholders involved in end-of-life decision-making processes, 3) identified an appropriate measure of perceived control in the LVAD population, which could be a

target in future interventions related to end-of-life decision making, 4) and described experiences and attitudes related to end-of-life discussions related to deactivation and pump exchange in a cohort of patients with an LVAD.

In a large cohort of ICD patients I identified factors that were significantly associated with having a discussion with their provider regarding end-of-life. Understanding that end of life discussions are predicted by having an ICD shock, having a high level of concerns related to the ICD, and high levels of anxiety can help identify individuals in larger populations who may be more willing to have end-of-life discussions. I also established that there are large segments of the population who never want to have end-of-life discussions, and isolated a new group of people who may need more innovative and targeted ways to educate and involve them in end-of-life decision-making and care planning.

Next, in the integrative review of end-of-life experiences and processes for providers, families, and patients with an LVAD, I identified a dearth of research in the area. The six articles that were identified, illuminated that patients and caregivers are unprepared to make the necessary decisions regarding deactivation at the end-of-life, and are left frustrated and confused at these times. Providers in multiple fields, including cardiology, palliative medicine, and cardiothoracic surgery, all have differing opinions on how to handle end-of-life scenarios for patients with an LVAD, and are unsure of the ethical permissibility of deactivation. This limited evidence highlights the need to develop a more comprehensive understanding of what patients are being told about end-of-life with an LVAD, and how providers' opinions are related to when these discussions occur. This review of the literature provided the foundation for the cross-sectional study

related to end-of-life experiences and attitudes for patients with an LVAD reported in Chapter Five.

In order to ensure there was an adequate measure of perceived control in the LVAD population, the findings in Chapter Four established that using the CAS-R in the LVAD population is a valid and reliable measurement of perceived control. This could aide future studies to identify the role perceived control plays in end-of-life decision-making and is also a modifiable trait that could be targeted in interventions to promote informed decision-making.

Findings in Chapter Five were the first exploration and description of end-of-life attitudes and experiences related to end-of-life deactivation and pump exchange of patients with an LVAD. These findings demonstrated, similar to those found in the ICD study, that there are significant portions of the population who have never discussed any scenarios related to end-of-life with their providers. There are also a large percentage of the population, despite the high risks associated with living with an LVAD, who would choose to never have a conversation related to end-of-life decision making. Unlike in the ICD study, we were unable to isolate specific factors that predicted having an end-of-life discussion with their provider or next-of-kin regarding end-of-life, and further research is needed to continue to understand these phenomena.

Finally, through all the findings from this dissertation, I am beginning to assemble the foundations of a conceptual model aimed at identifying factors associated with end-of-life decision making for patients with a cardiac device. By beginning to identify specific factors such as ICD shock history, and high levels of concern and anxiety, identified in the ICD study, we can see that there are certain predictors associated with

higher rates of end-of-life discussions. Through the integrative review, we can see that lack of education and guidance to patients, families, and providers result in disjointed and poor end-of-life setting for all shareholders involved. By having a validated tool to measure a possible factor involved in end-of-life decision making, as seen in the CAS-R testing, we can begin to test perceived control as a possible target in end-of-life decision making framework. And lastly, by examining the experiences and attitudes related to end-of-life decision-making in the LVAD population, we can start to analyze various factors that this unique population all needs addressed in their decision-making process. Also, in the LVAD end-of-life study, we aimed to identify the role that cognition may play in end-of-life decision making, and while in this study, it did not impact decision-making, more research in the future is needed to clearly identify the role that cognition plays in these complicated processes. Through these studies, an outline of a framework can begin to be deciphered and more thoroughly tested in the future.

6.4 Recommendations for Practice and Research

End-of-life decision making is an over-looked component of care for patients with a cardiac device. In multiple studies, evidence has shown that patients with cardiac devices are not informed about the decisions that should be made prior to end-of-life scenarios, which could ultimately end up harming the patient. Future studies should continue to examine the experiences of patients and their families regarding the experiences related to end-of-life situations they are experiencing, especially in the LVAD community. I hope to continue the study described in Chapter Five at other institutions to identify if there are similar themes observed when other care-providers are involved.

Another large gap in the current literature and practice is what providers are being taught and what are they experiencing when trying to discuss end-of-life scenarios with their patients. In two populations of patients who have cardiac devices, and both demonstrated that 40% had never discussed end-of-life scenarios with their providers. It is critical to understand what may deter providers from discussing end-of-life with certain patients, or if there is a disconnect where providers feel they have discussed a concept adequately, but in fact the patient does not feel the issue has been discussed. In discussing this phenomenon with another LVAD researcher, Colleen McIlvennan, DNP, RN, she also agrees that more research is needed on provider education about end-of-life discussions, and she is currently in the grant-submission process on a study within this area.

Additional studies are also needed in the area related to reaching people who do not want to discuss end-of-life decision making. In both the LVAD and ICD study, around 40% said they never wished to have a discussion with their provider regarding deactivation or end-of-life. It would prudent to qualitatively evaluate these types of patients to see what their concerns related to this topic are and how healthcare providers and researchers can more adequately meet their needs, increase their comfort surrounding these types of conversations, and ensure they have the tools they need to make decisions for end-of-life care.

Last, over the course of my career I hope to continue to build on the conceptual model around decision-making at the end-of-life. By continuing to identify factors involved in these processes, we can begin to target interventions aimed at improving

patient, family, and provider participant in this extremely complicated decision-making process.

REFERENCES

Chapter One References

1. Xu J, Murphy SL, Kochanek KD, Bastian B, Arias E. Deaths: Final Data for 2016. *National vital statistics reports : from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*. 2018;67(5):1-76.

2. Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart Disease and Stroke Statistics-2017 Update: A Report From the American Heart Association. *Circulation*. 2017;135(10):e146-e603.

3. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circulation Heart Failure*. 2013;6(3):606-619.

4. Allen LA, Fonarow GC, Liang L, et al. Medication Initiation Burden Required to Comply With Heart Failure Guideline Recommendations and Hospital Quality Measures. *Circulation*. 2015;132(14):1347-1353.

5. Guaricci AI, De Santis D, Rabbat MG, Pontone G. Cardiac magnetic resonance imaging and primary prevention implantable cardioverter defibrillator therapy: current recommendations and future directions. *Journal of cardiovascular medicine (Hagerstown, Md)*. 2018;19(5):223-228.

6. Connolly SJ, Hallstrom AP, Cappato R, et al. Meta-analysis of the implantable cardioverter defibrillator secondary prevention trials. AVID, CASH and CIDS

studies. Antiarrhythmics vs Implantable Defibrillator study. Cardiac Arrest Study Hamburg . Canadian Implantable Defibrillator Study. *European heart journal*. 2000;21(24):2071-2078.

7. Fonarow GC, Yancy CW, Hernandez AF, Peterson ED, Spertus JA, Heidenreich PA. Potential impact of optimal implementation of evidence-based heart failure therapies on mortality. *American heart journal*. 2011;161(6):1024-1030.e1023.

8. Fonarow GC, Hernandez AF, Solomon SD, Yancy CW. Potential Mortality Reduction With Optimal Implementation of Angiotensin Receptor Neprilysin Inhibitor Therapy in Heart FailureImplementation of Angiotensin Receptor Neprilysin Inhibitor TherapyImplementation of Angiotensin Receptor Neprilysin Inhibitor Therapy. *JAMA Cardiology*. 2016;1(6):714-717.

9. Caraang C, Lanier GM, Gass A, Aronow WS, Gupta CA. Left Ventricular Assist Device in Older Adults. *Heart failure clinics*. 2017;13(3):619-632.

10. Rose EA, Moskowitz AJ, Packer M, et al. The REMATCH trial: rationale, design, and end points. Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure. *The Annals of thoracic surgery*. 1999;67(3):723-730.

11. Stevenson LW, Miller LW, Desvigne-Nickens P, et al. Left ventricular assist device as destination for patients undergoing intravenous inotropic therapy: a subset analysis from REMATCH (Randomized Evaluation of Mechanical Assistance in Treatment of Chronic Heart Failure). *Circulation*. 2004;110(8):975-981.

12. Kirklin JK, Naftel DC, Stevenson LW, et al. INTERMACS database for durable devices for circulatory support: first annual report. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2008;27(10):1065-1072.

13. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: Special focus on framing the impact of adverse events. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2017;36(10):1080-1086.

14. Lampert R, Hayes DL, Annas GJ, et al. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart rhythm*. 2010;7(7):1008-1026.

15. Jacues L, Schafer, J, Smith, K et al. Decision Memo for Ventricular Assist Devices for Bridge-to-Transplant and Destination Therapy (CAG-00432R). 2013. Accessed September 29th, 2017.

16. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: Executive summary. *The Journal of Heart and Lung Transplantation*. 2013;32(2):157-187.

17. Mitchell LB, Pineda EA, Titus JL, Bartosch PM, Benditt DG. Sudden death in patients with implantable cardioverter defibrillators: the importance of post-shock

electromechanical dissociation. *Journal of the American College of Cardiology*. 2002;39(8):1323-1328.

18. Sherazi S, Daubert JP, Block RC, et al. Physicians' preferences and attitudes about end-of-life care in patients with an implantable cardioverter-defibrillator. *Mayo Clinic proceedings*. 2008;83(10):1139-1141.

19. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of implantable cardioverter defibrillators in end-of-life care. *Annals of internal medicine*. 2004;141(11):835-838.

20. Goldstein NE, Mehta D, Siddiqui S, et al. "That's like an act of suicide" patients' attitudes toward deactivation of implantable defibrillators. *Journal of general internal medicine*. 2008;23 Suppl 1:7-12.

21. Kobza R, Erne P. End-of-life decisions in ICD patients with malignant tumors. *Pacing and clinical electrophysiology : PACE*. 2007;30(7):845-849.

22. Chamsi-Pasha H, Chamsi-Pasha MA, Albar MA. Ethical challenges of deactivation of cardiac devices in advanced heart failure. *Current heart failure reports*. 2014;11(2):119-125.

23. McLean S, Dhonnchu TN, Mahon N, McQuillan R, Gordijn B, Ryan K. Left ventricular assist device withdrawal: an ethical discussion. *BMJ supportive & palliative care*. 2014;4(2):193-195.

24. Phan JA, Muthiah K, Robson D, et al. Death on an LVAD-Two sides of a coin. *Heart, lung & circulation*. 2013;22(11):952-954.

25. Rady MY, Verheijde JL. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: left ventricular assist devices and total artificial hearts. *Journal of intensive care medicine*. 2014;29(1):3-12.

26. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD. Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients With a Left Ventricular Assist Device. *JAMA internal medicine*. 2016;176(4):534-539.

27. Barg FK, Kellom K, Ziv T, Hull SC, Suhail-Sindhu S, Kirkpatrick JN. LVAD-DT: Culture of Rescue and Liminal Experience in the Treatment of Heart Failure. *The American journal of bioethics : AJOB*. 2017;17(2):3-11.

28. Brush S, Budge D, Alharethi R, et al. End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2010;29(12):1337-1341.

29. Swetz KM, Cook KE, Ottenberg AL, Chang N, Mueller PS. Clinicians' attitudes regarding withdrawal of left ventricular assist devices in patients approaching the end of life. *European journal of heart failure*. 2013;15(11):1262-1266.

30. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *Journal of cardiac failure*. 2017;23(9):708-712.

31. Swetz KM, Wordingham SE, Armstrong MH, Koepp KE, Ottenberg AL. Hospice and Palliative Medicine Clinician Views of Deactivation of Ventricular Assist

Devices at the End of Life. *Journal of pain and symptom management*. 2015;50(2):e6-8.

32. Lee CS, Mudd JO, Gelow JM, et al. Background and design of the profiling biobehavioral responses to mechanical support in advanced heart failure study. *The Journal of cardiovascular nursing*. 2014;29(5):405-415.

Chapter Two References

1. Benjamin EJ, Virani SS, Callaway CW, et al. Heart Disease and Stroke Statistics-2018 Update: A Report From the American Heart Association. *Circulation*. 2018.
2. Fonarow GC, Yancy CW, Hernandez AF, Peterson ED, Spertus JA, Heidenreich PA. Potential impact of optimal implementation of evidence-based heart failure therapies on mortality. *American Heart Journal*. 2011;161(6):1024-1030.e1023.
3. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of implantable cardioverter defibrillators in end-of-life care. *Annals of internal medicine*. 2004;141(11):835.
4. Westerdahl AK, Sutton R, Frykman V. Defibrillator patients should not be denied a peaceful death. *International journal of cardiology*. 2015;182:440-446.
5. Lampert R, Hayes DL, Annas GJ, et al. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy: This document was developed in collaboration and endorsed by the American College of Cardiology (ACC), the American Geriatrics Society (AGS), the American Academy of Hospice and Palliative Medicine (AAHPM); the American Heart Association (AHA), the European Heart Rhythm Association (EHRA), and the

Hospice and Palliative Nurses Association (HPNA). *Heart Rhythm*. 2010;7(7):1008-1026.

6. Goldstein NE, Mehta D, Siddiqui S, et al. "That's Like an Act of Suicide" Patients' Attitudes Toward Deactivation of Implantable Defibrillators. *Journal of General Internal Medicine*. 2008;23(1):7-12.

7. Kobza R, Erne P. End-of-life Decisions in ICD Patients with Malignant Tumors. *Pacing & Clinical Electrophysiology*. 2007;30(7):845-849.

8. Thylen I, Wenemark M, Fluur C, Stromberg A, Bolse K, Arestedt K. Development and evaluation of the EOL-ICDQ as a measure of experiences, attitudes and knowledge in end-of-life in patients living with an implantable cardioverter defibrillator. *European journal of cardiovascular nursing* . 2014;13(2):142-151.

9. Thylen I, Moser DK, Stromberg A, Dekker RA, Chung ML. Concerns about implantable cardioverter-defibrillator shocks mediate the relationship between actual shocks and psychological distress. *Europace* 2016;18(6):828-835.

10. Pedersen SS, van Domburg RT, Theuns DA, Jordaens L, Erdman RA. Concerns about the implantable cardioverter defibrillator: a determinant of anxiety and depressive symptoms independent of experienced shocks. *American heart journal*. 2005;149(4):664-669.

11. Olsson I, Mykletun A, Dahl AA. The Hospital Anxiety and Depression Rating Scale: a cross-sectional study of psychometrics and case finding abilities in general practice. *BMC psychiatry*. 2005;5:46.

12. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica*. 1983;67(6):361-370.

13. Moorey S, Greer S, Watson M, et al. The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *The British journal of psychiatry : the journal of mental science*. 1991;158:255-259.

14. Kramer DB, Mitchell SL, Brock DW. Deactivation of Pacemakers and Implantable Cardioverter-Defibrillators. *Progress in Cardiovascular Diseases*. 2012;55(3):290-299.

15. Stewart GC, Weintraub JR, Pratibhu PP, et al. Patient Expectations From Implantable Defibrillators to Prevent Death in Heart Failure. *Journal of Cardiac Failure*. 2010;16(2):106-113.

16. Steiner JM, Patton KK, Prutkin JM, Kirkpatrick JN. Moral Distress at the End of a Life: When Family and Clinicians Do Not Agree on Implantable Cardioverter-Defibrillator Deactivation. *Journal of pain and symptom management*. 2018;55(2):530-534.

17. Kramer DB, Matlock DD, Buxton AE, et al. Implantable Cardioverter-Defibrillator Use in Older Adults: Proceedings of a Hartford Change AGEnts Symposium. *Circulation Cardiovascular quality and outcomes*. 2015;8(4):437-446.

18. Stromberg A, Fluur C, Miller J, Chung ML, Moser DK, Thylen I. ICD recipients' understanding of ethical issues, ICD function, and practical consequences of withdrawing the ICD in the end-of-life. *Pacing and clinical electrophysiology : PACE*. 2014;37(7):834-842.

19. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine*. 2012;366(9):780-781.

20. Vermorgen M, De Vleminck A, Deliens L, et al. Do physicians discuss end-of-life decisions with family members? A mortality follow-back study. *Patient education and counseling*. 2018.

21. Truglio-Londrigan M, Slyer JT. Shared Decision-Making for Nursing Practice: An Integrative Review. *The open nursing journal*. 2018;12:1-14.

22. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. *American journal of health promotion : AJHP*. 1997;12(1):38-48.

Chapter Three References

1. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circulation Heart failure*. 2013;6(3):606-619.

2. Costanzo MR, Mills RM, Wynne J. Characteristics of "Stage D" heart failure: insights from the Acute Decompensated Heart Failure National Registry Longitudinal Module (ADHERE LM). *American heart journal*. 2008;155(2):339-347.

3. Englert JA, 3rd, Davis JA, Krim SR. Mechanical Circulatory Support for the Failing Heart: Continuous-Flow Left Ventricular Assist Devices. *The Ochsner journal*. 2016;16(3):263-269.

4. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: Special focus on framing the impact of adverse events. *The Journal of heart and*

lung transplantation : the official publication of the International Society for Heart Transplantation. 2017;36(10):1080-1086.

5. Rose EA, Gelijns AC, Moskowitz AJ, et al. Long-term use of a left ventricular assist device for end-stage heart failure. *N Engl J Med*. 2001;345(20):1435-1443.
6. Stehlik J, Estep JD, Selzman CH, et al. Patient-Reported Health-Related Quality of Life Is a Predictor of Outcomes in Ambulatory Heart Failure Patients Treated With Left Ventricular Assist Device Compared With Medical Management: Results From the ROADMAP Study (Risk Assessment and Comparative Effectiveness of Left Ventricular Assist Device and Medical Management). *Circulation Heart failure*. 2017;10(6).
7. Kirklin JK, Naftel DC, Pagani FD, et al. Seventh INTERMACS annual report: 15,000 patients and counting. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2015;34(12):1495-1504.
8. Dunlay SM, Strand JJ, Wordingham SE, Stulak JM, Luckhardt AJ, Swetz KM. Dying With a Left Ventricular Assist Device as Destination Therapy. *Circulation Heart failure*. 2016;9(10).
9. McIlvennan CK, Grady KL, Matlock DD, Helmkamp LJ, Abshire M, Allen LA. End of life for patients with left ventricular assist devices: Insights from INTERMACS. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2018.

10. Jacues L, Schafer, J, Smith, K et al. Decision Memo for Ventricular Assist Devices for Bridge-to-Transplant and Destination Therapy (CAG-00432R). 2013. Accessed September 29th, 2017.

11. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: Executive summary. *The Journal of Heart and Lung Transplantation*. 2013;32(2):157-187.

12. Chamsi-Pasha H, Chamsi-Pasha MA, Albar MA. Ethical challenges of deactivation of cardiac devices in advanced heart failure. *Current heart failure reports*. 2014;11(2):119-125.

13. McLean S, Dhonnchu TN, Mahon N, McQuillan R, Gordijn B, Ryan K. Left ventricular assist device withdrawal: an ethical discussion. *BMJ supportive & palliative care*. 2013.

14. Phan JA, Muthiah K, Robson D, et al. Death on an LVAD-Two sides of a coin. *Heart, lung & circulation*. 2013;22(11):952-954.

15. Rady MY, Verheijde JL. Ethical challenges with deactivation of durable mechanical circulatory support at the end of life: left ventricular assist devices and total artificial hearts. *Journal of intensive care medicine*. 2014;29(1):3-12.

16. Nakagawa S, Yuzefpolskaya M, Colombo PC, Naka Y, Blinderman CD. Palliative Care Interventions before Left Ventricular Assist Device Implantation in Both Bridge to Transplant and Destination Therapy. *Journal of palliative medicine*. 2017;20(9):977-983.

17. Metzger M, Song MK, Devane-Johnson S. LVAD patients' and surrogates' perspectives on SPIRIT-HF: An advance care planning discussion. *Heart & lung : the journal of critical care*. 2016;45(4):305-310.

18. Metzger M, Song MK, Ward S, Chang PP, Hanson LC, Lin FC. A randomized controlled pilot trial to improve advance care planning for LVAD patients and their surrogates. *Heart & lung : the journal of critical care*. 2016;45(3):186-192.

19. Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International journal of nursing studies*. 2009;46(4):529-546.

20. Hong QN, Gonzalez-Reyes A, Pluye P. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the Mixed Methods Appraisal Tool (MMAT). *Journal of evaluation in clinical practice*. 2018;24(3):459-467.

21. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD. Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients With a Left Ventricular Assist Device. *JAMA internal medicine*. 2016;176(4):534-539.

22. Barg FK, Kellom K, Ziv T, Hull SC, Suhail-Sindhu S, Kirkpatrick JN. LVAD-DT: Culture of Rescue and Liminal Experience in the Treatment of Heart Failure. *The American journal of bioethics : AJOB*. 2017;17(2):3-11.

23. Brush S, Budge D, Alharethi R, et al. End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *The*

Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation. 2010;29(12):1337-1341.

24. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *Journal of cardiac failure*. 2017;23(9):708-712.

25. Swetz KM, Wordingham SE, Armstrong MH, Koepp KE, Ottenberg AL. Hospice and Palliative Medicine Clinician Views of Deactivation of Ventricular Assist Devices at the End of Life. *Journal of pain and symptom management*. 2015;50(2):e6-8.

26. Swetz KM, Cook KE, Ottenberg AL, Chang N, Mueller PS. Clinicians' attitudes regarding withdrawal of left ventricular assist devices in patients approaching the end of life. *European journal of heart failure*. 2013;15(11):1262-1266.

27. Verdoorn BP, Luckhardt AJ, Wordingham SE, Dunlay SM, Swetz KM. Palliative Medicine and Preparedness Planning for Patients Receiving Left Ventricular Assist Device as Destination Therapy-Challenges to Measuring Impact and Change in Institutional Culture. *Journal of pain and symptom management*. 2017;54(2):231-236.

28. Warraich HJ, Maurer MS, Patel CB, Mentz RJ, Swetz KM. Top Ten Tips Palliative Care Clinicians Should Know About Caring for Patients with Left Ventricular Assist Devices. *Journal of palliative medicine*. 2019.

Chapter Four References

1. Thompson SC, Sobolew-Shubin A, Galbraith ME, Schwankovsky L, Cruzen D. Maintaining perceptions of control: Finding perceived control in low-control circumstances. *Journal of Personality and Social Psychology.* 1993;64(2):293-304.
2. Nesbitt T, Doctorvaladan S, Southard JA, et al. Correlates of quality of life in rural patients with heart failure. *Circulation Heart failure.* 2014;7(6):882-887.
3. Agren S, Berg S, Svedjeholm R, Stromberg A. Psychoeducational support to post cardiac surgery heart failure patients and their partners--a randomised pilot study. *Intensive & critical care nursing.* 2015;31(1):10-18.
4. Hwang B, Moser DK, Dracup K. Knowledge is insufficient for self-care among heart failure patients with psychological distress. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association.* 2014;33(7):588-596.
5. Benjamin EJ, Virani SS, Callaway CW, et al. Heart Disease and Stroke Statistics-2018 Update: A Report From the American Heart Association. *Circulation.* 2018;137(12):e67-e492.
6. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: Special focus on framing the impact of adverse events. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation.* 2017;36(10):1080-1086.
7. Adams EE, Wrightson ML. Quality of life with an LVAD: A misunderstood concept. *Heart & lung : the journal of critical care.* 2018.

8. Casida JM, Abshire M, Ghosh B, Yang JY. The Relationship of Anxiety, Depression, and Quality of Life in Adults With Left Ventricular Assist Devices. *ASAIO journal (American Society for Artificial Internal Organs : 1992).* 2017.

9. Moser DK, Riegel B, McKinley S, et al. The Control Attitudes Scale-Revised: psychometric evaluation in three groups of patients with cardiac illness. *Nursing research.* 2009;58(1):42-51.

10. Hallas CN, Burke JL, White DG, Connelly DT. Pre-ICD illness beliefs affect postimplant perceptions of control and patient quality of life. *Pacing and clinical electrophysiology : PACE.* 2010;33(3):256-265.

11. Moser DK, Dracup K. Psychosocial recovery from a cardiac event: The influence of perceived control. *Heart & Lung: The Journal of Acute and Critical Care.* 1995;24(4):273-280.

12. Moser DK, Dracup K. Impact of cardiopulmonary resuscitation training on perceived control in spouses of recovering cardiac patients. *Research in Nursing & Health.* 2000;23(4):270-278.

13. Callahan LF, Brooks, R. H., Pincus, T. Further analysis of learned helplessness in rheumatoid arthritis using a "Rheumatology Attitudes Index". *Journal of Rheumatology.* 1995;15(3):418-426.

14. Dracup K, Westlake C, Erickson VS, Moser DK, Caldwell ML, Hamilton MA. Perceived control reduces emotional stress in patients with heart failure. *The Journal of Heart and Lung Transplantation.* 2003;22(1):90-93.

15. Lee CS, Mudd JO, Gelow JM, et al. Background and design of the profiling biobehavioral responses to mechanical support in advanced heart failure study. *The Journal of cardiovascular nursing.* 2014;29(5):405-415.

16. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med.* 2001;16(9):606-613.

17. Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *Jama.* 1999;282(18):1737-1744.

18. Hammash MH, Hall LA, Lennie TA, et al. Psychometrics of the PHQ-9 as a measure of depressive symptoms in patients with heart failure. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology.* 2013;12(5):446-453.

19. Derogatis LR, Melisaratos N. The Brief Symptom Inventory: an introductory report. *Psychological medicine.* 1983;13(3):595-605.

20. Waltz CFS, O. L., & Lenz, E. R. *Measurement in Nursing and Health Research.* 5th Edition ed. New York, N.Y.: Springer Publishing Company; 2016.

Chapter Five Refernces

1. Englert JA, 3rd, Davis JA, Krim SR. Mechanical Circulatory Support for the Failing Heart: Continuous-Flow Left Ventricular Assist Devices. *The Ochsner journal*. 2016;16(3):263-269.

2. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: Special focus on framing the impact of adverse events. *The Journal of heart and*

lung transplantation : the official publication of the International Society for Heart Transplantation. 2017;36(10):1080-1086.

3. Trivedi JR, Cheng A, Gallo M, Schumer EM, Massey HT, Slaughter MS. Predictors of Donor Heart Utilization for Transplantation in United States. *The Annals of thoracic surgery*. 2017;103(6):1900-1906.
4. Heidenreich PA, Albert NM, Allen LA, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circulation Heart failure*. 2013;6(3):606-619.
5. Rose EA, Gelijns AC, Moskowitz AJ, et al. Long-term use of a left ventricular assist device for end-stage heart failure. *The New England journal of medicine*. 2001;345(20):1435-1443.
6. Stehlik J, Estep JD, Selzman CH, et al. Patient-Reported Health-Related Quality of Life Is a Predictor of Outcomes in Ambulatory Heart Failure Patients Treated With Left Ventricular Assist Device Compared With Medical Management: Results From the ROADMAP Study (Risk Assessment and Comparative Effectiveness of Left Ventricular Assist Device and Medical Management). *Circulation Heart failure*. 2017;10(6).
7. Kirklin JK, Naftel DC, Pagani FD, et al. Seventh INTERMACS annual report: 15,000 patients and counting. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2015;34(12):1495-1504.
8. Kirklin JK, Naftel DC, Pagani FD, et al. Pump thrombosis in the Thoratec HeartMate II device: An update analysis of the INTERMACS Registry. *The*

Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation. 2015;34(12):1515-1526.

9. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *Journal of cardiac failure*. 2016.

10. Swetz KM, Cook KE, Ottenberg AL, Chang N, Mueller PS. Clinicians' attitudes regarding withdrawal of left ventricular assist devices in patients approaching the end of life. *European journal of heart failure*. 2013;15(11):1262-1266.

11. Ben Gal T, Jaarsma T. Self-care and communication issues at the end of life of recipients of a left-ventricular assist device as destination therapy. *Current opinion in supportive and palliative care*. 2013;7(1):29-35.

12. Rossi Ferrario S, Omarini P, Cerutti P, Balestroni G, Omarini G, Pistono M. When LVAD Patients Die: The Caregiver's Mourning. *Artificial organs*. 2016;40(5):454-458.

13. Vogels RL, Scheltens P, Schroeder-Tanka JM, Weinstein HC. Cognitive impairment in heart failure: a systematic review of the literature. *European journal of heart failure*. 2007;9(5):440-449.

14. Lee CS, Gelow JM, Bidwell JT, et al. Blunted responses to heart failure symptoms in adults with mild cognitive dysfunction. *J Cardiovasc Nurs*. 2013;28(6):534-540.

15. Huynh QL, Negishi K, Blizzard L, et al. Mild cognitive impairment predicts death and readmission within 30days of discharge for heart failure. *International journal of cardiology*. 2016;221:212-217.

16. Thylen I, Wenemark M, Fluur C, Stromberg A, Bolse K, Arestedt K. Development and evaluation of the EOL-ICDQ as a measure of experiences, attitudes and knowledge in end-of-life in patients living with an implantable cardioverter defibrillator. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*. 2014;13(2):142-151.

17. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*. 2005;53(4):695-699.

18. Borland E, Nagga K, Nilsson PM, Minthon L, Nilsson ED, Palmqvist S. The Montreal Cognitive Assessment: Normative Data from a Large Swedish Population-Based Cohort. *Journal of Alzheimer's disease : JAD*. 2017;59(3):893-901.

19. Cameron J, Worrall-Carter L, Page K, Stewart S, Ski CF. Screening for mild cognitive impairment in patients with heart failure: Montreal cognitive assessment versus mini mental state exam. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*. 2013;12(3):252-260.

20. Montreal Cognitive Assesment Normative Data 2018.

21. Jacues L, Schafer, J, Smith, K et al. Decision Memo for Ventricular Assist Devices for Bridge-to-Transplant and Destination Therapy (CAG-00432R). 2013. Accessed September 29th, 2017.

22. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: Executive summary. *The Journal of Heart and Lung Transplantation*. 2013;32(2):157-187.

23. McIlvennan CK, Grady KL, Matlock DD, Helmkamp LJ, Abshire M, Allen LA. End of life for patients with left ventricular assist devices: Insights from INTERMACS. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2018.

24. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *Journal of palliative medicine*. 2000;3(3):287-300.

25. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD. Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients With a Left Ventricular Assist Device. *JAMA internal medicine*. 2016;176(4):534-539.

26. Klein MHS. Improving Care at the End of Life

27. Shrestha A, Martin C, Walters S, Collins K, Burton M, Wyld L. Quality of life versus Length of Life Considerations in Cancer Patients: A Systematic Literature Review. *Psycho-oncology*. 2019.

28. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *Journal of cardiac failure*. 2017;23(9):708-712.

29. Barg FK, Kellom K, Ziv T, Hull SC, Suhail-Sindhu S, Kirkpatrick JN. LVAD-DT: Culture of Rescue and Liminal Experience in the Treatment of Heart Failure. *The American journal of bioethics : AJOB*. 2017;17(2):3-11.

Chapter Six Refences

1. Xu J, Murphy SL, Kochanek KD, Bastian B, Arias E. Deaths: Final Data for 2016. *National vital statistics reports : from the Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System*. 2018;67(5):1-76.

2. Kirklin JK, Pagani FD, Kormos RL, et al. Eighth annual INTERMACS report: Special focus on framing the impact of adverse events. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation*. 2017;36(10):1080-1086.

3. Fonarow GC, Hernandez AF, Solomon SD, Yancy CW. Potential Mortality Reduction With Optimal Implementation of Angiotensin Receptor Neprilysin Inhibitor Therapy in Heart FailureImplementation of Angiotensin Receptor Neprilysin Inhibitor TherapyImplementation of Angiotensin Receptor Neprilysin Inhibitor Therapy. *JAMA Cardiology*. 2016;1(6):714-717.

4. Mitchell LB, Pineda EA, Titus JL, Bartosch PM, Benditt DG. Sudden death in patients with implantable cardioverter defibrillators: the importance of post-shock electromechanical dissociation. *Journal of the American College of Cardiology*. 2002;39(8):1323-1328.

5. Sherazi S, Daubert JP, Block RC, et al. Physicians' preferences and attitudes about end-of-life care in patients with an implantable cardioverter-defibrillator. *Mayo Clinic proceedings*. 2008;83(10):1139-1141.

6. Goldstein NE, Lampert R, Bradley E, Lynn J, Krumholz HM. Management of implantable cardioverter defibrillators in end-of-life care. *Annals of internal medicine*. 2004;141(11):835-838.

7. McIlvennan CK, Jones J, Allen LA, Swetz KM, Nowels C, Matlock DD. Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients With a Left Ventricular Assist Device. *JAMA internal medicine*. 2016;176(4):534-539.

8. Barg FK, Kellom K, Ziv T, Hull SC, Suhail-Sindhu S, Kirkpatrick JN. LVAD-DT: Culture of Rescue and Liminal Experience in the Treatment of Heart Failure. *The American journal of bioethics : AJOB*. 2017;17(2):3-11.

9. Kramer DB, Mitchell SL, Brock DW. Deactivation of Pacemakers and Implantable Cardioverter-Defibrillators. *Progress in Cardiovascular Diseases*. 2012;55(3):290-299.

10. Stewart GC, Weintraub JR, Pratibhu PP, et al. Patient Expectations From Implantable Defibrillators to Prevent Death in Heart Failure. *Journal of Cardiac Failure*. 2010;16(2):106-113.

11. Steiner JM, Patton KK, Prutkin JM, Kirkpatrick JN. Moral Distress at the End of a Life: When Family and Clinicians Do Not Agree on Implantable Cardioverter-Defibrillator Deactivation. *Journal of pain and symptom management*. 2018;55(2):530-534.

12. Moser DK, Riegel B, McKinley S, et al. The Control Attitudes Scale-Revised: psychometric evaluation in three groups of patients with cardiac illness. *Nursing research*. 2009;58(1):42-51.

13. Huynh QL, Negishi K, Blizzard L, et al. Mild cognitive impairment predicts death and readmission within 30days of discharge for heart failure. *International journal of cardiology*. 2016;221:212-217.

14. Verdoorn BP, Luckhardt AJ, Wordingham SE, Dunlay SM, Swetz KM. Palliative Medicine and Preparedness Planning for Patients Receiving Left Ventricular Assist Device as Destination Therapy-Challenges to Measuring Impact and Change in Institutional Culture. *Journal of pain and symptom management*. 2017.

15. McIlvennan CK, Wordingham SE, Allen LA, et al. Deactivation of Left Ventricular Assist Devices: Differing Perspectives of Cardiology and Hospice/Palliative Medicine Clinicians. *Journal of cardiac failure*. 2017;23(9):708-712.

16. Swetz KM, Cook KE, Ottenberg AL, Chang N, Mueller PS. Clinicians' attitudes regarding withdrawal of left ventricular assist devices in patients approaching the end of life. *European journal of heart failure*. 2013;15(11):1262-1266.

17. Lampert R, Hayes DL, Annas GJ, et al. HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart rhythm*. 2010;7(7):1008-1026.

18. Jacues L, Schafer, J, Smith, K et al. Decision Memo for Ventricular Assist Devices for Bridge-to-Transplant and Destination Therapy (CAG-00432R). 2013. Accessed September 29th, 2017.

19. Feldman D, Pamboukian SV, Teuteberg JJ, et al. The 2013 International Society for Heart and Lung Transplantation Guidelines for mechanical circulatory support: Executive summary. *The Journal of Heart and Lung Transplantation*. 2013;32(2):15

VITA

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Curriculum Vitae

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EMPLOYMENT:

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May 2013- August 2013	Central Baptist Hospital, Lexington, KY	SPICEE Externship, Cardiovascular Progressive Care

HONORS AND AWARDS:

September 2018	Outstanding Nursing Student Award, Saha Award for Cardiovascular Research and Education
June 2018	Top Graded Abstract, American Society for Artificial Internal Organs, Annual Conference
March 2017	Top PhD Poster, University of Kentucky Center for Clinical and Translational Science, College of Nursing Showcase
August 2016- July 2019	Robert Wood Johnson Future of Nursing Scholar, Fellowship Recipient
May 2017	Future Leaders in Heart Failure Symposium, Selected Participant
April 2017	Inducted into Sigma Theta Tau International Honor Society
May 2014	Summa Cum Laude, University of Kentucky

PUBLICATIONS

Accepted for Publication:

*J. Harman, I. Thylen, & D.K. Moser. Shared Decision-Making about End-of-Life Care Scenarios Compared Among Implantable Cardioverter Defibrillator Patients with and without Heart Failure: A National Cohort Study. *Circulation: Heart Failure*. 2019, *revisions requested*

Submitted:

*J. Harman, C.S. Lee, & D.K. Moser. Psychometric Testing of the Control-Attitudes Scale-Revised for Patients with a Left Ventricular Assist Device. *Journal of Nursing Measurement*. 2019

Published Abstracts:

S. Griggs, J. Harman, J. Jones, J. Coles, A. Harris, & R. Coghill. ECMO Transport in Rural Appalacia: Improving Access Through A Nurse Led Transport Tea. ASAIO May-June 2019. 64 (Supplement 1).

J. Harman, D.K. Moser, & I. Thylen. Shared decision-making about end-of-life care compared among implantable cardioverter defibrillator patients with and without heart failure: a national cohort study. Heart & Lung, November-December 2018. 47(6) p.653

ORAL PRESENTATIONS

March 2017	*Shared Decision-Making about End-of-Life Care. Poster presentation. J.L. Harman, I. Thylen, & D.K. Moser. University of Kentucky Center for Clinical and Translational Science, College of Nursing Scholarship Showcase, Lexington, KY.
June 2018	*ECMO Transport in Rural Appalachia: Improving Access Through a Nurse-Led Transport Team. S. Griggs, J. Coles, J. L. Harman. Podium Presentation. American Society for Artificial Internal Organs, Annual Conference, Washington D.C.
June 2018	*Shared Decision-Making about End-of-Life Care. Podium presentation. J. L. Harman. AAHFN Annual Conference, Chicago, IL.

October, 2018	*End-of-Life Documentation: The Muddy Waters in Kentucky. J. L. Harman. Podium Presentation. University of Kentucky Nursing Research Papers Day, Lexington, KY.