

1-3-2012

Patients' and caregivers' inside perspectives: living with a left-ventricular assist device as destination therapy

Linda Marcuccilli
Wayne State University,

Follow this and additional works at: http://digitalcommons.wayne.edu/oa_dissertations

 Part of the [Nursing Commons](#), and the [Other Medical Specialties Commons](#)

Recommended Citation

Marcuccilli, Linda, "Patients' and caregivers' inside perspectives: living with a left-ventricular assist device as destination therapy" (2012). *Wayne State University Dissertations*. Paper 516.

This Open Access Dissertation is brought to you for free and open access by DigitalCommons@WayneState. It has been accepted for inclusion in Wayne State University Dissertations by an authorized administrator of DigitalCommons@WayneState.

PATIENTS' AND CAREGIVERS' INSIDE PERSPECTIVES: LIVING WITH A LEFT-VENTRICULAR ASSIST DEVICE AS D ESTINATION THERAPY

by

LINDA MARCUCCILLI, MSc, RN

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2012

MAJOR: NURSING

Advisor

Date

**©COPYRIGHT BY
LINDA MARCUCCILLI
2012
All Rights Reserved**

DEDICATION

To God, my husband, my dad, and all my friends and family here on earth and in heaven who
believed in me.

ACKNOWLEDGEMENTS

This dissertation research would not have been possible without the support, encouragement, and guidance of all my professors and mentors. First, I wish to acknowledge Dr. Jean Davis, the College of Nursing, and the Graduate School for providing me with the scholarships and grants to fund my doctoral education. It was through these resources that allowed me to concentrate on my studies, and become a productive nurse scientist. Next, I would like to acknowledge my primary mentor, Dr. April Vallerand, who has not only exuded her knowledge and expertise in facilitating my training as a research scholar, but has remained my pillar of strength when I needed it the most.

I also wish to acknowledge my mentor and colleague, Dr. Rosalind Peters, who with her dedication to my learning needs, patience, and understanding, believed in my potential as a future nurse scientist. She also introduced me to my research advisor and colleague, Dr. Jessie Casida. Dr. Jessie Casida is a remarkable mentor, who not only invited me to participate in his innovative research, but also took the time and patience to help me develop my scholarly writing skills. I am looking forward to advancing the science of life-sustaining technology with him. My dissertation proposal would not be complete without the qualitative expertise of Dr. Karen Tonso. She not only imparted her wisdom of the interpretive paradigm, but also taught me how to expand my thinking “outside of the box” and bring the voice of participants’ experiences and meanings to life. A special acknowledgement goes out to Dr. Janet Harden, who guided me with her knowledge and passion of caregiving amongst vulnerable populations – thank you. I also wish to thank Dr. Kay Klymko, my gerontology specialist. She not only shares my passion for promoting quality care for older adults, but also gave me extra time to complete my coursework so I can concentrate on my dissertation. Dr. Klymko has role-modeled a gentle, encouraging, and

inspiring attribute that I can only hope to mirror in my research, teaching, and mentoring career.

I also wish to acknowledge the staff at the Center for Circulatory Support at The University of

Michigan Health Systems — Dr. Francis Pagani, Director, and Susan Wright, RN, MS,

Supervisor, for allowing me continued access to the LVAD population, and Sarah Fox, BS,

clinical coordinator, for her diligence in recruiting study participants.

Next, I would like to acknowledge my family, close friends and fellow colleagues who were

always there for me as I progressed throughout the program — thank you for all your support,

encouragement, and most of all, your comradery.

Last but not least, it is with great honor to not only acknowledge, but to also thank the participants in my inquiry. It was their courage, love of life, and strength in their voices, hearts and souls, that created the foundation for the experiences and meanings behind living with a life-sustaining device. These voices will go on for all patients with mechanical circulatory support,

their caregivers, and health care providers caring for such patients.

PREFACE

When we are struck with wonder, our minds are suddenly cleared of the clutter of everyday concerns that otherwise constantly occupy us. We are confronted by the thing, the phenomenon in all of its strangeness and uniqueness. The wonder of that thing takes us in, and renders us momentarily speechless as.

Van Manen, 2002

FOREWORD

The dissertation set forth consists of five chapters. The first chapter (Chapter 1) sets the stage for the dissertation research and consists of the following eight (8) sections which set the stage for the rest of the inquiry: 1) Experiential context, 2) Assumptions, biases, intuitions, and perceptions, 3) The phenomenon, 4) Background, 5) Justification for studying the phenomenon, 6) Phenomenon discussed within a specific context, 7) Selective qualitative research methods and justification for its potential, and 8) Significance to nursing. In order to facilitate inquiries into the research methods, journal entries, procedures, and participant responses are followed by: (Audit trail). The second chapter (Chapter 2) presents the evolution of the study from a historical context, and presents a synthesis of the literature in several aspects, including: 1) Health care practices among patients with heart failure and advanced heart failure, 2) Quality of life among patients with left-ventricular assist devices (LVADs) as a bridge to transplant (BTT), 3) LVADs as a destination therapy (DT), 4) Caregiver support in situations similar to LVADs as DT, 5) Caregiving in the heart failure population, 6) Caregiving in patients with a BTT, 7) Caregivers of patients with advanced heart failure: a palliative care and end of life care perspective, 8) Caregiving in patients with life-sustaining devices, 9) Ethical dilemmas, and ends with the statement of the problem. The third chapter (Chapter 3) defines and discusses phenomenology, a brief historical review of phenomenology as a philosophy and methodology, and discusses van Manen' (1990) phenomenological method of inquiry as the guide for the inquiry. The research activities are outlined, including strategies for ensuring methodological rigor, human subject considerations, and conclude with the strengths and limitations of the method of inquiry. A view into the incorporation of humanities, the living arts, and photography is provided to illustrate the creativity used in interpreting participants' voices. The fourth chapter (Chapter 4) presents the

findings from patients' and caregivers' voices in biographical format, using themes and sub-themes to illustrate the lived experience. Finally, the fifth chapter (Chapter 5) attempts to explicate the essence of the lived experience of DT using the extant literature and Roy's Adaptation Model as a theoretical framework. Conclusions and implications preface the need for future research and building a sustainable program of research dedicated to meet the palliative care and end of life care needs for patients with life-sustaining devices and their family caregivers.

TABLE OF CONTENTS

Dedication.....	ii
Acknowledgements.....	iii
Preface.....	v
Forward.....	vi
List of Tables.....	xviii
List of Figures.....	xix
Chapter 1 Introduction: Aim of the Study.....	1
<i>Experiential Context</i>	2
<i>Assumptions, Biases, Intuitions, and Perceptions</i>	3
<i>Palliative care, end of life care, and end-stage heart failure</i>	3
<i>The Phenomenon</i>	5
<i>Background</i>	6
<i>Characteristics of heart failure</i>	7
<i>Stages, symptoms, and medical management</i>	7
<i>Stages of heart failure</i>	8
<i>Medical management for advanced or end-stage heart failure</i>	9
<i>Intravenous positive inotrope therapy</i>	9
<i>Heart transplant</i>	10
<i>Evolution of mechanical circulatory support</i>	11
<i>First generation LVADs</i>	14
<i>Second generation LVADs</i>	14

<i>Third generation LVADs</i>	15
<i>Justification for Studying the Phenomenon</i>	16
<i>Phenomenon Discussed Within a Specific Context</i>	18
<i>Destination therapy</i>	18
<i>Caregivers of patients with LVADS as DT</i>	19
<i>Selected Qualitative Research Methods</i>	21
<i>Significance to Nursing</i>	21
<i>Summary</i>	22
Chapter 2 Literature Review: Evolution of the Study.....	24
<i>Historical Context of the Study</i>	24
<i>Health care practices among patients with heart failure and advanced heart failure</i>	24
<i>Palliative care and end of life care—the distinction</i>	25
<i>Barriers in physician-patient communication</i>	25
<i>Preferences for palliative and end-of-life care</i>	27
<i>Comfort measures only at the end of life</i>	28
<i>Lack of communication in prognostication</i>	28
<i>Palliative and end of life care among patients with an LVAD as DT</i>	29
<i>Quality of life among patients with an LVAD as a BTT</i>	31
<i>Adaptation among patients with left-ventricular assist devices</i>	34
<i>Left-ventricular devices as a DT</i>	35
<i>Caregiver support in situations similar to LVADs as DT</i>	37
<i>Caregiving in the heart failure population</i>	37
<i>Depression and anxiety</i>	38

<i>Caregiver burden</i>	39
<i>Limited socialization</i>	40
<i>Differences in gender-related care giving outcomes</i>	40
<i>Lifestyle changes</i>	41
<i>Caregiving in patients with LVADs as BTT</i>	43
<i>Caregiving at the end of life</i>	47
<i>Caregiving in patients with life-sustaining devices</i>	49
<i>Caregiving and mechanical ventilation</i>	51
<i>Caregiving and percutaneous implants for peritoneal dialysis</i>	50
<i>Caregiving and implantable cardioverter defibrillators</i>	51
<i>Ethical dilemmas and caregiver decision-making in palliative and end-of-life care</i>	53
<i>Principle of justice</i>	53
<i>Discontinuing the LVAD</i>	54
<i>Respect for persons</i>	54
<i>Communication about end-of-life care and advanced directives</i>	54
<i>Statement of the Problem</i>	56
<i>Summary</i>	57
Chapter 3 Methods.....	59
<i>Method of Inquiry: General</i>	59
<i>Lifeworld: Lived experience</i>	59
<i>1st person perspective</i>	60
<i>Consciousness</i>	60
<i>Intentionality</i>	61

<i>Historical Perspective</i>	61
<i>Method of Inquiry: Applied</i>	62
<i>van Manen's phenomenological method of inquiry</i>	62
<i>Rationale for Selection of the Phenomenological Method</i>	63
<i>Research Activities and Procedures</i>	64
<i>Turning to the lived experience</i>	65
<i>Exploring the experience</i>	65
<i>Reflection on essential themes</i>	67
<i>Lived space</i>	68
<i>Lived body</i>	68
<i>Lived time</i>	68
<i>Lived other</i>	69
<i>Capturing the essence through writing and rewriting</i>	69
<i>Remain focused and oriented</i>	69
<i>Balancing the inquiry through parts and wholes</i>	70
<i>Hermeneutic reduction: Bracketing</i>	71
<i>Design</i>	72
<i>Setting</i>	72
<i>Sample</i>	73
<i>Data Collection Procedures</i>	75
<i>Recruitment</i>	77
<i>Human Subject Considerations</i>	77
<i>Study Measures</i>	80

<i>Data Collection</i>	81
<i>Participant appreciation</i>	85
<i>Data Analysis – Data Interpretation</i>	85
<i>Thematic analysis</i>	86
<i>Wholistic approach</i>	86
<i>Selective approach</i>	86
<i>Detailed approach</i>	87
<i>Capturing the phenomenon through writing</i>	88
<i>Finding meaning through art</i>	88
<i>Family</i>	90
<i>Return to a new normalcy: van Gogh self portraits</i>	90
<i>Portraying worry through art</i>	93
<i>Fear of morbidity and mortality</i>	94
<i>Given another chance at life</i>	94
<i>Thank you Lord</i>	95
<i>The phenomenon of silence and interpretation of meaning</i>	96
<i>Structure of the phenomenological story</i>	98
<i>Data Management</i>	99
<i>Trustworthiness</i>	100
<i>Credibility</i>	100
<i>Transferability</i>	101
<i>Confirmability</i>	101
<i>Dependability</i>	101

<i>Summary</i>	102
Chapter 4 Results.....	103
<i>Sociodemographic and Clinical Characteristics</i>	103
<i>Participants as patients</i>	103
<i>Participants as caregivers</i>	103
<i>Part I: Patients with LVADs as DT</i>	104
<i>In the beginning</i>	104
<i>Theme 1: Life begins to change with heart failure</i>	104
<i>Weakness, shortness of breath</i>	105
<i>Profound limitations</i>	106
<i>On death's door</i>	106
<i>Hope for life through LVAD</i>	107
<i>Determined to live</i>	108
<i>Theme 2: Learning to live with an LVAD: An evolving process</i>	109
<i>The postoperative period</i>	109
<i>A time of initial adjustments and discovery</i>	110
<i>Limitations with the LVAD</i>	111
<i>Carrying equipment can be uncomfortable</i>	111
<i>Implement precautions</i>	113
<i>Having a foreign body</i>	113
<i>Carrying around extra equipment</i>	114
<i>Clothing challenges</i>	115
<i>Being tethered</i>	117

<i>Can't take showers or baths</i>	118
<i>Have to have a caregiver</i>	118
<i>Daily dressing changes</i>	119
<i>Caregiver does all driving</i>	120
<i>Adjusting to IADLs with the LVAD</i>	121
<i>Limited sexual activity</i>	122
<i>Theme 3: Adjustments and acceptance come with time</i>	123
<i>Improved quality of life</i>	124
<i>Theme 4: Living outweighs restrictions</i>	125
<i>Theme 5: Hope for life through new technology</i>	127
<i>Theme 6: Thank the Lord</i>	128
<i>Summary</i>	129
<i>Part II: Caregivers of patients with LVADs as DT</i>	129
<i>Theme 1: Advanced heart failure is a life changing event</i>	130
<i>Hope for life renewed</i>	132
<i>Theme 2: Self-doubt about LVAD caregiving improved overtime</i>	134
<i>Learning to care all over again</i>	134
<i>Theme 3: Lifestyle adjustments come with time</i>	136
<i>A reversal of roles</i>	136
<i>Self interests on hold</i>	138
<i>Keeping it normal</i>	139
<i>Doing all the driving</i>	140
<i>Dressing changes</i>	141

<i>Increasing independence after LVAD</i>	143
<i>Move forward</i>	144
<i>Theme 4: Persistent worry and stress</i>	145
<i>Theme 5: Caregiving is not a burden—it's part of life</i>	148
<i>Summary</i>	150
<i>Dyadic reflections</i>	150
<i>Theme 1: Good family support</i>	150
<i>Theme 2: Good interpersonal relationships</i>	151
<i>Theme 3: Destiny is you die</i>	152
<i>Theme 4: Uncertain future</i>	153
<i>Theme 5: Given more time</i>	155
<i>Summary</i>	157
Chapter 5 Discussion of Findings.....	158
<i>Roy's Adaptation Model: Theoretical Assumptions</i>	158
<i>Focal stimuli</i>	159
<i>Life changes with advanced heart failure</i>	159
<i>Learning to live with an LVAD: An evolving process</i>	161
<i>Post-operative recovery</i>	162
<i>Having a foreign body</i>	162
<i>Stress and coping</i>	163
<i>Contextual stimuli</i>	165
<i>Theoretical constructs and the process of adaptation</i>	166
<i>Coping processes</i>	166

<i>Cognator subsystem</i>	166
<i>Regulator subsystem</i>	167
<i>Adaptive modes</i>	168
<i>Physiologic-physical</i>	168
<i>Self-concept-group identify</i>	169
<i>Role function</i>	172
<i>Interdependence</i>	173
<i>Adaptive levels</i>	173
<i>Integrated life process</i>	173
<i>Meaning of living with an LVAD as DT</i>	176
<i>Uncertain future</i>	175
<i>Compensatory</i>	178
<i>Compromised</i>	178
<i>Strengths and limitations</i>	179
<i>Implications and relevance to nursing</i>	180
<i>Directions for the Future</i>	181
<i>Conclusion</i>	182
Appendix A: Tables A1-A5.....	184
Appendix B: Figures B1-B18.....	190
Appendix C: The University of Michigan Institutional Review Board Approval.....	209
Appendix D: Wayne State University Human Investigation Committee Approval.....	213
Appendix E: The University of Michigan IRB Amendment: Continuation of Study.....	214
Appendix F: Wayne State University Amendment: Continuation of Study.....	218

Appendix G: Letter of Support.....	219
Appendix H: Recruitment Protocol for research coordinator.....	220
Appendix I: Outreach Protocol: Inclusion of Women and Minorities.....	222
Appendix J: Recruitment Slip.....	224
Appendix K: Mini-Cog.....	225
Appendix L: Demographic Profile of Adults with LVADs as DT.....	227
Appendix M: Demographic Profile of Caregivers of Adults with LVADs DT.....	229
Appendix N: Patient Interview Script	231
Appendix O: Caregiver Interview Script.....	233
References.....	235
Abstract.....	260
Autobiographical Statement.....	262

LIST OF TABLES

Table A1: Stages of Heart Failure.....	189
Table A2: New York Heart Association Functional Classifications.....	185
Table A3: Heart Transplant Criteria.....	186
Table A4: Patients' Sociodemographic and Clinical Data.....	188
Table A5: Caregivers' Sociodemographic and Clinical Data.....	189

LIST OF FIGURES

Figure B1: External components of LVAD.....	190
Figure B2: 1 st , 2 nd , and 3 rd generation LVADs.....	191
Figure B3: Internal components of 2 nd and 3 rd generation LVADs.....	192
Figure B4: Structure of the Hermeneutic Circle.....	193
Figure B5: My husband.....	194
Figure B6: My boy.....	195
Figure B7: van Gogh Self Portrait. 1889.....	196
Figure B8: van Gogh Self Portrait. 1889.....	196
Figure B9: LMR Self Portrait. 2011.....	197
Figure B10: Pablo Picasso. Woman with a Chignon. 1899.....	198
Figure B11: Pablo Picasso. Lola, Picasso's Sister. 1899.....	199
Figure B12: Pablo Picasso. Woman with a Crow.....	200
Figure B13: Vincent van Gogh. The Raising of Lazarus. 1890.....	201
Figure B14: Praise My Sol the King of Heaven.....	202
Figure B15: Thank You, Lord, for This Great Day.....	204
Figure B16: Health and Well-Being Trajectory of Patients Before and After the LVAD.....	205
Figure B17: Caregivers' Trajectory of Adjustments and Pervasive Worry Overtime.....	206
Figure B18: Program of Research.....	207
Figure B19: LMR Self Portrait. 2012.....	208

CHAPTER 1: INTRODUCTION

AIM OF THE STUDY

“This device is the only therapy we have left for your husband....he is not eligible for a heart transplant....he will have this device for the rest of his life — ma’am....if he doesn’t get this LVAD, he will die.” These words just echoed unmercifully in her head as the surgeon’s words became a muffled, buzzing sound. She became dizzy and weak, clutching the side rail for support while sinking down in the chair. As her eyes turned towards her husband hooked up to every line, tube and machine possible – she could only hear those words, “he will die....” over, and over again. She sat very still in her chair. “It seemed like only yesterday,” her eyes filling with tears, as she recalled the conversation with the transplant surgeon only three month ago. She had never heard of such a device – a mechanical heart that will make him live? Can that be so? The memories of her husband laying almost life-less in bed, ineligible for a heart transplant, and how she had to make the decision for a surgical implantation of a mechanical heart seemed liked yesterday. She was torn with this decision – should we get this LVAD? Can we handle such a high-tech machine? Yet, her husband remembered the day quite vividly. He recalled hearing a voice in the background. He turned his head towards this voice and saw flickering lights. Much to his shock and disbelief, a picture of Jesus Christ surrounded in brilliant pink and White lights covered the TV screen. He could not believe his eyes. It was as if Jesus was right there calling out to him and supporting him in his time of need. He recalled that at that precise moment, he knew that it was his destiny to receive the mechanical heart. As he heard his wife talk to the doctor about this LVAD, he reached over to her, touched her hand, and said, “I want to live – I want this mechanical heart.” And so it was. The couple was faced with a life-and-death decision but through what the patient felt as divine intervention, wanted to take the risk

for another chance at life.

This vignette provides an example of the initial uncertainties and experiences patients in the final stages of heart failure and their caregivers face as they make the decision for a surgical implantation of an LVAD. The patient in this vignette received an LVAD as a DT — the final therapeutic option for patients ineligible for a heart transplant. This vignette, however, prefaces a world unknown to those who are not recipients of this life-sustaining device — what is life like with this life-sustaining device for these patients and their caregivers once they are released from the hospital? This phenomenological inquiry aims to explore the experience of living with DT from patients' and caregivers' perspective. My interest into this phenomenon stemmed from many years of caring for patients with chronic and terminal illnesses, who have palliative care and end of life care needs.

Experiential Context

For the past 25 years, I provided the palliative and end of life needs for patients in various settings, such as maternal child health, critical care, and case management. Given this knowledge, I wanted to become part of a research team dedicated to advancing the science in this field, including the health and well-being of caregivers. In January 2009, I was invited to participate in a qualitative study exploring self-concept and life-style modification of patients with implantable LVADs. That summer, I commenced my first interview with a BTT patient. In subsequent interviews, I met a patient with DT. As I listened to this patient, he described how lucky he was to have this life-sustaining device and that if he was given the chance to do it all over again, he would so in an instant. Another interview with a patient with DT revealed a similar story. It appeared that for any LVAD indication, they were grateful to receive the device and perceived this opportunity as a second chance at life. Yet, it was the story of a caregiver

for a DT patient that aroused my interest in researching both patients with an LVAD as DT and their caregivers.

As I listened to her story and the stories of other participants in my inquiry, I couldn't help think of how similar these perspectives were in my own field experiences with palliative care and end of life care. On August 8, 2010, I commenced my first research as primary investigator to explore the lifestyle adjustments of caregivers of patients with LVADs. It was the particular story of a woman caring for her husband with DT that specifically aroused my interest. She described for me a conversation that occurred with another caregiver of a patient with a DT. It appeared that that particular patient experienced multiple strokes, blood clots, and died at about 7 months. This weighed heavily on my participant's mind. Subsequently, she was afraid to leave him alone, even for an hour, because she was "concerned that something serious will happen and nobody will be there to help him."

Assumptions, Biases, Intuitions, and Perceptions

It is important to understand and make explicit my assumptions related to palliative and end of life care and DT in order to give voice to the experience and meaning of living with such a life-sustaining device. Let me share with you my knowledge about palliative care and end of life care.

Palliative care, end of life care, and end-stage heart failure.

Palliative care is defined as a holistic approach to improve the quality of life of persons afflicted with life-limiting illnesses and their caregivers (National Consensus Project for quality Palliative Care [NCPQP], 2004; World Health Organization [WHO], 2010). Nurses and other health care providers are part of this holistic, palliative care approach, including timely discussions of palliative and end of life options (Hunt et al., 2005). End of life discussions,

however, may not occur until these patients are nearing death (Goodlin, 2009; Hupcey, Penrod, & Fogg, 2009; Rizzieri, Verheijde, Rady, & McGregor, 2005). These discussions occur infrequently due to the unpredictable nature of heart failure, even provider and patient barriers such as lack of knowledge and fear (Aldred et al., 2005; Exley, Field, Jones & Stokes, 2005; Selman et al., 2007). Improving communication, timely discussions, and education about diagnosis, symptoms and disease trajectory are warranted among this expanding population. Therefore, nurses must continually assess educational and palliative care needs, including timely preparation for end of life for this emerging population (Goodlin, 2009; Hupcey et al., 2009; Quaglietti et al., 2005; Rizzieri et al., 2005).

As I reflect upon my assumptions and prior knowledge, I strove to remain unbiased and open to my phenomenon. There is always a possibility that one's values and beliefs may be challenged by their personal perceptions and knowledge (Munhall, 2008). By identifying assumptions and biases prior to engaging in research, van Manen (1990) posited that one can hold them at bay, possibly even turning the knowledge against itself. I assumed that patients with DT and their caregivers want to talk about their experiences so they can help other patients, even health care providers. Furthermore, study participants understand that having an LVAD as a DT is the last therapy available to alleviate the incapacitating symptoms from end-stage heart failure. I understand that participants may not even talk about this experience as a final therapy and I must remain open to these responses. My assumption is that when the patient will share their experience about living with such a life-sustaining device, I will not know what they are going to say. Although my assumptions are based on conjectures as I reviewed the literature on end of life and caregiving at the end of life, these patients may view the LVAD as a second chance at life, not even thinking about it as the beginning to the end of life.

In my own practice, I provided the inpatient care, discharge preparation, and resources necessary for patients and their caregivers to continue with palliative and/or end of life care at home. I noticed that many times, when nurses speak to patients and their caregivers individually, they often talk about their needs and issues differently. Both patients and caregivers are grateful for the care received, yet caregivers tend to “pull-aside” nurses or other health care providers to relay more in-depth information. This information usually included concerns for the patient, self, uncertainties related to delivering palliative and end of life care. It was the paucity of literature on the inside perspective of DT, and the vacillating concerns between both patients and their caregivers, that stimulated my interest to explore the experience of living with a DT from a patient and caregiver perspective.

Until I explore this phenomenon, we may never know what it’s like for these individuals to be living with such a life-sustaining device. I believe it is necessary for this population to tell us what this experience means to them so we can provide holistic care that is sensitive to the complex realities of living with and caring for someone with a DT. Therefore, the focus of my research was to explore patients’ and caregivers’ inside perspective of living with an LVAD as a DT.

The Phenomenon

The phenomenon explored in this inquiry is the experience of living with a mechanical heart from patients’ and caregivers’ perspectives. The context of this inquiry is destination therapy. As we see an increasing number of patients in the community with these long-term devices, the number of persons serving as caregivers will also rise. The following questions will guide this inquiry:

- 1) What is the experience and meaning of living with an LVAD as DT from patients’

perspectives?

2) What is the experience and meaning of caring for a patient with an LVAD as DT?

The following discussion provides the background for an inquiry into my phenomenon of interest.

Background

Heart failure is a major public health concern affecting almost 6 million persons in the United States (AHA, 2010). Despite improvements in diagnosis and medical management, there are over 650,000 new cases diagnosed yearly, with almost 300,000 deaths reported annually (AHA, 2010). Heart failure remains the leading cause of hospital admissions in older adults (e.g., ≥ 65 years old) (i.e., over 1 million with a primary diagnosis of heart failure) with high re-admission rates (50% within six months of discharge) (AHA, 2010; Fang et al., 2008). The incidence of heart failure effects almost 10 per 1,000 in the ≥ 65 age group, with the annual rate doubling every 10 years as older adults progress in age (Roger et al., 2012), and is often preceded by hypertension and diabetes (AHA, 2010a; Roger et al., 2012). Moreover, heart failure disproportionately affects racial and ethnic minorities, specifically Blacks compared to Whites—a 50% higher incidence than in the general heart failure population (Crowder, Irons, Meyerrose, & Seifert, 2010; Gordon, Nowlin, Maynard, Berbaum, & Deswal, 2010). Blacks develop heart failure symptoms earlier than Whites (e.g., ≤ 65 years old) due to the higher prevalence of risk factors, such as hypertension, diabetes, and have higher mortality rates compared to Whites (AHA, 2010; Crowder et al.; Gordon et al., 2010). Since there is no cure for heart failure, the progressive and debilitating nature of this disease poses significant societal burdens and is estimated to cost the health care system over \$39 billion in 2011 (AHA, 2010). This trend is expected to escalate due to an aging population, better prevention of sudden cardiac

death, and improved survival after myocardial infarction (Fang et al., 2008; Gheorghiade & Pang, 2009; Hugli, 2005). In order to grasp an understanding of heart failure, it is necessary to discuss the characteristics, signs, symptoms, and therapies used to treat heart failure.

Characteristics of heart failure.

Heart failure is a chronic, progressive syndrome characterized by impaired cardiac functioning and altered systemic perfusion (AHA, 2010b; Hunt et al., 2009). Subsequently, patients with heart failure are at high risk for several disease-related outcomes, such as atrial fibrillation with rapid ventricular response, pulmonary edema, hypertensive crisis, hypotension, low-output syndrome, and acute or chronic renal failure, all which contribute to frequent hospitalizations, high re-admission, and mortality rates (Fonarow, Gawlinski, Moughrabi, & Tillisch, 2001; Gheorghiade & Pang, 2009). Heart failure can be systolic (e.g., reduced cardiac contractility) or diastolic (e.g., altered cardiac relaxation and abnormal ventricular filling) (AHA, 2010b). Left ventricular systolic dysfunction is most common and affects nearly 60% of patients afflicted with heart failure (AHA, 2010b; Hunt et al., 2009). Studies report that persons have a greater risk for developing heart failure if they have certain risk factors, such as coronary artery disease (CAD), diabetes, hypertension, coronary artery disease (CAD), obesity, family history of heart disease or cardiotoxin exposure (AHA, 2010b). Despite the incidence and prevalence of this disease, there remains no cure for heart failure. It is the progressive, yet unpredictable nature of this disease that continues to mystify, even frustrate, health-care providers, patients and their caregivers alike. Decades of research into treatment has culminated in improvements in diagnosis, preventative measures, and optimal medical management to improve overall quality of life for many patients and their caregivers.

Stages, symptoms, and medical management.

In order to determine the best treatment for patients with heart failure, health care providers determine the stage and functional class of heart failure. As shown in Table A2, this classification system subjectively determines the degree of functional limitation from Class I (e.g., patient experiences no dyspnea or undue fatigue with ordinary physical activity) to Class IV (e.g., dyspnea at rest or with very little exertion) (AHA, 2010b). More recently, the ACC/AHA has identified the stages of heart failure. These stages complement the NHYA classification, by objectively identifying patients along the heart failure continuum, and linking them to recommended medical management at each stage of the disease (Francis et al., 2010; Hunt et al., 2009).

Stages of heart failure. Stage A is the first stage of heart failure. Patients in this stage have risks for heart failure but do not exhibit heart disease —prevention is stressed at this stage (Francis et al., 2010; Hunt et al., 2009). In stage B, patients have been diagnosed with heart failure but no clear symptoms are reported (Francis et al., 2010; Hunt et al., 2009). Physicians may prescribe ACEIs, beta blockers and closely monitor blood pressure along with other symptoms. The goal is prevention of left-ventricular remodeling (e.g., progressive ventricular dilatation) which may lead to HF (Francis, 2010; Hunt et al., 2005). In stage C, patients have structural heart disease and usually experience dyspnea, fatigue, and exercise intolerance. Medical management includes the addition of diuretics, digoxin, aldosterone antagonists, or possibly cardiac resynchronization therapy, which is a specialized pacemaker designed to re-coordinate actions of the right and left ventricles) (Francis, 2010; Hunt et al., 2009). Despite these advances and the progressive nature of the disease, many patients will progress to Stage D, which is advanced or end-stage heart failure. This is the final stage many patients endure prior to transplant or mechanical circulatory support. Patients in this trajectory of heart failure

experience profound shortness of breath at rest, profound fatigue, and marked physical limitations, with sudden onset and/or recurrence of symptoms despite maximal management (Francis et al., 2010; Hunt et al., 2009). These patients must be referred for specialized treatments, including continuous positive inotropic infusions, heart transplant or LVADs (Hunt et al., 2009).

Medical management for advanced or end-stage heart failure.

Almost a century of research has culminated in significant advancements aimed at improving the quality of life of those afflicted with heart failure. These significant advances, or optimal medical management, includes pharmacologic, surgical, and technological therapies aimed at improving the function of the failing heart, such as: 1) diuretics, 2) beta-blockers, 3) angiotensin II receptor blockers (ARBs), 4) angiotensin-converting enzyme inhibitors (ACEIs), 5) implantable cardioverter defibrillators, 6) cardiac resynchronization, 7) cardiomyoplasty, and 8) left ventriculectomy, aimed at improving the function of the failing heart (Krishnamani, DeNofrio, & Konstam, 2010). There are also specialized treatments for patients with advanced heart failure whose symptoms continue to progress despite optimal medical management, which may include: 1) intravenous positive inotropic infusions, 2) heart transplant, and 3) mechanical circulatory support, such as an LVAD (Hunt et al., 2005).

Intravenous positive inotropic therapy. If patients exhibit volume overload, continue to deteriorate, and progress towards cardiogenic shock (inadequate tissue perfusion resulting from cardiac dysfunction), they are usually admitted for intravenous infusions including positive inotropic agents (e.g., milrinone) and vasodilators, such as nitroprusside (Hunt et al., 2009). If patients are eligible for a heart transplant or even mechanical circulatory support, they may remain on these infusions while waiting for a donor heart or even a mechanical circulatory

support device (Francis, 2010). However, if patients are not eligible for either a transplant or LVAD, inotropic infusions are utilized as a palliative and end of life care strategy (Felker & O'Connor, 2001; Francis et al., 2010; Hauptman et al., 2006; Hershberger et al., 2003). Patients who meet the transplant eligibility criteria (Table A3), however, are placed on a waiting list.

Heart transplant. To date, heart transplant is the best treatment for advanced or end-stage heart failure. It is estimated that almost 5,000 heart transplants are performed worldwide, with over 2,000 performed in the United States alone (Stehlik et al., 2010). Yet, not everyone on the transplant list, however, receives a donor heart. For example, in 2010, there were 3160 patients on the heart transplant list, but only 2211 donor hearts were implanted in the United States in 2010 (Organ Procurement & Transplant Network [OPTN] and Scientific Registry of Transplant Recipients [SRTR] (OPTN/SRTR, 2011). As a result, thousands of patients on the transplant list must wait almost one year for a donor heart (i.e., 302 days in 2011), continue to experience a poor quality of life, or may even die without a transplant (OPTN/SRTR, 2011). Estimates show that little more than half patients on the waiting list receive a donor heart, while the rest face a mortality rate of 21% at 6 months and 47% at 10 months respectively (Lietz et al., 2005). However, when patients received a heart transplant, mortality rates significantly improve. For example, the median survival post-transplant is 10 years, with a median survival rate of 13 years during the first year (Stehlik et al., 2010). In addition, the number of older adults ≥ 65 years old receiving a heart transplant is on the rise, with estimates reaching almost 12% amongst a predominantly White male population (75%) (Stehlik et al., 2010). Given the increasing number of older adults with advanced heart failure and a limited pool of donor organs, mechanical circulatory support provides increased survivability and improved quality of life while waiting for a transplant, or as a DT, if ineligible for transplant (Francis et al., 2010; Rose et

al., 2001).

Despite these advances, recent estimates show over 100,000 patients progressed to end-stage (Stage D) heart failure (American College of Cardiology/American Heart Association [ACC/AHA]), and exhibited class III or IV symptoms as described by the New York Heart Association (NYHA) (Tables A1 and A2). Patients with this most advanced stage of heart failure have end-organ damage as a result of poor organ perfusion and consequently experience a poor quality of life. Symptoms resulting from organ dysfunction include marked shortness of breath at rest or with minimal exertion, profound fatigue, and debilitating physical limitations (Hunt et al., 2005; Hunt et al., 2009). Prognosis is grim, as the 1 year mortality rate reaches almost 50% if a heart transplant or a mechanical circulatory support device is not performed (Krishnamami & DeNofrio, 2010). These specialized treatments, specifically heart transplant and LVADs, are final options for a chance at improved quality of life (Hunt et al., 2009). Yet many patients are ineligible for heart transplant due to strict transplant criteria, such as malignancies, various comorbidities, and advanced age (e.g., ≥ 72 years old), as shown in Table A3 (Jessup et al., 2009; Milano et al., 2006; Park et al., 2005). Innovative technological advances dedicated to improving the quality of life among for these patients culminated in the development of an alternative to transplant, better known as DT.

Mechanical circulatory support. Mechanical circulatory support technologies, such as LVADs, (Figure B1), provide mechanical assistance to the failing heart. These devices are mostly utilized as a BTT, and/or bridge to myocardial recovery, to sustain the function of the failing heart and improve overall quality of life while waiting for transplant. Distinct from total artificial hearts which permanently replaces the heart, an LVAD supports the failing heart but does not replace it. Most current models of LVADs are implanted in the upper abdomen, have a

percutaneous lead (e.g., driveline) protruding from the abdomen, and connected to tubes from which blood is drawn from either the right or left ventricle, and empties into the pump. An extracorporeal controller initiates pumping and blood is propelled into the circulatory system (Figure B1). These devices primarily assist the left ventricle, the ventricle most often affected in heart failure (Maher, Butler, Poirier, & Gernes, 2002). LVADs are mostly indicated for viral, ischemic, or peripartum cardiomyopathy, recurrent and/or refractory arrhythmias, acute myocardial infarction, post-cardiotomy failure, and other types of heart failure (Hunt et al., 2009; Rose et al., 2001). For patients ineligible for transplant, LVADs are implanted as a permanent alternative to transplant, or DT. These patients must be classified as NYHA class IV heart failure, and meet the following criteria, as shown in Table A3: 1) received optimal medical management 60 out of the last 90 days, 2) left-ventricular function < 25%; 3) life expectancy < two years, and 4) ineligible for heart transplant (Hunt et al., 2009).

Evolution of mechanical circulatory support.

In the last several decades, almost 7000 mechanical circulatory devices were implanted in the United States to support the failing heart and improve overall quality of life for patients with advanced heart failure (Interagency Registry for Mechanically Assisted Circulatory Support [INTERMACS, 2011], Kirklin et al., 2011). The increased utilization of LVADs is reflected in the number of patients bridged to transplant — over 20% of recipients have an LVAD and 3% have a right ventricular assist device at the time of transplant (Stehlik et al., 2010). The design and application of the first mechanical circulatory support device can be traced back to the works of several pioneers in Europe and in the United States. In 1937, a 21-year old Russian medical student, Vladimir Demikhov, partially implanted a para-corporeal (pump outside the body) mechanical assist device into the thorax of a dog, which sustained the function of the heart for

almost 5 ½ hours (Schumaker, 1994).

With the advent of open heart surgery as an acceptable treatment for heart disease and heart failure in the 1950s, cardiopulmonary bypass was developed to mechanically support circulation during surgery (Cohn, 2003). However, failure to wean from cardiopulmonary bypass necessitated extended mechanical support for myocardial recovery (Delgado, Rao, Ross, Verma, & Smedira, 2002). It was at this time that the first artificial heart program began through the direction of the National Heart, Lung, and Blood Institute (NHLBI) in 1964, with the intent to develop both long and short-term mechanical circulatory support systems, as well as the total artificial heart (Hogness & VanAntwerp, 1991; Stevenson et al., 1999). Despite initial advancements in total artificial hearts, mechanical problems, high mortality rates, and the growing number of patients dying while waiting for heart transplant fueled the impetus to develop implantable, electrically powered mechanical circulatory support devices which allowed better patient mobility (Stevenson et al., 1999).

The first LVAD was developed in 1962 by Domingo Liotta (Liotta et al., 1963). In 1966, DeBakey implanted the first pneumatically driven LVAD (an air-powered push plates) in a woman after complicated cardiac surgery which supported her for 10 days (DeBakey, 1971). With the advent of clinical trials of LVADs as a BTT in 1975 (Hogness & VanAntwerp, 1991), Phillip Oyer performed the first BTT with an electrically powered LVAD in 1984 (Portner, 1985). Continued developments and refinement of mechanical circulatory technology culminated in electrically driven pneumatic and vented LVADs (i.e., volume displacement pumps). Eventually, these devices were approved by the U. S. Food and Drug Administration (FDA) as a BTT in 1994 (pneumatic) and 1998 (vented) (Maher, Butler, Poirier, & Gernes, 2001). These devices were mobile and patients were discharged home while waiting for

transplant. Also, with an LVAD, the patient keeps the natural heart, so it can receive signals from the brain to slow or speed up the heart rate as needed. The development of pneumatically and electrically driven LVADs marked the era of first generation LVADs.

First generation LVADs While these first generation pumps mimic the pulsating heart, referred to as pulsatile flow LVADs, (i.e., pulsatile), second generation pumps provide continuous, or non-pulsatile flows) (Figure B1). In most first generation devices, the blood enters the LVAD via an inflow device attached at the top of the left ventricle. Blood fills the left ventricle, enters the pump, and an external controller signals the pump to start pumping. The blood-filled chamber becomes pressurized by the push plate, forces a pliable diaphragm upward and blood is propelled through an outflow channel to the aorta. Check valves located on both sides of the LVADs pumping chamber keeps blood flowing in a single direction. This pusher plate is free floating, allowing for fluctuations in blood supply (Maher, Butler, Poirier, & Gernes, 2001). However, there are several drawbacks related to first generation LVADs which include: (a) the large size of the device, or the device pocket [which required extensive surgical dissection, especially in small statured patients]; (b) poor mechanical durability related to long-term use (e.g., bearing and/or bioprosthetic valve wear and tear; and (c) infection, bleeding, or concurrent bi-ventricular support. In addition, these devices were uncomfortable for patients because they weight three pounds and were very noisy. Several design alterations to these first generation devices had led to the development of second generation, non-pulsatile, continuous flow LVADs, which show promising long-term durability and less adverse events.

Second generation LVADs. Second generation LVADs are continuous flow devices which weigh less than their first generation predecessors (12 ounces compared to three pounds), more durable, and last longer than pulsatile flow LVADs (Pagani, Long, Dembitsky, Joyce, &

Miller, 2006; Pagani et al., 2009). As shown in Figure B1, most second generation pumps weigh only 12 ounces while previous devices weighed 3 pounds (Stahovich, Chillcott & Dembitsky, 2007). Termed continuous flow LVADs (or non-pulsatile LVADs), these devices house either a centrifugal or axial flow pumps. Pump housings are comprised of a rotor with magnets. As electric run through the coils, forces are applied to the magnets and the rotors start to spin. LVADs with centrifugal pumps have rotors shaped to accelerate the blood circumferentially towards the outer edge of the pump (Maher, Butler, Poirier, & Gernes, 2001). In contrast, the axial pumps have cylindrical rotors with helical blades, which make the blood accelerate towards the rotor's axis. These pumps produce a steady pressure by a continuously rotating impeller, housed within blood lubricated bearings (Figure B2) (Maher et al., 2001). The interior of the pump has two surfaces: a textured, bead-like surface made out of titanium (a metal used often in medical devices), and the other side is a textured polyurethane diaphragm. These textured surfaces form a lining inside the LVAD which mimics the internal surfaces of the blood vessels. Since second-generation devices have only one single moving part, there is less device wear, improved longevity, and reduction in pump-pocket and driveline infections (Pagani et al., 2006; Pagani et al., 2009). However, increased thrombogenicity in second generation devices requires anticoagulation, rendering some patients high-risk for gastrointestinal bleeding (Crow et al., 2008; Grasso, Fenkel, Sorensen, & Felier, 2007). Subsequently, third generation devices were designed to address issues with first and second generation devices such as thrombogenicity, device durability, and long-term outcomes.

Third generation LVADs. Advancements in mechanical circulatory support focused on noncontact bearing designs, such as magnetic or hydrodynamic levitation (Maher et al., 2001). Similar to their second generation predecessors, these devices are continuous flow and utilize

either centrifugal or axial flow pumps. What is distinct between second and third generation LVADs is the design use to suspend the rotor. As shown in Figure B2, most second generation designs used solid bearings (e.g. a ball-shaped device used to reduce friction between stationary and moving parts). These newer, third generation pumps use either hydrodynamic or electromagnetic suspension, contain only one moving part, and have an impeller that is hydrodynamically or magnetically levitated, as shown in Figure B3. (Krishnamani, DeNofrio, Konstam, 2010). This was designed to improve device durability with the elimination of bearings utilized in first and second generation models (Krishnamani et al., 2010). Compared to second generation LVADs, third generation devices have the potential for greater efficiency and less device wear (Maher et al., 2001). Other technology, such as trans-cutaneous induction power to control the LVAD rather than percutaneous cables, are currently being evaluated for clinical effectiveness (Francis et al., 2010; Krishnamani et al., 2010; Nguyen & Thourani, 2010). Despite these innovative technological advancements, the overall mortality rate due to the progressive nature of this disease remains high and patients continue to die while waiting for a transplant (Rose et al., 2001; Hunt et al., 2009). While over 4 decades of research into mechanical circulatory support devices focused on survivability and quality of life for this patient population, the shift in focus from a BTT to long-term support was motivated by the increasing prevalence and grim prognosis of this disease (Rose et al., 2001).

Justification for Studying the Phenomenon

There are almost 7000 registered patients in 140 centers nationwide who have received an LVAD while waiting for a donor heart, as DT, or as bridge to recovery (e.g., used to recover the myocardium due to cardio-toxins, etc.) — a 50% increase since 2006 (Kirklin, 2011). Most patients received an LVAD as a BTT (36.3%), followed by likely to be eligible (26.2%),

then DT (20%) (Kirklin et al., 2011). Patients were mostly White (70.5%) males (78.6%), 40-59 (45.2%) years old, followed by the 60-79 year-old age group (39.2%) (Kirklin et al., 2011). The main indications for an LVAD included overall progressive decline in cardiac functioning (42.1%) followed by patients who are stable, but inotrope dependent (21%) (Kirklin et al., 2011). Despite the expanded indications, current data demonstrate that the utilization of LVADs as DT has more than doubled in just one year (120%) compared to a 65% increase in BTT/possible BTT indications (Kirklin et al., 2011). Moreover, older adults (e.g., 72 years and older) are currently the second largest group requiring LVADs and most frequently referred for DT since they are not eligible for a heart transplant (Kirklin et al., 2011) Krishnamani, DeNofrio, & Konstam, 2010). Since the number of persons 65 years or older is projected to increase from 35 million today to 72 million by 2030 (Administration on Aging [AOA], 2010; Older Adults, 2010), this trend will continue, especially in view of FDA approval and Medicare/Medicaid reimbursement of LVADs (Kirklin et al., 2011). Moreover, advancements in LVAD design have made the transition from hospital to home more feasible with smaller, durable, and more mobile devices. As these patients transition from hospital to home, it is imperative to explore what life is like living with such a life-sustaining device in order to better assist them with their long-term needs.

Patients with DT and their caregivers have needs, issues, and concerns which have not been explored. Nurses and other healthcare professionals provide the education for living with such a life-sustaining device, yet, may lack the knowledge of these needs, issues, and concerns while living with an LVAD. My inquiry seeks to shed light on the experience of living with an LVAD as DT from patients' and caregivers' perspective. This inquiry will not only uncover what it is like to live with this device, but also has practice and research implications. The

knowledge obtained will enhance the understanding of what the experience is like from a patient and caregiver perspective and assist nurses and other health care workers to provide a holistic approach to care.

Phenomenon Discussed Within a Specific Context

I sought to explore the experience of patients with LVADs and their caregivers. The context of this inquiry is DT—the only option left for patients ineligible for heart transplant, and those who care for them.

Destination therapy.

Decades of clinical research have culminated in technological advancement aimed at developing such a long-term device with improved morbidity and mortality. However, it was the landmark study, the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) trial, which revealed these technological achievements. Findings of the REMATCH trial demonstrated a 48% reduction in mortality in patients who received an LVAD versus optimal medical management ($P = 0.001$) (Rose et al., 2001). In this study, ($N = 129$) patients who did not qualify for heart transplant and had evidence of NYHA class IV symptoms and were randomized into two groups, those who received a HeartMate VE LVAD as DT ($n = 68$); or those who received optimal medical management ($n = 61$). There was a significant improvement in one year survival compared to two-years (52% and 25% respectively), in patients with a HeartMate VE LVAD versus 25% and 8% (1 and 2-year intervals, respectively), in patients on optimal medical management only (Rose et al., 2001). Subsequently insurance coverage of LVAD implantation for began for Medicare beneficiaries beginning Oct. 1, 2003. Continued improvements in LVAD and clinical management since the REMATCH trial have illustrated a sustained increase in overall quality of life, improved survival

rates, reduced adverse effects, and device durability in long-term DT patients (Lietz et al., 2007; Long et al., 2008). Despite increased longevity and better quality of life outcomes, living with a mechanical circulatory support device may cause severe complications and sometimes life-threatening conditions, including infections, thrombosis and device failure. For example, almost 90% of patients may experience some type of adverse event during LVAD support (Genovese et al., 2009; Holman et al., 2009). Most occur during the first 30-60 days after implantation (Esmore et al., 2008; John et al., 2008), and primarily includes bleeding, infection (Schaffer et al., 2010), cardiac arrhythmias, and more surgical interventions (Genovese, 2009; Holman et al., 2009). Despite these negative outcomes, most adverse events were related to utilization of first-generation devices. However, technological improvements in second-, even third generation devices have reduced the number of adverse events in patients with LVADs as DT. Nevertheless, as the limited availability of donor hearts and long-waits for transplants continues to rise, the number of LVAD implantations has increased dramatically in recent years (Kirklin et al., 2011). As we begin to see an increasing the number of patients in the community with these long-term devices, the number of persons serving as caregivers will also rise.

Caregivers of patients with LVAD as DT.

Designated caregivers are vital to the promotion and maintenance of health and well-being among patients with DT. Patients with LVADs of any indication are required to have a designated caregiver to assist with daily dressing changes, device maintenance, and the ability to respond to and carry-out the emergency protocol (Casida, 2005). A designated caregiver for a patient with DT is usually a family member, or a significant other. Intensive training begins the day after patients receive an LVAD and continues as both patients and caregivers transition from hospital to home.

Although LVAD nurses are available around the clock when discharged home, caregivers of LVAD patients face the reality of caring for a loved one with complex technology all by themselves. Feeling overwhelmed was expressed in a recently completed study exploring lifestyle adaption among LVAD caregivers (Marcuccilli & Casida, 2011). Coping strategies such as positive thinking, fatalism and religiosity, and acceptance, helped caregivers adapt to their new roles (Marcuccilli & Casida, 2011). Consequently, these participants accepted and eventually adapted to their new caregiving roles (Marcuccilli & Casida, 2011). Despite the intensive training for device maintenance and patient care, most caregivers of LVAD patients in other studies reported an overall positive experience while caring for patients with LVADs —yet continued to express concerns related to patient safety, uncertain future, even death (Dew et al., 2000; Dew et al., 2004; Baker et al., 2009; Casida, 2005; Kaan et al., 2010). However, much of this research is based on the perspective of BTT patients awaiting heart transplant and their caregivers (Casida, 2005; Dew et al., 2004; Baker et al., 2010; Kaan et al., 2010). The experience and meaning of living with DT may be much different than someone awaiting a heart transplant (Baker et al., 2010). Utilizing focus group methodology to explore the LVAD caregiving experience of ($N = 13$) participants caring for BTT recipients, Kaan and colleagues (2010) discovered that the burden and stress in caregiving for BTT patients are diminished once they received a donor heart. Such an outcome may not be the same as in caregivers for LVAD DT patients. For example, in a small, qualitative study, one DT caregiver described the constant fear, uncertainty, and anxiety she lived with on a daily basis knowing that her husband, the LVAD recipient, could die or have a stroke at anytime (Marcuccilli & Casida, 2011). Despite these fears, the realization remains that DT is the final option for many of these patients. Yet, no literature explored these issues among the DT population at this time. This gap in knowledge

may result in overall poorer health outcomes and reduced quality of life among this growing population. This knowledge is vital for health care professionals to provide the knowledge, resources, and support for optimal health, well-being and quality of life, including palliative care options and preparation for the end of life. Given the unpredictable nature of heart failure and the growing number of patients with DT and their caregivers, research is needed now to explore the experience of living with DT from a patient and caregiver perspective.

Selected Qualitative Research Method

Qualitative research is appropriate for exploring research problems when little is known about the phenomenon of study and more must be learned from persons experienced with the proposed phenomenon (Creswell, 2005). The research questions, “What are the lived experiences of DT patients and their caregivers?” lends itself to phenomenology, which is an inquiry into the lived experience (van Manen, 1990). Phenomenology guides understanding of the meaning of the research phenomena from the insiders’ perspectives through description, reflection, and interpretation of the lived experience (Morse & Richards, 2002). The research questions necessitate a qualitative inquiry, specifically phenomenology, to explore the essence of the phenomenon of DT. Since no published research has been done to address these questions, phenomenology is best suited to engage in a dialogue with patients and caregivers who have lived with an LVAD as DT and can give voice to their experiences.

Significance to Nursing

To date, 20% of patients registered in the INTERMACS registry have an LVAD as a DT (Kirklin et al., 2011). However, many patients with a BTT have a moderate to unlikely chance at receiving a transplant (Kirklin et al., 2011). Given the number of patients who will never receive a donor heart, many of these patients will eventually transition to a DT. These

patients will live with a mechanical device attached to their bodies for the rest of their lives and face the end of life with uncertainty, even fear. Although most studies examined survivability, quality of life, and improved outcomes while living with such a device, patients' and caregivers' inside perspectives of living with DT were not explored. Since the population of DT patients and caregivers is predicted to rise, the chance for optimal quality of life, palliative and end of life care is dependent upon an understanding of this experience.

This investigation is significant because as one the first known inquiry to uncover these inside perspectives, findings have the potential to enhance the understanding of living with DT. Findings could also assist nurses and other health care workers to provide a holistic approach to care. Additionally, this inquiry will provide the foundation for a program of research aimed to developing evidence-based practice guidelines, specifically for the ACC/AHA and other professional societies. Currently, the ACC/AHA recommendations for palliative care and end of life care utilize "Class C" evidence (e.g., expert consensus, case studies, etc.), thereby denoting an area of much needed research in palliative and end of life care within this population (Hunt et al., 2005; Hunt et al., 2009). Since patient preferences and values are incorporated into the decision-making process about the type of care provided (Melynk & Fineout-Overholt, 2004), findings from this inquiry can be used to inform evidence-based practice for patients with DT and their caregivers. Finally, initial findings will begin to bridge the gap and advance the science of palliative and end of life care for patients with life-limiting illnesses, and life-sustaining technologies, and thus promoting quality of life for them and their caregivers.

Summary

Chapter 1 described the aims of my study, the phenomenon of interest, the background and context of the research, the justification, and its significance to nursing. The context is the

experience of living with DT from patients' and caregivers' perspectives. The specific context of DT, caregiving, and the palliative care and end of life concerns were described. This phenomenon merits recognition for investigation, as it will advance the science of palliative and end of life care for patients with life-limiting illnesses, life-sustaining technologies, and promoting quality of life for this expanding population.

CHAPTER II

LITERATURE REVIEW: EVOLUTION OF THE STUDY

Historical Context of the Study

The following review of the literature is divided into 9 sections: 1) Palliative care and end of life care among heart failure patients, 2) Palliative care and end of life care among patients with DT; 3) quality of life among patients with LVADs as BTT, 4) Left ventricular assist devices as DT, 5) Caregiving in the heart failure population, 6) Caregiving in patients with LVADs, 7) Caregiving in advanced heart failure population, 8) Caregiving in patients with other life-sustaining technology, and 9) Ethical dilemmas related to LVAD therapy. Since DT is the final treatment option for end-stage heart failure, the palliative care and end of life concerns of this population may mirror the concerns, issues, and experiences of advanced heart failure patients without mechanical circulatory support or those with other life-sustaining devices. Therefore, the review is supplemented with this literature. Chapter two ends with an identification of the gaps in the literature, statement of the problem, purpose, study aim, and a preface to Chapter 3, *Methods*.

Health care practices among patients with heart failure and advanced heart failure.

DT is not only the last treatment option for patients ineligible for transplant, but also a chance for improved quality of life at the end-stage of an unpredictable, yet progressive clinical syndrome. Since this is the last therapeutic option for these patients, palliative care and end of life issues/concerns described by these patients and their caregivers may mirror those with advanced heart failure without mechanical circulatory support. Therefore, the review is supplemented with this literature. An integral part of this review includes a description of palliative care and end of life care as distinct, yet complimentary entities, including the barriers

to providing and implementing these vital services.

Palliative care and end of life care—the distinction. Palliative care is defined as a multi-disciplinary and holistic approach aimed at improving the quality of life of patients with life-limiting illnesses and their caregivers, regardless of the stage of the disease or the need for concurrent therapies (National Consensus Project for Quality Palliative Care [NCPQP], 2004). Palliative care is designed to meet the bio-psycho-socio-spiritual needs of patients and their caregivers by optimizing quality of life by assessing, treating, and preventing pain and suffering, and promotes autonomy through informed decision-making (National Hospice and Palliative Care Organization [NHPCO], 2008). Conversely, end of life care is comprised of resources to support patients and their caregivers during and at the end of life (NCPQP, 2004). Despite the similarities among resources and supportive care, palliative care focuses on the reduction of symptom burden and improving quality of life before the final stages of life (Curtis, 2008; NCPQP, 2004; NHPCO, 2008). Patients with heart disease experience significant symptom burden throughout the disease trajectory, especially at the end of life (Goodlin, 2009). Early referrals to palliative care, including timely end of life discussions could improve symptom burden and provide much needed resources for both patients and their caregivers (Goodlin, 2009; Rizzieri et al., 2008). Yet many patients do not receive these services until death is imminent due to patient, caregiver, provider, and communication barriers (Goodlin, 2009; Hupcey, Penrod, & Fogg, 2009; Quaglietti, Pham, & Froelicher, 2005; Rizzieri, Verheijde, Rady, & McGregor, 2005).

Barriers in physician-patient communication. Effective, collaborative physician-patient communication is necessary for all patients (von Guten, 2000; von Guten, Ferris, & Emanuel, 2000), but especially for those experiencing terminal illnesses, such as cancer (Bernard, de

Roten, Despland, & Stiefel, 2009; Fallowfield & Jenkins, 2004). Engaging in discussions for end of life care preferences (Tierney, Dexter, Grameispacher, Perkins, Zhou & Wolinsky, 2001), including advanced care planning (Saraiya, Bodnar, Leventhal & Leventhal, 2007), ensures death with dignity for all patients with life-limiting illnesses (NHPCO, 2009). However, promoting quality end of life care requires a range of skills, including mutual decision-making with family members, timely communication, and personal psychosocial factors impacting end of life care (von Gunten, Ferris, & Emmanuel, 2000). Barriers to effective communication at the end of life, such as communication difficulties, anxiety about patients' reactions to end of life discussions, time constraints, and limited end of life conversations have been ignored in the literature (Teno et al., 2007; Saraiya, et al., 2007). Challenges examined in the literature include when to initiate discussions and referrals to end of life care, especially when prognostication is uncertain among non-malignant diseases, such as advanced heart failure (Goodlin, 2009; Hupcey, Penrod, & Fogg, 2009; Quaglietti, Pham, & Froelicher, 2005; Rizzieri, Verheijde, Rady, & McGregor, 2005).

Communication barriers are also seen in palliative care referrals. For example, the literature reports that patients with cancer diagnoses are usually referred to palliative care services more frequently (Cosgriff et al., 2007; Crawford, 2010; Murray, Boyd, & Kendall, 2002; Rogers et al., 2000) than those with advanced heart failure (Goodlin, 2009; Hupcey, Penrod, & Fogg, 2009; Quaglietti et al., 2005; Rizzieri et al., 2005). Yet, patients with heart failure also have palliative care needs. As patients' symptoms progress to more advanced stages, discussions about therapeutic options for palliative care, even end of life care, is necessary in order to facilitate timely and highly quality care (Goodlin, 2009; Hunt et al., 2009; Hupcey et al., 2009; Rizzieri et al., 2005). Many of these patients, however, are referred only when they are

near death (Goodlin, 2009; Quaglietti et al., 2005; Rizzieri et al., 2005). Although preferences for early referrals to palliative care and continued life support were reported (Aldred et al., 2005; Selman et al., 2007), patients with heart failure and their family caregivers continue to report a lack of communication about palliative and end of life choices (Aldred et al., 2005; Levenson, McCarthy, Lynn, Davis, & Phillips, 2000; McCarthy et al., 2008; Selman et al., 2007). Communication is vital to convey preferences for palliative care and end of life care to ensure a good quality of life and death with dignity. Following is a summary of palliative care and end of life care preferences among patients' with advanced heart failure.

Preferences for palliative care and end of life care. Patients afflicted with advanced heart failure expressed some end of life preferences and arrangements (Levenson et al., 2000; McCarthy et al., 2008). For example, of the surviving participants ($N = 220$) of the original cohort of the Framingham Heart Study, most had a designated health care proxy (75%), a living will (55%), or both (41%) (McCarthy et al., 2008). With regards to end of life care preferences, McCarthy and colleagues (2008) reported that the majority of the sample (69%) discussed end of life care preferences with another person other than a health care provider. Over 2/3's of the cohort (80%) preferred comfort care over life-extending care, and would rather die than receive long-term life-prolonging interventions, such as mechanical ventilation (63%), or tube feedings (64%) (McCarthy et al., 2008). Similarly, patients with heart failure in other studies reported an overall preference for improved quality of life using comfort measures only during the end of life (Levenson et al., 2000; McIver et al., 2008). Levenson and colleagues (2000) found that many participants were willing to tolerate some stressful health conditions, yet 46% preferred to die than live the rest of their lives with a lot of pain (46%) or be in a confused and/or forgetful state of mind (45%). As patients approached the end of life, however, patients' preferences remained

consistent for comfort measures only (Levenson et al., 2000; MacIver et al., 2008).

Comfort measures only at the end of life. Levenson and colleagues (2000) examined end of life preferences among ($N = 539$) patients entering the last 6 months of life. Patients reported a preference for a Do No Resuscitate (DNR) status as death approached (Levenson et al., 2000). These preferences significantly rose from 33% at 6 months to 47% one month and up to 3 days before death ($p < 0.05$). These results are consistent with a study reported by MacIver and colleagues (2008) which described the end of life treatment preferences of 91 patients with either NYHA II ($n = 48$) or NYHA IV ($n = 43$) heart failure. Given the limited functional capacity or symptom severity, 55% chose oral inotropes over medical management (including LVADs) preferring a significantly shorter life (i.e., 182 days) with improved symptoms, whereas 45% chose medical management and longer life with worsening symptoms of heart failure, compared to a shorter survival time with fewer symptoms (MacIver et al., 2008). This population not only preferred for comfort measures only at the end of life, but also wanted to know about their prognosis.

Lack of communication in prognostication. Patients' and caregivers' reported a lack of communication about prognostication for advanced heart failure throughout the literature. For example, in a cross-sectional qualitative study exploring palliative and end of life preferences and communication among advanced heart failure patients ($n = 20$), caregivers ($n = 11$), palliative ($n = 6$) and cardiologists ($n = 6$), both patients and caregivers described a lack of understanding of congestive heart failure and its symptoms (Exley et al., 2005). Whether it was prognostication, palliative or end of life care, evidence illustrates that a lack of communication remained a major concern for these patients' and their family caregivers. Despite the desire for improved communication at the outset of their diagnosis, many of these patients continue to

experience unnecessary symptom burden and distress as they progress along the illness trajectory. Since palliative care can be initiated regardless of any disease or the need for concurrent therapies, DT represents an innovative component of a holistic, palliative care approach. Many patients, however, will continue to deteriorate due to the unpredictable, progressive nature of heart failure, including device-related events. These patients may eventually experience adverse events (i.e., sepsis, stroke) related to device therapy, device failure, and/or become ineligible for LVAD re-implantation (Hunt et al., 2009). Deteriorating quality of life, knowledge of impending death, and the difficult decision for patients and/or their caregivers to deactivate this life-sustaining device may further contribute to fear, anxiety, and depression for this expanding population (Rizzieri et al., 2008). Early referrals to palliative care, including timely end of life discussions, therefore, could improve symptom burden, provide much needed resources, including preparation for a peaceful death (Byram, 2012; Goodlin, 2009; Rizzieri et al., 2008; Swetz, 2011). Clearly, palliative care and end of life issues are unavoidable for patients with advanced heart failure. How best to approach these issues remain understudied. Meeting these sensitive, yet vital issues among this growing population is needed now to ensure death with dignity.

Palliative and end of life care among patients with and LVAD as DT.

Currently, recommendations are in place for initiating palliative care and end of life care discussions along the advanced heart failure trajectory (Hunt et al., 2005). With the increase in utilization of LVADs as DT and improving technology, there will be an increase in LVADs as DT for longer periods of time, and more patients and their family caregivers will be confronted with necessity for ongoing palliative care and end of life preparation. To date, limited literature identifies the need for pre-implantation palliative medicine consultations and end of life

discussions among the expanding population of DT patients (Brush et al., 2010; Byram, 2012; Swetz et al., 2011a; Swetz et al., 2011b). Only two studies provided empirical evidence for initiating palliative care consultations and establishing end of life care goals among patients with DT and their caregivers (Brush et al., 2010; Swetz et al., 2011a). For example, Swetz and colleagues (2011) examined the implementation of palliative medicine consultation aimed at identification of goals for care and quality of life preferences prior to implantation. Palliative care consultation ranged from 5 days before to 16 days after implantation (Median = 1 day before implantation). Thirteen (68%) out of 19 patients were consulted about palliative care and subsequently completed advance directives. Both the implant team and family caregivers reported that palliative care discussions prior to implantation made postoperative care clearer and that complications were dealt with more efficiently. Findings indicated that proactive palliative care planning improved completion of advanced directives and contributed to overall improved care. Studies exploring end-of-life among DT were scant, however. However, 1 study was found on the end-of-life decision making amongst patients with DT. Brush and colleagues (2011) retrospectively examined end-of-life decision making among ($N = 20$) patients who died with DT and qualitative inquiries with their surviving ($N = 20$) caregivers. Findings indicated that decreases in quality of life as a result of new and/or decline in current comorbidities prompted end of life discussions.

Despite anecdotal assumptions in the literature and studies presented thus far, no known published research explored the palliative care and end of life issues and concerns among patients who were still alive with DT. Furthermore, several issues, concerns, quality of life, or other experiences related to living with a DT remain unknown. Thus, I began to wonder, “How do advanced heart failure patients with LVADs as DT describe their palliative and end-of-life

needs?” Section II of this literature review continues with the limited evidence examining short- and long-term quality of life outcomes in patients with BTT.

Quality of life among patients with an LVAD as BTT.

Previous research illustrates an overall improvement of quality of life of patients with BTT (Dew et al., 1999; Dew et al., 2000; Grady et al., 2001; 2002; 2003; 2004; Moskowitz, Weinberg, Mehmet & Williams, 1997). One of the first studies examining quality of life among bridge-transplant patients elicited the preferences of patients (N = 29) via standard gamble (i.e., responses obtained by participants after the introduction of a hypothetical scenario) prior to LVAD implant ($n = 14$), while on LVAD support ($n = 20$), and after heart transplant ($n = 11$). Mortality risk scores before LVAD implantation were worse and participants were willing to risk a 45% chance of death in exchange for a return to health (Moskowitz et al., 1997). Scores on participants’ willingness to take on a death risk to improve overall health reduced significantly after LVAD implant and after heart transplant (19.1% and 3.6% respectively) (Moskowitz et al., 1997). The findings suggest that LVAD recipients reported better quality of life than those treated with medical management only, but not as good as heart transplant (Moskowitz et al., 1997). Consequently, results of this study lead to an acceptance of long-term utilization of LVADs in the healthcare community.

However, few studies have explored the experience of living with an LVAD from patients’ perspectives. For example, a phenomenological study by Savage and Canody (1999) explored the lived experiences of 6 hospitalized LVAD patients. Five overarching themes were constructed by the researchers which illustrated bio-psychosocial issues, concerns with performing ADLs, quality of life, and coping strategies. Religiosity and participation in diversional activities were other coping strategies described by patients hospitalized with

LVADs (Savage & Canody, 1999). However, inpatients and out-patients with LVADs stressed the importance of good family support as they strove to cope with their new device, which are consistent with the findings in other studies (Dew et al., 1999; Grady et al., 2001; 2002; 2003). In contrast to LVAD inpatients, those discharged home reported overall improved quality of life (Dew et al., 1999; Grady et al., 2001). For example, Dew and colleagues (1999) assessed quality of life among both inpatient ($n = 25$) and outpatient ($n = 10$) LVAD patients one month after implantation. Second interviews were performed to assess quality of life on patients discharged to outpatient settings. Those discharged to an outpatient setting were interviewed again after discharge to evaluate their quality of life. Quality of life for outpatients with LVADs was significantly different ($p = 0.05$) compared to inpatients, with the majority of improvements in emotional and physical and social functionality (Dew et al., 1999). Similarly, several studies conducted by Grady and colleagues continued to support improved quality of life among discharged LVAD patients (Grady et al., 2001; 2002; 2003). Grady and colleagues (2001) reported improved quality of life (i.e., lower symptom distress, improved functionality, and an overall perception of good health) among a convenience sample of 81 patients 1-2 weeks pre-compared to 1-2 weeks post-LVAD implantation. Since these studies examined quality of life from a short-term perspective, more studies were needed to reveal quality of life from a long-term perspective (Grady et al., 2001). One study examined the relationships between physical, psychosocial, clinical variables, and quality of life (Grady et al., 2002). The researchers found that psychological factors, such as satisfaction with health care providers, good emotional support, and having significant others were the strongest predictors of satisfaction with quality of life, accounting for 46% of variance in quality of life. Similar long-term quality of life improvements following LVAD implantation were reported in one of the largest, prospective,

multi-site studies of patients with BTT ($N = 62$). Despite fairly good quality of life outcomes and improved health status of inpatients and outpatients, significant differences were reported in functional disability related to self-care disability ($p = 0.001$), and a reduction in overall physical disability ($p = 0.006$) in patients discharged with LVADs. However, quality of life outcomes were mostly measured in patients bridged to transplant in the immediate and 6-week post-operative recovery period. Since many of these patients must wait almost one year for a donor heart, examining quality of life beyond 6 weeks, therefore, was necessary. In a prospective, longitudinal study, Grady and colleagues (2004) examined quality of life among patients ($N = 78$) with an LVAD as a BTT from 1 month to 1 year post implantation (Grady et al., 2004). These patients perceived their health status as quite good, with moderate stress levels, coped fairly well, and experienced improved social and relationships from 1 month to 1 year post LVAD implantation (Grady et al., 2004). Similarly, findings from few qualitative studies reported overall improved quality of life from both physical and psychosocial dimensions. For example, an interpretive phenomenological study of based on the methods of van Manen (1990) explored sex and intimacy among patients ($N = 9$) who had an LVAD from 3 months to 2 ½ years (Marcuccilli & Casida, 2011). The researchers reported that as overall improved health, their intimate and sexual relationships improved as well (Marcuccilli & Casida, 2011). In a related hermeneutic phenomenological inquiry, one overarching theme elucidated by several sub-themes constructed from the data illustrated the process of lifestyle adjustments required by patients with LVADs (Casida, Marcuccilli, & Peters, 2011). Phases of adjustment and acceptance were delineated into an early and late adjustment phases, in which participants learned to live with the LVAD as part of their bodies and lives. Overall improved quality of life from a psychosocial perspective was noted in a more recent hermeneutic phenomenological

study exploring self-concept among patients ($N = 9$) with LVADs (Marcuccilli, Casida, & Peters, 2012). Two themes were constructed from the data, “Having an LVAD means living,” and “A desire to be ‘normal’ in public.” Participants accepted the LVAD as necessary to live making it easier for them to modify their self-concept and accept the changes to their bodies and daily lives. Finally, attaining a sense of normalcy was more difficult in public and required additional lifestyle modifications. Despite these findings, some participants in other studies continued to report some type of functional disability related to work, care of the home, sleeping and rest, social interaction, self-care ability, and physical disability up to 1 year into the study (Grady et al., 2004). Moreover, patients reported across all time periods (e.g., one month to one year) negative emotions, such as anxiety, sadness, feelings of helplessness, even depression (Grady et al., 2004). It is important to point out, however, that the participants used in these studies represented the population of patients with a BTT. Patients who will be on LVADs, such as in DT, may also experience these negative quality of life outcomes warranting further research. With the increasing number of patients ineligible for heart transplant or may never receive a donor heart, LVADs as DT represent the final palliative care option for the relief of progressive and debilitating symptoms of the final stages of heart failure. Thus, I began to wonder, “How do patients describe their quality of life (inclusively considering the wide range of issues expected in the literature) as advanced heart failure patients with LVADs as DT?”

Adaptation among patients with left-ventricular assist devices.

Although some other studies exploring quality of life have addressed the bio-psycho-social aspects of living with the LVAD (Dew et al., 1999; Grady et al., 2003; Grady et al., 2003b; Savage 2003), no published studies to date have addressed how patients adapt to an LVAD. In a related phenomenological inquiry exploring lifestyle adjustments among 9 adults

with LVADs, one overarching theme, “Adjustments take time,” were elucidated by 2 sub-themes, “Early phase: Changes in the basics of everyday life,” and “Late phase: New way of living,” constructed from the data. Themes illustrated the process of lifestyle adjustments required by patients with LVADs (Casida, Marcuccilli, & Peters, 2011). Phases of adjustment and acceptance were delineated into an early and late adjustment phases, in which participants learned to live with the LVAD as part of their bodies and lives. Themes constructed from the data illustrated that participants were able to overcome physical, emotional, and psychosocial issues as they learned to incorporate a mechanical heart into their lives.

Left-ventricular devices as a DT.

Several studies have emerged illustrating the clinical benefits of receiving an LVAD as a DT (Long et al., 2008; Park et al., 2005; Rose et al., 2001; Slaughter, 2009). In the landmark study of the REMATCH trial, Rose and colleagues (2001) reported that patients implanted with the HeartMate VE, a first generation pulsatile LVAD. Patients demonstrated an improvement in survival, functional status, and overall quality of life when compared to patients receiving maximal medical management. As a result of this study, LVADs were approved for use of DT in 2002, and subsequently approved for Medicare and Medicaid in 2003. A 2-year follow-up, post-hoc analysis by Park and colleagues (2005) demonstrated that two-year survival rates for LVAD patients post REMATCH trial more than doubled compared to patients receiving optimal medical management (52% to 28% and 29% to 13%, 1 and 2 years respectively). Patients participating in the second part of the study compared with the first part also demonstrated a significant improvement in survival (Park et al., 2005).

Continued improvements in LVAD technology since the REMATCH trial have showed a sustained increase in overall quality of life and survival rate outcomes in patients supported with

HeartMate XVE as a DT (Long et al., 2005; Long et al., 2008). Similar results were also found in a prospective, nationwide study of 4 high-volume LVAD institutions and demonstrated that patients implanted with the new Heart Mate XVE LVAD as a DT had improved morbidity and mortality rates. Patients implanted with DT had a 40% reduction in mortality and were less likely to experience long-term complications, such as sepsis or stroke (Long et al., 2005). Improved survival rates were reported at 30-day and 1-year intervals among patients with DT compared to the REMATCH cohort (i.e., 30 days = 90% to 81% respectively; 1 year = 61% and 53% respectively). Subsequent studies following the REMATCH trial continued to demonstrate a reduction in mortality and adverse events, as described previously (Long et al., 2008). Yet, more research on second generation devices was necessary to evaluate long-term outcomes. This prompted the investigation of the newer, second generation devices for use in the destination therapy population.

In a random control trial of 200 participants from 38 centers, 46% of 134 patients implanted with a second-generation, nonpulsatile pump, were still alive two years post-implantation with no reported adverse events such as stroke or need for LVAD re-implantation compared to 11% of 66 patients in the control group with pulsatile LVADs (Slaughter et al., 2009). Based on these data, HeartMate II[®] was approved by the FDA 2010 as a DT for patients ineligible for heart transplant or unresponsive to optimal medical management. Although these studies provide for us evidence of improved morbidity and mortality rates among patients with long-term LVADs, I began to wonder about what life is like living with such a life-sustaining device, specifically, “What do advanced heart failure patients with LVADs as DT suggest healthcare providers need to know based on patients’ lived experiences? Moreover, I began to wonder, “With respect to healthcare practices, how do patients describe their lived experiences

as people with advanced heart failure, and with LVADs as a DT?”

The second part of the literature review examining the evidence on patients with LVADs comes to a close. I now turn my focus to the caregiving literature within the context of LVADs, advanced heart failure, palliative and end of life caregiving, life-sustaining technologies, and ethical considerations.

Caregiver support in situations similar to LVADs as DT.

As the numbers of patients with DT continues to rise, so will their caregivers. Yet we know little about the caregiving experience of this population. Due to the long-term care required for DT patients, these caregivers may exhibit burden, stress, even an overall poor quality of life, as experienced by caregivers of heart failure patients (Alfred, Gott, & Gariballa, 2005; Pressler et al., 2009; Saunders, 2010). Since it is possible that the DT caregiving experience may be comparable to chronic heart failure caregiving [and the heart failure caregiving literature is more substantial than the LVAD caregiving literature], this evidence was used to compliment the LVAD caregiving literature.

Caregiving in the heart failure population.

Over two decades of research on caregiving have been dedicated to heart failure caregiving. Since most patients with heart failure are over 75 years of age, they will experience progressive functional decline and require frequent hospitalizations (AHA, 2010c) and a caregiver, often provides care and support at home (Artinian, Artinian, & Saunders, 2004). Caregivers are essential to the overall health and well-being of heart failure patients (Aldred, Gott & Gariballa, 2005; Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006; Clark & Dunbar, 2003; Saunders, 2008; 2009; 2010). Caregiving responsibilities and tasks include assisting with and promoting self-care, monitoring compliance, recognizing worsening signs and symptoms of

heart failure (Pattenden, Roberts & Lewin, 2007), and continuing to manage household tasks and finances (Saunders, 2009; Saunders, 2010). In view of the responsibilities and tasks required for heart failure caregiving, these caregivers must adapt current lifestyles, even balance caregiving roles. However, adapting to this new role can be an overwhelming experience (Martensson, Dracup, & Fridlund, 2001; Murray et al., 2002; Scott, 2000). Consequently, heart failure caregivers are at risk for negative health outcomes such as depression (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007a; Luttik, Jaarsma, Veeger, & van Vledhuisen, 2005; Mahoney, 2001; Molloy, Johnston, & Whitham, 2005; Murray et al., 2002), caregiver burden (Karmilovich, 1994; Saunders 2008; 2009), worsening overall health (Luttik et al., 2007a; Luttik et al., 2005; Pressler et al., 2009), and poor health-related quality of life (Luttik et al., 2007b; Pressler, 2009). Since caregivers' must make lifestyle changes due to the progressive and debilitating nature of heart failure, the following review illustrates the most commonly cited bio-psycho-social outcomes in the literature.

Depression and anxiety. Negative emotional health, such as depression and anxiety, has been studied extensively in the general caregiving literature. Caregiving has been associated with negative emotional health (Dew et al., 2004; Molloy et al., 2005; Yee & Schulz, 2000), including increased anxiety or depression with greater caregiving burden (Dew et al., 2004). Several studies have illustrated this emotional burden in the literature. For example, a review of 30 studies of caregivers and psychiatric morbidity found higher depression, including clinical, or major depression, among women (Yee & Schulz, 2000). Similarly, a meta-analytic review by Molloy and colleagues (2005) found that informal caregiving contributes to poor psychiatric and physical health among caregivers. Several studies have also reported moderate to severe levels of depression in the heart failure caregiving literature (Molloy et al., 2006; Pattenden et al., 2007;

Schwarz & Dunphy, 2003; Schwartz & Elman, 2003). Although previous research showed that heart failure caregivers experience depression, emerging studies continue to illustrate other outcomes related to the negative effects of burden on heart failure caregivers.

Caregiver burden. Negative outcomes reported in the caregiving literature include physical and health-related morbidity due to increased caregiver burden. While caregiver burden has been documented in other illnesses such as stroke (Bakas, Austin, Jessup, Williams, & Oberst, 2004; Foster & Chaboyer, 2003) and heart failure (Bennett & Sauve, 2003; Gure, Kabeto, Blaum, & Langa, 2008), factors influencing heart failure caregiver burden have been occasionally described and poorly understood (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008). Several studies have examined both objective and subjective factors related to health-related quality of life in caregiving (Ågren, Evangelista, & Strömberg, 2010; Alfred et al., 2005; Pihl, Jacobsson, Fridlund, Stromberg, & Martensson, 2005; Luttik et al., 2005; Pressler et al., 2009; Saunders, 2009). Caregiver burden has both objective (e.g., degree of interruption to the one's life) and subjective (one's perceptions and feelings about caregiving) components (Braithwaite, 1992; Foster & Chaboyer, 2003). For example, subjective and objective variables in health-related quality of life were examined in relation to caregiver burden. Saunders (2009) examined health-related quality of life among 50, mostly White female caregivers of older heart failure patients. In this study, an increase in caregiver burden explained 62% of the variance in health-related quality of life (adjusted $R^2 = 0.58$, $p < 0.01$). Predictors of caregiver burden included poorer patient functionality (Ågren, Evangelista, & Strömberg, 2010; Saunders, 2008). Ågren and colleagues (2010) used the Caregiver Burden Scale to determine predictors of caregiver burden on a sample of mostly female caregivers ($N = 135$). The researchers found that a higher degree of caregiver burden was associated with poorer physical function of the patient, similar to

findings in Saunders (2008). Other studies also reported higher caregiver burden with poorer patient functionality and mental health problems (Alfred et al., 2005; Luttik et al., 2005; Pihl, Jacobsson, Fridlund, Stromberg, & Martensson, 2005). Another negative outcome reported in the caregiving literature is a reduction in socialization or personal interests.

Limited socialization. Negative outcomes related to social well-being are illustrated in the heart failure caregiving literature (Gott et al., 2006; Pattenden et al., 2007; Pressler et al., 2009). For example, few qualitative studies reported that participants felt socially isolated as a caregiver for patients with heart failure (Aldred et al., 2005; Murray et al., 2002). Other studies continue to report limited opportunities for socialization for these caregivers (Bakas et al., 2006; Karmilovich, 1994; Pressler et al., 2009). In a prospective study utilizing 63 patients and 63 caregivers, Pressler and colleagues (2009) reported 43% of caregivers had limited socialization. A descriptive, correlational study by Bakas and colleagues (2006) reported less time for socialization among ($N = 21$) White female heart failure caregivers. The results of these studies supported further exploration of the demographic variables, gender and lifestyle changes.

Differences in gender-related caregiving outcomes. Although the majority of the studies focused on the experience of White, spousal female caregivers, gender differences have been reported among the caregiving experience (Karmilovich, 1994; Lutzky & Knight, 1994; Rohrbaugh et al., 2002). Generally, female caregivers of patients with chronic illnesses were found to be more distressed (Karmilovich, 1994; Lutzkey, 1994; Lutzik & Knight, 1994; Pinquart & Sorensen, 2003; Pinquart & Sorensen, 2006; Rohrbaugh et al., 2002), and experienced overall worse well-being and health (Pinquart & Sorensen, 2006; Rohrbaugh et al., 2002) than males. Notably, females have reported more distress in the heart failure caregiving literature. Karmilovich (1994) was first to report gender differences in the heart failure

caregiving population. Karmilovich found that (50%) of female spouses felt helpless and had difficulty watching male spouses, and (40%) had concerns about the future and their ability to care for their spouses. In addition, (36%) of the sample reported higher role alterations than male caregivers, and the inability to share concerns with spouses while male caregivers experienced less distress than female caregivers (Karmilovich, 1994; Evangelista et al., 2002), gender differences were also explicated on an intimacy level. Male caregivers reported concerns over less time for intimacy compared to females (Karmilovich, 1994). Given the variety of negative outcomes caregivers of patients with heart failure can experience, the following section describes the evidence related to lifestyle modifications required for caring for these patients.

Lifestyle changes. Previous studies have documented worsening lifestyle changes among caregivers, such as stroke patients (Bakas et al., 2004; Bakas, Champion, Perkins, Farran, & Williams, 2006). However, few studies have specifically examined lifestyle changes in the heart failure caregiving population. Lifestyle changes reported by heart failure caregivers include providing care (Brostrom, Stromberg, Dahlstrom, & Firdlund, 2003; Martensson et al., 2003; Scott, 2000), lack of sleep and increased worry over patients (Brostrom et al., 2003), financial worries (Bakas et al., 2006; Pressler, 2009; Saunders, 2008; Saunders, 2010), and limited socialization. However, significant life changes for heart failure caregivers include an overall worsening of life. Caregivers have reported that their lives have changed for the worse (Bakas et al., 2006; Pressler, 2009). For example, over 48% of heart failure family caregivers rated future outlook, finances, energy level, and time for social activities as changed for the worse, while 57% of heart failure caregivers rated their emotional well-being as changed for the worse (Bakas et al., 2006). Similarly, Pressler and colleagues (2009) found that caregivers reported a change in their lives for the worst after 4 months ($p = 0.03$), while symptoms of depression predicted

emotional health-related quality of life both at 4 and 8 months intervals ($p < 0.001$, and $p = 0.001$ respectively). Since these caregivers have experienced depression, burden, limited socialization, and more difficult lifestyle changes, clearly, it is imperative to support patients and caregivers to improve overall quality of life (Dracup et al., 2004; Pressler, 2009; Saunders, 2008; Saunders, 2010).

Despite decades of heart failure caregiving research illustrating the negative outcomes of caregiving, caring for patients with chronic illnesses can be a positive, even a rewarding experience (Kramer, 1997; Rees, O'Boyle, & MacDonagh, 2001). For example, caregiving has been related to enhanced self-esteem, gratification, pride, even closer personal relationships in patients with chronic illnesses (Chappell & Reid, 2002; Kramer, 1997; Rees, O'Boyle, & MacDonagh, 2001). Kramer (1997) reported that some caregivers experienced pride in caregiving challenges, enhanced self-esteem, deeper meanings and overall pleasure in their new roles and relationships. Similarly, Chappell and Reid (2002) reported overall satisfaction and quality of life among caregivers ($N = 234$) of dementia and non-dementia patients, despite caregiver burden. However, empirical research limits the personal experience of many of these chronic caregivers. As a result, personal meanings associated with caregiving among patients with chronic illnesses, such as heart failure, may never be known. Therefore, researchers argued that qualitative research is necessary to explore the caregiving experience of heart failure caregivers (Karmilovich, 1994; Luttik et al., 2007a).

A qualitative study by Aldred and colleagues (2005) utilizing focused interviews among patient/caregiver dyads which uncovered four overarching themes reflecting the impact of heart failure on the lives of both patients and caregivers: 1) Impact of heart failure on life, 2) relationships, 3) professional support, and 4) concerns for the future. Similar to other studies

(Gott et al., 2006; Karmilovich, 1994; Luttik et al., 2007a; Pressler et al., 2009), patients and caregivers alike reported about how heart failure affected their overall life, including limited social activities [even staying indoors]. Moreover, respondents in Aldred and colleagues' study partially blamed health care providers for not addressing their needs and concerns. Concern for caregiver 'burden' was expressed by heart failure patients, although caregivers did not perceive caregiving as a burden. Collectively, respondents reported the need for more information about prognosis and condition, in spite of the understanding that heart failure was a life-limiting illness.

Given the limitations inherent in qualitative studies, the value of providing an inside perspective of the heart failure caregiving experience is noteworthy. Understanding the inside perspective of heart failure caregiving provides a holistic approach to care. Since heart failure is a chronic, incurable condition, patients and caregivers alike may continue to experience negative outcomes with little opportunity for a good quality of life. Although evidence suggests that LVADs enhance quality of life for many patients as previously indicated, researchers have projected that the overall caregiving experience can increase burden for LVAD caregivers (Pressler et al., 2009; Rizzieri, Verheijde, Rady, & McGregor, 2005). However, the integral role of the LVAD caregiver has only recently begun to emerge.

Caregiving in patients with LVADs as BTT.

Despite overall improvements in quality of life with LVADs as a BTT, some negative patient outcomes and general anxiety was expressed among LVAD caregivers. In a descriptive, correlational study by Dew and colleagues (2000), caregivers ($N = 20$) expressed overall positive experiences with caregiving but reported several worries and concerns related to possible infection (52%), device malfunction (40%), and device noise (32%). Open-ended responses about living with an LVAD illustrated an overall improved quality of life from a caregiver

perspective, including: “It allows [my spouse] to live until a transplant is available,” “[My spouse] feels better physically,” even concern related to the overall well-being of the LVAD recipient: “the risk of infection,” and “the uncertainty of how long [my spouse] will be on the device” (Dew et al., 2000). Although physical and psychosocial variables were measured among LVAD patients, these variables were not examined among LVAD caregivers. Examining bio-psycho-social variables such as functionality, depression, burden, and lifestyle adjustments, would shed light on the caregiving needs and health related and overall quality of life among LVAD caregivers, and provide the direction for future research studies.

More recently, four qualitative studies illustrated the experience of LVAD caregiving. A phenomenological study based on the philosophy and methodology of van Manen (1990) was utilized to explore and uncover the lived experience among female spouses of LVAD patients awaiting heart transplant (Casida, 2005). Despite the sample size ($N = 3$), three main themes were identified (i.e., emotional distress, determination, and optimism: a new lease on life), which were further explained by 8 subthemes: guilt and realization of severity of illness, fear and anxiety, caregiver’s role: an overwhelming experience and a burden, coping, living with hope, realization of a loving relationships, adaptation to a new life, and joyful feeling (Casida, 2005). Themes and sub-themes reflected participant’s personal experiences from the initial realization of needing an LVAD up to time of transplantation (Casida, 2005). Casida noted that it was during this time that LVAD caregivers became “more resilient” and felt better prepared for future caregiving responsibilities. Casida’s study provided the foundation for the development of future studies aimed at exploring caregiving experiences and examining factors associated with LVAD caregiving. Although Casida utilized in-depth interviews to explore the lived experience of LVAD caregiving, utilizing various perspectives of the human experience

(e.g., personal life stories, favorite quotes, photography, etc.) would assist the researcher to arrive at a deeper meaning of phenomenon being researched (van Manen, 1990). van Manen argued that conducting an existential investigation from many perspectives of human experience, including the phenomenological literature, is necessary to fully capture the essence of the true lived experience.

Another qualitative study by Baker, Flattery, Salyer, Haugh, and Maltby (2009) described the experience of one male and five women caregivers of BTT patients awaiting heart transplant. One overarching theme, commitment, was further explicated by two subthemes: sacrifice and moving beyond. The theme suggested that the role of caregiving required many lifestyle changes, including personal, health-related, even financial sacrifices as participants strived to cope with LVAD caregiving (Baker et al., 2009). Participants described sacrificing relationships with family, social relationships, health, even jobs, and peace of mind to care for the LVAD recipient was necessary (Baker et al., 2009). Although scant studies have illustrated LVAD caregiving experiences, similar themes were reported in two studies. Casida (2005) identified the theme “caregiver’s role: overwhelming, difficult, and to some extent a burden” which explicates the unwavering acceptance of roles amidst the “burdens” and responsibilities of LVAD caregiving (p. 149). One participant described interference with sleep and work schedules, while another participant described LVAD caregiving as “...one of the hardest things I had to deal with...” (p. 149). Concerns with infections, device malfunction, rose as patients had the LVAD. Similarly, Dew and colleagues (2000) reported that caregiver burden was described mostly as worries about infection and device malfunctions. In the second sub-theme, Baker and colleagues (2009) described “moving beyond” as the ability of the LVAD caregiver to adapt to the role of LVAD caregiver, even in the face of adversity. Resiliency was suggested as an

attribute, or even process, utilized by LVAD caregivers to positively cope in an otherwise overwhelming or difficult situation. However, Baker and colleagues argued that the caregiving experiences of LVAD patients who are not awaiting transplant, such as DT patients, could be very different.

The latest qualitative study employed a focus-group and grounded theory methodology to explore the lived experiences of 13 caregivers caring for LVAD patients at home (Kaan, Young, Cockell, & Mackay, 2010). Supporting the majority of findings in other qualitative studies (Casida, 2005; Dew et al., 2000; Baker, Flattery, Salyer, Haugh, & Maltby, 2009), the authors described four themes: fear and anxiety, loss, burden, and coping, elucidated by several sub-themes. Although the majority of these studies utilized in-depth interviews to explore the experiences of LVAD caregiving, again, incorporating various perspectives of this lived experience, such as personal life stories, favorite quotes, and photography would assist the researcher to arrive at a deeper meaning of the phenomenon being researched to further understand the LVAD caregiving phenomenon (van Manen, 1990). Using the hermeneutic-phenomenological approach by van Manen (1990), Marcuccilli and Casida (2011) explored and described the lifestyle adjustments involving 5 caregivers. Themes found were caregiving: a “24/7” responsibility, coping strategies, and satisfaction, where elucidated by thirteen sub-themes describing the process of how participants adjusted to caring for an LVAD patients. The researchers concluded that lifestyle adjustments with caregiving may become easier over time, and with effective use of coping strategies, caregivers accepted their new caregiving role as part of life.

Clearly, the limited literature to date has portrayed the critical need to continue to examine LVAD caregiving in view of this expanding LVAD patient population. However, most

studies explored the experience of LVAD caregiving among mostly White, female spouses of BTT LVAD patients, limiting the responses and experiences from more diverse sociodemographic participants. Since the majority of caregivers are White females and reflect the current national data (NFCA, 2009), this proportion may soon reflect an older and even more racially and ethnically diverse population in the next decade (Aging Statistics, 2010; Older Americans, 2010). Future studies addressing caregiver variables (e.g., burden, health-related quality of life, and quality of life) and more qualitative studies in an older and culturally diverse population may shed light on important areas in need for developing nursing intervention. Since this population is predicted to rise (Krishnamani, DeNofrio, & Konstam, 2010), more research is needed to better assist nurses and other health care professionals to improve overall quality of life. Therefore, I began to wonder, “with respect to healthcare practices, how to caregivers of heart failure patients with LVADs as DT talk about and explain their lived experiences: a) with heart failure (or advanced heart failure) and b) with LVADs as DT? Also, “how do caregivers of heart failure patients with LVADs as DT describe their quality of life? (inclusively considering the wide range of issues expected in the literature).

Because DT is utilized for as the last therapeutic option available for patients with end-stage heart failure, experiences may be parallel with the knowledge of caregivers of patients living with chronic, advanced heart failure patients near the end of life.

Caregiving at the end of life.

Caregivers of advanced heart failure patients with palliative care and end of life needs encounter a number of caregiving stressors. Responsibilities include learning how to perform complex nursing care at home, care coordination, and patient advocacy (e.g., making medical and financial decisions for patient) (American Cancer Society, 2009). Caregiving burden and

strain mirrors psychosocial and physical morbidities of caregivers in chronic illnesses previously described, including emotional distress (e.g., depression, anxiety, fatigue, and sleep problems) health concerns, unemployment, financial difficulties, and limited socialization (Braun et al., 2007; Clark et al., 2006; Fang et al., 2001; Given et al., 2004; Harding, Higginson, & Donaldson, 2003; Herbert, Arnold & Schulz, 2007; Kozachik et al., 2001). Despite this evidence, caregivers of patients with heart failure, COPD, even cancer, and have expressed the need for more assistance with caregiving tasks (Garlo, O'Leary, Van Ness, & Fried, 2010; Gysels & Higginson, 2009), better support, knowledge, and resources on how to care for these patients (Fried & O'Leary, 2008; Gysels & Higginson, 2009). Garlo and colleagues (2010) examined caregiver burden over 12 months among caregivers of patients with terminal cancer, heart failure, or COPD ($N = 179$). High caregiver burden was related with the need for more assistance with activities of daily living (odds ratio = 23.13, 95% CI) and the desire for more communication with the care recipient (odds ratio = 2.54, CI = 1.16-5.53) (Garlo et al., 2010). Similarly, communication difficulties with care recipients were described in a cross-sectional investigation of caregivers of patients in the community with advanced cancer, COPD, or heart failure ($N = 64$) (Fried & O'Leary, 2008). Communication difficulties stemmed from differing preferences for advanced care planning, including place of death (Fried & O'Leary, 2008). Despite this evidence, results generally indicated that caregivers reported a lack of knowledge on how to provide the best care for symptom reduction, including a lack of support for caregiver psychosocial needs (Fried & O'Leary, 2008; Garlo et al., 2010; Gysels & Higgins, 2008).

While studies report the need for ongoing psychosocial and educational needs among palliative and end of life caregivers, limited evidence demonstrated effective interventions for meeting their needs (Bee, Barnes, & Luker, 2008; Harding & Higginson, 2003; Lorenz et al.,

2008). A meta-analysis by Lorenz and colleagues (2008) evaluated evidence about interventions designed to improve palliative care and end of life care. Among other results, there was weak evidence found for interventions to improve burden in cancer caregiving, and no evidence of interventions aimed at improving advanced heart failure caregiver burden (Lorenz et al., 2008). Notably, there was no citation of caregiving interventions for patients with COPD. These findings were confirmed by Caress and colleagues (2009) reporting a lack of interventions for ongoing education and support for caregivers of COPD patients. Despite two decades of intervention studies aimed at supportive services for caregivers, and the growing number of patients with palliative and end of life care needs, much more intervention research must be done to address caregivers' needs (Harding & Higginson, 2003; Hudson, Remedios, & Thomas, 2010; Lorenz et al., 2008). Addressing these gaps in caregiver research is crucial because of the increasing role of caregivers for an expanding number of patients with life-limiting illnesses requiring palliative care and end of life care (Lorenz et al., 2008). Therefore, I began to wonder, "How do caregivers of heart failure patients with LVADs as DT describe their experiences with palliative and end-of-life needs?"

Caregiving in patients with life-sustaining devices.

With the projected increase of older patients in the next decade (i.e., ≥ 65 years) (Aging Statistics, 2010), we are expecting to see an increase of chronic illnesses [including LVADs] among this population, including their caregivers. As these patient and caregiver groups continue to expand, bio-medical advancements will continue to evolve permitting long-term care in the home. However, limited evidence illustrates the caregiving experience of individuals and families caring for patients with other implantable, life-sustaining devices, such as long-term mechanical ventilation, peritoneal dialysis, and intracardioverter defibrillators.

Caregiving and mechanical ventilation. Limited research has explored caregiving among patients with long-term mechanical ventilation (e.g., a machine used to take over breathing) (Douglass & Daly, 2003; Im, Belle, Schulz, Mendelsohn, & Chelluri, 2004). The majority of caregivers in these studies were White women (76.5%) caring for their husbands (52.2%) (M = 52.9 years old, *SD*, 14.2). Although 33 of the caregivers (28.7%) were working, 30% had to reduce work hours in order to care for the patient (Im et al., 2004). Similar caregiver outcomes of other chronic caregiving populations, such as depression, burden, and decreased emotional and physical health, were reported in caregivers of long-term mechanical ventilation (Douglass & Daly, 2004). A prospective descriptive longitudinal study of (N =135) caregivers of patients receiving long-term mechanical ventilation reported that perceptions of physical health and overload ($p = 0.025$, and $p = 0.006$, respectively), were significant explanations for depression among caregivers (Douglass & Daly, 2004). The researchers concluded that caregivers of long-term mechanical ventilation in institutions reported higher levels of depression compared to other chronic caregiving populations, including heart failure and COPD (Douglass & Daly, 2004). However, patients with implantable, life-sustaining devices also report negative outcomes.

Caregiving and percutaneous implants for peritoneal dialysis. By 2020, almost 800,000 people aged 65-years and older people will be afflicted with end-stage renal disease (ESRD) (Buemi et al., 2008; Stengel et al., 2003; United States Renal Data System Annual Data Report [USRDS], 2010). Out of the 368,544 patients who received hemodialysis, almost 27,000 patients received peritoneal dialysis (PD) in an ambulatory or home-care setting (USRDS, 2010; Lin-sun Fan, Sathick, McKitty, & Punzalan, 2008). Despite this prediction, limited evidence describes caregiver characteristics, including quality of life, while assisting with PD.

Patients on PD rely on caregivers to perform the daily exchanges of continuous PD or to connect, disconnect, and troubleshoot problem with the peritoneal dialysis machine (Lin-sun Fan, et al., 2008). Although caring for an LVAD patient may be more cognitively difficult, caregivers of patients with PD share similar tasks at home, such as assisting with or performing fluid balance, assessment, and adjustments — even the home environment must be adapted to accommodate the supplies required to care for a PD patient (Lin-sun Fan, et al., 2008). A descriptive exploratory study of caregivers of elderly patients on hemodialysis (n = 84), PD (n = 40), and caregivers of non-elderly patients with heart failure found that 32% of caregivers of older PD patients experienced depression, significant burden, and negative effects on their quality of life (Belasco et al., 2006). Like caregiving in other chronic illnesses discussed previously, stress, anxiety, fatigue, social isolation, and decline in personal and familial relationships may occur among caregivers of home dialysis for children or adults (Belasco, 2002; Belasco et al., 2006).

Caregiving and implantable cardioverter defibrillators. Caregivers of patients with implantable cardioverter defibrillators (ICDs) experience significant changes in the psychosocial dimensions of quality of life within the first year of implantation (Dougherty & Thompson, 2009; Jenkins et al., 2007; Sears, Todaro, Lewis, Sotile, & Conti, 1999; Sowell, Sears, Walker, Kuhl, & Conti, 2007). Most caregiver/partners were employed, White females, with an average age of 60.96 ± 12.8 (Jenkins et al., 2007). Similar to caregivers of patients with heart failure, studies reported a decline with mental and physical health (Dougherty & Thompson, 2009; Jenkins et al., 2007), even limited family support (Dougherty & Thompson, 2009) during the first 12 months after implantation especially if the ICD patient was elderly or had more disease burden (Dougherty & Thompson, 2009; Jenkins et al., 2007). Yet, as caregivers of ICD patients

became adjusted to their changes new role 12 -30 months after implant, they reported overall enjoyment and satisfaction with life, and reduced uncertainties about patient death (Jenkins et al., 2007). Sowell and colleagues (2007) reported similar findings as patient and partner dyads adjusted to the ICD. Measurements of anxiety and marital adjustments within 30 months of ICD placement showed no statistical differences between these dyads. Satisfaction with caregiving was also reported amongst caregivers of patients with LVADs (Marcuccilli & Casida, 2011). These caregivers eventually adapted to caring for an LVAD patient and expressed satisfaction with their new roles. Although declining physical and mental health remain significant burdens for caregivers of other chronic illnesses, limited literature suggests that both LVAD and ICD caregivers face similar challenges while caring for a patient with an implantable device, but they eventually adjusted lifestyles and caregiving roles.

As patients with these and other life-sustaining technology transition from hospital to home, caregivers will be required to learn new skills and adapt lifestyles to care for these vulnerable patients. Since the population of patients with life-sustaining devices and their caregivers is expected to increase, it is imperative for nurses and other healthcare providers to have the knowledge and understanding of their preferences and needs in order to better care for them. Since caregiving is recognized as a national priority (NCA, 2009) and a forefront for nursing research (National Institute of Nursing Research [NINIR], 2006), future studies must include caregivers in order to develop priority interventions on how to maintain health, promote socialization, and prevent caregiver burden in this increasingly vulnerable population. Given the need for more caregiving research, no evidence demonstrates the experience of DT caregivers. Therefore, I began to wonder, “How do caregivers of heart failure patients with LVADs as DT describe their experiences with caring for someone with an implantable device? Despite the

limited evidence, there are several ethical dilemmas both health care providers and this expanding population may face.

Ethical dilemmas and decision-making within the context of palliative care and end of life care.

Ethical issues raised in the LVAD literature relate to several ethical principles, including the principle of justice, and respect for persons.

Principle of justice. In the principle of justice, location of donor hearts, and current transplant eligibility targeting younger patients and those with less comorbidities, remains an ongoing area of debate, especially with the predicted increase in the older population (Brush, 2010; Dudzinski, 2006). Secondly, the principle of respect for persons, and the patient-provider discussions of risks and benefits of LVAD therapy (e.g., increased risk for stroke, infection), including the unpredictable nature of advanced heart failure and device therapy (e.g., gradual decline in quality of life and functionality, device malfunction and failure; not being a candidate for device exchange out due to increased morbidities or chance of death). However, withdrawal of the LVAD poses practice and ethical boundaries which is projected to increase as more patients receive this device.

Discontinuing the LVAD. Decreasing quality of life, worsening and/or new comorbidities are issues this population must face while living with this device (Hunt et al., 2009). Eventually, a natural death for an LVAD patient may occur by device deactivation, device failure, progressive cognitive or functional decline, or progression of HF (Bramsted et al., 2001; Dudzinski, 2006; Kirkpatrick, Fedson, & Verdino, 2007; MacIver & Ross, 2005; Weigand, & Kalowes, 2007). However, concerns related to the ethical permissibility of discontinuing the LVAD are the pinnacle of discussions (Bramsted et al., 2001; Dudzinski, 2006; MacIver & Ross,

2005; Rizzieri, Verheijde, & Rady, 2008; Simon & Fischbach, 2008). For example, when a device is deactivated, blood backflows and pooling may cause thrombosis and disrupt contractility of the heart (Bramsted & Wenger, 2001; Rizzieri et al., 2008; Dudzinski, 2006). Arguments about the cause of patient death surrounds the process of actual device deactivation as cause of death or the underlying disease (advanced heart failure) (Bramstedt & Wenger, 2001; Dudzinski, 2006; MacIver & Ross, 2005; Rizzieri et al., 2008). Despite these justifiable concerns, patients (and their caregivers as surrogate decision-makers) are autonomous human beings and have the right to self-determination.

Respect for persons. The principle of respect for persons mandates that patients and their families have right to refuse or withdraw medical treatment at anytime (ANA, 2001; Patient self-determination act, 1992). Since the LVAD is a medical treatment, patients and their caregivers have a right to deactivate and/or disconnect the LVAD, especially if quality of life is deteriorating and the risks of the device outweigh the benefits. Therefore, it is imperative for nurses and other health care providers to engage in timely end of life discussions, and advanced directives.

Communication about end of life care and advanced directives. Although it recommended that all patients diagnosed with heart failure receive palliative care and timely end of life consultations, with or without the need for LVADs, (Francis et al., 2010; Jessup et al., 2009; Waterworth & Gott, 2010), the unpredictable nature of heart failure represents an additional hurdle for health care providers on when to best initiate these sensitive discussions (Dudzinski, 2006; Goodlin, 2009; Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). First, device implantation and the hopes of receiving a donor heart may dissuade or prevent or suspend important conversations between LVAD patients, their caregivers, and mechanical heart health

care providers (Dudzinski, 2006; Goodlin, 2009; Goodlin et al., 2004). Second, the shift from a life-saving focus to the end of life can certainly be a source of great anxiety for everyone involved, and further repress discussions about palliative and end of life care among this population. Despite these issues, the literature recommends these discussions to commence prior to LVAD implantation (Francis et al., 2010; Goodlin, 2009; Hupcey, Penrod, & Fogg, 2009). However, barriers to effective communication in end of life care have been documented and reported previously, including physicians' anxiety that patients might react negatively to these discussions (Saraiya, Deren, Leventhal, & Leventhal, 2008; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Yet, evidence illustrates that generally, physicians are more willing to have end of life discussions with patients who have cancer compared to those with heart failure, because prognosis and expected decline are more predictable with cancer (Carter et al., 2006). This conclusion parallels with argument that physicians assert the moral imperative to treat patients (beneficence vs. nonmaleficence) (Cockerham, 2010), hence, the development and advancement of mechanical circulatory support. That is, even at the end of life, medical emergencies and do-not-resuscitate orders maybe largely ignored because physicians have an obligation to treat patients (Hippocratic Oath, 2002). Yet, the *principle of respect* for persons mandates that patients and their families are informed of all treatment options, including palliative and end of life options (ANA, 2001; Patient self-determination act, 1992). Since there is no cure for advanced heart failure, *respect for persons* mandates that preparation for palliative care and end of life care should commence at the initial diagnosis of heart failure (ANA, 2001; Patient self-determination act, 1992). However, effective doctor-patient relationships are necessary for these timely discussions (Tierney et al., 2001; Goodlin, 2009), including advanced care planning and the appointment of a surrogate decision-maker (Francis et al., 2010; Goodlin, 2009; Goodlin et

al., 2004; Hupcey, Penrod, & Fogg, 2009). Given these arguments, nurses have an integral role in preserving the autonomy of patients with DT and their caregivers, which includes effective communication and shared decision-making (ANA, 2001). Although these principles have molded nursing care, practice, and research for decades, the advent of health care reform and the timely report on the future of nursing (Institute of Medicine [IOM], 2010), has acknowledged the integral role nurses play in the health and welfare of patients, families, communities, and society. Therefore, nurses must continually take the lead in all levels of the health care system, research, and policy development, and advocate for timely palliative and end of life discussions for this emerging population not only prior to device implantation, but at the onset of heart failure (Francis et al., 2010; Goodlin, 2009; Hupcey et al., 2009). Therefore, I began to wonder, “What do caregivers of advanced heart failure patients with LVADs as DT suggest healthcare providers need to know based on caregivers’ lived experiences?”

Statement of the problem

Patients with heart failure have limited access to palliative care resources, understand less about their illness, and have poor quality or limited communication with their health care providers about end of life care. Despite preferences for improved communication at the outset of their diagnosis, many of these patients continue to experience unnecessary symptom burden and distress as they progress along the illness trajectory. Since palliative care can be initiated regardless of any disease or the need for concurrent therapies, mechanical circulatory support represents an innovative component of a holistic, palliative care approach. Yet despite this innovative technology, many patients will continue to deteriorate while they wait for a transplant or even as a DT, due to the unpredictable, progressive nature of heart failure. Eventually, they will experience adverse events (e.g., sepsis, stroke) related to device therapy, device failure,

and/or become ineligible for device exchange (Hunt et al., 2009). With the projected increase of older patients in the next decade (NPP, 2008), chronic illnesses, such as advanced heart failure will necessitate long-term, life-sustaining devices, such as LVADs. As these patient and caregiver groups continue to expand, technological advancements will continue to evolve requiring more sophisticated, complex, long-term care in the home. Caregivers will be vital in promoting the health and well-being of patients on life-sustaining devices. However, limited studies described patients' and caregiver's issues and concerns about living with an LVAD as a BTT, leaving out the perspectives of living with DT. Patients with DT and their caregivers have needs, issues, and concerns which have not been explored. Nurses and other healthcare professionals provide the education for living with this device, however, may lack the knowledge of these needs and day-to-day challenges experienced while living with an LVAD. It is imperative to explore what life is like living with such a life-sustaining device in order to better assist them with their long-term needs. The purpose of this inquiry, therefore, is to explore and describe the experience of DT from patients' and caregivers' perspectives. This study aims, through a phenomenological inquiry, to understand the meaning of the DT experience from patients' and caregivers' perspectives.

Summary

This chapter described the evolution of the study from the historical and experiential contexts. The historical context described the extant literature describing the evolution of studies from several perspectives, including: 1) palliative care and end of life perspective, 2) BTT, 3) DT, 4) caregiving, and 5) ethical issues. This provided the context for the development of the research questions and justification for the method of inquiry. The chapter concludes with the purpose and aims. Chapter three, *Methods*, describes the phenomenological method of inquiry,

general, and applied, for this study.

CHAPTER III

METHODS

The Method of Inquiry: General

This study aimed to understand patients' and caregivers' inside perspective of DT. A qualitative design, specifically van Manen's methods, guided this inquiry. Chapter 3 begins with a brief discussion of phenomenology, describes van Manen's philosophy and methodology, and ends with the applied phenomenological method of inquiry (procedures and research activities) chosen to explore the inside perspective of patients' and caregivers' living with DT.

The Merriam Webster dictionary defines phenomenology as the study of "phenomena" - observable facts, events, objects, or aspects known through the senses rather than by thought or intuition, including the meanings attributed to them. As both a philosophy and methodology, phenomenology assumes that there is a formal structure of the objects of awareness (human consciousness), or all human experience, which culminates to the experience as lived by human beings (Smith, 2011, Thorne, Kirkham, & MacDonald-Emes, 1997). Thus, phenomenology is focused on exploring the experience of a phenomenon as perceived through human awareness. The essential structures of phenomenology includes: 1) lifeworld – lived experience, 2) first person perspective, 3) intentionality, and 4) consciousness.

Lifeworld – lived experience.

The lifeworld is the world in which one lives —the world of experience—a world complete with relationships, experiences, and the lifeworld in which the person has lived the experience (van Manen, 1990). The lifeworld for participants in this inquiry represents the culmination of their experiences and how they live their life with a DT. Through a phenomenological method of inquiry, I explored the lifeworld of patients with an LVAD and

their caregivers from the context of living with a DT.

First-person perspective.

Edmund Husserl (1859-1938) believed that the meaning of the lived experience can only be obtained from the first person perspective. The lived experience represents the totality of life as lived; it is already present and is part of our awareness, or consciousness (van Manen, 1990). The meaning of living with an LVAD as a DT, however, can only be described from those who live with such a device. My method of inquiry sought participants who gave voice, or recounted a first-hand experience, of living with such a device. Although the LVAD is already implanted in the patient and has a designated caregiver, this life-sustaining device is a visible, tangible part of their awareness. It is an awareness that living with an LVAD will create experiences in the lifeworld only known to those who live with and care for someone with this life-sustaining device. The first person perspective is an integral component of the structure of the lived experience. Yet, it is this realization, this self-awareness, which represents the third structure of phenomenology, that is, consciousness.

Consciousness.

van Manen (1990) described that by being conscious, “we are already related to the world” (p. 9). In other words, we are connected – aware of our presence and our surroundings. The structure of consciousness has both phenomenological (what the experience is like) and ontological (the experience of being) qualities (Smith, 2011). To be conscious of an experience means that one must have experienced the phenomenon. Within the context of this study, consciousness means that patients with DT have lived with this life-sustaining device, and their designated caregivers have experienced the caregiving context as well. However, van Manen asserted that it is not possible to view an experience *introspectively* (to search within oneself), but

retrospectively (inward reflections of the past). Reflection on lived experience, therefore, is a recollection or reflection on past lived experience (van Manen, 1990). Given these premises, the essential structure of an experience is its *intentionality*, or mental representation of a phenomenon.

Intentionality.

Intentionality represents the features of several mental states, such as beliefs, hopes, judgments, intentions, love, and hatred (Smith, 2011). It is intersection of these mental states and events of the lifeworld (intentional or non-intentional, perceived or not-perceived), which represent the experiences of life (Husserl 1926/1971). van Manen (1990) concurs, describing intentionality as “the inseparable connectedness of the human being to the world” (p. 181). Van Manen (1990) affirmed, however, that “we are not reflexively conscious of our intentional relation to the world...intentionality is only available to consciousness upon retrospective reflection” (p. 181). In other words, a persons’ orientation to intentionality is not always conscious but a reflection on the lived experience (van Manen, 1990). Intentionality, therefore, is key to deeper reflections and meaning of the lived experience.

In order to explicate these experiences, it was important for me as researcher to set aside any assumptions about the phenomenon in order to “hear” the intersection of my participants’ experiences. This was accomplished through *bracketing*, or *phenomenological reduction*. Bracketing my assumptions, biases, and beliefs assisted me to remain objective about the experience of living with a DT from a patient and caregiver perspective, and to uncover the essence of this phenomenon.

Historical Perspective

Drawing from the works of Husserl, Heidegger, Merleau-Ponty (1945) proposed that

phenomenology aims to search for the meanings or *essences* of the lived experience through returning to the things themselves (e.g., rediscovery). Since human understanding stems predominantly from the experience of the world as perceived, humans cannot conceive what is not perceived or perceptible (Merleau-Ponty, 1945). By returning to the things themselves, such a re-discovery of the phenomenon leads one to find meaning and understanding in life through descriptions of the lived experiences of human beings in their world. According to Merleau-Ponty, the researcher's interaction with the study participant and the interpretation of the description of the phenomenon of interest constitutes the hermeneutic (e.g., interpretive) approach to the phenomenological method of inquiry. This interconnectedness is the central tenet of hermeneutic phenomenology, the methodological foundation for van Manen's phenomenological approach, and the method of inquiry for my research.

Method of Inquiry: Applied

The following section introduces van Manen's phenomenological approach. The application of van Manen's approach to the phenomenon of the inside perspective of patients and caregivers living with DT is discussed.

van Manen's phenomenological method of inquiry.

van Manen believed that the phenomenological inquiry starts with the lived experience. van Manen's methods incorporate description and interpretation of the phenomenon to elicit the meaning of the lived experience. This approach incorporates a more reflective approach to uncover the meaning of lived experiences. van Manen described his human science approach as the way one orients to the experience as lived. This is accomplished through interpretation, or hermeneutics, which describes how the researcher interprets participants' lived experiences. In this inquiry, the experience of DT was explored through the collective language of those who

have experienced this phenomenon. Although personal experiences of living with and caring for someone with such a life-sustaining device may remain private, some of these personal experiences can be revealed through this method of inquiry. It is the intersection of participants' descriptions of their private experiences and the researchers' ability to interpret the verbal and non-verbal language of these words (e.g., semiotics), which further illuminates the meaning of living and caring for someone with such a life-sustaining device. This form of hermeneutic, or interpretive phenomenology, uncovers the hidden meaning of the lived experience from insiders' perspective (van Manen, 1990).

The *essence* or *nature* of the lived experience, as described by van Manen (1990), has been uncovered through writing if the phenomenological story illuminates the significance of the lived experience in a most profound manner. In order to assist my interpretation of the meaning of my phenomenon, van Manen discussed incorporating many types and sources of meaning to aid in the interpretation of the lived experience (van Manen, 2002). These sources include poetry, artwork, everyday life experiences, language, social science, historical, cultural, literary, and phenomenological literature sources. A description of these sources is provided in the *data analysis section*. The final product of my research is a phenomenological story uncovering the meaning and significance of the experience of DT as lived.

Rationale for selection of the phenomenological method.

Since the research method should be guided by the research question (Creswell, 1998), van manen's phenomenological method of inquiry was best suited to answer the research questions, which aimed to uncover the meaning of living with DT. van Manen's (1990) phenomenological method of inquiry has hermeneutic underpinnings that enabled me to uncover the experiences and meaning of living with and caring for someone with a DT as described by

participants. Although van Manen's phenomenology of practice stems from an educational and pedagogical perspective, it can also be used to guide nursing research. Recently, several studies used this philosophy and method of inquiry to advance the science and discipline of nursing (Cashin, Small, & Solberg, 2008; Marcuccilli & Casida, 2011a; Marcuccilli & Casida, 2011b; Moene, Bergbom, & Skott, 2006). Finding will provide an understanding of how patients and caregivers live with and adapt to such a life-sustaining device. Additionally, findings can aide in knowledge development for nursing practice. By articulating this knowledge, we can explore additional possibilities and use them as a basis for new research.

As I continue to develop my phenomenological inquiry, an interpretation of van Manen's research methods and activities are presented. The interpretation is followed by an integration of the methods and research activities within the procedures of my research.

Research Activities and Procedures

van manen's (1990) method involves a variety of empirical and reflective research activities designed for performing a phenomenological inquiry. The empirical activities are designed to explore experiential material about phenomenon, while the reflective activities are performed to interpret meaning associated with the phenomenon (van Manen, 2010). The empirical and reflective activities are incorporated into six methodological themes, or research activities, which guided my study: 1) Turning to the lived experience, 2) Exploring the experience, 3) Reflection on essential themes, 4) Capturing the essence through writing and rewriting, 5) Remain focused and oriented, and 6) Balancing the inquiry through parts and wholes (van Manen 1990). van Manen (1990), however, cautioned against using these activities in a mechanistic way, but rather to "animate inventiveness and stimulate insight" while exploring the phenomenon (p. 31). The six research activities interfaced with one another and were used to

explore the experience of living with an LVAD as DT from patients' and caregivers' perspectives.

Turning to the lived experience.

The first research activity required a commitment to the phenomenon of interest and formulating the phenomenological question. According to van Manen, turning to a phenomenon of interest requires the researcher to become full of thought, to “recognize our lot minding the whole – that which renders fullness or wholeness to life” (p. 31). This inquiry began with an exploration of my interests and research activities. These included my own interest in palliative and end of life care, the qualitative studies and interviews I performed as part of my doctoral studies, and how it has led me to inquire about patients' and caregivers' lived experience of DT. By turning to my phenomenon of interest, no published literature was found exploring this experience as lived. As I focused on my research question and the method of inquiry, this research activity continued with an inquiry into the experience of living with DT by formulating a phenomenological question suitable for inquiry into the experience as lived, “What is the experience and meaning of living with a DT from a patient and caregiver perspective?” I remained true to the phenomenological question by selecting participants who gave voice to the experience and meaning of living with DT. Since I am committed to promoting quality of life among patients with chronic and terminal illnesses, life-sustaining devices, and their caregivers, choosing such a sample provided a beginning understanding of living with and caring for someone with this device. Despite not having clinical expertise with this population, the mentored research experience helped develop a program of research that may not be exclusive to LVADs, but for similar conditions or other life-limiting illnesses.

Exploring the experience.

The second research activity commenced with the strategies to investigate the experience as lived. To investigate the experience of DT as lived means that I must become filled with the world of the experience of living with such a life-sustaining device. This is necessary in order to gain a deeper understanding of this phenomenon. To actualize this activity, I engaged in several activities to explore my phenomenon of interest. The first activity was a vignette written in my reflective journal to illustrate my own personal experience of caregiving. van Manen (1990) recommended using one's own personal experience as a foundation to begin to understand the experience of others because we may share common experiences. Although I have not personally experienced a life-threatening situation such as LVAD patient, both patients and caregivers have been plunged into an unknown world. I can share the personal, experiential account of being a caregiver plunged into this unknown world from the perspective of caring for my dying father. As I wrote and reflected on this experiential primer, my voice remained private until I explicated my personal story of caregiving for a dying person. The voices of those experiencing DT patients and their caregivers, for example, may remain private as well. The interaction with participants in this study and my interpretation of the descriptions and meaning of living with DT co-created an understanding of living with and caring for someone with such a life-sustaining device.

Secondly, my experience with palliative and end of life care, experience with developing phenomenological inquiries, and performing qualitative interviews, has provided me with the background to explore participants' experiences as lived and described. As the investigation of the phenomenon continued, I explored phenomenological literature by reading Heidegger (1962, 1968, 1971), Husserl (1970) and van Manen (1990, 1997), including several phenomenological studies performed in the literature (Esdaile, 2009; Maxton, 2008; Cashin, Small, & Solberg,

2008; Eggenberger & Nelms, 2007; Cangelosi, 2007; Moene, Bergbom, & Skott, 2006; Gasquoine, 2005). I also observed photographs, videos, and stories of patients with LVADs on a support website for patients with mechanical circulatory support devices and their caregivers to understand the experience of living with such a life-sustaining device. Next, I gathered information from participant interviews as part of my research inquiry from the Center for Mechanical Circulatory Support (CMCS) at The University of Michigan Systems (U of M). These participants are required to have an LVAD as a DT, or served as a designated caregiver. In the inquiry, participants were encouraged to describe their experiences in a face-to-face, tape-recorded conversation (i.e., interview). van Manen (1990) discussed that by engaging in conversations with participants, meanings are uncovered. Next, van Manen discussed the importance of the researcher becoming a participant observer by recounting living phrases of participants. While engaging in conversations with my participants, I gathered *interview notes* which included “living phrases” and key events that brought to life participants’ experiences to life. These interview notes illustrated the setting of conversations, body language, and feelings and perceptions I had during these conversations. The culmination of this data provided the essence, or meaning of the lived experience. According to van Manen (1990), these data obtained from these interviews are the *human experiences*.

Reflection on essential themes.

The third research activity involved thoughtful reflection to understand the meaning about a specific phenomenon. van Manen (1990) described that this research activity uncovers the essence of the phenomenon by reflecting upon participants lived experiences. I reflected on all data gathered during conversations and incorporated the four existentials of the lifeworld as a guide for reflection throughout thematic analysis: 1) Spatiality, or *lived space*, 2) Corporeality,

or *lived body*, 3) Temporality, or *lived time*, and 4) Relationality, or *lived other* (van Manen, 1990).

Lived space. Lived space is the physical and emotional world known to and described by participants in my inquiry. Here, participants described how their lives were before the LVAD and the emotions surrounding that experience. Descriptions of their physical world included things that they liked to do which were, in some ways, limited due to their new lives with the LVAD. Emotions ranged from being scared, overwhelmed to feelings of happiness, gratitude, even uncertainty as they continue to live with this life-sustaining device.

Lived body. Lived body is an awareness of the presence of the physical and metaphorical body towards one another, both revealing and concealing aspects of this awareness. As my participants and I engage in conversation, we may both reveal and conceal something about ourselves. There were many times that the context of conversations took an emotional toll on both me and my participants. Asking participants to describe the feelings that surrounded a particular situation usually ended up in both of us reaching for tissue to wipe away our tears. Yet, we both seemed comfortable in revealing aspects of our deep emotions, and, in some unusual way, found comfort in one another's presence as participant descriptions continued. I remain amazed that these participants felt comfortable enough to talk to me about their experiences.

Lived time. van Manen (1990) describes lived time as “subjective time” instead of “clock time or objective time” (p. 104) with temporal components of being in the world, such as childhood or young adulthood. Participants may describe the temporal dimensions of past, present, and future as they reflect upon their experiences as lived. During their interviews, participants' expressed emotions from the time before patients had heart failure, how they

improved with the device, and how they watched and cared for their loved ones living with DT. Descriptions included the times they spent in the hospital, time for recovery and rehabilitation at home, feeling comfortable with living with the device, and how grateful they were for being given more time to live.

Lived other. Lived other is the acknowledgement of others within our space, such as researcher and participant (van Manen, 1990). Participants acknowledged the instrumental role caregivers, family, and the team at U of M played in giving them more time

Capturing the essence through writing and rewriting.

The fourth research activity entails the process of ongoing writing to capture the meaning of the lived experience. While reflecting on participants' descriptions, I continued to write and rewrite phrases of participants' descriptions that suggested themes. By writing, rewriting and reflecting, I engaged in deeper reflection upon my interpretations to capture the essence of living with and caring for someone with a DT. van Manen (1990) concluded that the themes constructed through this process illustrates the meanings ascribed to the human experience. A phenomenological story illustrating the experience and meaning of living with DT was constructed with overarching themes and sub-themes uncovering the essence of the experience of living with a DT (Chapter 4, *Results*).

Remain focused and oriented.

This activity calls for the researcher to have a focused orientation towards the phenomenon of interest, the research questions, and the phenomenological inquiry. I remained focused on the research questions and methods through interviews with participants and maintained close observation. While focused, I remained open to the words of the lived experience from participants' descriptions and not my own. This was achieved by listening to

descriptions and formulating probing questions as conversations unfolded. An excerpt from a section of my ongoing journal, *Living and Finding Meaning Through Arts*, illustrates how I strove to remain true and oriented to my inquiry:

These participants openly talked about their experiences with me, a stranger, who asked to enter their private world of living with DT. As I examined how and why these participants recounted their personal experiences with me, I realized that I became a participant observer. van Manen discussed the importance of the researcher becoming a participant observer by recounting living phrases of participants. But it was not only gathering “living phrases” that captured participants’ experiences, but my ability as researcher to elicit experiences as lived through open dialogue, encouraging deep, reflective thoughts, without influencing thoughts during conversations. Examples include my research skills to promote an open, comfortable environment for my participants, such as using open-ended questions, positioning and utilizing my body language to make participants feel comfortable. The feelings of comfort felt in the room, the amazing, heart-felt stories, the fears and detailed descriptions of very personal experiences, led me to conclude that I was capable of putting aside my own thoughts, biases, and assumptions in order for participants to reveal their lived experiences.

Finally, I closely examined the data that was relevant in order to maintain my commitment to the phenomenon and the research question. This process enabled me to reflect on the experiential descriptions of participants’ stories to deeply understand and therefore, interpret the essence of living with and caring for someone with a DT.

Balancing the inquiry by considering parts and whole.

The final research activity focuses on balancing the phenomenological inquiry by taking

into account the whole design compared to the parts. In this activity, I questioned the overall design, or *whole* of the study (e.g., phenomenological method of inquiry), against the *parts*, (e.g., tape recorded interviews, transcribed texts, ongoing reflective journals, constructed themes, etc.). This final research activity enabled me to describe the experience of living with a DT, and their interplay in the development of the final phenomenological story. I continuously questioned my reflections and interpretations by stepping back and looking at the whole to see if my phenomenological story explicated the meaning of living with a DT. This circular movement from the parts to the whole, stepping back, and reflecting on my interpretations, constitutes the hermeneutic circle. I provided an illustration of this process in Figure B4. This process not only broadened my thinking to deeper levels, but also helped to confirm participants' descriptions and interpretation of their meanings. Part of the process of interpreting the experience as lived is the ability of the researcher to put aside any pre-understandings, assumptions, or any scientific knowledge about the phenomenon of concern which could influence interpretation of results (van Manen, 1990).

Hermeneutic reduction: Bracketing.

Within van manen's methods, reductions in thinking, or openly disclosing perceptions, assumptions, and biases about a phenomenon of concern, begins prior to data collection and throughout the interpretive process. Reductions in thinking facilitate reflection on the phenomenon in the lived world — the researcher needs to be cognitively and deliberately aware of holding prior knowledge and assumptions *at bay*, continually questioning those assumptions and “turning the knowledge against itself” (van Manen, 1990, p. 47). By suspending prior knowledge of the phenomenon, the researcher remains open to the descriptions of the phenomenon and allows the meaning to be revealed by the participants (van Manen, 1990). In

other words, I strove as a researcher to hear my participants' voices — rather than allowing my own beliefs and biases to superimpose the meaning of living with a DT. Bracketing (e.g., suspending), or keeping at bay these preconceived ideas, is the technique used in phenomenology. Bracketing was accomplished through maintaining an ongoing reflective journal to record my professional and personal feelings about my phenomenon of interest. Reflective journaling is a strategy recommended to ensure transparency, so that both ethical and methodological decisions can be questioned during an audit trail (Munhall, 1994). In my reflective journal, I made it explicit that my assumptions, biases, and experiential content described in my inquiry. I strove to bracket the knowledge acquired from my past experiences as a palliative and end of life care practitioner, as well as the literature identifying conjectures about my phenomenon of interest. Other strategies to enhance my openness and objectivity included open discussions with other members of the research team. Although van Manen asserts that *complete* phenomenological reduction is impossible, and that full or final descriptions are unattainable, we need to pursue human science research with “extra vigour” (p. 18). I realize that it is impossible to forget all of my preconceived notions. By continuing, however, to explicate these assumptions, beliefs, and interests, it enhanced my ability to remain unbiased as much as humanly possible as I listened and probed into participants' stories.

Design

A hermeneutic phenomenological inquiry was developed to explore the experience of living with an LVAD as DT from the inside perspectives of patients' and caregivers'.

Setting

Concurrent institutional review board approval was obtained prior to data collection.

(Appendices C & D). Concurrent IRB approval was required since I accessed my patient

population at the U of M. I also obtained approval for my previously completed study as required by the IRB/HIC regulation (Appendices E & F).

Data collection took place at the U of M's CMCS. The CMCS is an internationally renowned group of physicians and multi-disciplinary professionals providing medical treatments and therapies for patients experiencing cardiac disorders resulting in advanced heart failure or cardiogenic shock. As a regional and national referral center offering state-of-the-art options for mechanical circulatory support (such as LVADs), the CMCS is one out of three implant centers in the State of Michigan, implanting over 430 LVADs (i.e., BTT = 377, and DT = 53) since 2005. Susan Wright, former supervisor for the CMCS, has a long history of providing support to nursing research. Ms. Wright provided me with a letter of support (Appendix G), and facilitated access to the CMCS outpatient clinic, including providing the office space necessary for conducting private interviews with the participants. The office space included a private, spacious, conference room with a large table and six chairs located in the CMCS outpatient clinic. The conference room also contained a telephone, a computer, and a printer. A photocopier and a facsimile machine for the CMCS were located just down the hall from the conference room and were easily accessible for my use.

Sample

Once HIC/IRB approval was obtained, a purposive sample of patients with destination therapy patients and their caregivers who could collectively give voice to their lived experiences were recruited for this study. van Manen (1990) described that by borrowing other people's experiences we can arrive at a better understating of the deeper meanings of the collective human experiences. Purposive samples are not only recommended to obtain rich data for data exploration (Denzin & Lincoln, 2005), but to also bring forth participants who can purposefully

describe an understanding of the phenomenon in relation to the research question (Creswell, 2007), in contrast to overall generalizability through quantitative studies.

Participants met eligibility for the inquiry as patients and caregivers living with DT. Participants as patients met the following inclusion criteria: 1) had LVAD as a DT for at least three months, 2) men and women 18 years old and over, 3) able to read, write, and speak English, 4) have no evidence of cognitive decline, 5) come from all races and ethnicities, and 6) voluntarily consent to participate in a tape recorded interview. Inclusion criteria are the same for participants as caregivers of DT patients, except that they must have cared for these patients for at least 3 months post-hospital discharge. The three-month period was assumed to be sufficient in adjustment and reflection of living with this device (Casida, Marcuccilli, & Peters, 2011). Exclusion criteria for both patients and caregivers includes: 1) unable to read, write, or speak English, 2) less than 18 years of age, 3) exhibiting evidence of cognitive decline, and 4) have an LVAD as a BTT, or cared/caring for a patient with a BTT. Exclusion criteria specific to participants as caregivers of DT patients includes: 1) cared/caring for a patient with DT for less than three months post-hospital discharge, and 2) cared/caring for an explanted LVAD patient who received a heart transplant. Additionally, certain groups of special vulnerable populations were excluded from the study. For example, neonates and young adults were excluded since having an LVAD is relatively rare in the 0-18 age group. Pregnant women were excluded in the patient population since LVADs are contraindicated in pregnancy. The population of pregnant women occurs naturally in the general caregiver population therefore are neither excluded nor included in the proposed study. Institutionalized individuals and prisoners are excluded since the proposed study is targeted at the free-living communities of patients and caregivers.

To date, the number of patients receiving LVAD is growing. The CMCS has implanted

almost 500 LVADs to date – BTT ($n = 377$) and DT ($n = 53$). Despite the limited number of patients available at the CMCS, I initially projected that the number of patients and caregivers required to illuminate the meaning of DT as lived will be a minimum of five (5) patient/caregiver dyads, but no more than twenty (20) participants total (ten(patients and ten caregivers). Although there are no statistical formulas for determining sample size for qualitative research (Sandelowski, 1995), the final sample size was determined by information obtained from participants. Phenomenological studies typically achieve data redundancy, or data saturation (if no more new information from participants) with 10 or less participants (Dukes, 1984; Lincoln & Guba, 1985). Although these numbers are estimates, data redundancy, was determined as data collection and analysis were ongoing.

Data Collection Procedures

Since I accessed my population from U of M, both institutional review boards advised that potential participants must be recruited by an employee of U of M with no direct clinical relationships. The research coordinators for the CMCS are employees at the university medical center who have no direct clinical relationship with research participants. They are primarily responsible for recruiting potential participants. I trained the research coordinator in the study protocol (Appendix H). This protocol contains the inclusion and exclusion criteria for participant recruitment. To ensure equitable recruitment of both genders, races, ethnicities, and minorities, and a representative sample of the national indices reported by the national registry for mechanical circulatory support (Kirklin et al., 2012), I developed an outreach protocol guided by the National Institute of Health Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research (Appendix I). According to the 2012 INTERMACS national registry, White ($n=2074$; [69%]), males ($n = 2338$; [78%]) comprise the majority of the LVAD

population, followed by females ($n = 653$; 22%) and Blacks ($n = 672$; 22.4 %) (Kirklin et al., 2011). In my qualitative study exploring the sexual and intimate aspects of living with an LVAD, my sample reflected this national average, 7 males (77.8%) and 2 females (22%). However, data on ethnicity was not reported by INTERMACS and current datasets do not reflect racial/gender compositions (e.g., Hispanic/Latino population). Out of the participants eligible for participation in the study, no Hispanic/Latino participants were eligible for inclusion in the study. All the participants as patients who met the inclusion criteria were White males ($n = 7$) (Table A4).

With regards to the caregiver population, The National Family Caregivers Association [NCA] (2009) reported that nearly 66% of caregivers in the United States are approximately 49-years old, married, employed, and caring for a widowed mother living on her own. In the limited LVAD caregiving literature, caregivers were predominantly White women, family caregivers (e.g., wife, mother, and daughter) of patients who are also predominantly living with a patient with BTT, with slightly younger ages reported than the national averages. Ages ranged from 38 to 62 years (Mean = 47.5; SD \pm 14) (Baker et al., 2009; Casida, 2005; Dew et al., 2000; Dew et al., 2004; Kaan et al., 2010). Notably, only one study indicated that most spousal caregivers worked full-time outside the home ($n = 2$) (Casida, 2005). Contrary to these findings, my qualitative study exploring the lifestyle adjustments of caregivers of patients with LVADs, my sample reflected an older caregiving population with mean age of 57 years and a standard deviation of 15. This older caregiving population could be because most patients with LVADs comprise the 40-59 age group ($n = 1410$; [48.7%]), followed by the 60-79 year-old age group ($n = 1037$; [33=4.6%]) (Kirklin et al., 2012), and the indications for LVADs has been reported to older adults in recent years. The caregiver sociodemographic profile was comprised

predominantly of retired, White females, ages ranging from 50-74 years old, $M = 65$, $SD = 8.3$ (Appendix A, Table A5). It must be noted that the 40-59 age group are mostly patients bridged to transplant (Kirklin et al., 2011), whereas participants in my inquiry reflect the older adult population who are only eligible for a DT.

Recruitment.

Potential participants were recruited by the research coordinator via telephone. Twenty-four participants were identified as eligible according to the recruitment protocol provided (Appendix J). Recruitment letters were mailed out to these participants. Only two patients called the research coordinator to express interest in participating in the study. Before the day of a routine clinic visit, the research coordinator asked eligible participants if they were interested in volunteering for the study. Potential participants were informed that they were required to participate in one face-to-face interview, lasting for no more than one hour, and one follow-up telephone call, lasting for no more than 30 minutes after the interview. The recruiter approached 13 participant dyads prior to their routine clinic visits. Nine patients and nine caregivers volunteered for the study. Four participant dyads were approached but declined to participate in the study. Once potential participants expressed an interest in the study and volunteered, dates and times in which both participants and researcher could meet at the CMCS were arranged. The recruiter secured availability of a private conference room prior to the interview. On the day of the interview, she met with participants in the CCS waiting room, and escorted them to the private conference room. We exchanged introductions, and the process of informed consent began.

Human Subjects Consideration

Every effort was made to protect both the participants' health and personal information

from inappropriate disclosure. In order to ensure privacy, participants as patients and their caregivers were interviewed separately to promote privacy and confidentiality, and a “do not disturb” sign was placed outside the door before the start of the interview. One caregiver requested to be present during the patient interview because of occasional forgetfulness. The caregiver spoke only when the patient needed assistance. While participants waited for each other’s interviews, they were offered the opportunity to wait in the CCS waiting room/lounge area equipped with comfortable chairs and sofas, free refreshments, and reading materials. I went over the consent form with each participant in the private conference room, allowed ample time for questions, and answered any questions or concerns they had. I ascertained knowledge about the purpose, risks and benefits of the study, as well as their role in the study prior to obtaining informed consent. Participants were informed that participation was strictly voluntary, they could elect not to answer any questions, and could end the interview at anytime without fear of repercussions (e.g., plan of care would remain the same regardless of participation in the study). They were informed that all information would be held in the strictest confidence with no identifiable markers on any data, and that no information would be shared with their respective partners. In order to ensure confidentiality, I continually reinforced their privacy and confidentiality with each step of the data collection procedures. Participants were informed that if results of the study are published, information would be presented in such a way that it will not be traced to the respective participant. Since follow-up interviews were performed via telephone, participants were encouraged to find a quiet, private place in the home.

The research did not expose the participant to any known risks. Despite the possibility of any unforeseeable risks associated with any research, the risks associated with the proposed research were minimal, such as physical harm manifested by fatigue. Since there are human

subject considerations specific to patients with LVADs, I ensured the participants' comfort by suggesting several comfort strategies prior to commencing the interview, such as: 1) encouraged use of bathroom facilities, 2) offered a cold or warm beverage (free in the CMCS waiting room/lounge, 3) made sure the batteries to the LVAD are fully charged, 4) keep cell phone turned on so participants and caregivers can check on each other if needed, and 5) informed them that they can stop the interview at any time for breaks, or if they want to end the interview. If participants exhibited any signs of fatigue, such as shortness of breath while talking, the interview would be stopped. No participants exhibited any signs of fatigue in which the interview had to be stopped. The other minimal risk to participants might have included psychological harm, such as anxiety. Since participants have this LVAD as a final therapy for end-stage heart failure, reflecting upon these inside perspectives may be considered sensitive and possibly upset the participant). If any participants were to experience any of the minimal risks, consultation services with either a member of the CMCS staff or the psychosocial team was available upon request. Some participants began to cry when they reflected upon experiences that elicited emotional feelings. I offered to stop the interview, but participants wanted to continue with the interview, stating they were fine to proceed with the interview. No patients required or requested any follow-up consultation with either a member of the CMCS staff or the psychosocial team.

Despite steps taken to minimize risks to participants, there may be additional, unforeseen risks. Participants were instructed to notify me, the CMCS Supervisor, and their physicians of any problems that may have occurred during the research. There were no known reported risks related to this study. Additionally, participants were informed that participation in more studies may increase the risks, and/or affect the results of the studies. Participants, therefore, were

advised not to enroll in more than one study without approval from their doctor. Participants in this inquiry denied participation in other studies.

In the event that an adverse event occurs, such as a serious illness, death, or even incarceration of a participant, the outreach program was designed to develop a continuing rapport with the research coordinators. This is especially important since patients with DT have received this device as the final recourse for the palliation of the progressive symptoms of heart failure. Although the average life-span for patients with such a life-sustaining device can reach six or more years, it is very difficult to predict any illnesses, including the development of co-morbidities, device failure, or even death while patients are living with such a life-sustaining device. Therefore, the research coordinator was instructed to call me as soon as they were aware of any adverse events, so it could be reported to the HIC/IRB in accordance with the Federal Common Rule for reporting adverse events of participants in research). There were no known adverse events reported during the course of the research. After participants were given time to answer questions, informed consent was obtained on nine (9) patients and nine (9) caregivers.

Study Measures

Cognitive ability was assessed with the **Mini-Cog**, a reliable and valid tool developed by Borson and colleagues (2000) (Appendix K). This instrument can be used in a variety of health care settings, is suitable for older adults with varying literacy levels, even culturally-diverse populations. It can be administered under 3 minutes and used to distinguish between patients with and without dementia (Borson et al., 2000). Sensitivity and specificity ranges from 76-99%, and 89-93% with 95% confidence, respectively (Borson et al., 2000). All participants (n = 18) recalled all three words and received a Score = 3 (e.g., non-demented). All participants (n = 18) passed the clock drawing test (CDT), because the numbers on the clock were in the

proper sequence, and the hands were drawn as requested, on 3:00. Participants, therefore, received a normal, non-demented score. The instrument was delivered in less than 5 minutes across all participants.

Data collection

As previously described, data collection begins with bracketing procedures. These procedures included maintaining a reflective journal to openly unveil personal perceptions, assumptions, and biases about living with an LVAD, and engaging in discussions with other members of the dissertation committee members. This information was utilized throughout the duration of my study. I used open-ended, in-depth, face-to-face interviews and direct observation for my hermeneutic phenomenological inquiry. As recommended by LeCompte and Schensul (1999), I strove to keep my participants focused on a particular topic while not interrupting the natural flow of the interview.

Interviews commenced with participants as patients and caregivers individually, except as noted for one dyad. First, I obtained sociodemographic data from each participant (Appendix L & M). Next, participants were informed that the interview will now start and the audio-tape, placed on the table between me and the participant, was turned on. The order of participants (i.e., patient or caregiver) was of no importance and the dyads decided amongst themselves who went first. For the patient interview, the interview commenced by me asking the following opening question: “Tell me about your experience of living with an LVAD as DT?” (Appendix N) As the patients described their experiences, I used probing questions such as “tell me more about that experience...” When the patient described an experience, I asked for more information, such as, “What was the experience like for you?” The context of these elicitation phrases remained open, yet stimulated the participant to think deeply and reflectively on their

experiences, and to clarify and/or expand these experiences as lived. van Manen (1990) described that probing questions are the gateway for discovery of the meaning of the phenomenon as participants' experience, since meanings are accompanied by reflecting and refocusing on the phenomenon. Likewise, it was important for me to bracket my beliefs, assumptions, and presuppositions at this critical juncture of exploring the experience as lived. The openness of these elicitation phrases assisted me in the exploration of the experience as lived and helped keep my personal beliefs and biases at bay.

The following research question was developed to explore the meaning of living with such a life-sustaining device: "Tell me about the meaning of having an LVAD as a DT?" Similar elicitation phrases, such as, "tell me more about those feelings..." "How does that make you feel?" were asked to probe deeply into the meaning of the experience as lived. I also asked participants for stories, including key events, about their experiences that illustrate life with and the meaning of living with a DT. LeCompte and Schensul (1999) described stories as, "stories and storytelling permit interviewees to speak from experience about situations that illustrate points important for the researchers study" (p. 138). Probing questions to guide the story includes, "Tell me about the day you learned about the LVAD...what you remember first?" Continued probing questions, such as, "What happened after that..." as well as additional probes, for example, were used to encourage the participant to remember what led him/her to finally decide to receive the LVAD, and the emotions and/or feelings experienced during that time, and so on and so forth. Participant interviews ranged from 33 to 81 minutes with a mean time of 53, and standard deviation of 17.1. Length of 1st interview transcripts ranged from 11 to 18 pages, with a mean length of 10.7 and standard deviation of 2.3.

For the participant as caregiver, I followed the same procedures as described above. The

opening question for these participants was: “Tell me about your experience of caring for someone with an LVAD as a DT,” followed by “What does it mean to you to care for someone with an LVAD as a DT?” “Tell me more about those feelings...” and “how does that make you feel?” I asked participants as caregivers for stories, including key events, about their experiences that illustrate life with and the meaning of caring for a patient with a DT (Appendix O). Caregiver interviews ranged from 27-69 minutes (M = 51.3; SD= 15.1). Length in pages of 1st interview transcripts ranged from 8-15 (M = 11.1; SD = 2.5).

While engaged in participant interviews, I acknowledged and enacted my role as a participant observer. van Manen discussed the importance of the researcher becoming a participant observer by recounting living phrases of participants. During participant interviews, I made note of the usage particular words, phrases, and the association of non-verbal body language, such as tears, silence, upper and lower limb gestures, and facial expressions. Unlike field notes which include an overall description of the setting, the researcher constructs the *experiential anecdote* “trimmed of all extraneous, possibly interesting but irrelevant aspects of the stories.....to highlight specific points that require further reflection and it is this point that needs honing” (p. 69).

Interview notes were written immediately after each interview, including initial thoughts about areas needing further exploration in subsequent interviews. After each interview was finished, the tape-recorded interviews were transcribed by trained transcriptionists and verified by me for accuracy. The transcribed files and demographic summaries were downloaded in the NVivo 9 qualitative software program, which are available for audit. If participant transcriptions were not available prior to starting subsequent interviews, I listened to the recorded voices of participant interviews and reviewed interview notes several times prior to engaging in further

interviews. This is critical step in performing my study. Data collection progresses along with data analysis. This means that I am continually engaging in a dialogue with participants' descriptions. This is necessary because in order to interpret the meaning of living with DT, I must always look at the data, question the data, and probe deeply into the meanings of the experiences of my participants. If subsequent participants described similar experiences and meanings, I can probe more deeply into these thoughts, words, and phrases, and hopefully construct what the essence of living with and caring for someone with such a life-sustaining device. Van Manen (1990) describes this process as *immersion*. Immersion requires engaging with the meaning of the texts to gain insight into preliminary or emerging themes (van Manen, 1990).

While data collection was ongoing, I continued the process of immersion by listening to tape-recorded voices, read, and re-read the transcribed texts in order to *uncover* statements, emerging themes and meanings ascribed to experiences. As I reviewed the completed interviews and commenced subsequent interviews, any unclear, incomplete, or areas needing further clarification during the first interviews were identified and labeled as *areas for further probing*. I engaged in a cyclical process of data collection, data analysis, and member checking (e.g., data checked with participants). For example, after about 4 patient and 4 caregiver primary interviews were collected and analyzed, areas for probing were ascertained. Deeper probing questions were formulated on initial analysis of these interviews, and then added in a cyclical way to the ongoing interviews. This constitutes 'ongoing member-check,' in which the second half of primary interviews. For example, interviews with participants 5 through 9 and follow-up interviews for participants 1 through 9 were done that encompassed the entire set of preliminary data.

The 2nd interview consisted of one follow-up telephone call to explore the initial interview questions, including the second set of questions generated from preliminary data analysis. One participant was called twice and never responded. There were (n = 5) caregivers for the 2nd follow-up interview. Second interview times for caregivers ranged from 23 to 60 minutes with a mean of 38.1 and standard deviation of 14.2. Number of pages for second interview ranged from 5 to 21 pages, with a mean of 12.5 and standard deviation of 6.9. Second interview times for (n = 7) patients ranged from 10 to 129 minutes, with a mean of 50.6 and standard deviation of 41.3. Pages for second interview ranged from 3 to 26 pages, with a mean of 11.5 and standard deviation of 7.3. Enrollment ceased once there was a determination that there was no more new information from participants. According to Lincoln and Guba (1985), “Sampling is stopped when there is no new information coming from newly sampled units; redundancy is the primary criterion” (p. 202). A total of 18 participants (n = 9 patients and n = 9 caregivers) were interviewed. Data saturation was determined after participant interviews with (N = 7) patients and (N = 7) caregivers became redundant. Two patients and two caregivers were excluded from the study because of the possibility of receiving a heart transplant. Participant sociodemographic profiles were constructed (Tables A4 & A5).

Participant appreciation.

As a token of appreciation for participating in my research, participants received \$25 cash for travel expenses (\$25 total in travel expenses for each patient/caregiver dyad), and \$25 cash for each participant (\$50 total for each patient/caregiver dyad) (e.g., funds did not exceed \$75 total for each patient/caregiver dyad).

Data Analysis – Data Interpretation

According to van manen (1990), data analysis in a phenomenological inquiry aims to

construct descriptions from the participants' texts in order to elicit the essence of the lived experience. As a result, phenomenological descriptions are rich descriptions eliciting in readers the *phenomenological nod*, that is, an experience we may have experienced or even recognized (van Manen, 1990). This is accomplished through *thematic analysis*, which is done across all participants' text to elucidate similarities and differences, and *phenomenological writing*, in which a phenomenological story explicating the essence of living with DT through themes and sub-themes was constructed.

Thematic analysis.

van Manen (1990) described three approaches for reviewing the data from macro- and micro- perspectives. From a macro-perspective, or wholistic (sententious) approach, the texts were reviewed as a whole. From a micro-perspective, the selective (highlighting) and detailed (line-by-line) approach, focuses on the parts. All three approaches involve reading, rereading, reflection, and writing.

Wholistic approach. This goal of the wholistic or sententious approach is to find the overall meaning of the participants' voices. First, I separated and grouped the participant texts into *patients* and *caregivers* to preserve the inside perspective of each experience. Then, I read, reread, and reflected on each text individually. As I read over the texts, I asked questions of the whole text, such as: "How does this text reveal the meaning of living with DT?" "What are the phrases that capture the meaning of the text as a whole?" (van Manen, 1990).

Selective approach. In the selective or highlighting approach, I read each sentence or phrase very carefully. While reading and rereading the texts, I reflected on the words and asked: "What phrases stand out in the text? Which phrases, sentences or parts of sentences may represent a theme of my phenomenon? (van Manen, 1990). Then, I *highlighted particular*

statements, words, or phrases that represented my phenomenon. I reflected on each word and/or phrase, as I attempted to understand participants' experiences and meaning into the phenomenon of LVAD as DT. The goal of this preliminary approach is to identify words, phrases, and rich descriptions that illustrate the essence of living with DT.

Detailed approach. Also described as the *line-by-line* approach, I read each phrase very carefully. While reflecting and rereading the texts, I will ask: "What does each phrase, sentence or parts of sentences appear to uncover about the meaning of my phenomenon?"(van Manen, 1990). After highlighting meaningful words and phrases, I compared parts to the whole of transcribed transcripts to search for shared meanings and differences (van Manen, 1990). Words, phrases, and clustered topics were coded as nodes and organized into separate patient and caregiver folders in the NVivo 9 qualitative software.

In van Manen's (1990) method, both analysis and reflection is done to obtain an understanding of the phenomenon by comparing and contrasting participants' texts collectively. In this phase of analysis and reflection, the research questions were applied to emerging themes to highlight those which illuminate/uncover the experience of living with DT. Moving back and forth from the lived experience sources to the whole of the inquiry allowed me to develop an understanding of the phenomenon and generate new interpretive questions as the process of thematic analysis and reflection continues. Constant comparison of my personal journal entries, transcribed texts, interview notes, and demographic profiles were ongoing as interviews continued, and collectively utilized to capture the essence of the participants' experiences. By writing, rewriting, and reflecting across all texts, the culmination of these three approaches produced clustered topics which were organized into emerging overarching themes and sub-themes illustrating the experience and meanings of living with DT. The second part of data

analysis/interpretation includes phenomenological writing as a process of creating a story describing the essence of participants' experience as lived.

Capturing the phenomenon through writing.

It is through the process of writing that the meaning of the lived experience emerges (van Manen (1990). The process of writing and reflecting is an important process to uncover the essence of phenomenology, as described by van Manen. As a result, thematic phrases constructed through analytical reflection provide initial meanings ascribed to the phenomenon and a foundation for ongoing reflection, writing and re-writing.

As part of phenomenological writing, I continued to explore the lived experience sources to interpret the essence of my phenomenon. As the phenomenological story started taking form, I used personal reflections from phenomenological literature, and experiential descriptions to spark creativity in interpreting, developing and presenting the essence of the DT phenomenon. The experiential descriptions included entries in my personal reflective journal, which are available for audit. In addition, I used various forms of artwork, such as poems written by phenomenologists, and videos of patients and their caregivers living with LVADs, to stimulate phenomenological writing. van Manen (1990) described that paintings, sculptures, music, and cinematography has its own language which gives shape and form to the lived experience. I utilized many aspects of the arts and humanities, including music and meditation, to help me create the final phenomenological story. The following section is a compilation of the artwork articulated with to stimulate phenomenological writing.

Finding meaning through art.

van Manen discussed incorporating many types and sources of meaning to aid in the interpretation of the lived experience (van Manen, 2002). These sources included poetry,

artwork, everyday life experiences, language, social science, historical, cultural, literary, and phenomenological literature sources. Sources of adding meaning to assist me in the interpretation of the lived experience is artwork, photography capturing everyday life experiences, and music. As I forged on in the construction of the experience and meaning of living with an LVAD as DT, there came many times where I had to stop and reaffirm my own life, my own being, and those who are an integral part of my world. I found this step necessary to recollect my thoughts and pursue my dedication to make the world of DT come to life.

Family. The majority of participants described how important family is and the integral role good family support plays in all aspects of life. From being there before the LVAD implant, recovery, and rehabilitation, the importance of having good family support was vital for a happy, productive life. I, too, can identify with the importance of having a good family support. It was rummaging through a collage of pictures of those who inspired me the most that helped me understand what the meaning of life really is. The next two pictures are those of my family – pictures which to me, bring out the meaning of what it’s like to have the love, support, and feeling of being cared for by family.

Pictured here is my husband, my pillar of strength, who has played a vital role in the pursuit of my graduate studies (Figure B5). He is a gentle soul, one who loves all creatures great and small. Of those creatures walking on twos, fours, or eights, covered with fur, feathers, scales or leather, he is particularly sensitive to those who are victims of a sometimes cruel world. His advocacy for these victims shows in all his actions and words, even visible through silence and tears. I see him here in a mini-reproduction of a Brazilian rainforest in my own home - exotic birds, green foliage, and flowers indigenous to his native land. His focused, pensive expression mirrors his ongoing love and perseverance to make this world a better place for everyone. In

doing so, he made, and continues to make, my life comfortable, filled with love, and a never-ending commitment to making all my dreams come true.

Another source of happiness and inspiration is my senior citizen Wheaton terrier (Figure B6). The expression in this picture represents many years of loyalty and unconditional love as my protector and companion in times of loneliness and despair. There was never a day gone by that this crazy but lovable dog has touched my heart and soul in ways beyond expression. His fun-spirited, zest for life in younger years has now culminated to an attitude of ‘acceptance’ and a ‘job well-done.’ He continues to wait in joyful hope for his ‘mommy’ to hang out with him, even if for a few moments.

Return to a new normalcy: Van Gogh self portraits. While writing and rewriting themes and considering possible interpretations of the lived experience of DT, I turned to the works of famous artists in hopes of constructing the meaning of living with such a life-sustaining device. Once again, I knew it was important for me to understand my role as researcher, and to continue to hold at bay my own personal beliefs. While reviewing the famous paintings and artwork of many painters and sculptors, I was drawn to the works of van Gogh, specifically his self-portraits (Figures B7 & B8).

Van Gogh painted over 30 self-portraits in the late 1800s. I found it interesting that the majority of his self-portraits always portrayed the same expression – a glaring, intense look in his eyes, tightly drawn lips, and a right or left profile. The bold use of colors and outlining, and the thick, purposeful brush-strokes exudes an expressive and emotional feeling when observing his paintings. Circumstances surrounding van Gogh’s tumultuous life are splattered across an array of canvases, but, the expressions, the expressions of who he is, remains the same. What was the impetus for creating these self-portraits? Were these self-portraits a way to express his

emotional and dramatic world by trying to regain a sense of normalcy? Believing that the latter is true, we cannot control external forces that influence our thoughts and actions, but we all try to regain some type of normalcy in the process. This is achieved in realizing that we have the ability to keep and/or return to normalcy.

As I reflected upon the van Goghs' self-portraits, I can't help but think about how external influences have shaped my thoughts and actions, particularly my journey through nursing doctoral training. I strove to maintain my normalcy as I progressed through my studies, but my normalcy was replaced with a *new normalcy* – the ability to think and perform in ways never dreamed possible. This was very evident while I interacted with participants' during interviews. These participants openly talked about their experiences with me, a stranger, who asked to enter their private world of living with DT. As I examined how and why these participants recounted their personal experiences with me, I realized that I became a participant observer. van Manen discussed the importance of the researcher becoming a participant observer by recounting living phrases of participants. But it was not only gathering "living phrases" that captured participants' experiences, but my ability as researcher to elicit experiences as lived through open dialogue, encouraging deep, reflective thoughts, without influencing thoughts during conversations. Examples included my research skills to promote an open, comfortable environment for my participants, such as using open-ended questions, positioning and utilizing my body language to make participants feel comfortable. The feelings of comfort felt in the room, the amazing, heart-felt stories, the fears and detailed descriptions of very personal experiences, led me to conclude that I was capable of putting aside my own thoughts, biases, and assumptions in order for participants to reveal their lived experiences.

The ability to keep in abeyance any confounding thoughts was certainly beneficial for my

research, but took an emotional and physical toll on my overall well-being. I felt such a deep remorse for these patients and caregivers. I knew that many of these patients will eventually die, and that the caregivers will be left alone and distraught with the memories of what could and/or should have been. Participant description of their life experiences (e.g., external forces), influenced my thoughts and actions in such a profound way that I became more pensive and secluded. I had to search for ways to regain normalcy in my life again (Figure B9). Their stories just seemed to paralyze me emotionally and physically. A lot of their stories reminded me of how much I loved my father and how I cared for him day and night as he approached his final destiny. The images of his pain, suffering, and all those horrible emotions I felt certainly made me realize that many caregivers can experience post-traumatic stress disorder (PTSD). This condition is certainly one of my biggest concerns for these caregivers and caregivers in general. Will they experience PTSD once the patients have passed on?

I have learned that, no matter how destitute you are, there is always hope. There is always that light at the end of the tunnel. Eventually, we all will find ‘the light of hope’ and eventually the peace that follows in our hearts when all seems lost. Similar feelings of hope echoed throughout participant descriptions. From the first time they learned that a mechanical heart could keep them alive, to hope for new technology when their device stops working, hope for life seemed a constant and strong feeling expressed across participants’ experiences.

Just like van Gogh painted an array of self-portraits illustrating the forces of change surrounding him, a desire to return to normalcy was also expressed by participants across the board. Participants spoke how they strove to achieve a sense of normalcy by adjusting to living with the device. From caregivers helping patients adjust, to patients themselves accepting and adjusting in their own ways, the journey to normalcy, for a desire to live life like before, was

clearly evident in this sample of participants. Although many participants achieved a sense of normalcy, for many of them, it was a new normal – a normal with nuisances and inconveniences – but they were all good nuisances and inconveniences – because it gave them more time to live. Like van Gogh’s self-portraits, external influences continued to affect his life, his world, but, his search for normalcy through creations on canvas created a world in which, for the moment, was a distraction from the nuisances of his tumultuous life. We too, change with these external forces, but continue to search for normalcy in what we have come to know as a new normalcy.

Portraying worry through art. As I continued my search for artwork to help me create the meaning of living with a DT, I focus on the major feeling expressed by caregivers across the board: persistent worry and stress. There were several paintings by Picasso (1881 – 1973) which instilled in me a deeper understanding of the feelings of worry and stress among caregivers. The first painting is called *Woman with a chignon* (Figure B10). It is a single painting/portrait of a woman sitting down, with her hands folded underneath her chin almost as if to hold her head up. Her eyes look worn and tired, her mouth and lips closed as she just seems to stare off into space. Her slouched body language exudes a feeling of exhaustion as she seems to listen to what someone has to say, but is in a far away land. What is she thinking? My participants as caregivers portrayed this same expression on their faces – the look of exhaustion, worry, stress – but only when they talked about their experiences of worry and stress, or recounted what worried them the most. For example, patients were not careful, they wanted to regain their independence and do what they normally did before, etc. When they started talking about the ‘good part’ of having an LVAD, like being given more time and feeling better, their eyes seemed to lighten as if a spark of sunshine came into the room. But once they continued to recall feelings of worry and stress, their expressions mirrored the woman in the painting.

Other artwork by Picasso included to illustrate the meaning of persistent worry and stress where also found that illustrated the experience of being worried. Here, we see the painting, *Lola, Picasso's Sister* (Figure B11). Lola is pictured sitting down with her hands set down in her lap looking outside. There are lights and what appear to be people in the distance, but Lola is by herself and appears to be in deep thought. Although her facial features appeared dull, once can see a very deep, almost lost look in her eyes. Her body language, however, seems to tell us something else – she is leaning forward, looking outside, as if to see what's going on outside, or waiting for the return of someone. This also mirrors what the caregivers have described – there was never a moment that passed that they didn't think about their loved ones. Whether the patient was out by themselves, with friends, or if the caregivers left for some period of time, the patients were always on their mind. Here, Picasso's painting, once again, has helped me to illustrate persistent worry and stress that echoed throughout caregivers' voices.

Fear of morbidity and mortality. This next painting by Picasso, *Woman with a Crow* (Figure B12) illustrates a woman caressing a black crow. In European mythology, the black crow symbolizes imminent or impending death. Picasso's drawing brings to life the constant fear many of the caregivers had —the fear that something bad is going to happen, or worse yet, the patient was going to die. Thoughts of the patients getting sick again, having to face an elongated hospitalization, protracted illness, even death, has come across the minds of many caregivers. How are the patients going to die, what are the signs, how long does he has to live? This was one of the most difficult parts of my interviews—hearing the stories of their fears, concerns, and ongoing stress related to knowledge of potential deterioration and the unknown about the end of life.

Given another chance at life. When participants as patients reflected upon life before the

LVAD compared to life with their new device, they unanimously described feelings of impending doom. Phrases used to describe this feeling included, “I was on death’s door,” “I thought I was going to die,” and “I didn’t think I would see the day I would come out of the hospital.” Symptoms described by these patients included profound shortness of breath, marked physical limitations, and having to ‘sit down’ or ‘use a wheelchair.’ One participant even spoke of making end of life decisions, even saying good-bye to his wife, reminiscing about the good life they had together. I combed through galleries of paintings, sculptures and artwork to help me find something that illustrated what these patients were feeling, and how I can construct the meaning of what it was like to have another chance at life. I turned to the paintings of van Gogh and found *The Raising of Lazarus* (Figure B13). At first, I wasn’t sure about it, but as I re-read patients’ lived experience sources, feelings of being scared, worried about leaving loved ones, and having the LVAD for the family illustrated their close brush with death. When they heard about the LVAD, it brought immediate hope for life, where hope was lost. Although patients didn’t actually die, they were close to dying. The LVAD brought to them not only the gift of life, but an overall improved quality of life as they regained the strength and confidence once again, to enjoy life.

Other artwork I found was lived experience sources from personal websites. For example, I found several LVAD blog sites, where participants told their stories about living with an LVAD. The most impressive blog was titled, “From the bottom of my LVAD” (<http://fromthebottomofmylvad.blogspot.com/>), mirrors responses made by my participants’ feelings for being given another chance at life. One response was, “I am blessed for a better life because of my LVAD.”

Thank you Lord. One of the most inspiring themes that came up from participants was

thanking the good Lord for being given more time. Phrases expressed by participants included, “Praise the Lord, that’s all I have to say,” “Thank the Lord,” and “Thank the Lord to give the doctors the knowledge.” In a religious hymn by Lyte (1793-1847) titled, *Praise My Soul the King of Heaven* (Figure B14), the words sung by this chorus seemed to fill my heart and soul with the true meaning of being thankful to the Lord. The words appeared to mimic the feelings many participants felt before they had the LVAD – “well our feeble frame he knows, in His hands he gently bears us,” to after having the LVAD, “ransomed, healed, restored, forgiven.” It was the tears of joy that were expressed by these participants, the endless groping for words, the stillness and silence of the room that made me feel this, this, was the true meaning of being thankful for having an LVAD.

One of the participants wrote a poem for his 50th wedding anniversary, *Thank you, Lord, For This Great Day* (Figure B15). In this poem was the phrase, “I guess this is all I have to say, except Thank you, Lord, for this great day.” Once again, we come across the junction of language and silence, where, according to Bollnow (1982), we have arrived at the truth of a phenomenon. It is the searching for words, or lack of finding words, to describe a feeling, a meaning so deep, that there are no words to describe a feeling, a meaning, or a phenomenon.

The phenomenon of silence and interpretation of meaning.

Consulting the phenomenological literature can also assist in describing and interpreting the meaning of the lived experience. The phenomenon of silence particularly fascinates me. Understanding the power of meaning behind non-verbal body language is necessary to fully grasp the meaning behind a phenomenon. This is true when trying to describe and interpret non-verbal language, such as silence, during participant observation. van Manen (1990) described that in the absence of speech or language, we find that silence is more powerful than words

themselves. van Manen (1990) described three types of silence. The silence we experience when we think of the unthinkable, such as death (i.e., epistemological silence), or the silence that follows when we are moved by an enlightening or stimulating conversation, such as what may happen in my interviews (i.e., ontological silence). In the ontological silence, I can best explicate this silence during one of my interviews in our recently published study exploring the experience of caregiving for patients with LVADs (Marcuccilli & Casida, 2011). For example, when the mother of a 21-year-old daughter with an LVAD tried to describe for me the meaning of what it was like to care for someone with an LVAD, she appeared at a loss for words. As she reflected upon this experience, phrases shortened and words were few. Finally, she said, “I don’t see it as caregiving...she is my daughter...and I am her mother.....that’s just the way it is...” As our stances locked, she nodded. “...yep...that’s it.....that’s it...” Also during my interviews, I watched and listened for what van Manen (1990) calls *literal silence*. This silence occurs as the pauses and periods of silence “while the conversation halting gropes forward” (p. 113). Expressions of the types of silence were revealed in this section, and described in more detail in Chapter 5, *Discussion*.

Prior to finalizing main themes, I reflected on preliminary themes for at least two weeks prior to composing overarching themes. Reflection upon preliminary themes involves a process of inductive thinking (i.e., intuiting), which facilitates *reduction* revealing essential themes (Munhall, 1994). During this time, I presented my themes to two members of my dissertation committee. Themes are considered essential when they reveal the *essence* of living with DT and fundamental to the collected descriptions of living this experience (van Manen, 1990). Final themes were validated by the qualitative methodologist in my committee and consensually validated by all members of the dissertation committee. A phenomenological story illustrating

the experience and meaning of living with DT was developed with overarching (i.e., main themes) and sub-themes (Chapter 4, *Results*).

Structure of the phenomenological story.

van Manen (1990) suggested several strategies for developing and organizing phenomenological writing, these include: 1) thematically (e.g., according to themes); 2) analytically (e.g., description/analysis of a particular experience); 3) exemplificatively (e.g., use descriptions and examples of other similar phenomenon), 4) exegetically (e.g., through the thinking of another phenomenological author), and 5) existentially (e.g., weave descriptions with the existentials of temporality, spatiality, corporeality, and sociality (van Manen, 1990). Although van Manen asserted that the phenomenologist can utilize one, a combination, or another structure, I organized the structure of story thematically. How I came to this decision was the result of my ongoing reflection and interaction with the lived experience sources. As I continued to write and reflect on participants' experiences, it was very clear that they were not only recounting their experiences, but also the story of their life. From the beginning of diagnosis with heart failure and deterioration, to living their new life with the LVAD, these were stories – stories of a world only known to them.

As I continued to reflect on the lifeworld of these participants, the philosophy of existentialism as described by Søren Kierkegaard (2000) came to mind. Kierkegaard (2000) argued that we as individuals are the ones that give meaning to our lives. We decide what our lives mean and how we want to live our lives – period. Considering my role as interpreter of the lived experience, I decided to structure my phenomenological story as an *existential biography*— which means that these participants have voiced about how they live their lives with a DT, and what their life means to them. Although not a complete biography with all the details of their

life history, the existential biography is a snapshot of their lives before and after being implanted with a DT.

The existential biography that is presented in Chapter 4, *Results*, which represents the culmination of van Manen's research methods and activities which assisted in my interpretation of the experiences of living patients and caregivers living with DT. With the help and guidance of the hierarchical taxonomy and rich descriptions, I was able to construct this existential biography that draws readers close to what life was like for these participants. While reading through my interpretations, it was clear that we were given an initial glimpse into the world of living with DT. Albeit a glimpse into a world in which we have only begun to understand.

Data Management

In order to maintain the privacy and ensure confidentiality of participants and all data collection materials, all tape-recorded and transcribed interviews, and demographic data were assigned a unique numerical code and placed in a locked storage cabinet which was only accessed by me. I used a numbering system for organization of data into cases. For example, for participant one, I entered "participant 001" on the demographic profile. I prefaced the tape-recorded interviews as follows: "This is participant 001." The interview note was labeled "participant 001," and so on and so forth for other participants. This was necessary in order to keep all data organized and keep me on track of evolving questions. The transcriptionist removed all identifying names during transcriptions and replaced them with 'name.' I listened to tape-recorded interviews and reviewed transcripts for accuracy and completeness of information. In addition, data was stored on my computer which is password-protected, encrypted computer, which was locked in a file cabinet in my home office when not in use. I exclusively maintained the NVivo 9 database which is also located on my personal computer. The name and number of

the participants were entered on a master list which is kept separate from the data. This master list was located and locked in a separate filed cabinet in my home office and kept long enough to perform the second follow-up telephone call. At the end of the inquiry, the data was kept for future reference and the master list was destroyed.

Trustworthiness

It is necessary to demonstrate methodological rigor in qualitative studies in order to ensure credibility (Sandelowski, 1995). To ensure rigor, Morse and Field (2002) recommended building strategies into the phenomenological inquiry so that trustworthiness is evaluated on an ongoing basis. Strategies designed to enhance rigor included adherence to the overall methodological approach of van Manen, and methods and procedures of the study. Additionally, methodological rigor was enhanced by adhering to the four criteria for trustworthiness: 1) credibility, 2) transferability, 3) dependability, and 4) confirmability (Lincoln and Guba, 1985).

Credibility.

Credibility confirms reliable findings (Lincoln & Guba, 1985). Triangulation of the data, prolonged engagement, peer debriefing, and member check were strategies utilized to ensure credibility. To address credibility, triangulation of the data included constant comparison of my reflective journal entries, demographic profiles, taped and transcribed interviews, field notes, to uncover the essence of living with DT. Second, prolonged engagement was demonstrated by a thorough documentation of participant interviews, length of immersion with data, discussions with dissertation committee members. Member check consisted of one telephone call performed by me during second interviews to further elicit my understanding of the meaning of living with and caring for someone with a DT and to confirm emerging themes. While other researchers (Morse, 1994; Sandelowski, 1993) report differing opinions with credibility of member checks,

participants may change their minds about the experience, and/or may disagree with researcher's interpretation, Lincoln and Guba (1985) discussed that member checking is key to determining credibility. Third, peer debriefing included an independent review of the overarching themes and sub-themes by two members of my dissertation committee.

Transferability.

Transferability is the extent to which the findings of the study can be applied to other studies (Lincoln & Guba, 1985). Determining transferability is the responsibility of the person making a transfer (Lincoln & Guba, 1985). Transferability was facilitated by utilizing a purposive sample, providing details regarding the research context, and presenting thick descriptions of procedures, findings, and underlying assumptions.

Confirmability.

Confirmability measures how well the results are supported by the data collected (Lincoln & Guba, 1985). An audit trail was maintained by me and examined by the dissertation advisor to determine confirmability. Audit trails are utilized to enhance validity of the study design and outcomes (Sandelowski & Barroso, 2007), and allow other researcher to follow the *decision trail* utilized by the researcher (Guba & Lincoln, 1990; Koch, 1995). The independent audit consisted of a thorough examination of all documents obtained in the study and the procedures.

Dependability.

Dependability assesses the quality of the methodological procedures (Lincoln & Guba, 1985). To address dependability, an inquiry audit was performed by a member of the dissertation committee with qualitative expertise. Validation of research findings was confirmed through a thorough examination of the research process, methods, procedures, findings, and implications.

Summary

This chapter described van Manen's (1990) philosophy and methodology which guided my phenomenological inquiry. The six methodological research themes were described and incorporated into the procedures of my study. The procedures are described. The chapter concluded with strategies to ensure trustworthiness.

CHAPTER IV

RESULTS

Chapter 4 presents the findings of a hermeneutic-phenomenological inquiry which aimed to uncover the experience and meaning of patients' and caregivers' living with an LVAD as DT. This inquiry aimed further to understand the inside perspective of living with such a life-sustaining device. This chapter is prefaced with a description of the sociodemographic and clinical characteristics of participants. Participant experiences are presented as an existential biography and divided into three parts: 1) *Patients with LVADs as DT*, 2) *Caregivers of patients with LVADs as DT*, and 3) *Dyadic meanings*. Themes are organized around the research questions posed for this inquiry. The chapter ends with a preface to chapter 5, *Discussion*.

Sociodemographic and Clinical Characteristics

Participant demographics were aggregated using descriptive statistics (e.g., mean, range, standard deviation). Data were separated into participants' as patients and participants' as caregivers (Table A4 & A5).

Participants as patients.

Patients were all retired White males, ages ranged from 71-76 years old, with a mean age of 73 and standard deviation of 1.8, attained 13 or more years of education, and length of time with DT ranged from 8 to 24 months, with a mean implant time of 12.3 and standard deviation of 6.0 (Table A4).

Participants as caregivers.

Caregivers were predominantly retired, White females (n = 1 man, n = 6 females), ages ranged from 50 to 74 years old with a mean age of 65 and standard deviation of 8.3. (Appendix A, Table A5). Each of the caregivers in this inquiry were actually a caregiver of the patients in

this inquiry.

Part I: Patients with an LVAD as DT

Findings in Part I represent patients' experiences and meanings of living with an LVAD as a DT. Six (6) main themes, eight (8) sub-themes, and eleven (11) sub-sub themes were constructed from the data and formed the foundation for an existential biography depicting the essence of living with a DT: 1) *Life begins to change with heart failure*; 2) *Learning to live with an LVAD: An evolving process*; 3) *Adjustments and acceptance come with time*; 4) *Living outweighs restrictions*; 5) *Hope for life through new technology*, and 5) *Thank the Lord*. The first three (3) themes illustrate patients' inside perspective of living with a DT, and have addressed the research question, "What is the experience of living with an LVAD as DT from patients' perspectives?" The later themes addressed the research question, "What is the meaning of living with an LVAD as a DT from patients' perspectives?"

In the beginning.

As patients' sat before me in the private conference room, we engaged in cordial exchanges throughout conversations, even shared beverages and snacks, while waiting for doctor appointments, routine blood work, or diagnostic testing. As their stories unfolded, most patients described a normal, full, active life before the onset of advanced heart failure. Responses such as "I lived a complete, full life," "I was a super active guy," and "I was a guy that lived to fish and hunt, see, and I liked to go camping and stuff like this," were reported amongst the majority all participants. Patients worked, played, and lived full lives on their own terms. It was the onset of heart failure, however, that began the downward spiral of health and the beginning of what seemed like the end to a familiar life.

Theme 1: Life begins to change with heart failure.

This theme describes the world of patients with heart failure as they began treatments, the progressive symptoms of shortness of breath and weakness, learning about the LVAD, and described their determinism to live. Patients' lives began to change when they were diagnosed with heart failure. They were bound to a strict regimen of medications, diet, and exercise. Some patients talked about being diagnosed with congestive heart failure after having a heart attack. Others described treatments used and being managed with medications, intercardiac devices, and even intravenous infusions to reduce the pressure on the left side of the heart. It was the progressive symptoms of heart failure, however, that patients reported across the board. Five (5) sub-themes were constructed to illustrate the changes experienced by participants: 1) *Weakness, shortness of breath*; 2) *Profound limitations*; 3) *On death's door*; 4) *Hope for life through LLVAD*; and 5) *Determined to live*.

Weakness, shortness of breath. As patients went on with their lives after being diagnosed with heart failure, they described experiencing weakness, shortness of breath, with any physical activities. Phrases used to describe this experience included, "I would get out of breath pretty easy when I tried to do anything, and "I couldn't walk from my house to the car and I had to set to down to take a break." One participant richly and succinctly described this experience with even the smallest amount of exertion:

A couple years before the LVAD I was weak, couldn't do much. Lightest, slightest exercise I was short-winded. I had trouble walking from the living room to the bathroom and the living room to the bedroom. Getting bad. And I mean it really winded me. And, um, if I went down in the basement, I even had to stop half way down. And then when I came back up I had to stop two times on the stairs, okay (Patient A, p. 10).

While patients struggled with these symptoms, the progressive nature of heart failure

reared a ferocious wrath on their bodies and lives as they struggled to live their lives.

Profound limitations. This subtheme illustrates the experience of living with profound limitations as heart failure progressed. As patients began experiencing the end stages of heart disease (e.g.,) decreased end-organ perfusion, marked shortness of breath, and marked physical limitations now overshadowed the activities of a once active and fulfilling life. Some phrases used to describe this experience included, “ I came in, you know, with shortness of breath and they had to wheel me in, I could hardly walk,” and “I couldn’t, you know, I was losing my liver, my kidneys and this, and I couldn’t function, see. And they said this was it.”

The majority of patients eventually succumbed to a life of inactivity as this disease progressed and seemed to ravage their very existence. One participant vividly described his experience of being unable to do anything while he was in the end stage of heart failure:

I couldn’t do anything. And, you know, I’m sure that would bother people that like to do certain things. But I had gotten to the point where I was so short of breath that I couldn’t, you know, when I did something I was so short of breath that I stopped doing things (Patient A, second interview, p. 5).

Some patients recounted that this progressive deterioration began approximately “4-5 months” to “a year or so before they received an LLVAD.” It was during this time that patients unanimously began to fear for their lives.

On death’s door. Patients vividly recalled thoughts and images of death while living in end-stage heart failure. Words such as scared, afraid, worried, and concern dominated phrases describing their feelings. One patient talked to me about these emotions while engaging in a face-to-face conversation. He stopped speaking for a moment, then, with a wide-eyed look and stilled facial expression; he trembled while recalling these feelings during our conversations: “I

was scared. I was one scared individual. Before the LVAD came into the picture, I was afraid I was going to die. I had a feeling that I was not going to last long, and that's not a good feeling. I'll tell you that, it's not a very good feeling."

Amidst ongoing thoughts of death and dying, patients knew they needed help. It was during their search for relief, search for answers to relieve their progressive symptoms, that some patients described a confirmation of their dreaded fears as they met with cardiovascular specialists: that they didn't have long to live. Some patients' recalled that these specialists only gave them less than a year to live: "I could stay, they couldn't guarantee me six months later, see. I might stay, and I might not." It was during this phase that patients' heard about the only treatment option that was left for them – the LVAD.

Hope through the LVAD. Whether it was through a transferring physician or at the implant hospital, it seemed that just when all seemed lost, the LVAD was their ticket to life. Patients collectively described when they first learned about the LVAD. One particular patient poignantly illuminated these feelings through his own words:

Well, anyway, I was, went in and I wasn't sure I was going to see the day out of the hospital when I went in January. And that's when the great physician (name of city) said to me, he thought there might be a little more tread on his tire. And that was his exact expression. We got a little more tread on this tire, we're going to get you [to come] down to Ann Arbor and see if you would be a candidate for an LVAD.

(Audit Trail, Patient E, 1st interview transcript, p. 5)

Conversations with specialists filled their minds with hope for the future. It was during these conversations that patients were informed of some rather unexpected news: they will never be a candidate for a heart transplant because of advanced age. Some of them felt that they were

victims of age discrimination at first. But as they continued to reflect upon their experiences, it seemed as if they accepted the fact that they were never going to receive a donor heart:

You know, it really bothered me at first. Because, you know, when he said I was too old for a heart transplant I felt that, you know, that was discrimination somewhat. Age discrimination. And, uh, but you know, then I decided rules are rules and I have to abide by them (Audit Trail, Patient A, 1st interview transcript, p. 11).

Feelings of being ineligible for a heart transplant, however, didn't seem to dowse hope for these patients.

Determined to live. In this sub-theme, patients spoke of their will to live. Given a poor physical constitution and close brush with death, these patients' were determined to live. Whether it was for personal reasons or for their family, they described a determination to live, as recounted by one patient:

But we were always talking, the family was always talking, uh, well let's, we'll go here. Or we'll go there. Or we'll go to Cleveland or something, so I always had, no one bought into well that's it. Nobody bought into that philosophy. Everyone around me just, including myself, well there's other people in other hospitals so let's look that over before we resign ourselves to, uh, there's nothing can be done. So that's, that's what got me through those two rejections (Audit Trail, Patient H, 1st interview transcript, p. 8).

Patients' now entered a new phase in their life – one that included having an LVAD implanted in their body. Whether they were already an inpatient at U of M or were transferred, patients' had to be admitted pre-operatively for a battery of tests to determine eligibility for implant. For the sample in this inquiry, pre-testing ranged from 7-28 days (7, 7, 7, 28; M = 12.2, SD = 12.5). Some patients described being carefully 'checked out' before they were cleared for

surgery: “They check you out pretty good to make sure you’re a good candidate. And, uh, apparently I was because on February 9th I got my LVAD.”

This preoperative phase marks the close of the 1st theme of this existential biography and a preface to a world only known to these patients’: the initial encounters of living with an LVAD as a DT.

Theme 2: Learning to live with an LVAD as DT: An evolving process.

This theme illustrates the timeframe in which patients first received their LVADs, and the immediate adjustments required to live with this device. Two distinct phases delineated this evolving process: 1) The postoperative period, and 2) A time for discovery and adjustment.

Post-operative experience. The post-operative experience varied among patients. It seemed that the severity of the symptoms prior to admission dictated post-operative recovery and rehabilitation for these patients. The post-operative period, therefore, was experienced very differently for the majority of them. Severity of illness was also exemplified by the duration of hospital stay, which ranged from 14 – 120 days (14, 28, 28, 120, M = 47.5, SD = 48.8). During this time-frame, patients individually described experiencing ICU psychoses, to having difficulty adhering to the “strictures of being ‘micro-managed’” in the hospital. Feelings associated with this post-operative experience were also individualized and included frustration, depression, anger and tired. For example, some patients described feeling ‘tired’ of anything and everything that had to do with being in the hospital, as richly recounted by one patient:

I wanted, I was tired of the strictures of the micromanagement. And all the trappings that go with it. You know, coming in your room every 20 minutes to do a blood pressure check, medications, the medication regimen I was on. Drive line changes, dressing changes, and this whole thing was just not what I really wanted to do. I just wanted to

go home. Well, obviously I didn't (Audit Trail, Patient E, 1st interview transcript, p. 8).

It seemed that during the recovery phase, about half of the patients described an almost immediate sensation of improvement. One patient described this experience for us: "Well, I guess what stood out, I mean I could tell, I just went two days after I put it in [the LVAD] how much better I felt. I think that probably stood out more than anything."

Patients eventually progressed through the immediate postoperative phase and were discharged home. It wasn't until they arrived at home, however, that they realized how their lives were going to change. The latter phase of this evolving process reveals a time of adjustment and recovery — a time where patients unanimously described how they incorporated the LVAD system into their lives.

A time of initial adjustment and discovery. This subtheme reveals some of the initial struggles, realizations, and emotions surrounding the initial period of adjustments when patients first came home. Eleven (11) sub-sub themes elucidated these patients' experiences as they first came home and as their new lives with the LVAD evolved: 1) *Limitations with the LVAD*; 2) *Carrying equipment can be uncomfortable*; 3) *Implement precautions*; 4) *Having a foreign body*; 5) *Carrying around extra equipment*; 5) *Clothing challenge*; 6) *Being tethered*; 7) *Can't take showers or baths*; 8) *Have to have a caregiver*; 9) *Daily dressing changes*; 10) *Caregiver does all driving*; 11) *Adjusting to IADLs with the LVAD*, and 12) *Limited sexual activity*, were constructed to illustrate this overarching theme.

Limitations with the LVAD. Patients unanimously described that living with an LVAD imposed some limitations to a familiar life before the LVAD. From being limited to participating in sports, such as golf and hunting, to even activities around the house, patients described being restricted from these activities. Words used to describe these limitations

included, “inconveniences,” “restrictions,” and “confinements.” One patient richly described having to give up one of his favorite outdoor activities:

That’s my, my problem is because I, I went to do the sports and stuff and I can’t do it, see. And, you know, I can’t go too far. I’ve got to stick around where, you can’t just go up north for something like that, see, because you got, this has got to be working all the time, see. So, you know, I used to go up salmon fishing and go up and put the waders on and go out in the lake and I can’t do that no more, see. And I can’t do no ice fishing anymore because that’s, I can’t get in water. It’s, it’s part of the restriction.

That’s about what it is (Audit Trail, Patient F, 1st interview transcript, p. 1).

Patients continued to talk about the imposing restrictions as interviews continued. These limitations, or ‘inconvenience’ as described by patients are discussed in order of greatest to least imposition of living with an LVAD.

Carrying equipment can be uncomfortable. This theme reflects the experience of carrying around the LVAD system on their body. According to the majority of patients, the biggest limitation to living with the LVAD was having to carry the LVAD equipment around (e.g., batteries and controller). This meant having to wear the LVAD system attached to them for the rest of their lives. Words and phrases used to describe the experience of carrying around the batteries and controller were “uncomfortable,” “tiresome,” “feel the extra weight,” “pulling on your neck.” For most patients, this was described as an uncomfortable feeling. One patient further elucidated the experience of feeling tiresome with the equipment even though he had it for almost a year now: “And its, you got to carry this 24/12 and it gets tiresome after awhile. I’ve had it for, since December [almost 1 year] and it really gets tiresome of carrying that.”

Another patient described that even though the weight of the equipment wasn’t significant, it was

still uncomfortable:

It's just a difference of where, I only got two ways to wear the batteries, so, uh, but it don't sound like much but they're 3 pounds a piece, you know, and it just, uh, carrying 6 pounds of extra weight, you know, body weight, it's like, 6 pounds can be [uncomfortable] a little bit, you know what I mean, as far as carrying the weight (Audit Trail, Patient B, 2nd interview transcript, p. 3).

One patient provided a living visual of what it was like to carry an LVAD around:

I've had it around my neck [now for] eleven months, and it's part of me now, you know what I mean? I would like to take it off my neck sometimes, but I can't do it.

I'd like to set it down there and go over to the bathroom and take a shower, but you just can't do it, you've got to take it with you everywhere you go. It's always got to be there.

You know how you carry a purse... When you go in the house, you [set yours] down, I can't do that (Audit Trail, Patient F, 1st interview transcript, p. 5).

An important aspect described by some patients was having to always remember that the LVAD is permanently attached to you – that it is now part of your life. Patients described that it was not only vital to remember that that you have this equipment attached to you, but to always secure it before you make any moves. Here, I can remember the initial conversations with one participant, and how he looked at me – eyes wide open, slightly leaning forward towards me and pointing his right index finger in the air, as he described for me in a very serious tone, how important it was to “grab your lifeline bag before you walk away”:

Uh, the carrying you have to always be aware that, uh, you don't get up and walk away with it, pull it off of a chair or off of a table. Uh, so you always have to be, no matter what's going on, how busy it is, or, or in the heat of an argument, you don't

get up and forget that you have that lifeline bag that you've got to have control of. You know, you always have to, you always have to make sure you grab it before you walk away (Audit Trail, Patient H, 1st interview transcript, p. 1).

Being aware of your surroundings and implementing necessary precautions was also an important aspect of learning how to adjust with the LVAD.

Implement precautions. Implementing precautions while living with the LVAD was a major highlight of the discovery and adjustment phase. As patients started adjusting to living with their new device, they found that they were not only aware of having the device attached to them, but were also more protective of it. For example, patients who were trialing the Heartware LVAD described being careful and making sure the shoulder strap secured the controller. Other precautions included just being aware of the LVAD itself, your surroundings, and how to protect the LVAD. A constant vigilance of these precautions was described as having a whole new responsibility for the LVAD:

Um, other than that, uh, it, it gives you a new respons – it's like having a new baby.

You've got a, you've got a whole new responsibility that you didn't have before.

You're, I mean you could climb ladders and go cut Christmas trees and, uh, these things are, uh, you just have to, you have to learn to, that you could endanger yourself if, if you were reckless with the, with the charging bag and with the lifeline. That's mostly it.

(Audit Trail, patient H, 1st interview transcript, p. 2).

Having a foreign body. When patients described the actual feeling of having the LVAD inside their bodies, most of them didn't feel it. Responses such as "I don't notice it," "the LVAD doesn't bother me at all," and "actually, you don't even feel it," were general statements made by patients. Generally, patients recalled feeling uncomfortable with the LVAD at first. There some

nuisance described which occur to date, such as the external components “pinching,” or feeling “uncomfortable with the wires in here, where they go it,” or even the “constant itching” under the binder or from the tape. One participant succinctly summarized the overall consensus that the LVAD is a part of you:

Well, you know, you know you acclimated to it to some degree. Um, but there’s always pinch points and itching underneath, especially the binder, you know, just full grade itching. Um, uh, the, uh, the cord gets stand out a little, reach in there the cords, the battery cords and the drive line cord are, are kinking, you know. And, um, but, um, it’s, it’s surprising how you get acclimated to it. To the weight, the positioning of it, you get to the point where, I don’t know, it’s not in your conscience that you’re wearing that, you know, it’s just part of you. (Audit Trail, patient E, 2nd interview transcript, p. 4)

Carrying around extra equipment. Patients also described the burden of having to carry around an extra bag of batteries, controller, even the main power base unit if they had to travel away from home. They usually transported the extra equipment in a variety of luggage-type equipment, similar to carry-on luggage. Patients described this experience however, as “confining,” and even “inconvenient,” and richly described by one patient:

“Well, you know, it’s not just this equipment that’s an inconvenience. We, when we want to go someplace I have to take a battery charger and I have to take my night time hookup. You know the batteries, when we go someplace.” Other patients even objected to toting along extra equipment: “[the equipment], which weighs a ton, and I have to manage that in this big travel case. I don’t like that. I don’t think it’s necessary, I really don’t.” (Audit Trail, patient I, 1st interview transcript, p. 10)

As patients began to live their lives with the LVAD, they began to experiment with

different types of clothes or gear designed to protect the outer components of the LVAD. This was not only limiting, but challenging in itself.

Clothing challenges. Patients unanimously described a trial and error period of finding comfortable outwear, or gear, designed to protect the external components of the LVAD. At the forefront of getting dressed was using an abdominal binder to protect the driveline and keep the dressing intact. The actual process of getting dressed, however, seemed to pose more difficulties. As patients began to dress themselves, they described dressing as “a little more difficult,” “challenging,” or even being aware of and more cautious of the LVAD while getting dressed, for example: “I try to be very careful as soon as I get my shirt on, then I put the strap around my neck so that it won’t fall out, and it’s just being cautious, that’s all.” One particular patient even vividly illustrated the process of getting dressed every morning:

Linda: Describe that for me, how you get dressed.

P: This thing gets in the way when I want to pull my pants up past it.

Linda: The controller?

P: Yeah, the controller.

Linda: The controller gets in the way.

P1: Yeah, and then what I do is, is in some cases it’s easier for me to get the, unfasten the belt and kind of scotch into the pants.

Linda: What is that experience like for you?

P: It was a pain, you know, in the butt. So to speak. At first. But then, you know, it’s something that I got used to (Audit Trail, patient A, 1st interview transcript, p. 2).

Eventually, patients described “getting used to” or getting “acclimated to getting dressed,” and even talked about finding the best clothing strategy for them: “So we’re pretty well

settled on, um, on the arrangement, the clothing arrangement that works for me.” The other aspect of clothing challenges included finding comfortable outdoor wear to protect the external components of the LVAD.

To protect the external components of the LVAD, about half of the patients described using the shoulder strap and securing the controller [housed in a fanny-type pouch] with their belt-loops and belt for extra protection. One particular patient described his procedure for protecting and securing the external components of the LVAD:

And the only other thing that I do is, like sometimes when I bend over to get up, the controller would swing out a little bit in front of me, and I didn't like that, so what I did was I just kind of rigged the belt and I put it through the handle, and I have the belt around my waist, and so that's just another precaution thing that I've done (Audit Trail, NVivo nodes: patient D, 2nd interview transcript, p.3).

When patients were discharged from the hospital, they were provided with a vest, called the *GoGear*, to house the external components of the LVAD. Many of the patients were not satisfied with the design of this vest and continued trialing other options to house the LVAD system. As the trial and error process continued, the majority of patients described finding alternate ways to house the LVAD when they were more active, such as working outside or engaging in social activities. They described other strategies used to secure these components, such as “suspender harness,” or “shirts designed for police officers,” or even vests made by their caregivers. Overall, patients seemed to prefer a fishing vest to keep the batteries and wires in place. It seemed that this fishing vest held the components better than other strategies as they engaged in outdoor activities, as described by one patient:

Now, the GoGear, actually it probably would have been better if it would have been the

smaller size, but they did have a connection between the two halves, but only one, okay. Whereas the fishing vest is a zipper, so it zips up. So it holds everything in one place. And I don't know why I didn't think of it sooner. I would have, I think I probably would have enjoyed golfing more than I did with the other equipment (Audit Trail, patient A, 1st interview transcript, p. 6).

Being tethered. The fourth most described limitation was being tethered to the power base unit. Patients collectively described being tethered at night. Before going to bed, they described unhooking from their batteries and connecting to the power based unit at night so they could sleep more comfortably without the batteries. Yet for most patients, being tethered made them feel limited to a certain degree. Words used to describe the experience of being tethered included “confined”, “limited,” and “you're really in the scope, to the scope of the cords, you know.” The major concern voiced by patients while being tethered was being limited by the 20-30 foot power cable cord, as recounted by one patient:

You have to take out the batteries and disconnect them and then hook up to the wall power for the night so that you can sleep more comfortably. And, of course, once you do that you're tethered and you're limited by the scope of that cord. It's about 25 feet. In my particular home it allows me to get in and out of bed and go to the bathroom and get into my closet. But, midnight snacks are out. You cannot get to the kitchen – at least in my home. Maybe that's a good point, I don't know. But you do feel confined. It's a confining feeling, a confined feeling, when you're on the wall power because your mobility limited (Audit Trail, patient E, 1st interview transcript, p. 3) .

To reduce the confined feeling and enhance mobility, half of the patients talked about switching to the battery packs as soon as they could: “when I'm on battery, I'm quite mobile

when we're out wherever we want to go, really.” Given restrictions and limitations illustrated thus far, most patients recounted that not being able to take a shower was a major limitation to living with an LVAD.

Can't take showers or bath. Patients cannot take a shower for at least 6 months after LVAD implantation to promote healing and prevent infections. After this 6 month period, patients can opt to shower with a shower bag or kit. This kit holds the external components of the LVAD. This shower kit is only available for those patients who have the 2nd generation LVADs, not those who trialing the newer 3rd generation LVADs. For those who have used the shower kit, phrases to describe the showering experience were straightforward and included, “Well, it's a lot easier to shower without this equipment.” One patient described for us the experience of showering with a shower kit:

I did it two different ways. I have a shower kit and you can either do it with batteries or you can do it with the tether. And I've tested both ways and I like showering with the batteries in the shower kit rather than hooked up to the tether because the tether gets in the way in the shower. Actually, it's not, like I say it would be easier to do without the equipment, but it's not that difficult once you get used to it. I've got a routine, you know, my routine changed in the shower (Audit Trail, patient A, 1st interview transcript, p. 2).

Although patients described taking longer time to take a shower, it seemed like it became part of their routine as they adjusted to the LVAD. This routine, however, poses another limitation in many ways – that is, having to have a designated caregiver.

Have to have a caregiver. Before patients are implanted with an LVAD, they must have a designated caregiver and one or more back-up caregivers. Caregivers are spouses, sons,

daughters, or even friends who have accepted the responsibility of caring for the LVAD patient. These designated individuals are instrumental in promoting the health and well-being of LVAD patients as they assist with the patients' recovery and beyond. Roles and responsibilities of LVAD caregivers include assisting patients with their activities of daily living, LVAD system maintenance, even staying with the patient. Two of the biggest caregiving responsibilities recounted by patients in this study is the caregivers taking over the driving and performing daily dressing changes.

Daily dressing changes. To date, daily sterile dressing changes are recommended for all LVAD patients. In many cases, patients are unable to perform dressing changes independently because of the position and insertion site of the driveline (e.g., either right, left or mid-abdominal area, usually above the umbilicus). This experience was described by a patient: "My wife, my caretaker, she takes care of the lifeline dressings and, um, I don't, uh, I don't do that. I can't do it the way it's located. I could do it with a mirror but I'm not sure I could work backwards." In addition, those who perform the dressing changes must don sterile gowns, gloves, mask, and prepare a sterile field with equipment. Patients may have difficulty maintaining a sterile field during dressing changes.

Maintaining the integrity of the patient's driveline, however, was collectively described as an integral role of the caregiver. Phrases used to describe the caregiver performing dressing changes included, "And she handles the bandages," "so she does the sterile dressing changes," and "my wife, she, uh, she changes dressings everyday with it." One patient succinctly provided a visual on how the dressing change was not only performed, but that it only took a few minutes out of the day: "It's easiest for me to lay down in the bed and [caregiver] will bring out all of the pads, the soaps, and different things, and we'll get it all straightened up, and in a matter of less

than 10 minutes, why, we're...I'm back in business.” (Audit Trail, patient I, 2nd interview transcript, p. 9). Most patients' didn't elaborate on the actual process of the dressing changes, but did talk about another limitation that appeared more difficult to accept: not being able to drive.

Caregiver does all the driving. Patients with LVADs are not allowed to drive. Reasons include equipment malfunction, controller failure with required change out, or batteries losing charge and eventual equipment shutdown. In the process, patients may experience a temporary loss of consciousness as blood may not circulate properly through cerebral arteries. Given these possibilities, designated caregivers must drive patients everywhere. For this reason, probably more so than others, LVAD patients must always have a designated driver. Many patients, however, did not like the fact that they were unable to drive. Words and phrases used to describe their feelings included, “terrible,” “you're an imposition on your spouse, caregiver,” “frustrating,” and “it's a great loss of your independence. One particular patient painted a vivid description of his feelings about not being able to drive:

Oh, I don't...like it. I don't like it a bit because I have drove for 50 years or more, and I'd get in the car and go. But I can't do it. And I have a hard time, you know, there's some stuff I'd like to do by myself, but I can't do it because I can't drive, see? You know, sometimes I'd just get in the car and go fishing, and I can't do that now because I can't drive. She drove with me, but I used to do...once in a while go out by myself, see. And I just can't go, you know, to the sporting good store or something like that because I can't drive. (Audit Trail, patient F, 2nd interview transcript, p. 2)

Just like the patients recalled how they integrated the LVAD into their basic activities of daily living (ADLs), the next sub-theme reveals the required instrumental activities of daily living (IADLs) necessary to promote health, well-being, and safety while living with this device.

Adjusting to IADLs with the LVAD. This theme delineates the ongoing adjustment phase in which patients talked about the care and maintenance of the LVAD, or LVAD-specific IADLs. Some of the LVAD-specific IADLs patients talked about were maintaining a daily log of LVAD system readings and performing daily vital signs. Patients are required to document daily readings found on the display of the controller [flow and pressure readings], vital signs (e.g., temperature, blood pressure, pulse), and daily weights. One patient richly described for us this experience shared by others in this inquiry:

First thing up is, what I do, is to start my regimen of taking numbers off of the control unit, that is the...for my daily log, um, which includes four numbers from the controller, what they call the TI flow and the tower, and then the RPM, and [then] take a blood pressure, and while I'm doing the blood pressure, I've got a thermometer in my mouth, and I get my temperature, and then, when I get through those, I check my machine [for the readings and] will get done with all that. I get myself weighed, just pull out a scale and jump on the scale and get my weight, and that completes the log (Audit Trail, patient I, 2nd interview transcript, p. 1).

The other LVAD-specific IADL includes changing batteries. Due to improved battery technology, the longevity of the batteries for LVADs has increased from 2-3 hours to over 17 hours in most cases. Patients, however, must remain vigilant about the status of their battery charge at all times and making sure spare ones are fully charged. Although patient phrases related to changing the batteries were fairly limited to “change the batteries,” one particular patient poignantly described the experience of what it was like caring for the batteries: “Caring for it is just a matter of always being ready with your batteries and knowing how long the

batteries last, and when an orange warning light comes up how much more you've got before the red change light comes on.” (Audit Trail, patient H, 1st interview transcript, p. 1). Another LVAD-specific IADL described by patients was emergency preparedness. Individualized strategies for emergency preparedness were described amongst most patients. They talked about various strategies, such as keeping emergency numbers with them, having instructions on how to change the controller, even carefully watching caregivers' performing dressing changes so they could inform others on how to do it if necessary. Phrases describing emergency preparedness included: “And I keep them close by in case I do have any alerts or something so I can look up. And also, the numbers to call the LVAD unit and so if I have any problems,” and “...you need a flashlight. Make sure you have a flashlight handy. At your bedside to help you through the darkness of an occasional power failure.” (Audit Trail, patient E, 1st interview transcript, p. 4)

Limited sexual activity. Participants' in this inquiry mutually described having very good relationships with one another. For example, patients described relationships with their caregivers as “very good, very good – we are very compatible,” “It's a pretty good relationship,” “I would say it's excellent. Yeah, we're very happy. Very content. We're still in love.” Caregivers' responses mirrored patients' as they talked about their relationships with responses such as, “It's great,” “we have a real good relationship. Yeah, I, he doesn't argue much,” and “I think we have a good relationship. I always thought that we were very, very close, and he was always my best friend.”

With our minds full of vivid and rich descriptions of the experience of living with an LVAD, theme 2 comes to a close as patients continue to live with DT. The next theme of this experiential biography illustrates more reflective responses which further shape our understanding of living with this device.

Theme 3: Adjustments and acceptance come with time.

Theme three (3) represents the culmination of the collective experiences of patients who reflected upon their initial experiences and fast-forwarded their lives as they see it now. Patients recalled that they eventually got used to the LVAD attached to their bodies, including carrying or toting around the extra equipment. Phrases describing this experience included, “But, you know, actually, it’s not as difficult now as it was a year ago,” “you get used to it,” highlighted these experiences. It seemed like patients just got used to not only carrying around the device, but it also became a part of their lives. One patient provided a thick description which for him, was overwhelming at first, but eventually accepted the device as part of life:

Well, when you first go home like, it’s just like any other recovery time. Except that, I’m going to say burden, but it’s not now, but at first the burden of, of this, of this bag attached to you forever, it’s kind of a little overwhelming for a while. But, just like anything, you actually grow out of it, you don’t, well, that’s just the way it is. Just think of people that, uh, have amputees, that’s the way it is. You have to live with whatever they deal you.” (Audit Trail, patient H, 1st interview transcript, p. 5)

As patients reflected upon how they accepted this life-sustaining device as necessary to live, most of the patients’ talked about the length of time it took to actually feel comfortable with the LVAD. The general timeframe for the sample of patients in this study ranged from 7 days (e.g., 1 week) to 365 days (e.g., 1 year) (7, 60, 152, 182, 365, $M = 189.7$, $SD = 127.8$) [Length of time was calculated in days]. It was within these timeframes that patients unanimously described a period of enhanced awareness of physical capabilities and ongoing strength as time went on. For many patients, this period also revealed a return to a normal life known to them. These reflective thoughts were elucidated through the following sub-theme,

Improved quality of life.

Improved quality of life. Patients collectively verbalized that their overall quality of life improved after LVAD implantation. Phrases used to highlight this theme included, “I am going to enjoy, I have a better quality of life,” “You’re able to do things. Um, I don’t know how to describe it really,” and “my quality of life is, is improved substantially. And, uh, I am back.” To help us understand what life was like before and then after receiving the LVAD, patients’ voices collectively painted a vivid picture of their lives what life was like before the LVAD. Improvements in physiological dimension of quality of life included overall well-being and functionality were described by the majority of patients. For example, one patient richly described for us how his overall well-being and functionality improved after the LVAD:

But now I just gradually started getting, you know, my strength back more and walking and I have been feeling pretty good. So, uh, in that case I’m much better than I was before I had it put in, because, um, I mean now I can go to the grocery store pretty much do all the shopping I want to do and even go more besides if I want. If I have to stop at another store to get, or something like that, I can do that too. (Audit Trail, patient B, 1st interview transcript, p. 2)

Another patient described a similar experience of improved functionality after the LVAD:

And I’m getting to do more than I was before I got it, see? I was just [barely able] to go and get up in the car. And I get outside now and walk around awhile and stuff like that, see? I go to my son’s place and walk out in the woods or something, and come back.

And I couldn’t do this before, and that’s part of the good points to it. (Audit Trail, patient F, 2nd interview transcript, p. 3)

Improvements in the psychosocial dimension of quality of life were also described by patients. Whether shopping, socializing, or enjoying fishing in a pontoon boat with their families, patients were once again able to get out and enjoy their lives. One patient illustrated how their social life improved after living with the LVAD:

P1: Well, like I say, I mean especially now that I'm feeling better again, it allows me to go out and do the, you know, do some more things. You know, eat out somewhere, you know I wasn't doing that before I had it put in because I didn't want to go, and I couldn't, it cut down a lot on my socializing because I just, sometimes I'd get too tired to go out, you know, to get together with anybody and I didn't want to ruin anybody else's plans by having to cut, cut everything short because I got too tired or whatever, you know. (Audit Trail, patient B, 1st interview transcript, p. 2).

This experiential biography proceeds while leaving us with memories about how patients' lives improved and how they appeared to reclaim their lives back. Themes presented thus far illustrate patients' emic perspective of living with a DT, and have addressed the research question, "What is the experience of living with an LVAD as DT from patients' perspectives?" The final three (3) themes represent the meaning of living with such a life-sustaining device and answered the research question: "What is the meaning of living with an LVAD as a DT?" 1) *Living outweighs restrictions*, 2) *Hope for life through new technology*; and 3) *Thank the Lord*.

Theme 4: Living outweighs restrictions.

For the majority of patients, limitations imposed by the LVAD were minimal once they realized what the LVAD meant to them - they were living. For many patients, talking about this experience seemed to make them feel alive. The overall consensus was that, yes, the restrictions were limiting, inconvenient, and restrictive, but, it also has enabled them to live. Phrases chosen

to describe the meaning of living despite limitations included: “Yeah, it’s just a miracle. When I, how did it save my life for the better. Not that it doesn’t have its little hang-ups and little inconveniences, but it’s so worth it. That’s all I can say about it, it’s so worth it,” and “I never thought much about it, having [it], it’s just that it helped me, and I wouldn’t be here if wasn’t for the device.”

One particular patient further clarified the meaning of this theme by describing the restrictions of having an LVAD as a negative, and being able to live as a positive:

Uh, it’s got, uh, a positive and a negative, see. I’m glad I got it because I’m still alive. And without it I, you know, I would like to be able to do what I used to do and I can’t, see. And it’s got the positive and a negative. I can’t do what I want to do but I’m glad I got it because I want, I need it to live, see. (Audit Trail, patient F, 1st interview transcript, p. 1).

It was the words of the following two patients that seemed to capture the meaning of having a DT. Here, the first patient describes for us how he “traded” the LVAD for life:

I did a trade off. Uh, you know, uh, to the hospital, I was in four hospitals for 75 days. And, uh, 2 of the hospitals just told me they could not do anything, and, uh, until the last, when (name of hospital) told me there’s nothing they could do because the risks were too high, my cardiologist down there, he says, well, I know who can help you. And he says U of M has an excellent program. So, so I got a bag [LVAD] and I didn’t have to go home and go on hospice. (Audit Trail, patient H, 1st interview transcript, p. 2).

Despite DT being described as ‘cumbersome’ to some degree, this particular patient stressed that LVAD-specific IADLs were not only necessary to live, but also didn’t “bother him anymore”:

Linda: Cumbersome. You mean by?

P: The whole thing. You know, moving equipment around and taking all the data down every day. Having the dressing changed and all that stuff. The whole package I've talked about is cumbersome. Makes me do things that I hadn't done before. But, it's all for the good, for the better. And it's something I decided, if I wanted to stay alive I had to live with this. It doesn't bother me much anymore. (Audit Trail, patient A, 1st interview transcript, p. 3).

Amidst reflections of life with a DT, there appeared a ray of hope that echoed throughout participant stories: hope for life through new technology.

Theme 5: Hope for life through new technology.

This theme illustrates hope of living as new technology becomes available. For many patients, they had already experienced lost hope before the LVAD. This device brought hope where there once was none. It is this sustaining hope that continued to fill the hearts and minds of these patients as they go on with their lives with a DT. For example, phrases used to illustrate this theme included: "I'm hopeful that I can live long enough with what I have to have another, to another, to another technological breakthrough that might offer me other options. Maybe I won't, but I'm not giving up," and "I'm sure it can fail, I imagine, sometime and with technology they got, they'll have something they can replace it with. So, I don't have any, uh, qualms there." Patients appeared excited and looked forward to being future recipients of new technology, as vividly described by two patients:

P1: But, uh, seven to ten years, or whatever the life expectancy of this particular device, I would think by the time I'm ready to change the technology will be so advanced that this will probably be in a pocket and that you just put it in your pocket. So, actually looking

forward to those kind of advances. (Audit Trail, patient H, 1st interview transcript, p. 5)

P2: I got to talk to somebody today about stem cell. That went out over the news last night, about stem cell research on hearts. So, I'm assuming that I will be one of the first candidates...I'm kidding. Um, but boy, I sure as hell would like to try. (Audit Trail, patient I, 1st interview transcript, p. 1).

As hope for continued life through new technology echoed throughout patients' voices, the final theme represents a spiritual gratefulness and gratitude for receiving the LVAD.

Theme 6: Thank the Lord.

While patients reflected on their lives with an LVAD as a DT, "thanking the good Lord" was an overall sentiment expressed. Phrases such as "praise the Lord I have to say now," "it's a Godsend," and "I thank the Lord every morning," were almost joyously exclaimed as patients recounted how grateful they were to have this device. One patient shared a poem that he wrote for his 50th wedding anniversary, titled "Thank you Lord, for This Great Day:

Thank you Lord, for This Great Day.

Thank you for all the good things and times along the way.

Thank you Lord for every friend,

May those friendships never end.

Thank you Lord for daughters and sons,

Thank you for all their little ones,

Thank you Lord for sisters and brothers,

Thank you for fathers and mothers.

A mother who said her boys didn't fight,

But what were they doing out of her sight!

Thank you Lord for the HeartMate Pump,
 It got me up and off my rump!
 Thank you Lord for this great life.
 Thank you for a wonderful wife.
 A wife who seldom got mad.
 Threw a slipper once,
 Thank you Lord, her aim was bad!
 I think this is all I have to say,
 Except thank you, Lord, for this great day! (Figure B15).

As with this patient and others who have expressed their gratitude for the opportunity to have this live-sustaining device, a brief period of silence prefaced by tears of joy, smiles, and soft bouts of laughter seemed to still the space that was once researcher and participant – a space now filled with understanding of how much living with a DT means to these participants. Patients were thanked for their amazing stories and willingness to relive all experiences as interviews came to a close.

Summary

Part one of this existential biography illustrated the essence of living with DT from the voices of those who are living with this life-sustaining device. This summary is complimented with a pictorial summarization illustrating the health and wellness trajectory for patients before and after receiving DT (Figure B16). I now turn to the world of those have watched, experienced, felt, and hoped for those they loved living with DT.

Part II: Caregivers of Patients with LVADs as DT

Part II of this existential biography presents caregivers' experiences and meanings of

caring for someone with a DT. Five (5) main themes and nine (9) sub-themes, were constructed from the data and formed the foundation for an existential biography depicting the essence of living with a DT: 1) *Advanced heart failure is a life changing event*; 2) *Self-doubt about LVAD caregiving improved overtime*; 3) *Lifestyle adjustments come with time*; 4) *Persistent worry and stress*; and 5) *Caregiving is not a burden – it's part of life*. The first four (4) themes illustrate caregivers' perspective of caring for someone with DT, and addressed the research question, "What is the experience of caring for someone with a DT?" Theme 5 addressed the research question, "What is the meaning of caring for someone with a DT?"

The setting of caregivers' interviews mirrored patients' – a quiet, comfortable conference room at the CCs with exchanges of introductions and pleasantries before commencing interviews. I encouraged caregivers to keep their cell phones turned on in case the patients needed them or were called in for their appointments. As caregivers stories unfolded, there appeared to be a more serious tone expressed throughout conversations – a tone I eventually understood as they cared for their loved ones with DT.

Theme 1: Advanced heart failure is a life changing event.

Similar to patients' experiences, caregivers spoke about leading active, full lives with their loved ones before the onset of advanced heart failure. From taking "wonderful vacations and trips," to enjoying personal time, they talked about leading happy, active lives with their loved ones. One particular caregiver richly described a full active life before DT came into play:

Um, what was it like before? I think we lived, um, in that great spot. I think we'd probably been happier than, you know, most of the time you're the kind of people, you get up, you're busy and especially my husband. He got up every day and was busy. Um, went to work, wrote plays, or did his errands, or, spent time with me. And we just lived

quite full active lives. (Audit Trail, caregiver E, 1st interview transcript, p. 2)

It was the onset of heart failure, however, that began the chain of events which changed life for many caregivers. Most of them described periods of difficulty [which spanned nearly a decade] as they managed the “ups and downs” of advanced heart failure. This experience was recalled by a caregiver:

C: “Um, well probably for the past ten years, it hasn’t been, you know, like it should be ‘cause he wasn’t feeling that good,” and... ‘cause this started, like I told you, ten years ago. When we... when we were in the head-on collision, and along came the [LVAD]. But it’s just been steady hospital for the past ten years. From one thing to another. [The accident,] the heart attack, when he had his back surgery. It destroyed his heart. (Audit Trail, caregiver F, 2nd interview transcript, p. 2)

Caregivers gave voice to the immediate period before LVAD implantation and how quickly patients deteriorated as heart failure progressed. Words and phrases used to describe the physical status of their loved ones included “getting weaker,” “getting quite weak,” and “getting really, really weak.” It was during this time that caregivers individually spoke about seeking help for patients, or even taking on all the responsibilities of IADLs because patients were too sick. Some of them even described a reversal of roles as their loved ones continued their downward spiral. For example, some caregivers started doing all the work around the house and took over driving since patients were too weak to do any activities:

Um, but I, but I was doing a lot of the work because he was so sick that he couldn’t do it. We built a house when he was sick, and, um, our kids and I – he’d, and he’s always done that type of work and he couldn’t and that was what was so hard, was that, you know, I ended up stepping in and doing that. So, you know, I was used to doing

things. I had done that. I mean, I went out and shoveled the snow, I did a lot of the stuff.
(Audit Trail, caregiver A, 1st interview transcript, p. 7)

Caregivers feared for their loved one's lives as they continued to search for help. Many of them knew that life was limited for their loved ones and that they needed help. One particular caregiver bravely recounted the precise moment she felt her husband was going to die. Her voice became very low, while hiding back tears. Sniffles preceded almost every word as she looked off into the distance, almost as if she was reliving this experience:

“...what it's like to say goodbye because you know your husband's dying. Its interest, I thought it was interesting because there's not a whole lot you can say to each other. There's only a few things, you know, you just say to each other, it's been a wonderful life and, um, I don't want you to go and, um, um, I don't know, it's not real, definitely not out of the books or magazines, you know. Uh, love story, you know, even though we love each other very much and we have a great relationship, but, you know, sit in a room at the doctor's office and you don't know if that's the last time he's going to be hospitalized. You just hold hands and say it's been wonderful (Audit Trail, caregiver E, 1st interview transcript, p. 3).

It appeared that at this moment, caregivers experienced a feeling of helplessness for their loved ones. Just when all seemed lost, they heard about the LVAD. This theme was further elucidated by the sub-theme, *Hope for life renewed*, as caregivers described a flickering ray of hope for life.

Hope for life renewed. Once caregivers learned about the opportunity for a chance to live, they expressed feelings of hope and determinism for another chance at life. They unanimously recounted the experience of learning about the LVAD and how it provided hope

and the opportunity for life, as described by this participant: “I think it, uh, you always hope that things will, especially with the U of M and all the new things have come out medically. I felt that when they explained this LVAD, that this would be an answer to sustaining his life a little longer.” Amidst feelings for hope for life, caregivers seemed relieved that there was finally help for their loved ones. For example, one caregiver richly describe for us the feeling of hope revived as they learned about the LVAD:

So we're in the hospital room and there's, you know, you don't know what's going to happen. And this one particular doctor came in and, um, started, he was like a, we call him our Angel because he had the best, um, bedside manner. Dr. ----, came in, did the reports, talked about professions, you know, what do you do for a living and so now you've got two equal men talking to each other. And, um, in the conversation the doctor said I think we can go down that road. And I said, 'is there more road to go down?' We didn't know. And, um, he gave us a few more [details about] things and then he said, I think there's more tread on those tires. And, um, and I believe that he's the doctor who said “what about an LVAD.” So, it's like this doctor was so, um, such a [God-send] and, when he said there's more road to go down, (husband) shed a tear in the room and I slept. Because of what that one doctor said. And so we knew there was hope and within about 48 hours he was down here. (Audit Trail, caregiver E, 1st interview transcript, p. 5)

We leave the first theme of caregivers' existential biography with a better understanding of the initial struggles and feelings of hope for life as caregivers embark upon a new, but uncertain journey. Whether their loved ones were transferred or admitted to the hospital for pre-operative testing and eventually surgery, the next themes represent a plethora of mixed emotions

of fear, doubt, and worry, as they come to realize what caregiving for a patient with DT entailed.

Theme 2: Self-doubt about LVAD caregiving improved overtime.

While patients were hospitalized, health care professionals, including nurses, spoke to caregivers about their new roles and responsibilities as DT caregivers. Initial thoughts and feelings brought them back to the memories of watching their loved ones struggle to live. While recalling these experiences, the majority of them “burst into tears”. Words and phrases used to describe these feelings included “scary,” “overwhelming,” and “anxiety-producing.” Feelings of hope transformed into feelings of self-doubt and fear as the realization of making a life-long commitment as designated caregiver became an overwhelming experience: Phrases used to describe self-doubt included, “Could I do it?,” “I can’t handle this,” and “...am I going to be able to do this.” Caregivers poignantly described their experiences when they first learned about their new responsibilities, for example:

Um, you know, we’re going to have to learn how, how to maintain it and everything.

And, um, it was a bit overwhelming. But it was something we knew we had to do and so it really, there were moments that I was really concerned, could I do it? That was kind of scary. In the beginning, scary I’d say it was. (Audit Trail, caregiver D, 1st interview transcript, p. 4).

Caregivers began to learn about caring for the patient and the LVAD system as patients entered the postoperative phase. It was during this time that caregivers spoke about ongoing stresses as they learned to care for their loved ones. One sub theme shed light on how caregivers strove to overcome self-doubt and armed themselves with the knowledge to care for their loved ones.

Learning to care all over again. The majority of caregivers spoke about their LVAD

training experience in the hospital. Care including learning about the LVAD system, such as device maintenance, trouble-shooting and emergency procedures. One of the biggest challenges described by caregivers was learning how to do the sterile dressing changes. Fear, nervousness, even self-doubt were felt by caregivers as they learned how to perform dressing changes. It appeared that they were more 'nervous' in front of health care personnel, as recalled by one caregiver: "I think I was more nervous when we were in the hospital, and we would change the dressing everyday in the hospital with the nurse, you know, watching me." Similarly, other caregivers reported feeling uncomfortable in front of the nursing staff as recounted by another participant: "And, you know, of course they wanted me to do it for training, you know. I just didn't, you know, and maybe it was because people were watching me. Or maybe it's because I'm supposed to perform." One particular caregiver richly described feeling overwhelmed and how the nursing staff promoted and instilled confidence to learn:

Linda: Tell me about the experience of doing the dressing change. What's that like for you?

C: At first it was overwhelming. I didn't think I could do it. I really didn't. I mean, it was, that was, you know, it was scary for me. And probably part of, I never wanted to be a nurse. I, you know, that was not my calling, so I didn't even think I could do it to be perfectly honest. When they first told me I was like "I can't do that" you know. And then they explained to me, like, yes you can. It's like getting a new baby. You know, you learn how to take care of them step by step and then it's just part of the routine. And that's really the way it was. (Audit Trail, caregiver A, 1st interview transcript, p. 9)

Similarly, another caregiver vividly recalled these initial fears which eventually subdued

with time:

And then, ‘oh, you’re here, okay good, well, you know, we’re going to have you trained here and we’ll do that tomorrow.’ And of course, that is anxiety producing because you’re being trained on something that’s brand new and in the medic – when you’re not a medical person it’s not only very new, it’s terrifying, life and death at that point. Now it’s quite simple and you wonder what you were up tight about. But, and then, being trained to do the drive line dressing. I remember clearly having this desire to run.

Thinking in my mind, um, how if you didn’t like your husband, this would be one heck of a time to go. And again, because it’s given to you very intensely, you know, all sterile and you’re being trained very specifically. And you’re just thinking, am I going to be able to do this. Um, and of course, it’s a very simple thing to do now, but at the moment it’s quite frightening. (Audit Trail, caregiver E, 1st interview transcript, p. 6)

As patients recovered and LVAD training in the hospital was complete, it was time to go home. Discharge home signals the close of the 2nd theme and precedes the transition home for caregivers and patients. It was during this transition and beyond that caregivers met face to face with their new roles, responsibilities, and lifestyle modifications required to care for someone with a DT.

Theme 3: Lifestyle adjustments come with time.

This theme marked the transition and initial phase of adjustment for caregivers as they managed their new roles and responsibilities. It was during this phase that they described a plethora of responsibilities and lifestyle modifications necessary to care for a patient with DT. This theme was further explained by seven (7) sub-themes: 1) *A reversal of roles*, 3) *Personal interests on hold*; 3) *Keeping it normal*; 4) *Doing all the driving*; 5) *Dressing changes*; 6)

Increasing independence after LVAD, and 7) Move forward.

A reversal of roles. The majority of patients required a lot of assistance when they first came home and throughout recovery and rehabilitation. Roles and responsibilities of caregivers included performing ADLs such as bathing and dressing. Since patients are unable to take a shower or bath, most caregivers described having to bathe the patient when they first came home and to date. Some of them said they had to dress the patient in the beginning, as described by two caregivers: “It took us two hours to get him dressed in the morning, and I was, you know, helping him and, you know, he was confused at times putting his clothing on. And, you know, do I got suspenders first, or am I going to put it underneath or over,” and “Pretty much it was helping him with dressing and that, in the beginning, at the very beginning. Caregivers also individually described performing many of the IADLs, such as household chores, cooking, cleaning, running errands, paying bills while their loved ones recuperated. Words and phrases used to describe that caregivers performed many if not all of the duties included at the very “everything,” “I did everything,” and “I would do everything at home, everything that (name) used to do.” One caregiver richly described the experience of role reversal as her husband recuperated:

Linda: What are some of the other things that you had to take on?

C: Well, at first, when he first came home from the hospital, um, everything.

Everything, you know. You pack the bags *and* you load the bags in the car. And you, you do everything at first. And you drive. Our life was I pack my bags, he threw them in the car and he drove. And that, so, you know, that maybe typical male/female relationship, um, changes a little bit. (Audit Trail, caregiver E, 1st interview transcript, p. 8)

Other activities included performing LVAD-specific IADLs, such as daily monitoring and maintenance, performing vital signs, changing batteries, even describing emergency procedures they had in place.

Seeing these patients in a state of dependency sparked many feelings and concerns amongst caregivers, especially younger caregivers. In some cases, it was necessary to make some personal lifestyle modifications in order to care for the LVAD patient.

Self-interests on hold. Generally, most caregivers spoke about giving up some hobbies or personal activities while caring for the LVAD patient. It appeared, however, that some of the younger caregivers feared that their life was going to completely change. Younger caregivers' (e.g., 50, 61, 62) thoughts of losing their freedom were replaced with thoughts of being stuck in the house caring for their loved ones. One caregiver specifically described being scared that she would never be able to get out of the house. As she talked to me about this experience, she started to tremble – she looked at me with tears in her eyes, face flushed red, and sat very, very still. She looked at me with her eyes wide open, barely blinking:

I mean, I still was scared about him coming home, and what it was going to mean.

Was I ever going to be able to get out of the house, you know, just to leave...like, I would like to work out everyday, and I thought, “Am I not ever going to be able to do that again?” You know, is my whole life going to change totally? So, scary. (Audit Trail, caregiver I, 1st interview transcript, p. 1).

Another caregiver described a similar experience of not having as much free time anymore:

I'm not resentful, um, it can get tiring, um, play, I wish I had more opportunities to go laugh and play. I can remember the times where, um, you know, after the intensity of it

all, and just going someplace for three hours and maybe, and realizing, oh my God, I just had fun. You know, I just laughed because you get so wrapped up with it all. (Audit Trail, caregiver E, 1st interview transcript, p. 9)

Amidst adjusting to these lifestyle modifications, another role articulated by caregivers was striving to maintain a normal life as possible for patients.

Keeping it normal. In this theme, caregivers unanimously described how they tried to maintain normalcy for patients living with an LVAD. Strategies to promote and maintain normalcy included things like talking with patients, helping them with projects, maintaining the home environment, and enhancing personal interests. It seemed that caregivers were always ‘doing’ and ‘trying’ to help the patient live a normal life. One participant, for example, described how she and her family modified the patient’s environment so he could continue to fish and hunt:

So, he likes to fish and he likes to hunt. We had a boat that we, he was not safe in because he, if he was to fall into the water it would kill him. So, as a family, um, we talked it over, we got a pontoon and when he goes out we go with him. We watch him carefully. It has rails. He wants to hunt. My son has now built him a blind with a heater and a couple windows in it. And it’s like a treehouse with steps up it. So basically, with his type of personality, uh, he never, we, we get obstacles but we try to find a way of going around those obstacles. Uh, and not altering his life completely to a nothing.

(Audit Trail, caregiver F, 1st interview transcript, p. 1)

Caregivers continued to talk about promoting normalcy even against the recommended protocol for living with an LVAD—particularly, driving. Even though patients are allowed to drive with an LVAD, one caregiver similarly stressed how it important it was to promote

normalcy by maintaining regular activities for the patient:

You know, some of the precautions they have on the meds, don't drive, he doesn't drive but if I think he's okay to, I let him. Because that's one thing he's used to doing every day. Can't take everything away. If he feels like driving and he's not a hindrance to anybody or if he, he'll let me know if he can't do it anymore, you know, if he can't drive, or if he's tired. (Audit Trail, caregiver H, 1st interview transcript, p. 2).

Despite going against some of the recommended restrictions, caregivers strove to adhere to the required protocols – including driving. As caregivers continued to describe their experiences, having to do all the driving was another challenge which surfaced amongst conversations. Theme 3 is further elucidated by this change in roles and responsibilities.

Doing all the driving. As caregivers spoke about having to take over the driving, four (4) caregivers didn't mind doing all the driving. Several phrases from caregivers illustrated that taking over driving was not a problem for them, for example: “I don't mind traffic. Traffic is like the weather, you can't do a dang thing about it so there's no sense in whining or complaining about it. It's not going to change just for you. At least I get out and see things,” and “Me doing the driving? I love driving.” The rest of the caregivers, however, felt that having to drive was one of the biggest lifestyle modifications imposed by the LVAD. This experience was richly described by one caregiver:

Well, I think one of the big things, and probably one of the more difficult things for both him and me, is the driving. You know, he had to give up driving and I had to take it over. And that, that has been, that was probably the difficult thing because he still wants to drive, and I say, you know, well he drives but he just doesn't have the wheel in his hand. (Audit Trail, caregiver A, 1st interview transcript, p. 4).

Given the restrictions imposed by living with a DT, caregivers strove to maintain as much of a normal life as possible for these patients. It was still necessary to incorporate LVAD-specific IADLS care into their daily routines. This included performing daily sterile dressing changes.

Daily dressing changes. Caregivers unanimously stated that they performed the sterile dressing changes. Whether it was done after breakfast or before they went to bed, they described changing the dressing every day. For most caregivers, it seemed that they were comfortable performing dressing changes once they got home. Caregiver phrases to describe this experience included, "...the dressing part of it and, you know, that wasn't, that wasn't really bad," "The first week when we were home, it went very well, I would say," and "I'm very comfortable with it. I was very comfortable when I come home." Two caregivers specifically described for us what it was like when they first came home: (C1) "So then by the time I got home, I had quite a bit of experience doing it everyday. I had done it a couple weeks in the hospital and three weeks in the rehab, so I had, like, five weeks under my belt by then," and (C2) "Well, he was in there a month, so I changed it quite often in that month, in the room."

Feeling comfortable with dressing changes, however, was initially very anxiety-provoking for many caregivers. Words like "overwhelming," "scary," and "terrifying" echoed throughout initial experiences. Despite these feelings, caregivers eventually acclimated to the daily dressing changes. Phrases used to describe this adjustment included "dressing changes are part of life," and "...it's just part of the routine." Two phrases extracted from caregiver transcripts illustrate how they assimilated dressing changes into their daily lives: (C1) "But it seems so routine that we just, um, he wakes up in the morning and we immediately, before he even gets out of bed, we do, um, the sterile dressing," and (C2) "But, um, now it's, you know,

it's just like brushing my teeth, you know? We get ready for bed, I brush my teeth, I go in and I take care of his dressing. And that's it. It's just part of my life. It's just the way it is. It's not a big deal.” (Audit Trail, caregiver A, 1st interview transcript, p. 3).

It appeared that as caregivers adjusted to daily dressing changes, it took less time to set up and perform them. At first, times for dressing changes ranged from 25-45 minutes (25, 30, 35, 45; $M = 33.8$, $SD = 8.5$). As caregivers became more comfortable and confident with dressing changes, it took less time. Time reported by caregivers ranged from 5-17 minutes (5, 13, 15, 15, 17, $M = 13$, $SD = 4.7$). One caregiver richly and succinctly articulated the process of setting up the sterile field, including the initial and current time to perform the dressing changes:

Um, it took me, I would say a half hour at first, because I didn't... I'd have to stop and think, okay, I need to put the gown on, I need to put the cap on, I have to get two masks, one for him, one for me. And now, I have it all set up in our bedroom, where I have a little drawer where I have the gown, the next drawer I get the towel, the next drawer I get the face mask, and up on the top, I have all the gauzes lined up, and the gloves. Sterile gloves and the exam gloves. I got [bandages] that they're right near the bed, along with the solutions, the saline and the wash solutions. So...and the tape. I use both surgical tape and the paper tape, because he is allergic to the surgical tape. I don't feel I need the surgical tape, but he likes it covering the other tape, makes it feel a little more secure somehow. So now, I'm down to about 15 minutes. So I went from like a half hour to 15 minutes (Audit Trail, caregiver F, 2nd interview transcript, p. 3).

Caregivers also described feeling more comfortable with their new roles and responsibilities as time went on. Although times varied widely, comfort level ranged from 7 to 180 days (7, 67, 7, 30, 180, $M = 58$, $SD = 72.4$) after discharge from the hospital. It was during

this time that they noted that as patients started feeling better, they began to take over some of their own care. The next two sub-themes illustrate the final adjustment phase of both patients' and caregivers'.

Increasing independence after LVAD. Most caregivers described patients' reclaiming some of their own roles and responsibilities, including ADLs and LVAD-specific IADLs. Patients prepared their own meals, performed LVAD-specific IADLs, and even helped out caregivers. The following two phrases selected from participant voices illustrated how roles reversed after patients started feeling better: "I mean, actually he took over some of the stuff that I had been doing because he was feeling better," and "But it's been a few months now so he's really taken over, you know, doing whatever he can do, he does." One caregiver specifically described for us how her husband helped her after having the LVAD and became more independent as time went on:

Well, he's, um, basically trying to help me all the time. But, um, he's trying to do more and more for himself so I don't have that much to do. The main thing I do is change his dressing, his driveline every day, every morning. And, uh, wash his back when he gets, you know, uh, that's the only thing he can't do is his back and right after we do the driveline we do the bathing, you know, and he's to the point where he can do all of that for himself. So, mostly all I do is set him up and get him ready for the driveline. If it wasn't where it is, he'd probably do it himself. (Audit Trail, caregiver H, 1st interview transcript, p. 1)

As these patients became independent and started doing more things, it appeared that caregivers understood that it was necessary to keep going despite restrictions. The next sub-theme illustrates retrospective reflections of moving forward despite restrictions imposed by DT.

Move forward. While reflecting upon their experiences, it seemed as if caregivers just adjusted their lives to DT and continued to enjoy their lives despite restrictions. Several caregivers poignantly elaborated on their feelings as illustrated in the two exemplars below:

And, so, you know, I mean, every time there's a little bit, um, more progress where we can do more and more, uh, we're happy about it. Like, if there's a will, there's a way. For him, he's very much like, well, let's try to do this. Let's try to go if we can. So we do whatever we can do, um. He doesn't like to just sit around. (Audit Trail, caregiver F, 1st interview transcript, p. 5).

The other caregiver specifically and vividly illustrated that no matter what happens in life, you just adjust and 'must move on':

That's part of life, it's still moving on. So we have restrictions, it's okay. We still can find a way to enjoy ourselves. Neither one of us give up. That's the way we have run our lives and we encourage our grandkids, if you get hurt and that is one of the reasons that I think he's still on this earth, he is showing these people that you just can't give up. No matter what. If you sit and cry and whine about what's going on, you'll never move forward in your life at all. Never. You [wont]. This happened to me. And irregardless of what goes on in your life, you need to move forward and look forward, not back. (Audit Trail, caregiver F, 1st interview transcript, p. 10).

We close theme 3 with a growing understanding of how caregivers modified their lifestyle and adopted roles and responsibilities to promote and maintain health and well-being among patients with DT. Despite these roles, concerns about patient health, safety, and personal well-being were at the forefront of caregiving roles and responsibilities and continued to endure to this day.

Theme 4: Persistent worry and stress.

Theme 4 represents the culmination of worry and stress experienced by caregivers from the outset of advanced heart failure to living with a DT. Being a caregiver for DT marked the beginning of a life filled with persistent worry and stress across all caregivers. Words which predominantly echoed throughout caregivers' stories included "worry," and "stress." Caregivers' descriptions of worry and stress ranged from coming home early from social gatherings, to worrying about patient getting sick again. Phrases used to specifically illustrate this phenomenon are described by several caregivers as they go on with their lives:

Even when I go away, whether it's my friends or go away, I cut it short to get back to check on him because it's always underlying what if he can't get to the phone," and "But, you know, I keep an eye just to make sure that he's not getting too tired or something like that. And I'll tell him once in a while, time to quit."

Other caregivers recounted an ongoing concern of not getting "too comfortable" with patients' progress for fear of relapse. This was richly described by one caregiver, as she almost spoke very slowly and deliberately about this experience while wiping her eyes with a tissue:

I hover, I watch out for him, I take care of him, I think about him every minute.

And it's only been 9 months and I can go away from him and realize that I haven't thought him for the last hour. I'm worried about him unconsciously. And, uh, you worry about them. You think about him. You're, your life, you base, your life is based around him. And I go back to that thing, you know, there will be times when I'm gone away from him and he's off doing his thing and I'm doing mine and I realize I haven't worried about him for the last three hours. But then, you start to worry that the shoe is going to drop. Just that little anxiety, like, I don't want to get

too comfortable here because, you know. I think that's that destination thing. Um.

Linda: When you say you don't want to get too comfortable?

C: Well, because he's still a sick man and you just want to be in reality. Um, it can get bad again. (Audit Trail, caregiver E, 1st interview transcript, p. 1)

Similarly, another caregiver richly described her experience of persistent worry:

You're always, I believe you're always on edge, because this is something that is, you know. He is a medical patient. He is a cardiac cripple, really. Actually, a cardiac cripple because I, anything could happen at any time, and I think that, that part I didn't mention, you're always on edge. (Audit Trail, caregiver F, 2nd interview transcript, p. 11).

Worry continued to surface in caregivers' descriptions as they expressed feeling stressed over patients not being careful, even feeling invincible after they received the LVAD. This was described as very stressful experience. It seemed like caregivers had to always remain vigilant to patients' whereabouts and activities at all times. This experience was vividly recounted by one caregiver as she wiped away her tears during our conversation:

And there's still some things he's very, very uncautious about some things. So I have to remind him he's wearing this because he forgets he has it sometimes, you know. And, um, I look out for him...and sometimes he's not careful and I'm the one that watches, that's where I get, be careful (husband), you know. Don't lean by the stove. Things that he doesn't – he was reaching up over the stove and the burner was on, and I said, 'oh, you can't do that, you know'. You just have to figure out things, when you get to the sink make sure you're faucets are all that spray thing, um, it stuck and was spraying everywhere. Well it could have got the LVAD. Things like that, you've just got to be very careful what you're doing. It's stress. (Audit Trail, caregiver F, 1st

interview transcript, p.3)

One caregiver captured the collective feeling of worry and stress coupled with fear for patient's health:

C: Well, um, I don't want it, I don't want to see him – I mean I guess I don't know for sure how much his heart can take. Even though he has the pump, he's not Superman. And he is, you know, he's 75 years old and he still sometimes thinks he's a lot younger and he can do a lot more, and he can't. And I don't want him to overdo and then have to pay for it. That's why I worry.

Linda: What do you mean by having to pay for it?

C: Well, then maybe he'll do harm to his heart, or maybe, you know, then he has (unclear), then he is very tired, you know. And then the rest and, you know. But, I think, sometimes I think he forgets he has the LVAD and he just tries to live life like he did before. And probably I worry more about that than he does. (Audit Trail, caregiver A, 1st interview transcript, p. 1).

It appeared, however, that one of the most stressful feelings for caregivers was making sure that the LVAD system was always working. Caregivers knew that this device was saving their loved one's life so they were always checking battery status and the LVAD system itself. One caregiver described this experience for us: “Um, and I'm always keep looking over at them to see if there's any orange lights showing up in the (unclear). If it is, I go like this [caregiver nudging patients' arm]. And then he'll get up and change it or I'll go and get him a new battery or something.” (Audit Trail, caregiver H, 1st interview transcript, p. 5).

From looking over the patients' shoulder to personally making sure batteries were charged, a pervasive fear for the patients' life seemed to overcome every thought and action for

some caregivers. One caregiver vividly described her experience for us:

[Patient hooks up to power base unit at night] And sometimes he hasn't hooked it quite right. And, uh, called the alarm and he don't hear it. So he can never be left alone, um, at all. Um, and that's my biggest stressful thing. Him sitting in a chair and falling asleep and I'm not paying attention. Um, you know, and doing things in the yard and that turns yellow. I'm always afraid that the battery has been yellow for a while and he hasn't heard it. So I pretty well stay pretty close to him at all times. I think the stressful part is if I was to get sick or something. You know, not being [there] (Audit Trail, caregiver F, 1st interview transcript, p. 4).

It was readily apparent through caregivers' voices that persistent stress and worry prevailed in the heart and minds of these caregivers. One particular caregiver summed up the pervasive worry and stress experienced by caregivers – a feeling that seemed to capture the collective experiences, whether articulated, thought, or even felt:

So there's always worries and stress. But life is always worry and stress, so. Taking care of an LVAD patient is like life – a lot of worry and stress. It's like the weather, it's not going to change. It's like traffic—it's not going to change. They're not going to make special rules just for you. (Audit Trail, caregiver B, 1st interview transcript, p. 6).

This section of caregivers' existential biography marks the end of the experiences of caregiving for patients with DT. We turn to the final theme which illuminates the meaning, or essence of the experience of caring for a patient with a DT. This theme addressed the research question, "What is the meaning of caring for a patient with DT?"

Theme 5: Caregiving is not a burden – it's part of life.

In this final theme, caregivers unanimously described that caregiving is not a burden but

part of life. Reflections on caregiving for patients with DT included what the caregiving experience meant for these participants. Descriptions illustrating this theme ranged from ‘I’m just a son taking care of his father....but I’m just helping him. This isn’t anything about me, [its] about them,’ to “You know, you have a spouse, you take care of them, you do their laundry or whatever. You know, you just do those things and that’s all part of being married. Same like he does things for me, you know.” Although caregivers did describe that the overall caregiving experience can be overwhelming, they considered caregiving as part of life. Phrases used to describe this experience included, “I wouldn’t have it any other way,” “I certainly would do it all over again because we do have each other, and we do, you know, there are things that we do together still, and I love him. So, it’s worth it for sure,” and “I think, basically they’re just so grateful to see their husbands feeling better and being able to do things that, you know, it’s worth whatever extra effort you have to do just to see them thriving.” Several caregivers provided emotionally-provoking experiences, but one caregiver succinctly captured the essence of caregiving as a way of life:

I don’t see it as a big burden or anything like that. It’s just the way life is and you, you take what, you know, what is handed to you and you just deal with it, you know.

And I don’t anticipate any, I don’t know, I don’t anticipate any big hurdles, but if there are, we’ll face them, tackle them. You know, that’s the way I look at it.

(Audit Trail, caregiver A, 2nd interview transcript, p. 3)

Ending conversations with caregivers seemed to be a purging event as they collectively thanked me for listening to their stories. As with this caregiver and others in this inquiry, I thanked them for taking me along the road of emotions, trials and tribulations as they adjusted their lives to caring for someone with a DT.

Summary

Part two of this existential biography has illustrated the essence of living with DT from the voices of those caring for someone living with this life-sustaining device. This section is complemented with a figure illustrating that while adjustments took time, caregiving is not a burden despite pervasive worry and stress (Figure B17). I now turn to the shared meanings of participants' in this inquiry as the finale to the inside perspective of living with an LVAD as a DT.

Dyadic Reflections

The final part of this existential biography sheds light on the dyadic perspective of patients and caregivers, specifically, dyadic congruency (e.g., consistency in perspectives). Consistency in perspective was found in five (5) themes illustrating the essence of living with a DT: 1) *Good family support*; 2) *Good interpersonal relationships*; 3) *Destiny is you die*; 4) *Uncertain future*; and 5) *Given more time*.

Theme 1: Good family support.

The importance of having a supportive family was an integral component of recovery and rehabilitation. From learning about LVAD care, dressing changes and emergency procedures, to just being there, participants spoke about the importance of good family support and what it meant to them. Caregivers' experiences included family providing support from dog sitting to staying with the patient if they had to go out and run some errands, for example:

And my daughter and son-in-law, I mean, if we said would you, I mean they'd drop everything and do it. And our daughter has, a couple of times when we found out that we needed to go down to Ann Arbor and back in the same day, I mean she's taken off work and done it. She just, we don't even ask her, she says I'm going with you, you

know. So they're there for us, they're very supportive. (Audit Trail, caregiver E, 1st interview transcript, p. 5)

Similarly, patients collectively described the importance of good family support. Phrases used to illustrate patients' beliefs included: "Family. That's what's left. The family is [important], and what they do and what I do, we all just do it together. And, we're all family....my granddaughters, and my daughters, and my great-grandkids, they're looking out for me all the time."

One patient described for us how his other son learned to care for the driveline and help out as much as he can:

My other son, a while back he learned how to change my drive line too. He took vacation time and he learned how to do that so there's times that he does it. Sometimes he'll stop after work and a lot of times he does it on the weekends. So that helps give (name of son) a break too. And there's been times he's brought me up here for appointments. (Audit Trail, patient B, 1st interview transcript, p. 7).

Theme 2: Good interpersonal relationships.

Participants' in this inquiry mutually described having very good relationships with one another. For example, patients described relationships with their caregivers as "very good, very good – we are very compatible," "It's a pretty good relationship," "I would say it's excellent. Yeah, we're very happy. Very content. We're still in love." Caregivers' responses mirrored patients' as they talked about their relationships with responses such as, "It's great," "we have a real good relationship. Yeah, I, he doesn't argue much," and "I think we have a good relationship. I always thought that we were very, very close, and he was always my best friend." Family support and good interpersonal relationships are not only important for assisting

participants with ADLs and LVAD-specific IADLs, but for also ongoing support given the last therapeutic option available for patients.

Theme 3: Destiny is you die.

The reason why patients had a DT was known to the majority of participants: this was the last therapy available to them. Patient responses mirrored caregivers as they spoke about the phrase *DT*, and what it meant to them. When patients were asked if they every heard the phrase *DT*, three (3) out of seven (7) patients heard the phrase. Of those that never heard the phrase, responses included, “Oh, I don’t like that phrase,” “I’m not sure what that means,” “destination....that sounds.....ooooo....I don’t like that.” Patients who heard the phrase described that it meant, “till the end,” “destiny is you die,” and “I’m going to have it until the end.” One patient richly described his understanding of the phrase *DT* by talking about death and accepting *DT*: “Uh, in my mind, I accept it as, well, that’s no more than your destiny. That’s, uh, you’ll be on it until they change it or until you contract some other kind of, of problem, or until the end of your life.”

When caregivers were asked if they ever heard the phrase *DT*, four (4) of them never heard the phrase, while the other three (3) did. When I asked them about what the phrase meant to them, about half didn’t like the phrase and wished it meant something more positive. In the wake of these end of life reflections, it appeared that many patients had already reflected upon their own mortality. In the beginning of this existential biography, patients already talked about a close encounter with death. Some even described making funeral arrangements, or donating their body to science. Phrases illustrating acceptance of death included, “But if, you know, something else happens, it happens. That’s destiny too,” and “I don’t have any problems, I’m in a destination mode. I was in, I’m already in a destination, everybody’s in a destination mode.

We're all going to die someday, right?" These end of life decisions, including the following rich descriptions, suggested that patients have not only thought about death, but have accepted it:

Well, I kind of look at it that, uh, I'm 71 years old. I've lived a good life. And if I died tomorrow, God doesn't owe me anything. I've had a good life and so it wouldn't, I can't say it wouldn't bother me if I died, but it, uh, it's not, it doesn't scare me, you know. I'm content with where I am. (Audit Trail, patient D, 1st interview transcript, p. 10).

Caregivers' also knew that DT was the last option available for patients. Phrases used to describe this understanding included: "Because there's nothing more beyond the LVAD. He doesn't get a new heart after," and "It means that he's not going to get a transplant, and till destinate, till the end of his life." What was not known, however, is the how much more time they had with this mechanical device. Although participants' acknowledged that death is inevitable, they also described their feelings towards not knowing what the future holds. It was the uncertainty of the future, specifically related to how or the way patients were going to die that seemed to concern both patients and their caregivers.

Theme 4: Uncertain future.

Patients and caregivers shared the same feelings about an uncertain future. It seemed that most patients, although accepted death, didn't want to think about how they were going to die. The following phrases vividly recount patients' feelings of not wanting to know, or even not thinking about how they are going to die: "I don't think about what would happen if the pump would stop," and "how much longer have I got? I really don't know. I'm just going to take it one year at a time, not day, not day by day... I go by years. They go by too fast, though," and "if there's a time will come when I can't have it replaced again or something like that, I don't

know. I don't really think about that, so, um, until just now when I bring it up.”

One particular patient described what seemed to be the collective thoughts about the end of life:

If things start to shut down, is it going to be shutting down similar to what...will I be feeling something similar to what happens when the hemoglobin slows down? Or starts acting up? What's coming up for me? I don't know what to look for. Will I see it...will I notice anything? I guess I would. But I don't know...is it heart, is it blood, is it machine? What is it? So, I don't know if anybody can tell me that. I really don't. I don't think anybody can really forecast that to any degree of accuracy. It probably just depends on how well I continue to do the things I'm supposed to be doing. (Audit Trail, patient I, 1st interview transcript, p. 5).

Similarly, caregivers described an uncertain future for their loved ones. Some talked about not knowing “how long this would last, we don't know anything.” Others described the uncertainty surrounding devices still in clinical trials:

...we don't know how much, you know. He thinks probably 5 years, but I'm not sure.

Um, I support this new device, I don't know what the long term is. I don't know if anyone does. That's why I think it's important he's in a study to let other people know and that he's got longer to live. (Audit Trail, caregiver H, 1st interview transcript, p. 8).

Some caregivers reported a lack of information about how an LVAD patient dies. One particular caregiver captured the general uncertainties surrounding death with an LVAD. She also richly described her feelings about the lack of information provided about how an LVAD patient dies:

And now, you know, ‘go live, go live your life, go be happy, go live your life’ [patient

talking like health care providers at implant hospital]. And then that's the information you have. Then, I've had my mind, um, well like how does a person with an LVAD die? How's he going to die? Um, is it, I'll leave it at that. I don't have information on how he's going to die. Um, or what are the signs of things getting worse. (Audit Trail, caregiver E, 1st interview transcript, p. 11).

As both patients and caregivers reflected about an uncertain future, they were also grateful for another chance at life. The following sub-theme further elucidates the dyadic meaning of having another opportunity to live.

Theme 5: Given more time.

As participants recounted snap shots of life before the LVAD, both patients and caregivers alike described their gratefulness and gratitude for being given more time to live. Patients collectively agreed that if it wasn't for the LVAD, they wouldn't be alive right now. Patients in this inquiry viewed having a DT as chance to live. Patient phrases used to describe this theme included, "I'm still here," "I might not have been there if I wouldn't had it put in," and "And I talk it over with people now and they say, I mean, what is that [LVAD done for me] ...is that I'm still around. I probably would have been gone by now if it wasn't for this." One patient vividly expressed for that that being given more time is "a positive": "You know, just the fact that, that this thing could keep me going for another five, six or more years. That's a positive. Because if those doctors had been right, I'd have been dead anyways. I could have been dead now." Another patient pointed out that having DT is "an opportunity to live longer":

At 73, um, with the attitude I have and the lifestyle I have, it works for me, so, uh, I have no, have no, uh, no thoughts of I did it wrong. I don't have any of that. I, uh, I see it as a, it's an opportunity. Opportunity to live longer. If, uh, I've already, already outlived

what those first two hospitals gave me. So, I'm, uh, money in the bank so far. (patient 008, 1st interview transcript, p. 8).

This same patient poignantly stressed that just because you receive an LVAD doesn't mean that your life is over – it's just begun, “If someone says that they can't live with it, they're sadly mistaken. And, uh, they, uh, they need somebody to, uh, to talk to, that's for sure, because it's not a life stopper, it's a life giver, so, uh, that's, you know, that's, that's the way I feel about it.” (Audit Trail, patient H, 2nd interview transcript, p. 8).

Similarly, caregivers described patients being given another opportunity to live. Phrases used to explicated this experience included, “gift of life,” “new lease on life,” and “I'm going to have him longer.” Several caregivers provided rich descriptions about what it meant to have their loved ones live longer, for example: “It means everything. I mean, he wouldn't, I know he wouldn't be here today. We would not have the life we have today without it. It means everything to me. So, I'm very, very grateful.” Likewise, another caregiver vividly described being given the chance to enjoy life once again through the miracle of birth:

And we have one with the great-grandbaby, and you can see the joy in his face with her on his lap. This is after he had his...well, she was born on the 25th and he had it [LVAD] on the 29th, but you know, this is part of the joy of extending your life with his LVAD. That is one of the assets of having this and being alive, is being able to share that, you know? It is, it's just a miracle. It's coming up on a year, and we're so very, very fortunate to have him. (Audit Trail, caregiver F, 2nd interview transcript, p. 16).

Participants' voices are dimmed for now as this existential biography comes to a close. A close marked by the limited number of pages and an attempt by the researcher to capture the essence of living with DT. For these participants, DT is not only a device used to provide relief

from symptoms and extend life a little longer— but a device which has filled the hearts and minds with hope and life despite limitations and uncertainties.

Summary

Chapter 4 presented the findings of a hermeneutic phenomenologic inquiry aimed at uncovering and understanding the essence of living with DT from patients' and caregivers' perspectives. An existential biography illustrated participants' lives as patients, caregivers, and dyads, to illuminate a better understanding of the experience of living with such a life-sustaining device. Chapter 5, *Discussion of Findings*, presents an overall interpretation of the findings and concludes with implications for future studies.

CHAPTER 5

DISCUSSION OF FINDINGS

Chapter five discusses the findings of a hermeneutic-phenomenological inquiry which uncovered patients' and caregivers' inside perspective of living with an LVAD as DT. I chose this method of inquiry as a way to shed light on participants' experience from this life-sustaining device. Using this approach has uncovered the existential experience and meaning of living with an LVAD as DT—a perspective mostly heard from those waiting for a donor heart.

Roy's Adaptation Model ([RAM] Roy 1991; 1999), was used as the guiding framework through which the discussions of the findings are described. This conceptual model was chosen to frame the discussion because of the way participants' lifestyle adjustments mirrored the adaptive processes described in this model. Themes are discussed relative to the extant knowledge and emerging research. Weaving constructed themes and the extant literature through the major assumptions and concepts of the RAM will illustrate a clearer understanding of the DT experience. van Manen (1990) concurs, positing that discussion of the findings leads to a better understanding of the lived experience.

This chapter is divided into three sections. It begins with a discussion of findings framed within the RAM, is followed by the strengths and limitations, and concludes with implications for nursing practice and directions for future research.

Roy's Adaptation Model: Theoretical Assumptions

According to Roy (1991; 1999) persons are viewed as bio-psycho-social beings continuously interacting with an ever-changing environment. These persons have the capability to adjust to changes in this dynamic environment in order to promote and maintain survival, health, well-being and quality of life. Health and illness are inevitable dimensions within

dynamic environments. In order to respond positively to health and illness across the life-span, one must adapt. In order to respond to this dynamic environment, one must adapt. Roy posits that adaptation occurs when there is a positive response to environmental changes, and that persons possess both inherent and acquired mechanism to adapt. One's adaptation, however, is a direct outcome of internal and external stimulus exposed to environmental influences and the adaptation level of the individual. Roy describes three components of environmental stimuli: 1) Focal stimuli 2) Contextual, and 3) Residual. For the purposes of this inquiry, focal and contextual stimuli are discussed.

Focal stimuli.

Focal stimuli are described as internal and external factors predominantly faced by individuals. In this inquiry, the focal stimuli for participants reflects two different phases in their lives: 1) Life changes with advanced heart failure, and 2) Initial encounters with the LVAD as a DT. Lastly, an internal focal stimuli manifested by persistent stress and worry as described from caregivers' perspectives.

Life changes with advanced heart failure. The first theme in this inquiry, *Life begins to change with heart failure*, characterizes the external stimulus as the progressive symptoms of advanced heart failure overcame patients' lives. It was during this time that patients' in this inquiry and others (Casida, Marcuccilli, & Peters, 2011) revealed the experience of profound breathlessness and physical limitations imposed by the end-stages of advanced heart failure (inevitable illness). Patients in this inquiry, however, provided thick, rich descriptions of this experience as they reflected upon their initial experiences. These rich descriptions are an integral component of ensuring methodological rigor, and can facilitate trustworthiness of the data through transferability.

Patients' sentiments reflected the internal stimuli as they described their experiences with end-stage heart failure. The sub-themes, *On death's door*, *Hope for life through the LVAD*, and *Determined to live*, characterized an internal stimulus as patients' isolated personal feelings about their own mortality, yet expressed a determinism and a hope for life as they sought treatment for their progressive symptoms. It was during this time that caregivers' of patients with advanced heart failure began to experience and feel the changes associated with this progressive syndrome.

In the first theme, *Advanced heart failure is a life-changing event*, caregivers described the experience of a life-changing event as the patients progressed towards end-stage heart failure. Caregivers' external stimulus at this time was characterized by watching their loved ones struggle with marked shortness of breath and profound reductions in functionality. This external stimulus was also manifested by seeking help from any resource possible, to relieve these grievous symptoms, including taking on many duties once performed by patients.

Internal stimuli expressed as caregivers' feelings highlighted the experience of a life-changing event. For example, caregivers' feelings indicated fear and helplessness as they watched their loved ones succumb to the grips of end-stage heart failure. Feelings of helplessness and fear of death characterized caregivers' internal stimuli as there seemed no hope for life. When all seemed lost, the sub-theme, *Hope for life renewed*, replaced feelings of helplessness and fear of death among participants' —one which brought forth hope for life. This finding represents a new perspective not found in research exploring living with an LVAD from patients' perspectives (Canody & Savage, 1999; Casida, Marcuccilli, & Peters, 2011; Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; Samuels, Holmes, & Petrucci, 2004).

Hope for life, however, appears to be a shared sentiment between caregivers in this

inquiry and those caring for BTT patients (Casida, 2005; Marcuccilli & Casida, 2011). Whether caregivers' hoped for continued life with an LVAD as a BTT (Casida, 2005), a DT in this inquiry, or hoped for life through a donor heart (Marcuccilli & Casida, 2011), LVADs seem to restore hope and sustain hope where there once was none for these caregivers. For some patients with advanced heart failure and their caregivers, however, there is no hope for life. This is clearly evidence among older adults (e.g., ≥ 72 years old) with end-stage heart failure, and/or for who have one or more comorbid condition (e.g., diabetes, cancer, active infectious processes, stroke, etc.). These patients will not be eligible for a DT and will continue to experience uncomfortable symptoms refractory to maximal medical management. As a result, some caregivers, will continue to experience negative health-related outcomes reported in the literature, such as depression (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007a; Luttik, Jaarsma, Veeger, & van Vledhuisen, 2005; Mahoney, 2001; Molloy, Johnston, & Whitham, 2005; Murray et al., 2002), caregiver burden (Karmilovich, 1994; Saunders 2008; 2009), worsening overall health (Luttik et al., 2007a; Luttik et al., 2005; Pressler et al., 2009), and poor health-related quality of life (Luttik et al., 2007b; Pressler, 2009). These caregivers may never have the opportunity to experience hope for life for their loved ones and may continue to experience poor health outcomes once their loved ones are gone. For caregivers' in this study and beyond, the LVAD brought forth hope for life and the chance for a better quality of life for everyone involved. Implantation of the LVAD as a DT marked the second phase of the focal stimuli shared by participants' in this inquiry.

Learning to live with an LVAD: An evolving process. Patients' and caregivers' experiences in this phase represented two (2) related external foci: 1) Post-operative recovery, and 2) Having a foreign body.

Post-operative recovery. First of all, patients' were recovering from an extensive surgery. Patients' collectively described being in the hospital for pre-operative work-up, and up to two months for the post-operative phase. For some patients in this inquiry, being in the hospital was a very difficult experience. Having to stay in the hospital for several weeks meant having to comply with the "micro-management" of the hospital environment. This experience was a constant source of frustration for some patients' in this inquiry – an experience shared by other patients hospitalized for LVAD implantation (Dew et al., 1999; Grady et al., 2003).

Having a foreign body. Secondly, patients' were getting used to having a foreign body attached to them. In the sub-theme, *Having a foreign body*, patients' in this inquiry initially described feeling uncomfortable with the device attached to them. They mostly described soreness around the neck and shoulders initially, and nuisances experienced to date, such as itching under the binder, pinches, and wires curling under the binder. These patients, however, didn't elaborate about the first time they saw the LVAD attached to their bodies, as patients in other studies have (Casida, Marcuccilli & Peters, 2011; Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007). Internal stimuli manifested as feelings of shock and disbelief echoed throughout patients' voices as they tried to grip the reality of seeing a mechanical device attached to their bodies (Casida et al., 2011; Chapman et al., 2007). Patients in these studies, however, expressed feelings of self-doubt intermingled with the reality of living with this life-sustaining device (Casida et al., 2011; Chapman et al., 2007) — a feeling shared by caregivers in this inquiry and those in other studies (Marcuccilli & Casida, 2011; Baker et al., 2010; Casida, 2005).

Although caregivers in this inquiry and others unanimously reported the unwavering help and support of nurses and health care professionals (Casida et al., 2011; Kaan, Young, Cockell, & MacKay, 2010, Baker et al., 2010), the theme in this inquiry, *Learning to care all over again*,

captures the realization that they had to learn to care for their loved ones in a different way – a way laced with self-doubt, even continuous fear. Caregivers were now required to adapt to a mechanical device – a highly technical piece of equipment that will sustain the life of their loved ones. For many caregivers, they had no technical or medical/nursing background. For example, caregivers' descriptions were laced with feelings of uncertainty, lack of self-confidence, even expressions of vulnerability due to feelings of inadequacy and perceived lack of knowledge. Caregivers' feelings can be explained by an assumption of the theory of stress and coping (Lazarus & Folkman, 1984). This theory posits that highly stressful conditions may result in an increased perception of loss of control, vulnerability, even uncertainty. From the initial diagnosis of heart failure to caring for someone with an LVAD as a DT, persistent worry and stress appeared to remain an internal focal stimulus throughout caregivers' lives and emotions.

In the theme, *Persistent worry and stress*, caregivers' in this inquiry have described the experience of caregiving as pervasive worry coupled with stress. Keeping a watchful eye over patients' activities [including the LVAD system] delineated an ongoing burden despite patients' progression towards better health and well-being. Being 'hypervigilant' was also described among five ($N = 5$) caregivers of BTT patients (Marcuccilli & Casida, 2011). Strategies used by caregivers' to cope with their feelings included constantly checking LVAD battery status and power unit, looking out for patient safety, returning home early from social outings, even helping with projects around the house. Coping strategies utilized by participants in this inquiry can be further explained by the stress and coping theory.

Stress and coping theory. According to this theory, there are two coping strategies: 1) problem-focused coping (e.g., which involves using focused strategies by learning more about the problem, learn new skills to help deal with the problem, and/or adapt their lives around the

situation), and 2) emotion focused coping (e.g., altering thoughts and feelings about a situation, such as positive thinking or even accepting the situation as is) (Lazarus & Folkman, 1984). In the current inquiry, caregivers were faced with a life-threatening circumstance and had to learn how to care all over again. Caregivers' behaviors can be explained by one of two coping strategies described by Lazarus and Folkman (1984), namely *problem-focused coping*. This type of coping strategies involves using focused strategies by learning more about the problem, learning new skills to help deal with the problem, and/or adapt their lives around the situation. Keeping a watchful eye over patients' can be explained as a coping strategy, namely *problem-focused coping*, in which caregivers adapted their lives around the lives of their loved ones. Persistent worry and stress are major factors contributing to overall caregiver burden, and continues to be reported among caregivers of patients with heart failure (Martensson, Dracup, & Fridlund, 2001; Murray et al., 2002; Scott, 2000), caregivers of patients with advanced heart failure (Braun et al., 2007; Clark et al., 2006; Harding, Higginson, & Donaldson, 2003; Herbert, Arnold & Schulz, 2007), and caregivers of patients with LVADs as a BTT (Baker, Flattery, Salyer, Haugh, and Maltby, 2009; Casida 2005; Casida, Marcuccilli & Peters, 2011; Dew et al., 2000; Kaan, Young, Cockell, & Mackay, 2010). Although one caregiver in this inquiry openly, but quickly described a bout of "feeling blue," feelings of depression were not openly discussed among others. Caregivers of patients with DT may also experience negative health-related outcomes as described among caregivers of long-term life-sustaining devices, such as mechanical ventilation (Douglass & Daly, 2003; Im, Belle, Schulz, Mendelsohn, & Chelluri, 2004), percutaneous implants for peritoneal dialysis (Belasco, 2002; Belasco et al., 2006), and caregivers of ICD patients (Dougherty & Thompson, 2009; Jenkins et al., 2007; Sowell, Sears, Walker, Kuhl, & Conti, 2007). Nevertheless, pervasive worry and stress can increase one's risks

for negative health outcomes such as depression (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007a; Luttik, Jaarsma, Veeger, & van Vledhuisen, 2005; Molloy, Johnston, & Whitham, 2005), increased caregiver burden (Saunders 2008; 2009), worsening overall health (Luttik et al., 2007a; Luttik et al., 2005; Pressler et al., 2009), and poor health-related quality of life (Luttik et al., 2007b; Pressler, 2009). Ongoing assessments and screening for depression amongst the growing population of caregivers with long-term, life-sustaining devices is warranted.

Understanding the various external and internal focal stimuli as integral components of adaptation provided a deeper understanding of living with a DT. The discussion continues with a view into surrounding factors influencing participants'

Contextual stimuli.

Contextual stimuli are factors that contribute to the effect of the focal stimulus. The theme, *Good family support*, was recognized as a shared contextual stimulus from both patients' and caregivers' in this inquiry. Participants described the importance of having good family support, and how it plays a vital role in their overall health and well-being. Other studies also reported satisfaction with family support from patients' (Grady et al., 2002; Grady et al., 2004; Samuels, Holmes, & Petrucci, 2004) and caregivers' experiences (Casida, 2005; Marcuccilli & Casida, 2011), but from mostly a BTT perspective. Conversely, other qualitative studies reported sacrificing familial relationships as they cared for patients with LVADs (Baker, Flattery, Salyer, Haugh & Maltby, 2010; Kaan, Young, Cockell, & MacKay, 2010). Perhaps contextual factors related to a younger age cohort (ages ranging from 44 to 66 years old, with a mean age of 51 and standard deviation of 14), compared to an older age group in this inquiry (ages ranging from 50 to 74 years old, mean age of 65 and standard deviation of 15), could explain the differences and/or value in having good family support. Older adults may have more

support through children, grandchildren, and long-established relationships through extended family.

Another contextual stimuli related to the caregivers in this inquiry is reflected by the theme, *Personal interests on hold*. Caregivers' in this inquiry talked about giving up many things that they enjoyed to do, such as sewing, going to bible study, or even spending weekends away with friends. This experience was shared amongst caregivers of BTT patients, who spoke of sacrificing personal relationships, hobbies, even employment while caring for their loved ones (Marcuccilli & Casida, 2001; Baker, Flattery, Salyer, Haugh & Maltby, 2010; Casida, 2005; Kaan, Young, Cockell, & Mackay, 2010). Contextual factors related to gender (e.g., predominantly female caregivers), could explain the difference in having more personal interests.

The following section discusses the main concepts used to describe the process of adjustment among participants in this inquiry, and includes the extant literature to supplement/support discussions.

Theoretical Constructs and the Process of Adaptation

There are 3 main concepts in the RAM which illustrate the process of adaption: 1) Coping processes, 2) Adaptive modes; and 3) Adaptation levels. Each concept has sub-constructs which will be defined and discussed from patients' and caregivers' aspects within the context of DT.

Coping processes.

Coping processes are defined as inherent or acquired ways of interaction within a dynamic environment (Roy, 1980; 1990). Person's behaviors stem from two subsystems illustrating these coping processes: 1) Cognator subsystem, and 2) Regulator subsystem.

Cognator subsystem. This coping process includes four cognitive-emotion pathways

innate to all human beings: 1) perceptual and information processing, 2) learning, 2) judgment and 4) emotion (Roy, 1980; Hanna & Roy, 2001). Patients in this inquiry and others (Casida, Marcuccilli, & Peters, 2011; Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007) have demonstrated the intricate interplay between these cognitive emotion pathways as they described feeling frustrated about the restrictions imposed by the LVAD as they learned to operate, trouble-shoot, and live with the LVAD system. Similarly, caregivers described feeling overwhelmed, anxious, and even frightened as they learned to care for their loved ones.

Regulator subsystem. These adaptive processes are the inherent pathways in the human body that automatically respond through chemical, neural, and endocrine mechanisms. Patients in this inquiry had the added component of a mechanical circulatory support device attached to the left ventricle of their heart. The adaptive responses required to accept this device were manifested as patients' bodies physiologically accepting the device with no evidence of rejection. Although some patients' who had the 2nd generation HeartMate II (Thoratec Corporation) described some complications with their device (e.g., stroke, infection, device change-out, and GI bleeding), patients' bodies physiologically accepted the device without further complications to date. Their experiences mirrored the continued improvements in LVAD and clinical management since the REMATCH trial which reported fewer adverse effects, and device durability in long-term DT patients (Lietz et al., 2007; Long et al., 2005; Long et al., 2008; Park et al., 2005). Interestingly, three (3) of the patients' in this inquiry are enrolled in a clinical trial testing the 3rd generation, magnetically levitated LVAD (e.g., HeartWare, Thoratec Corp). To date, two (2) patients experienced adverse events with the 3rd generation LVAD. One (1) patient contracted bacterial pneumonia [which warranted hospitalization], but did not have to have the device replaced. The other patient experienced a

mild stroke which affected his speech and memory, all of which have improved since participation in this inquiry. No known published evidence has illustrated longevity, survival rates, or adverse events related to these latest technological advancements.

Caregivers' adaptive processes are related to the body's ability to function under continuous stress and worry. Although I do not have personal health information, the adaptive processes seem to be functioning in caregivers' as evidenced by overall healthy physical appearances and descriptions indicating the ability to function despite persistent worry and stress.

Adaptive Modes.

According to Roy, the coping processes described in the previous section interact with four adaptive modes: 1) Physiologic-physical 2) Self-concept-group identity, 3) Role function, and 4) Interdependence (Roy, 1980; Hanna & Roy, 2001).

Physiologic-physical. This mode includes maintaining physical integrity. Foundational human requirements to sustain life include the need for water, air, and nutrition, elimination, a balance between activity and rest, and protection are hallmarks of this level. In the theme, *A time for discovery and adjustment*, patients' talked about how they incorporated their basic human needs as they adjusted to DT. At first, there were many restrictions imposed by the LVAD which required immediate adaptation described by patients in this inquiry and others (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; Casida, Marcuccilli, & Peters, 2011). These included having to carrying around extra equipment (i.e., in case batteries ran down or controller needed to be changed), being unable to take a shower, swim or bathe, having their wound dressed everyday, protecting the LVAD, not being able to drive, performing LVAD-specific IADLs, and being tethered to the equipment. Patients' in this inquiry, however, did not report

difficulty with performing LVAD-specific IADLs, compare to those in other studies who reported fear and anxiety coupled with self-doubt as they learned to manage LVAD-specific IADLs (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007; Casida, Marcuccilli, & Peters, 2011).

Finding clothes to house and protect the outer components of the LVAD (e.g., batteries and controller) posed some challenges as the process of adjustment continued (Casida, Marcuccilli, & Peters, 2011). The trial and error process of trying on different vests and clothing strategies was described elsewhere (Casida et al., 2011), including a case report revealing the clothing challenges and body-image disturbances of a woman with an LVAD (Marcuccilli & Casida, 2012). Eventually, patients in this inquiry preferred a fishing vest from a local sportswear stores over the modular vests provided by the implant hospital and LVAD manufacturers. The fishing vest seemed to distribute the weight of the batteries and controller more evenly, thereby reducing discomfort in the neck area. Moreover, pockets and a “zip-up” jacket style gave the sensation of security as patients’ engaged in ADLs. Since men are the currently the largest group receiving and LVAD, more studies comparing and contrasting different clothing strategies to protect the external components of the LVAD are warranted. Additionally, most participants reported that choosing the right type of clothes makes a difference in engaging in activities. Early integration of proper clothing types, therefore, may facilitate earlier acceptance and adaptation. This inquiry provides an in-depth view into the clothing challenges of men but more research is needed to facilitate early, positive adaptation of living with a long-term LVAD.

Self-concept-group identity.

Roy (1991; 1999) described self-concept as an adaptation mode. For example, patients

with LVADs are attached to internal and external components which can cause psychological distress and potentially alter perceptions of self-concept (eg, mental images about the self in relation to the body). Although LVADs have improved the quality of life of patients with advanced heart failure (Grady et al., 2001; 2002; 2003; 2004; Casida, Marcuccilli, & Peters, 2011), living with this implanted device may also cause major psychosocial issues for patients. Thus patients may have difficulty in modifying self-concept which can affect their ability to carry out the required self-care of the LVAD system, affect ego integrity, and also affect their willingness to engage in social relationships. The ability to modify self-concept, therefore, is vital for promoting and maintaining emotional integrity, continued adherence to LVAD regimen, and the development and continuation of social relationships leading to improved quality of life. Although one study identified threats to self-concept (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007), a more recent study explored how patients with LVADs modify their self-concept (Marcuccilli & Casida, 2012). To date, scant literature suggested that recipients of LVADs may encounter difficulty modifying their self-concept, and therefore be able to achieve a level of self-acceptance to continue with prescribed medical regimen (Casida, Peters, & Magnum, 2009). Conversely, patients' experiences in this inquiry and those in a more recent study (Marcuccilli & Casida, 2012) did not appear to have difficulty with modifying self-concept. In fact, patients' unanimously indicated that the LVAD not only improved their quality of life, but also saved their life. They accepted themselves as needing the LVAD in order to live and therefore readily engaged in the prescribed medical regimen. However, in a related study exploring the impact of LVADs on recipients' bodies and lives (Chapman et al., 2007), retrospective reflections of living with an LVAD after participants received a heart transplant were dramatically different. They described a profound alteration in body-image elucidated by initial shock and bodily scarring.

Similar to Marcuccilli & Casida's (2012) study, patients in this study accepted the LVAD as necessary to live, even stating that it has become a part of their lives. Given the fact that these patients have never received a donor heart, it is likely that they modified their self-concept in order to accept the LVAD because they knew that this was the last treatment option for them, or because they were older (eg, ≥ 65), or knew that there was a shortage of organ donors and they would not likely receive a transplant.

Another integral component of maintaining self-concept and psychosocial health are sex and intimacy. Sexual activity and intimacy are normal human behaviors that are important dimensions of quality of life. Although this phenomenon is gaining interest, it remains underreported in the LVAD literature (Casida, Marcuccilli, & Peters, 2011; Grady et al., 2001; 2002; 2003; Samuels, Holmes, & Petrucci, 2004). Sex and intimacy represent normal human behavior and a vital component of promoting self-concept, psychosocial quality of life, and fostering satisfying interpersonal relationships. For example, a phenomenological study exploring sex and intimate behaviors among ($N = 9$) patient's found that as overall strength improved, sexual functioning improved, along with an increased sense of connectedness and intimacy. Casida (2005) also reported improved personal relationships among ($N = 3$) spousal caregivers of patients waiting for transplant. Few patients in this study described a desire for sexual activity, but accepted limited physical sexual activity due to aging, and ongoing disease process. Although Roy (1983; 1991; 1999) didn't discuss sex and intimacy as basic human requirements, sex and intimacy represent normal human functioning and an integral component of quality of life through fostering satisfying interpersonal relationships. Future studies honing in on improving sexual activity, or increasing intimate behavior among this group can improve and/or maintain satisfying sexual and intimate behaviors.

Role function.

Roles functions are the collective actions performed by individuals and the related feelings and attitudes attributed to these functions. In the theme, *Lifestyle adjustments come with time*, caregivers talked about their integral roles in helping the patient with their bio-psycho-social needs, recover, and adjust to living with an LVAD. For example, caregivers had to initially perform many of the functions required to maintain physical integrity, including monitoring the LVAD system, maintaining intake and output and providing nutritious meals for their loved ones. Other responsibilities included taking on roles once performed by the patients, doing all the driving, and performing dressing changes — roles described by caregivers of patients with LVADs in other studies (Baker, Flattery, Salyer, Haugh, & Maltby, 2010; Kaan, Young, Cockell, MacKay, 2010; Marcuccilli & Casida, 2011). These role functions mirror problem-focused coping strategies in which caregivers learned new skills (e.g., performing dressing changes), and adjusted their lives around the situation (e.g., role reversal, driving).

Caregivers in this inquiry described having the added burden of promoting and maintaining normalcy for patients despite restrictions imposed by the LVAD. In the theme, *keeping it normal*, caregivers unanimously described how they tried to maintain normalcy for patients living with an LVAD. Strategies to promote and maintain normalcy included talking to patients, assisting them with projects and activities they liked to do, and making the home environment more comfortable for them. It seemed that caregivers were always focused to ensure as much a normal life as possible for their loved ones. These problem-focused coping strategies were also articulated in a qualitative study exploring the caregiving experience of ($N = 6$) caregivers of patients waiting transplant (Baker, Flattery, Salyer, Haugh, & Maltby, 2010). It seemed that caregivers of patients with LVADs for any indication adopted problem-focused

coping strategies as necessary for promoting psychosocial health and well-being for their loved ones. Problem-focused coping strategies, therefore, are necessary for maintaining and promoting overall health and well-being among patients with LVADs across the board.

Interdependence.

Roy (1983; 1991; 1999) described the concept of interdependence as feeling secure in nurturing, interpersonal relationships. These relationships focus on the value of mutual love, respect and valuing of interpersonal relationships and support systems. Participants' in this inquiry mutually described very good relationships with one another. The majority of participants across the board talked about having a great relationship with their spouses, a finding also reported amongst spousal caregivers of patients waiting for transplant (Casida, 2005).

Adaptive levels.

Roy (1983; 1991; 1999) described that successful adaptation occurs as a result of positive responses to changes in the environment. Adaptive levels reflect the changing point of the process of adaptation and are characterized by three levels of adaptation: 1) Integrated life process, 2) Compensatory process, and 3) Compromised process.

Integrated life process. Indicates a level of adaptation where structure and functions of life are working together to meet one's needs. In the theme, *Adjustments and acceptance come with time*, patients talked about integrating and accepting the inconveniences, nuisances, and restrictions of the LVAD as necessary to life. They talked about being able to eat again, performing their own LVAD-specific IADLs, even engaging in more physical activities like walking and playing golf. As they felt stronger and were able to do more things, their overall quality of life improved – a shared perspective among patients in other studies (Grady et al.,

2001; Grady et al., 2002; Grady et al., 2003; Grady et al., 2004; Casida, Marcuccilli, & Peters, 2011). The essence of living with a DT became apparent as patients accepted and adapted their new lives with the LVAD.

Meaning of living with a DT. In the theme, *Living outweighs restrictions*, the meaning of having an LVAD as a DT became clear as patients' accepted this device as necessary to live. It was at this point that they began to reflect upon how their lives were before the LVAD — they not only accepted their restrictions, but embraced them because it enable them to live – a finding reported amongst patients waiting for transplant (Casida, Marcuccilli, & Peters, 2011). Accepting the LVAD in all aspects of lives, bodies, and emotions, can also be described as an emotive-focused coping strategy incorporated by these patients. Although patients' in Casida and colleagues (2011) phenomenological study revealed several strategies for coping, such as humor, remaining active, prayer, and church activities, patients in this inquiry talked about 'just accepting' the device. Perhaps an investigation into the coping strategies used by patients with DT would identify successful coping strategies for future LVAD recipients.

A novel finding that has not emerged in other studies was reflected in the theme, *Hope for life through new technology*. Patients' bridged to transplant must often wait for almost 1 year before receiving a transplant (OPTN/SRTR, 2011). Certainly these patients live with the hope that one day they will receive a heart transplant. Although patients in this inquiry understand that they will never receive a donor heart, mostly because of their age, they have the hope of the future. Whether it was stem cell injections, or new LVAD technology, these patients continued to hope for life through new technology.

Another theme representing the meaning of living with a DT was reflected in the dyadic theme, *Given more time*. The meaning of having and being given the chance to live, represented

the true essence of having a DT. Notably, it was participants' use of silence while recounting their experiences that gave voice to the meaning of being given more time. I also noticed that participants' bodily movements seemed to change prior to the silence. For example, participants' bodily movements seemed to still. Facial expressions and tonal inflections lowered and appeared more serious. Tears filled participants' eyes with subsequent tearing, and soft crying. This body language prefaced silence – the silence described by Bollnow (1982) through van Manen (1990) as having reached the limits of language and arriving at the essence of the phenomenon. For van Manen (1990), it was the powerful expressions of body language that made silence seem more powerful than words themselves, as participants' collectively described the meaning of being given more time. The silence expressed by these participants is also described by van Manen (1990) as ontological silence, in which participants seemed at a loss for words when they tried to describe for me what it was like to be given more time to live. Despite shared feelings of being given more time to live, participants' were also faced with an unknown future.

Uncertain future. This theme represents the mutual concerns of participants' in this inquiry about the end of life experience with a DT. Participants' across the board knew that DT was the last therapeutic option available for them. Although some of them never heard the phrase *DT*, they knew that they were eventually going to die – it was the surrounding circumstances about dying with an LVAD that remained a mystery to most of them. It is interesting to note here that most participants who talked about death, seemed to be actually afraid to mention the word death, dying, or even appeared uncomfortable with discussing the subject. The silence surrounding conversations about death was clear. This was described by van Manen (1990) as epistemological silence—the silence experienced when thinking of the

unthinkable, such as death. From wondering about future complications to uncertainty about the end of life, there seemed to be some unanswered questions about prognostication, the way patients were going to die, and how long they had to live. This made me think about the literature (Brush et al., 2010; Byram, 2012; Swetz et al., 2011a; Swetz et al., 2011b) and AHA/ACC guidelines identifying the need for pre-implantation palliative care and end of life discussions among patients' with heart failure and their family caregivers. When I inquired about any end of life conversations with health care providers, only one (1) patient talked about being approached by a social worker to ascertain any end-of-life care needs, whereas others had none such discussions with their health care providers. Some patients' with the 3rd generation HeartWare LVAD were told by their physicians that they don't know how long they were going to live – they could even outlive their spouses. Other participants', especially caregivers, wondered about what the end of life would entail for their loved ones. Some participants' talked about making funeral arrangements, even donating their body to science. Two (2) patients' articulated that they would prefer to die instead of having a long, protracted death – end of life options shared by other patients with advanced heart failure (Levenson et al., 2000; McCarthy et al., 2008). However, no one talked about having an advance directive in place, or having palliative or end of life care discussions with healthcare providers. This is consistent with the literature reporting a lack of communication about palliative and end of life choices among patients with heart failure and their family caregivers (Aldred et al., 2005; (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000; McCarthy et al., 2008; Selman et al., 2007). Current ACC/AHA guidelines concur with the expanding literature recommending timely palliative and end of life care in order to facilitate quality care among patients with advanced stages of heart failure (Brush et al., 2011; Goodlin, 2009; Hunt et al., 2005; Hunt et al., 2009; Hupcey et al., 2009;

Jessup et al., 2009; Rizzieri et al., 2005). Many of these patients, however, are referred only when they are near death (Goodlin, 2009; Quaglietti et al., 2005; Rizzieri et al., 2005). These results were exemplified in a recent retrospective analysis which reported that a reduction in quality of life or decline in health status resulted in end of life discussions with patients' and their family caregivers (Brush et al., 2011). We have done a disservice to this population in meeting the palliative care and end of life care needs. The prospect of impending death is certainly a very stressful situation for anyone. Identifying and incorporating approaches that integrate a discussion of palliative care at some point during the latter stages of illness but prior to the onset of very advanced disease has the potential to identify the end of life choices of the patient while not stripping hope for life. Initiating discussions about palliative care and end of life care preferences prior to deteriorating health status can help alleviate some stress by identifying care preferences and ensuring death with dignity (Brush et al., 2010; Byram, 2012; Swetz et al., 2011a; Swetz et al., 2011b). This could improve the quality of life of both patients' and their family caregivers during a very difficult time. More research, however, is needed to examine the palliative care and end of life preferences among this growing population. Perhaps a prospective, descriptive study examining palliative and end of life choices among a larger sample of patients' and caregivers' living with DT would illuminate preferences for palliative and end of life care.

The final theme, *Thank the Lord*, concomitantly reveals an ongoing faith and thankfulness to the Lord, as expressed in Casida and colleague's (2011) study. The theme in this inquiry captures a glimpse into patients' religious and spiritual beliefs about Divine intervention at a time when all seemed lost. These beliefs illustrate one philosophical assumptions delineating the RAM in relation to God— the acknowledgement of a symbiotic relationship

between the world and God.

Compensatory process. In this level, the cognator and regulator coping mechanism have been activated by a challenge to the person or group. For caregivers' in this inquiry and others (Baker, Flattery, Salyer, Haugh, & Maltby, 2010; Casida, 2005; Kaan, Young, Cockell, MacKay, 2010; Marcuccilli & Casida, 2011) persistent stress and worry were elements of this challenge as caregivers strove to continue in their roles and responsibilities—a finding which rings true amongst caregivers of patients with other chronic illnesses reported previously in this inquiry and elsewhere. The difference between those studies, this inquiry, and a phenomenological study by Marcuccilli & Casida (2011) were very clear – caregiving was not a burden, but a way of life. For these caregivers, it was all about what wives do for their husbands – what son's do for their fathers – a responsibility that wasn't termed a responsibility – but just the way life is. This coping strategy used by caregivers' in this inquiry can also be termed emotion focused coping, since they just seemed to accept and adapt to their new caregiving roles despite pervasive worry and stress. Perhaps this also could be explained by being in long-term relationship and a sense of commitment felt by virtue of being a spouse or a son. Either way, caregivers have incorporated a compensatory process of adjusting to persistent worry and stress by embracing their caregiving role as part of life.

Compromised process. The final level of the RAM represents inadequate integrations and compensatory life processes – an indication of an adaptation problem. Participants in this inquiry have not illustrated compromised processes, as they have accepted their lives and roles required of living with a DT. It is noteworthy to report that, despite a higher level of acceptance and adaptation in this inquiry and caregivers' in other studies (Casida, 2005; Marcuccilli & Casida, 2011), other qualitative studies report overall burden amongst caregivers of LVAD

patients awaiting donor hearts (Baker, Flattery, Salyer, Haugh, & Maltby, 2010; Kaan, Young, Cockell, MacKay, 2010). Further studies utilizing mixed-methods, larger samples across multiple settings, and longitudinal designs will be helpful in examining factors related burden and adaptation among this growing population. Perhaps examining a variety of instruments related to caregiving outcome, such as the Appraisal of Caregiving Scale (ACS) (Oberst, Thomas, Grass, & Ward, 1989), the Bakas Caregiving Outcomes Scale (BCOS) (Bakas & Champion, 1999; Bakas, Champion, Perkins, Farran, & Willilams, 2006), even the MOS 36-item short form health survey (SF-36) (McHorney, Ware, Lu, & Sherbourne (1994), can assist in the measurement of caregiving outcomes, even stimulate the development of future instruments, aimed at measuring caregiver outcomes among this growing population.

Strengths and Limitations

This hermeneutic phenomenologic inquiry provided an in-depth look into the experience of living with a DT among patients' and caregivers' living with DT. Although the sample, reflected exclusively White men and women recruited from a single university medical setting, participants are representative of the population of patients with an LVAD as a DT (Kirklin et al., 2011). Moreover, due to the possible sensitive nature of knowing that DT is the final therapy for them, participants may have not fully explicated their inside perspectives. By using a purposive sample, however, participants shared rich, in-depth descriptions regarding their adaptive processes, meanings about living with DT, and uncertainties about the end of life, thereby facilitating transferability at researchers' discretion. There are important limitations inherent in qualitative studies, such as phenomenology. Van Manen (1990) asserts that phenomenology does not purport to objectify the human experience; rather, it aims to increase the understanding of a certain phenomena and the meanings attributed to them. This is of

particular value to the practice of nursing, since we seek to understand the human experience. Understanding the experience of DT from patients and their caregivers may serve to enlighten nursing practice.

Implications and Relevance to Nursing

Despite the limitations, findings in this inquiry add to the knowledge of the experiences of DT among patients and caregivers. As the world begins to age, chronic illnesses will increase, specifically advanced heart failure. The utilization of life-sustaining devices, such as DT, will become a viable option for improving overall health and quality of life among this population. Given the growing body of knowledge related to advancement in technology and improvement in survival rates among LVAD recipients, very little has been implemented to address health behavior issues, palliative care and end of life care needs, and overall quality of life of older adults with DT, including their caregivers. Caregivers are instrumental to the health and well-being of patients with such life-sustaining technology. Yet, their health behavior needs and issues have only begun to emerge as well. To date, very little published have explored patients' and caregivers' inside perspectives of living with a DT. Findings from this inquiry have provided a significant contribution to the knowledge of life-sustaining devices from a palliative care and end of life care perspective. In doing so, findings have both pragmatic and research implications. First, it begins to address the paucity in the literature warranting investigations into the bio-psycho-social-spiritual needs, health behaviors, and quality of life dimensions of patients' and caregivers' living with a DT (Pressler, 2009; Kaan, Baker, Casida, Marcuccilli, & Peters, 2011; Marcuccilli & Casida, 2011). Second, findings can be used to help nurses and other health care providers understand the adaptive processes and needs and concerns of this population. Findings can also be used to inform a holistic approach to providing palliative care

and end of life care designed to improve well-being, quality of life and ensure death with dignity.

Directions for Future Research

Despite this new knowledge, more research is needed. For example, investigations using larger sample sizes, a more diverse demographic profile of participants across multiple settings, and other study designs, such as mixed-methods, longitudinal designs, and eventually interventional studies, can be developed to enhance generalizability. The Hispanic/Latino population is already the largest minority group in the nation, and is projected to make up 20% of the U.S. population by 2050 (Older Americans, 2010). Including these demographic compositions (and ethnicities) in the database should stimulate research among diverse groups so we can better understand behaviors, health outcomes, health care use, and eventually tailor culturally-sensitive interventions for this expanding population. Other theoretical constructs of the RAM (e.g., focal, contextual, and residual factors) can be used to examine the bio-psycho-social-spiritual variables predictive of patients' and caregivers' perceptions and capability to live with and adapt to DT. Finally, findings from this inquiry have helped me to recognize the need to optimize adaptation and health behaviors to improve the quality of life for this population. The opportunity to explore the lived experience of living with a DT has led to the development of a program of research dedicated to meet patients' and caregivers' palliative and end of life care needs (Figure B18). As my program of research emerges, investigations related to perceptions, health behaviors, and quality of life outcomes will culminate in the development of health behavior interventions aimed at modifying health behaviors to improve quality of life among my population of interest. One of the first intervention studies I plan to develop is a health behavior modification intervention aimed at reducing stress and promoting healthy behaviors among family caregivers of adults with advanced heart failure with palliative and end

of life care needs. Eventually, I plan to develop and test a nurse-led or community-based interventions aimed at modifying health behaviors to promote quality of life among older adults with advanced heart failure using life-sustaining technologies and their family caregivers. With the advent of health care reform by 2014, future studies can inform public health-based programs aimed at health behavior modification programs for both patients and their family caregivers. A very critical component of my program of research is the opportunity to integrate health behaviors interventions into health care systems and/or community-base settings. Translation into practice is paramount for population-based health behavior modification and to improve the quality of life for older adults with advanced heart failure using life-sustaining-technologies, as well as their family caregivers.

Conclusion

An interpretation of the lived experience from patients' and caregivers' perspectives culminated into an existential biography illustrating the evolving process of adjustment over time as participants' accepted and integrated DT into their lives. The themes identified in this hermeneutic-phenomenological inquiry were consistent with the concepts of adaptation within the RAM. Overall, positive adjustments were illustrated as patients' accepted their device as necessary to live, exhibited an improved overall quality of life, and gratefulness for life. Caregivers' also illustrated a positive adaptation during the caregiving process because they, too, where grateful for more time with their loved ones, and accepted caregiving as part of their lives, despite persistent worry and stress. Dyadic perspectives reflected the importance of good family support and nurturing interpersonal relationships amidst uncertainties about dying and death. Future studies are needed to drive evidence-based practice clinical guidelines and to continue to advance the science of life-sustaining technologies, caregiving, and palliative and end-of-life

care.

APPENDIX A

Table A1

Table A1

Stages of Heart Failure

Stage A	Stage B	Stage C	Stage D
Patients at high risk for developing heart failure. ^a	Evidence of structural heart disease. ^b	Evidence of heart failure symptoms and structural heart disease (symptomatic)	Refractory end-stage heart disease requiring frequent hospitalizations for treatment. ^c

Note. Adapted from “2009 focused update incorporated into the American College of Cardiology/American Heart Association 2005 guidelines for the diagnosis and management of heart failure in adults: A report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines,” by S. A. Hunt et al., 2009, *Journal of the American College of Cardiology*, 53, 1343-1382.

^aPatients may have high blood pressure, coronary artery disease, diabetes, history of drug or alcohol abuse, history of rheumatic fever, or a family history of cardiomyopathy. ^b Structural heart disease includes left ventricular enlargement, heart fibrosis, valve disease, previous heart, dyspnea, fatigue, exercise intolerance. ^c Patients may require inotropic infusions, an LVAD, an artificial heart, a heart transplant, or hospice care. Marked symptoms at rest despite optimal medical management.

APPENDIX A

Table A2

Table A2

New York Heart Association Functional Classifications

Class	Patient Symptoms
Class I (Mild)	No limitation of physical activity ^a
Class II (Mild)	Slight limitation of physical activity ^b
Class III (Moderate)	Marked limitation of physical activity ^c
Class IV (Severe)	Unable to carry out any physical activity without discomfort.

Note. Adapted from “Heart Failure Society of America, The Stages of Heart Failure – NYHA Classification,” accessed October 2, 2010 http://www.abouthf.org/questions_stages.htm.

^aOrdinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath). ^bComfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea. ^cComfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea. ^d Dyspnea at rest or with very little exertion. If any physical activity is undertaken, discomfort is increased.

APPENDIX A

Table A3

Table A3

Heart Transplant Eligibility Criteria

Inclusion criteria	Exclusion criteria	
Refractory cardiogenic shock	Systemic illnesses (< 2 year life expectancy	Other contraindications
Dependence on IV inotropes	Malignancies	Advanced age (> 72 years age)
Peak VO ₂ < 10ml/kg/min	AIDS	Any active infection (excluding device-related LVAD infections)
Ischemia limiting daily activity and not amenable to coronary bypass surgery (CABG)	Active manifestations of lupus, sarcoidosis, amyloidosis with multi-organ involvement.	Active peptic ulcer disease
Symptomatic/refractory ventricular arrhythmias	Irreversible renal or hepatic dysfunction.	Diabetes with neuropathies
	Significant obstructive pulmonary disease (FEV ₁ < 1 L/min).	Peripheral vascular or cerebrovascular disease
		Morbid obesity (body mass index > 35 kg/m ²)
		Cachexia (body mass index < 18 kg/m ²)

Pulmonary hypertension (pulmonary artery systolic pressure >60 mm Hg).	Creatinine > 2.5 mg/dL or Creatinine clearance < 25 mL/min Bilirubin > 2.5 mg/dL Severe pulmonary dysfunction with FEV ₁ < 40% normal Recent pulmonary infarction within 6 to 8 weeks Difficult-to-control hypertension Irreversible neurological or neuromuscular disorder Active mental illness or psychosocial instability Drug, tobacco, or alcohol abuse within 6 months Heparin-induced thrombocytopenia within 100 days
--	--

Note. Inclusion criteria: IV (e.g., intravenous); and VO₂ (e.g., oxygen consumption per unit time). Inclusion criteria adapted from, “ACCF/AHA/ACP/HFSA/ISHLT 2010 clinical competence statement on management of patients with advanced heart failure and cardiac transplant: A report of the ACCF/AHA/ACP task force on clinical competence and training,” by F. Pagani, et al., 2010, *Circulation*, 122, 644-672. Exclusion criteria adapted from, “Listing criteria for heart transplantation: International Society for Heart and Lung Transplantation Guidelines for the care of cardiac transplant candidates,” by M. Mehra, et al., 2006, *Journal of Heart Lung Transplant*, 25, 1024–1042.

APPENDIX A

Table A4

Table A4

Patients' Sociodemographic and Clinical Data

Participant	Age (Years)	Sex	Race	Education (Years)	Marital Status	Designated Caregiver	Reason for LVAD	Months with LVAD
	M = 73 SD 1.8			M = 15.4 SD = 1.1				M = 12.3 SD = 6.0
1	75	Male	White	16	Married	Spouse	DT	17.0
2	72	Male	White	12	Widowed	Son	DT	10.0
3	71	Male	White	16	Married	Spouse	DT	9.0
4	72	Male	White	15	Married	Spouse	DT	8.0
5	72	Male	White	13	Married	Spouse	DT	10.0
6	73	Male	White	16	Married	Spouse	DT	8.0
7	76	Male	White	16	Married	Spouse	DT	24.0

Note: DT = DT

APPENDIX A

Table A5

Table A5

Caregivers' Sociodemographic and Clinical Data

Participant	Age (Years) M = 65 SD = 8.3	Sex	Race	Education (Years) M = 13.4 SD = 1.5	Marital Status	Relationship to Patient	Employment Status	Time/day with patient
1	72	Female	White	14	Married	Spouse	Volunteer	Almost all day
2	50	Male	White	12	Single	Son	None	Almost all day
3	69	Female	White	12	Married	Spouse	Volunteer	All day
4	61	Female	White	16	Married	Spouse	Retired	18 hours/day
5	69	Female	White	12	Married	Spouse	Retired	24/7
6	74	Female	White	14	Married	Spouse	Retired	24/7
7	62	Female	White	14	Married	Spouse	Retired	24/7

Note: 24/7 = 24 hours a day, 7 days a week.

APPENDIX B

Figure B1

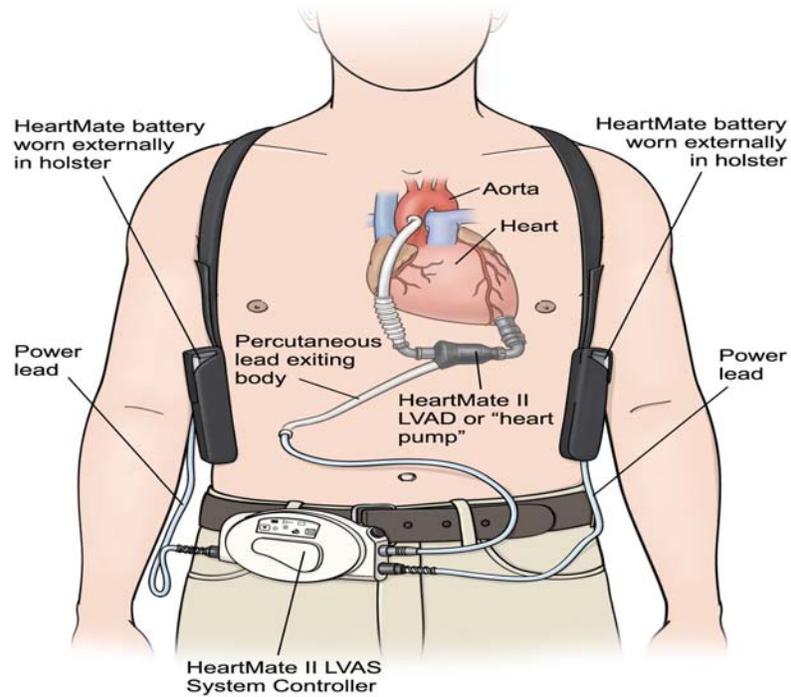


Figure B1. External components of LVAD. Reprinted with permission from Thoratec Corporation, 2011

APPENDIX B

Figure B2



Figure B2. Comparison of 1st, 2nd, and 3rd generation LVADs (Reprinted with permission from Thoratec Corporation, 2011).

APPENDIX B

Figure B3

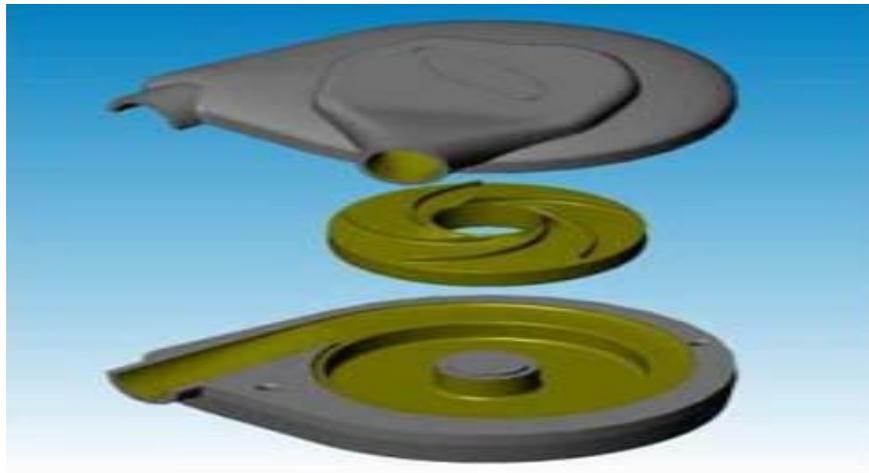
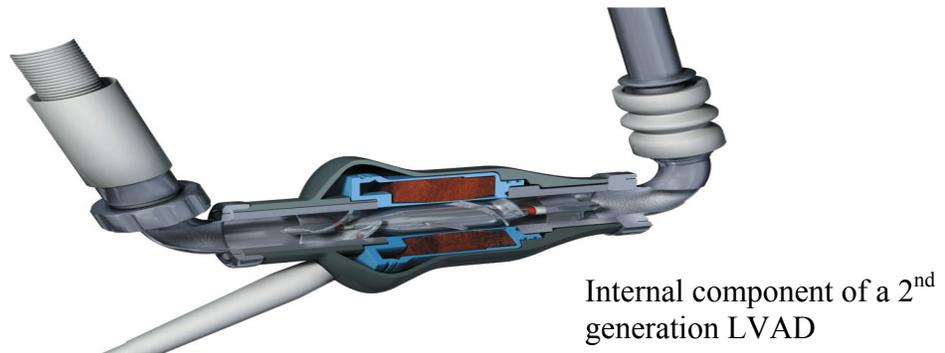


Figure B3. Internal components of 2nd and 3rd generation LVADs. Reprinted with permission from Thoratec Corporation, 2011.

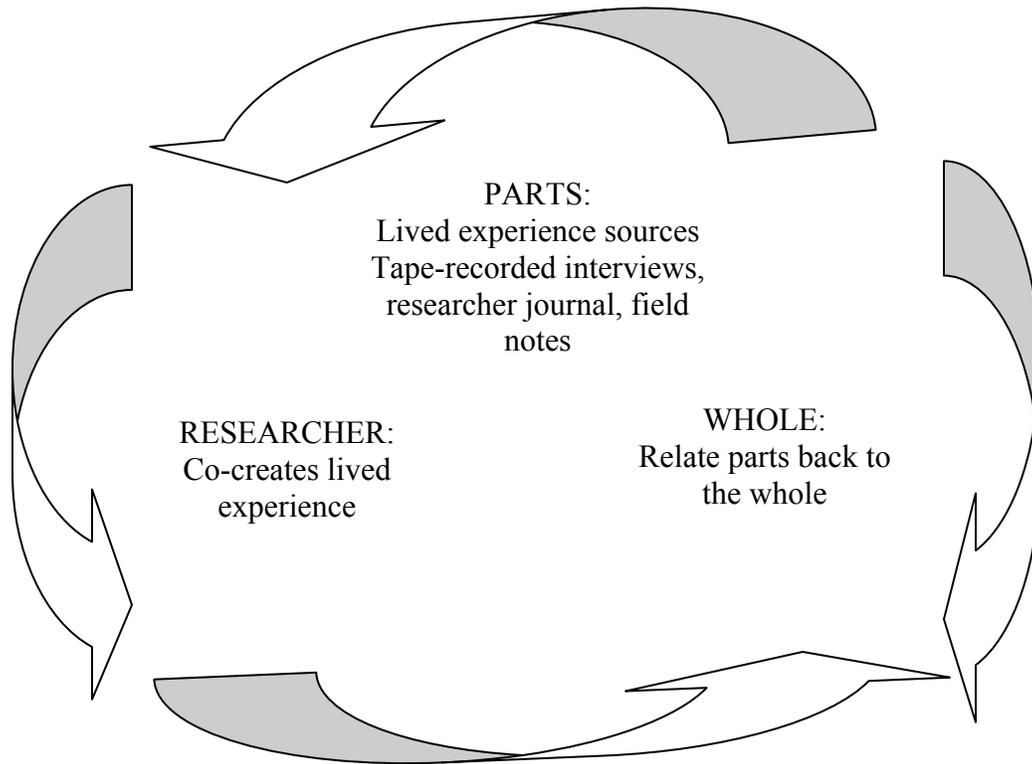
APPENDIX B**Figure B4**

Figure B4. Structure of the hermeneutic circle

APPENDIX B

Figure B5



Figure B5. My husband.

APPENDIX B

Figure B6



Figure B6. My boy.

APPENDIX B

Figures B7 and B8

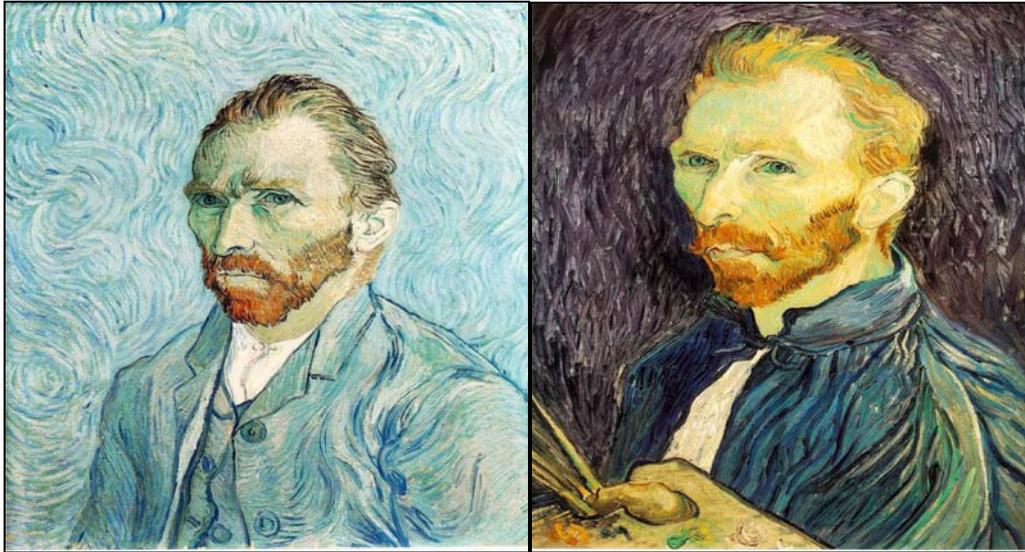


Figure B7. van Gogh Self-Portrait 1889.

Figure B8. van Gogh Self-Portrait 1889.

Musee d'Orsay, Paris.

APPENDIX B

Figure B9



Figure B9. LMR self-portrait. 2011.

APPENDIX B

Figure B10



Figure B10. Pablo Picasso. Woman with a Chignon. 1901. Oil on canvas. Fogg Art Museum, Harvard University, Cambridge, MA. USA.

APPENDIX B

Figure B11

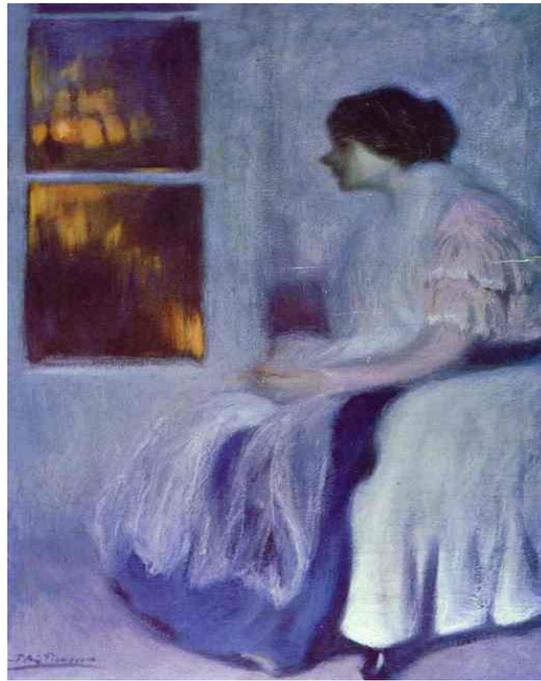


Figure B11. Pablo Picasso. Lola, Picasso's Sister. 1899. The Cleveland Museum of Art.

APPENDIX B

Figure B12

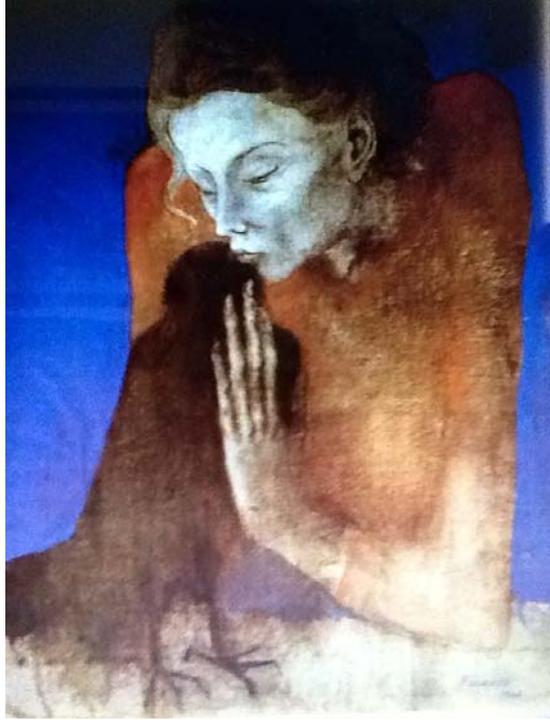


Figure B12. Pablo Picasso. *Woman with a Crow.* 1904. Charcoal, pastel, and water-color on paper. Toledo Museum of Art, Toledo, OH. USA.

APPENDIX B

Figure B13

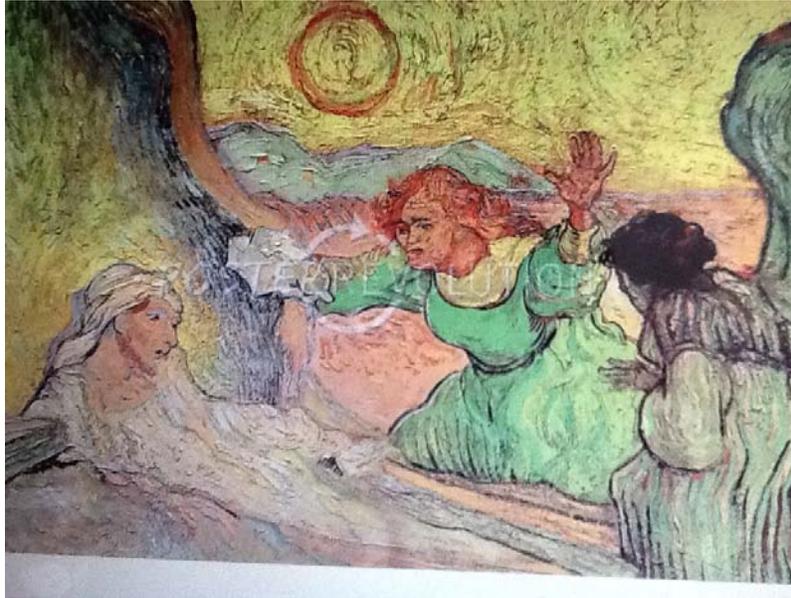


Figure B13. Vincent Van Gogh. The Raising of Lazarus. 1890. van Gogh Museum, Amsterdam.

APPENDIX B**Figure B14****Praise My Soul the King of Heaven**

Praise my soul the King of heaven
 to His feet they tribute bring
 ransomed, healed, restored, forgiven
 who like thee His Praise should sing
 Praise Him! Praise Him! Praise Him! Praise Him!
 Praise the everlasting King
 Praise Him for His grace and favour
 to our fathers in distress
 Praise Him still the same for ever,
 slow to chide and swift to bless.
 Praise Him! Praise Him! Praise Him! Praise Him!
 Glorious in His faithfulness
 Fatherlike he tends and spares us
 well our feeble frame he knows
 in His hands he gently bears us
 Rescues us from all our foes
 Praise Him! Praise Him! Praise Him! Praise Him!
 Widely as His mercy flows
 Angels helps us to adore Him

Ye behold Him face to face

Sun and moon bow down before Him

Dwellers all in time and space

Praise Him! Praise Him! Praise Him! Praise Him!

Praise with us the god of grace

Figure B14. Praise my soul the King of heaven.

APPENDIX B**Figure B15****Thank you, Lord, for This Great Day**

Thank you for all the good things and times along the way

Thank you Lord for every friend

May those friendships never end

Thank you Lord for daughters and sons

Thank you for all their little ones

Thank you Lord for sisters and brothers

Thank you for fathers and mothers

A mother who said her boys didn't fight

But what were they doing out of her sight

Thank you Lord for the HeartMate Pump

It got me up and off my rump

Thank you Lord for this great life

Thank you for a wonderful wife

A wife who seldom got mad

Threw a slipper once

Thank you Lord, her aim was bad

I think this is all I have to say

Except thank you Lord for this great day.

Figure B15. Thank you, Lord, for This Great Day. Author_patient participant.

APPENDIX B

B16

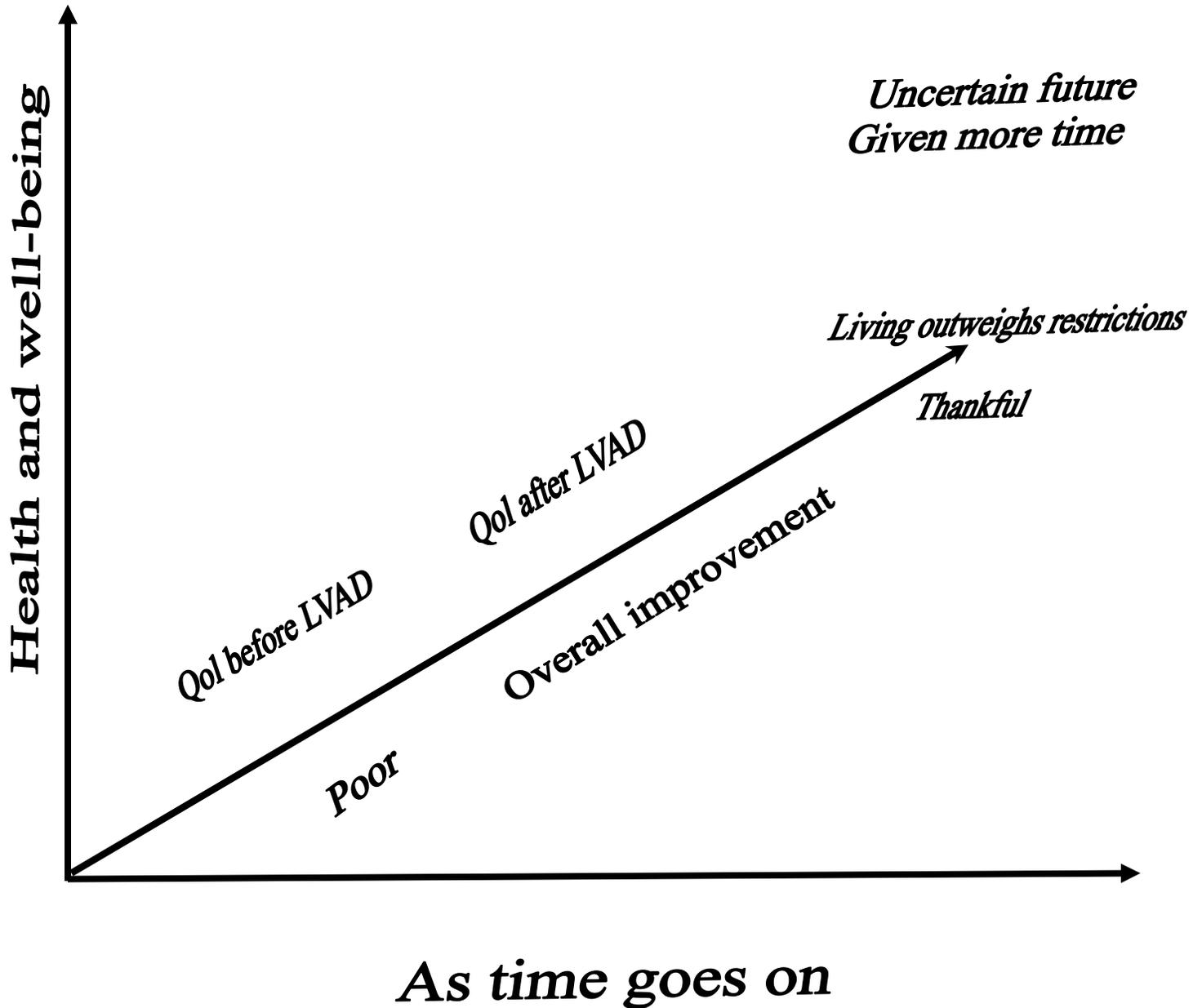


Figure B16. Health and wellness trajectory of patients before and after the LVAD.

APPENDIX B

Figure B17

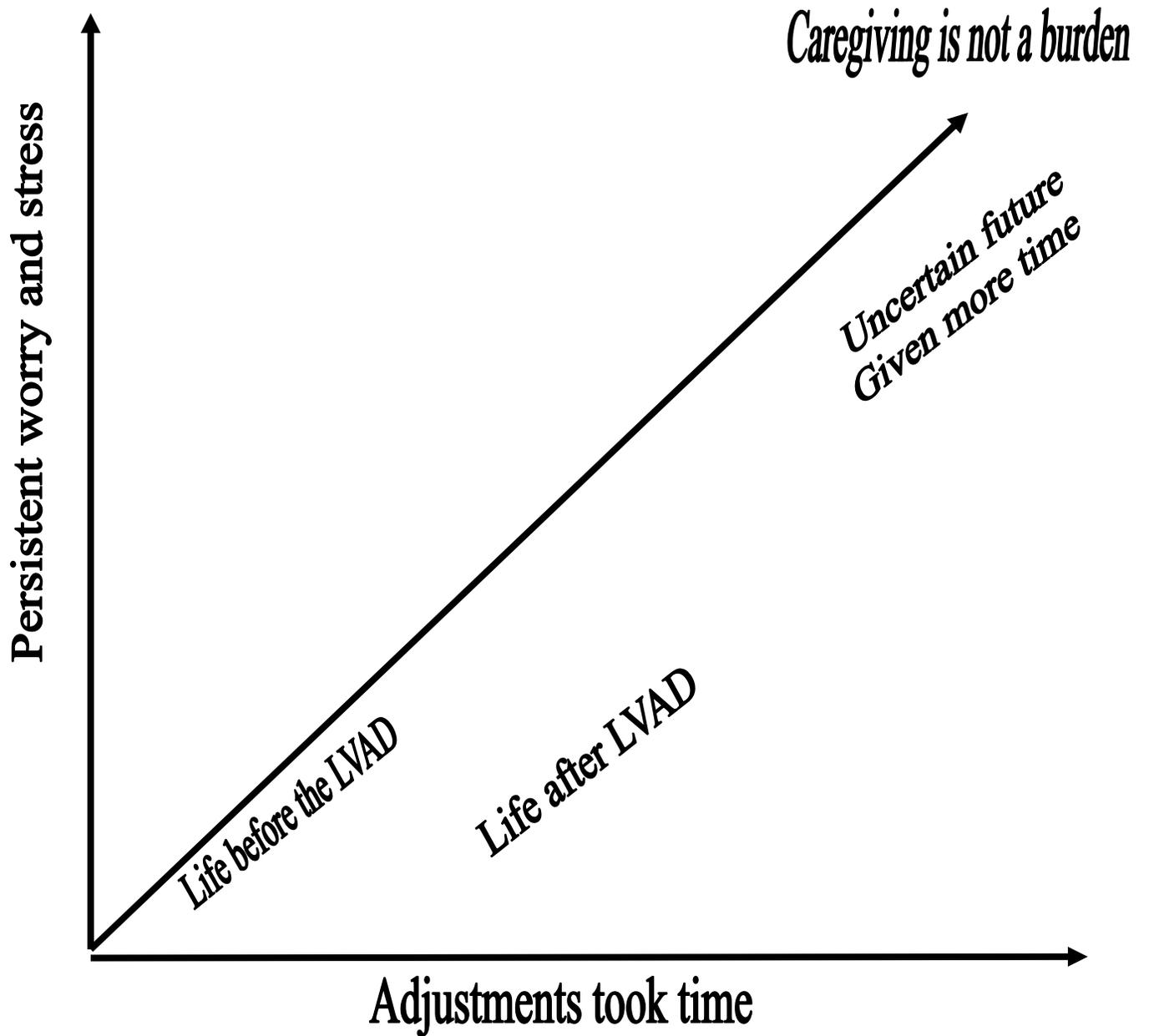


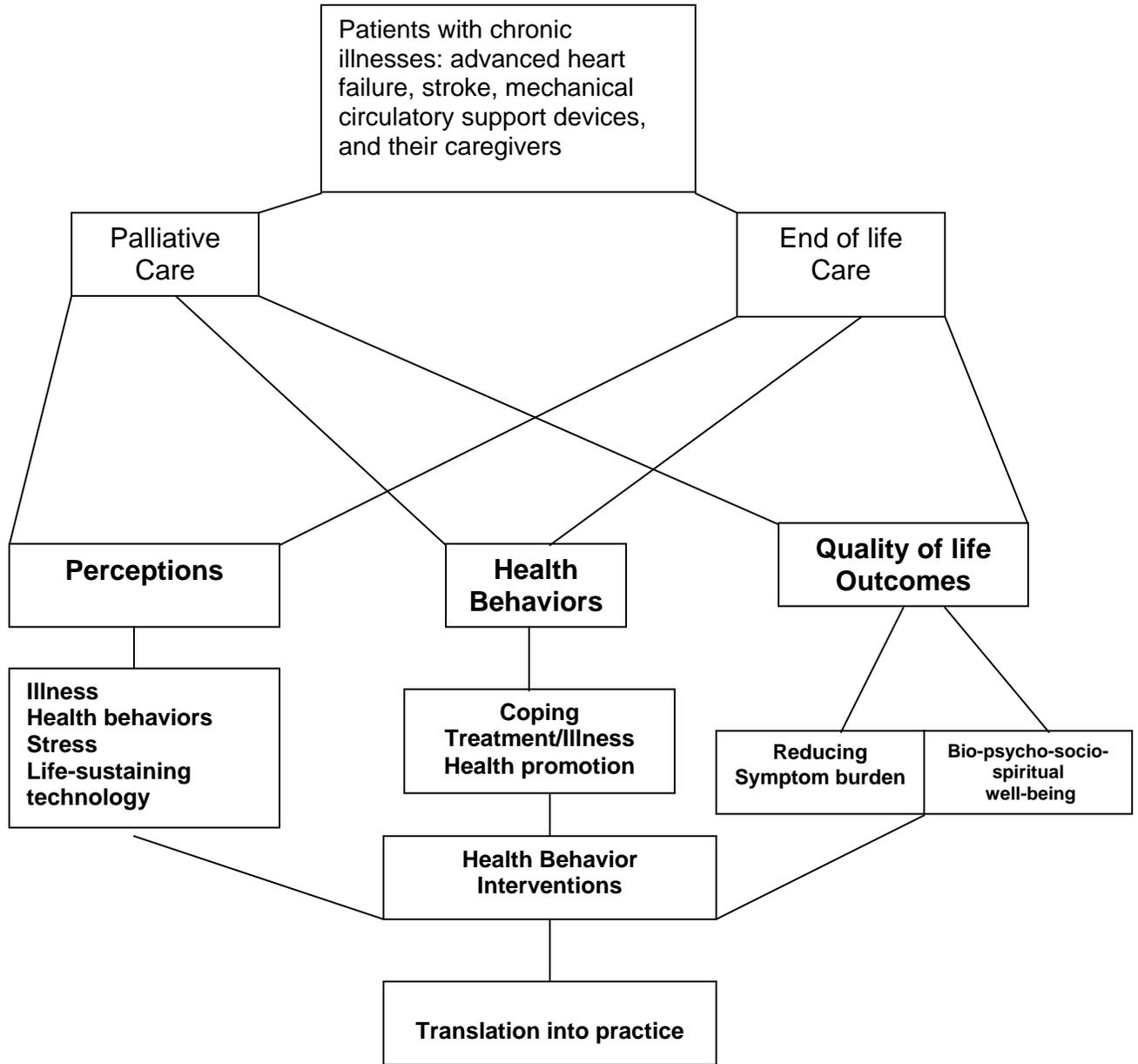
Figure B17. Caregivers' trajectory of adjustments and pervasive worry overtime.

APPENDIX B

Figure B18

Program of Research

*Palliative and End of Life Care in Older Adults with Chronic Illnesses Who Require Life-Sustaining Technology



*Adapted from Indiana University College of Nursing's Health Behaviors Research Framework

Appendix B**Figure 19**

Figure 19. New self-portrait: LMR.

APPENDIX C

The University of Michigan Institutional Review Board Approval



Medical School Institutional Review Board (IRBMED) • 2800 Plymouth Rd., Building 200, Room 2086, Ann Arbor, MI 48109-2800 • phone (734) 763 4768 • fax (734) 763 9603 • irbmed@umich.edu

To: Dr. Francis Pagani

From:

Michael Geisser

Alan Sugar

Cc:

Jesus (Jessie) Casida

Francis Pagani

Rosalind Peters

Lydia McGowan

Susan Wright

Sarah Fox

Linda Marcuccilli

Subject: Amendment [Ame00024322] Approved for [HUM00028567]

SUBMISSION INFORMATION:

Study Title: Self-Concept of Adults Living with Long-Term Implantable LVADs & Lifestyle Adjustments of Caregivers

Full Study Title (if applicable): Self-Concept and Lifestyle Modification of Adults Living with Long-Term

Implantable Left Ventricular Assist Devices & Lifestyle Adjustments of Caregivers

Study eResearch ID: [HUM00028567](#)

Amendment eResearch ID: [Ame00024322](#)

Amendment Title: HUM00028567 (AMDT Part 3)

Date of this Notification from IRB: 8/10/2011

Date of Approval for this Amendment: 8/9/2011

Review: Expedited

Current IRB Approval Period: 2/1/2011 - 1/31/2012

Expiration Date: Approval for this expires at **11:59 p.m. on 1/31/2012**

UM Federalwide Assurance (FWA): FWA00004969 expiring on 11/17/2011

OHRP IRB Registration Number(s): IRB00000244

Approved Risk Level(s) as of this Amendment:

Name	Risk Level
HUM00028567	No more than minimal risk

NOTICE OF IRB APPROVAL AND CONDITIONS:

The IRBMED has reviewed and approved the amendment to the study referenced above. The IRB determined that the proposed research continues to conform with applicable guidelines, State and federal regulations, and the University of Michigan's Federalwide Assurance (FWA) with the Department of Health and Human Services (HHS). You must conduct this study in accordance with the description and information provided in the approved application and associated documents, as amended.

APPROVAL PERIOD AND EXPIRATION: The approval period for this study is listed above. Please note the expiration date is not changed by the approval of this amendment. If the approval lapses, you may not conduct work on this study until appropriate approval has been re-established, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

IMPORTANT REMINDERS AND ADDITIONAL INFORMATION FOR INVESTIGATORS

APPROVED STUDY DOCUMENTS:

You must use any date-stamped versions of recruitment materials and informed consent documents available in the

eResearch workspace (referenced above). Date-stamped materials are available in the "Currently Approved Documents" section on the "Documents" tab.

RENEWAL/TERMINATION:

At least two months prior to the expiration date, you should submit a continuing review application either to renew or terminate the study. Failure to allow sufficient time for IRB review may result in a lapse of approval that may also affect any funding associated with the study.

FUTURE AMENDMENTS:

All proposed changes to the study (e.g., personnel, procedures, or documents), must be approved in advance by the IRB through the amendment process, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

AEs/ORIOs:

You must inform the IRB of all unanticipated events, adverse events (AEs), and other reportable information and occurrences (ORIOs). These include but are not limited to events and/or information that may have physical, psychological, social, legal, or economic impact on the research subjects or others.

Investigators and research staff are responsible for reporting information concerning the approved research to the IRB in a timely fashion, understanding and adhering to the reporting guidance

(http://www.med.umich.edu/irbmed/ae_orio/index.htm), and not implementing any changes to the research without IRB approval of the change via an amendment submission. When changes are necessary to eliminate apparent immediate hazards to the subject, implement the change and report via an ORIO and/or amendment submission within 7 days after the action is taken. This includes all information with the potential to impact the risk or benefit assessments of the research.

SUBMITTING VIA eRESEARCH:

You can access the online forms for continuing review, amendments, and AEs/ORIOs in the eResearch workspace for this approved study, referenced above.

MORE INFORMATION:

You can find additional information about UM's Human Research Protection Program (HRPP) in the Operations Manual and other documents available at: www.research.umich.edu/hrpp.

The image shows two handwritten signatures in black ink. The signature on the left is for Michael Geisser, and the signature on the right is for Alan Sugar. Both are written in a cursive, flowing style.

Michael Geisser

Co-chair, IRBMED

Alan Sugar

Co-chair, IRBMED

APPENDIX D

Wayne State University Human Investigation Committee Approval

**WAYNE STATE
UNIVERSITY**

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://irb.wayne.edu>



NOTICE OF EXPEDITED AMENDMENT APPROVAL

To: Jesus Casida
Adult Health/Administration
cc: Cohn
From: Dr. Scott Millis *S. Millis*
Chairperson, Behavioral Institutional Review Board (B3)
Date: August 24, 2011
RE: IRB #: 034909B3E
Protocol Title: Self-Concept and Lifestyle Modification of Adults Living with Long-Term Implantable Left Ventricular Assist Devices: A Qualitative Study
Funding Source: Unit: Nurse Anesthetist Program
Protocol #: 0903006906
Expiration Date: February 13, 2012
Risk Level / Category: Research not involving greater than minimal risk

The above-referenced protocol amendment, as itemized below, was reviewed by the Chairperson/designee of the Wayne State University Institutional Review Board (B3) and is APPROVED effective immediately.

- Protocol - Changes to enrollment criteria, data collection methods and/or instruments, telephone script, and other changes which includes the use of Appendix D: Mini-cog instrument to ascertain cognitive levels of participants prior to interviews, the use of Appendix H: Patient and Caregiver profile to tailor demographic profile to patients and caregivers, modifications to interview script to tailor to patients with destination therapy and their caregivers, and recruitment script modified to tailor to destination therapy patients and their caregivers. These changes do not affect risk to participants.
- Consent Form (revision dated 07/05/2011) - Consent Form updated to reflect changes to protocol and to include compensation for participation.
- Receipt of Amendment Approval notice from University of Michigan (dated 08/09/2011)

APPENDIX E**The University of Michigan IRB Amendment: Continuation of Study**

Medical School Institutional Review Board (IRB MED) • 2800 Plymouth Rd., Building 200, Room 2086, Ann Arbor, MI 48109-2800 • phone (734) 763 4768 • fax (734) 763 9603 •

irbmed@umich.edu

To: Francis Pagani

From:

Michael Geisser

Alan Sugar

Cc:

Jesus (Jessie) Casida

Francis Pagani

Rosalind Peters

Maureen Daly-Myers

Lydia McGowan

Sarah Fox

Linda Marcuccilli

Subject: Amendment [Ame00027519] Approved for [HUM00028567]

SUBMISSION INFORMATION:

Study Title: Self-Concept of Adults Living with Long-Term Implantable LVADs & Lifestyle Adjustments of Caregivers

Full Study Title (if applicable): Self-Concept and Lifestyle Modification of Adults Living with Long-Term Implantable Left Ventricular Assist Devices & Lifestyle Adjustments of Caregivers

Study eResearch ID: [HUM00028567](https://eresearch.umich.edu/HUM00028567)

Amendment eResearch ID: [Ame00027519](https://eresearch.umich.edu/Ame00027519)

Amendment Title: HUM00028567_12-28-11 Ame update CVs Casida-Peters

Date of this Notification from IRB: 1/18/2012

Date of Approval for this Amendment: 1/18/2012

Review: Expedited

Current IRB Approval Period: 12/20/2011 - 12/19/2012

Expiration Date: Approval for this expires at **11:59 p.m. on 12/19/2012**

UM Federalwide Assurance (FWA): FWA00004969 expiring on 6/13/2014

OHRP IRB Registration Number(s): IRB00001995

Supporting Documents: Updated CVs for Jessie Casida and Rosalind Peters

Approved Risk Level(s) as of this Amendment:

Name	Risk Level
HUM00028567	No more than minimal risk

NOTICE OF IRB APPROVAL AND CONDITIONS:

The IRBMED has reviewed and approved the amendment to the study referenced above. The IRB determined that the proposed research continues to conform with applicable guidelines, State and federal regulations, and the University of Michigan's Federalwide Assurance (FWA) with the Department of Health and Human Services (HHS). You must conduct this study in accordance with the description and information provided in the approved application and associated documents, as amended.

APPROVAL PERIOD AND EXPIRATION: The approval period for this study is listed above. Please note the expiration date is not changed by the approval of this amendment. If the approval lapses, you may not conduct work on this study until appropriate approval has been re-established, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

IMPORTANT REMINDERS AND ADDITIONAL INFORMATION FOR INVESTIGATORS

APPROVED STUDY DOCUMENTS:

You must use any date-stamped versions of recruitment materials and informed consent documents available in the eResearch workspace (referenced above). Date-stamped materials are available in the "Currently Approved Documents" section on the "Documents" tab.

RENEWAL/TERMINATION:

At least two months prior to the expiration date, you should submit a continuing review application either to renew or terminate the study. Failure to allow sufficient time for IRB review may result in a lapse of approval that may also affect any funding associated with the study.

FUTURE AMENDMENTS:

All proposed changes to the study (e.g., personnel, procedures, or documents), must be approved in advance by the IRB through the amendment process, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

AEs/ORIOs:

You must inform the IRB of all unanticipated events, adverse events (AEs), and other reportable information and occurrences (ORIOs). These include but are not limited to events and/or information that may have physical, psychological, social, legal, or economic impact on the research subjects or others.

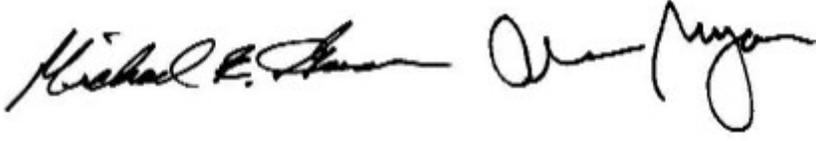
Investigators and research staff are responsible for reporting information concerning the approved research to the IRB in a timely fashion, understanding and adhering to the reporting guidance (http://www.med.umich.edu/irbmed/ae_orio/index.htm), and not implementing any changes to the research without IRB approval of the change via an amendment submission. When changes are necessary to eliminate apparent immediate hazards to the subject, implement the change and report via an ORIO and/or amendment submission within 7 days after the action is taken. This includes all information with the potential to impact the risk or benefit assessments of the research.

SUBMITTING VIA eRESEARCH:

You can access the online forms for continuing review, amendments, and AEs/ORIOs in the eResearch workspace for this approved study, referenced above.

MORE INFORMATION:

You can find additional information about UM's Human Research Protection Program (HRPP) in the Operations Manual and other documents available at: www.research.umich.edu/hrpp.



Michael Geisser

Co-chair, IRBMED

Alan Sugar

Co-chair, IRBMED

APPENDIX F

Wayne State University Amendment: Continuation of Study

WAYNE STATE
UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://irb.wayne.edu>

NOTICE OF EXPEDITED CONTINUATION APPROVAL

To: Jesus Casida
Adult Health/Administration
Cohn

From: Dr. Scott Millis *S. Millis, PhD*
Chairperson, Behavioral Institutional Review Board (B3)

Date: January 18, 2012

RE: IRB #: 034909B3E
Protocol Title: Self-Concept and Lifestyle Modification of Adults Living with Long-Term Implantable Left Ventricular Assist Devices: A Qualitative Study
Funding Source: Unit: Nurse Anesthetist Program
Protocol #: 0903006906
Expiration Date: January 17, 2013
Risk Level / Category: Research not involving greater than minimal risk

Continuation for the above-referenced protocol and items listed below (if applicable) were APPROVED following Expedited Review by the Chairperson/designee of the Wayne State University Institutional Review Board (B3) for the period of **01/18/2012 through 01/17/2013**. This approval does not replace any departmental or other approvals that may be required.

- Recruitment Letter
- Receipt of U of M Consent Form (dated 07/05/2011)
- Receipt of U of M Continuation Approval (approval period 12/20/2011 to 12/19/2012)

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval *before* the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (<http://www.irb.wayne.edu/policies-human-research.php>).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at **each** use.

*Based on the Expedited Review List, revised November 1998

APPENDIX G

Letter of Support



University of Michigan
Health System

Cardiovascular Center

Center for Circulatory Support

Susan M. Wright, RN, MS
F7859 Mott Extension, SPC 5230
1500 E. Medical Center Dr.
Ann Arbor, MI 48109
734-615-3068
734-936-6266, pager 8080

March 3, 2010

Linda Marcuccilli, RN, PhD Student
College of Nursing
Wayne State University
Detroit, Michigan

Dear Ms Marcuccilli,

Please be informed that I have reviewed the proposal titled: *The Lived Experience of Destination Therapy patients and Their Caregivers*, and discussed it with Dr. Casida. This project will include a purposive sample of 20 or less patient/caregiver dyads. I support this research project and will allow Dr. Casida and Linda Marcuccilli to access patients and their medical records.

Sincerely,

Susan Wright, RN, MS
The University of Michigan Health System
Supervisor, Center for Circulatory Support
Section of Cardiac Surgery

APPENDIX H**Recruitment Protocol for Research Coordinators****Inclusion Criteria for Patients with DT**

Able to read, write, and speak English

Men and Women

Must be 18 years of age and older

All races: American Indian/Alaska Native, Black or African American, Asian, Native Hawaiian/Other Pacific Islander, and White

All ethnicities: Hispanic/Latino, non-Hispanic/Latino

Voluntarily consent to participate in a tape recorded interview

No evidence of cognitive decline

Must have the LVAD as a DT for at least three months

Exclusion Criteria

Unable to read, write, or speak English

Less than 18 years of age

No evidence of cognitive decline

Has the LVAD as a BTT

Had an LVAD then received a donor heart

Inclusion Criteria for Caregivers of Patients with DT

Able to read, write, and speak English

Men and Women

Must be 18 years of age and older

All races: American Indian/Alaska Native, Black or African American, Asian,

Native Hawaiian/Other Pacific Islander, and White

All ethnicities: Hispanic/Latino, non-Hispanic/Latino

Voluntarily consent to participate in a tape recorded interview

No evidence of cognitive decline

Must have cared for someone with an LVAD as a DT for at least three (3) months.

Exclusion Criteria

Unable to read, write, or speak English

Less than 18 years of age

No evidence of cognitive decline

Cared for someone with an LVAD for less than three (3) months

Cared for someone with an LVAD as a BTT

Cared for someone who received a donor heart after LVAD implantation.

Thank you!

Linda Marcuccilli, PhD Student, RN

Linda Marcuccilli, PhD Student, RN

APPENDIX I

Outreach Protocol: Inclusion of Women and Minorities

***Proposed Outreach Guidelines**

Understand study population.

I will engage in culturally sensitive practices to enhance recruitment and retention of women and minority populations. I will meet potential participants at the Center for Circulatory Support outpatient clinic, or a setting of their choice, including community settings, in order to build trust and enhance the quality of interview. I will spend time with the potential participants before the interview to build rapport, establish trust, and understand cultural, ethnic, and racial backgrounds.

Establish an explicit outreach plan.

I will dialogue with LVAD coordinators and make suggestions for establishing set-goals for recruiting and retaining study participants. Suggestions for LVAD coordinators to enhance the inclusion of women and minorities, including: Engaging in culturally appropriate conversations and building trust to enhance recruitment and retainment of women and minorities. I will communicate with the LVAD coordinators on a weekly basis to keep lines of communication open.

Achieve agreement on research plans.

I will collaborate with Susan Wright, supervisor/facilitator, LVAD coordinators of the Center for Circulatory Support, [and community members if any], and members of the dissertation committee to achieve consensus about the aims and structure of the proposed research.

Design and conduct evaluations.

I will collaborate with the supervisor/facilitator, LVAD coordinators, [community members if any], and members of the dissertation committee to evaluate the recruitment and retention strategies. Strategies includes: 1) assessing potential participant responses to recruitment and retention strategies; and 2) assessing compliance through participation in first and second interviews. Additionally, participants will be asked [at the end of each interview] about the context of questions in relation to understanding the experience and meaning of living with DT.

Progress of study.

I will elicit feedback from the supervisor/facilitator and LVAD coordinators about the progress of the study, and number of accrued participants [including minority and ethnic study participants] on a weekly basis to evaluate recruitment and retention processes.

Establish and maintain communication.

I will keep supervisor/facilitator, LVAD coordinators, [community members if any], and members of the dissertation committee informed of research study progress, including emerging themes. Finally, as a token of appreciation for the participants, collaborating institution, and any involved community leaders, I will invite participants to a 30-minute presentation of the study results at the completion of the study.

*Based on the Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research. NIH Publication No. 97-4160, 1997. U. S. Department of Health.

http://Grants.nih.gov/grants/funding/women_min/women_min.htm.

APPENDIX J**Recruitment Slip**

Hello, Mr. /Mrs. _____.

We are looking for research participants who either have a LVAD as a DT, or care for a person with a DT. We would like to talk about your experience of living with and caring for someone with a LVAD as a DT. Research volunteers will participate in one face-to-face interview, lasting for no more than one hour, and one follow-up telephone call, lasting for no more than thirty (30) minutes after the interview. The study is strictly on a voluntary basis, and requires us to pass on your name and home phone number to the primary research investigator, Linda Marcuccilli, to contact you.

If you would like to hear more about the research, please let us know so that we can contact the primary research investigator to discuss your participation in the research study.

Thank you!

The Center for Circulatory Support

The University of Michigan Health Care Systems

Primary Research Investigator

Linda Marcuccilli, PhD Student, RN

Wayne State University College of Nursing

lckmster@hotmail.com

1.313.300.9269

APPENDIX K

Mini-Cog

The Mini Cog Administration

The test is administered as follows:

1. Instruct the patient to listen carefully to and remember 3 unrelated words and then to repeat the words.
2. Instruct the patient to draw the face of a clock, either on a blank sheet of paper or on a sheet with the clock circle already drawn on the page. After the patient puts the numbers on the clock face, ask him or her to draw the hands of the clock to read a specific time.
3. Ask the patient to repeat the 3 previously stated words.

Scoring

Give 1 point for each recalled word after the clock drawing test (CDT) distracter.

Patients recalling none of the three words are classified as demented (Score = 0).

Patients recalling all three words are classified as non-demented (Score = 3)

Patients with intermediate word recall of 1-2 words are classified based on the CDT (Abnormal = demented;

Normal = non-demented)

Note: The CDT is considered normal if all numbers are present in the correct sequence and position, and the hands readably display the requested time.

From Borson, S., Scanlan, J., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry*, 15(11), 1021-1027. Copyright John Wiley & Sons Limited.

Reproduced with permission (See below).

Mini-Cog Permission for Use

Copyright.com special order (10211320)

Confirmation Number: 10211320

Updates on Items You Ordered:

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY, 51252744

Current Status: Granted

Do you live with your caregiver? _____

*Adapted from Casida (2009) Self-Concept and Lifestyle Modification of Adults Living with Long-Term Implantable Left-Ventricular Assist Devices: A Qualitative Study

APPENDIX M

*Demographic Profile of Caregivers of Adults with LVADs as DT

Participant Code:

Age:

Gender:

Race (circle one):

African American Asian White/non-Hispanic Black/non-Hispanic
 Native American Alaska Native Pacific Islander other (please specify):
 2 or more races (please specify):
 3 or more races (please specify):

Decline to answer:

Ethnic Origin:

Hispanic Latino Other (please specify):

Marital Status (circle one):

Married Single Divorced Widow
 Domestic Partner Decline

Number of Children:

Highest Educational Level (circle one):

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 + Other (please specify):
 HS TT AD UG G D

(HS = high school; TT = technical trade; AD = associate degree; Undergrad = bachelor's degree;
 Grad = graduate degree; D = doctoral degree)

Relationship to LVAD patient: _____

Living Arrangement: (dwelling, number of people living in home): _____

Are you currently working? If so, hours per week: _____

Hours spent with LVAD patient per day: _____

*Adapted from Casida (2009) Self-Concept and Lifestyle Modification of Adults Living with Long-Term Implantable Left-Ventricular Assist Devices: A Qualitative Study.

APPENDIX N

Patient Interview Script

Questions for participants with LVAD DT

Tell me about living with an LVAD.

Tell me about a typical day about life with an LVAD – from the time you get up until the time you go to bed.

When you look back over the time when you have had this LVAD, what event stands out in your mind?

What are all the things you must do to care for your LVAD?

How would you describe your life just before you received this LVAD?

What are all the things that changed after you received this LVAD?

Who are designated as your caregivers?

What are all of the responsibilities of a caregiver?

How would you characterize your relationship with your caregiver?

As you know, you meet this research study's inclusion criteria because your LVAD was the only therapeutic option available to you. Could you describe what it means to you to have the LVAD under these circumstances?

I wonder if you know what medical practitioners call your circumstance.

Have you ever heard someone call this circumstance a "DT"?

In your opinion, what do you make of this terminology?

Imagine for a moment your caregiver's perspective on having an LVAD as a final therapy. In your opinion, how would they describe knowing that there are no other options?

Is there anything else that I didn't think to ask that, in your opinion, would help me understand

your experiences caring for someone with an LVAD as a final option?

Thank you for your time and patience. Your answers will help healthcare professionals provide care for recipients of LVADs.

Probing Questions:

Examples, neither inclusive nor exhaustive:

Are there other things that make it stand out?

Can you describe your feelings surrounding [name of their event]?

Are there other things that you do every day...

How did that make you feel...

Are there other things about living with an LVAD that would help me understand what it is like to live with it?

I'm not sure I understand what you mean when you say [their exact words]. Could you explain that for me?

Could you describe an example or situation that illustrates what you mean when you say [their exact words]?

Could you describe a situation that illustrates your relationship with your caregiver?

APPENDIX O

Caregiver Interview Script

Questions for caregivers for a patient with a DT

Tell me about caring for someone living with an LVAD.

Tell me about a typical day for caregivers caring for someone with an LVAD – from the time you get up until the time you go to bed.

When you look back over the time when you have been caring for someone living with this LVAD, what event stands out in your mind?

What are all the things you must do as a caregiver for someone with an LVAD?

Now, I'd like to go back in time and discuss the time when you first learned that the person you are caring for would receive this LVAD. How would you describe your life just before the person you are caring for received this LVAD?

Now think over the period from learning about this LVAD and now: What are all the things that changed after the person you are caring for received this LVAD?

Now, I would like to talk about how you coordinate your care with the LVAD recipient.

What are all of the responsibilities of the LVAD recipient?

How would you characterize your relationship with the LVAD recipient?

As you know, you meet this research study's inclusion criteria because an LVAD was only therapeutic option available to the person you care for. Could you describe what it means to you to care for someone with an LVAD under these circumstances?

How would you describe knowing that there are no other options?

I wonder if you know what medical practitioners call your circumstance.

Have you ever heard someone call this circumstance a "DT?"

Finally, imagine for a moment the LVAD recipient's perspective on having an LVAD as a final therapy. In your opinion, how would they describe the LVAD recipient's knowing that there are no other options? What do you think their feelings are about their having no other options?

Is there anything else that I didn't think to ask that, in your opinion, would help me understand your experiences caring for someone with an LVAD as a final option?

Thank you for your time and patience. Your answers will help healthcare professionals understand the needs of caregivers of recipients of LVADs.

Probing Questions:

Examples, neither inclusive nor exhaustive:

Are there other things that make it stand out?

Can you describe your feelings surrounding [name of their event]?

Are there other things that you do every day...

How did that make you feel...?

Are there other things about living with an LVAD that would help me understand what it is like to live with it?

I'm not sure I understand what you mean when you say [their exact words]. Could you explain that for me?

Could you describe an example or situation that illustrates what you mean when you say [their exact words]?

Could you describe a situation that illustrates your relationship with your caregiver?

REFERENCES

- Aging Statistics (2010). Retrieved March 10, 2011,
http://www.aoa.gov/AoARoot/Aging_Statistics/index.aspx.
- Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: Impact on older patients and informal caregivers. *Journal of Advanced Nursing*, 49(2), 116–124.
- American Heart Association (2010a). *Heart Transplant Statistics*. Dallas, TX: AHA.
 Retrieved February 1, 2010
http://www.americanheart.org/downloadable/heart/1265665152970DS-3241%20HeartStrokeUpdate_2010.pdf.
- American Heart Association (2010b). *Heart Disease and Stroke Statistics*. Dallas, TX: AHA.
- American Heart Association (2010c). Classification of Functional Capacity and Objective Assessment. Retrieved from
<http://www.americanheart.org/presenter.jhtml?identifier=4569>.
- American Nurses Association (2010). Code of ethics for nurses with interpretive statements.
 Retrieved from <http://www.ananursingethics.org/>
- American Psychological Association. (2009). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author
- Andren, S., & Elmstahl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing*, 17, 90-799.
- Artinian, N. T., Artinian, C. G., & Saunders, M. M. (2004). Identifying and treating depression in patients with heart failure. *Journal of Cardiovascular*, 19(6 Suppl), S47-56.
- Bakas, T., & Champion, V. (1999). Development and psychometric testing of the Bakas

- caregiving outcomes scale. *Nursing Research*, 48, 250-259.
- Bakas, T., Champion, V., Perkins, S. M., Farran, C. J., & Williams, L. S. (2006). Psychometric testing of the revised 15-item Bakas caregiving outcomes scale. *Nursing Research*, 55, 346-355.
- Bakas, T., Pressler, S., Johnson, E., Nauser, J., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research*, 55(3), 180-188.
- Baker, K., Flattery, M., Salyer, J., Haugh, K. K., & Maltby, M. (2009). Caregiving for patients requiring left ventricular assistance device support. *Heart & Lung*, 39(3):196-200. doi:10.1016/j.hrtlng.2009.07.007.
- Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S.,...Small, N. (2006). Characteristics and views of family caregivers of older people with heart failure. *International Journal of Palliative Nursing*, 12(8), 380-389.
- Barnett, M. (2005). Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *Journal of Clinical Nursing*, 14, 805-812.
- Bee, P. E., Barnes, P., & Luker, K. A. (2008). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing*, 18 1379-1393. doi: 10.1111/j.1365-2702.2008.02405.x.
- Bennett, S. J., & Sauve, M. J. (2003). Cognitive deficits in patients with heart failure: a review of the literature. *Journal of Cardiovascular Nursing*, 18(3), 219-242.
- Bollnow, O. F. (1982). On silence — findings of philosophico-pedagogical anthropology. *Universitas*, 24(1), 41-47.
- Borson, S., Scanlan, J.M., Brush, M., Vitallano, P., & Dokmak, A. (2000). The Mini-Cog: A cognitive 'vital signs' measure for dementia screening in multi-lingual elderly.

International Journal of Geriatric Psychiatry, 15(11), 1021-1027.

- Borson, S., Scanlan, J.M., Chen, P., & Ganguli, M. (2003). The Mini-Cog as a screen for dementia: Validation in a population-based sample. *Journal of the American Geriatric Society*, 51(10), 1451-1454.
- Bramstedt, K. A. (2008). Destination nowhere: a potential dilemma with ventricular assist devices. *American Society for Artificial Internal Organs*, 54(1), 1-2.
- Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *American Society of Clinical Oncology*, 25(30), 4829-4834.
- Brush, S., Budge, D., Alharethi, R., McCormick, A. J., MacPherson, J. E., Reid, B. B.,...Abdallah, G. K. (2010). End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *Journal of Heart & Lung Transplant*, 29, 1337-1341.
- Brush, S., Budge, D., Alharethi, R., McCormick, A. J., MacPherson, J. E., Reid, B.,...Kfoury, A. (2010). End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *The Journal of Heart and Lung Transplantation*, 12, 1337-1341.
- Byram, E. K. (2012). Upstream palliative care for the patient with a left ventricular assist device as DT. *Dimensions in Critical Care Nursing*, 31(1), 18-24.
- Caldwell, P. H., Arthur, H. M., & Demers, C. (2007). Preferences of patients with heart failure for prognosis communication. *Canadian Journal of Cardiology*, 23(10), 791-796.
- Cangelosi, P. R. (2007). Voices of graduates from second-degree baccalaureate nursing programs. *Journal of Professional Nursing*, 23(2), 91-97.
- Caress, A., Luker, K., & Chalmers, K. (2010). Promoting the health of people with chronic

- obstructive pulmonary disease: patients' and caregivers' views. *Journal of Clinical Nursing*, 9, 564-573. doi: 10.1111/j.1365-2702.2009.02982.x.
- Caress, A.L., Luker, K. A., Chalmers, K. I., & Salmon, M. P. (2009). A review of the information and support needs of family caregivers of patients with chronic pulmonary disease. *Journal of Clinical Nursing*, 18, 479-491.
- Carter, C. L., Zapka, J. G., O'Neill, S., DesHarnais S., Hennessy, W., Kurent, J., & Carter, R. (2006). Physician perspectives on end-of-life care: Factors of race, specialty, and geography. *Palliative Support Care*, 4(3), 257-271.
- Cartwright, Y., & Booth, S. (2010). Extending palliative care to patients with respiratory Disease. *British Journal Hospital of Medicine*, 71, 16-20.
- Cashin, G. H., Small, S. P., & Solberg, S. M. (2008). The lived experience of fathers who have children with asthma: a phenomenological study. *Journal of Pediatric Nursing*, 23(5), 372-385.
- Casida, J. (2005). The lived experience of spouses of patients with a left ventricular assist device before heart transplantation. *American Journal of Critical Care*, 14, 145-151.
- Casida, J., Marcuccilli, L., & Peters (2011). Lifestyle adjustments of adults with long-term implantable left ventricular assist devices: A phenomenological inquiry. *Heart & Lung: the Journal of Acute and Critical Care*, 40(6), 511-520.
doi:10/1016/j.hrtlng.2011.05.002.
- Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist*, 42, 772-780.
- Chronic Obstructive Pulmonary Disease (2007). Retrieved from

<http://www.nih.gov/about/researchresultsforthepublic/COPD.pdf>.

- Clark, P. C., & Dunbar, S. B. (2003). Family partnership intervention: a guide for a family approach to care of patients with heart failure. *American Association of Critical Care Nurses Clinical Issues*, 14(4), 467-476.
- Clark, M. M., Rummans, T. A., Sloan, J. A., Jensen, A., Atherton, P. J., Frost, M. H.,...Brown, P. D. (2006). Quality of life of caregivers of patients with advanced stage cancer. *American Journal of Hospice and Palliative Care*, 23(3), 185-191.
- Cockerham, P. (2010). *Medical sociology* (11th ed.). Upper Saddle River, NJ: Prentice Hall.
- Cohn, L. H. (2003). Fifty years of open-heart surgery. *Circulation*, 107(17), 2158-2170.
doi: 10.1161/01.CIR.0000071746.50876
- Cosgriff, J. A., Pisani, M., Bradley, E. J., O'Leary, J. R., & Friend, T. R. (2007). The association between treatment preferences and trajectories of care at the end-of-life. *Journal of General Internal Medicine*, 22(11), 1586-1571.
- Creswell, J. W. (1998). *Qualitative inquiry and research design choosing among five traditions*. Thousand Oaks, CA: Sage.
- Crotty, M. (1997). Tradition and culture in Heidegger's Being and Time. *Nursing Inquiry*, 4(2), 88-98.
- Crow, S., John, R., Boyle, A., Shumway, S., Liao, K., Colvin-Adams, M.,...Joyce, L. (2009). Gastrointestinal bleeding rates in recipients of nonpulsatile and pulsatile left ventricular assist devices. *Journal of Thoracic Cardiovascular Surgery*, 137(1), 208-215.
- Dahlberg, K. M. E., & Dahlberg, H. K. (2004). Description vs. interpretation – a new understanding for an old dilemma in human science research. *Nursing Philosophy*, 5, 268-273.

- DeBakey, K. (1971). Left ventricular bypass pump for cardiac assistance. *American Journal of Cardiology*, 27, 3-11.
- Denzin, N. K., & Lincoln, Y. S. (2005). *The SAGE handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Dew, M. A., Kormos, R. L., Winowich, S., Nastala, C. J., Borovetz, H. S., Roth, L. J.,...Griffith, B. P. (1999). Quality of life outcomes in left ventricular assist system inpatients and outpatients. *American Society for Artificial Internal Organs*, 45(3), 218-225.
- Dew, M. A., Kormos, R. L., Winowich, S., Stanford, E. A., Carozza, L., & Borovetz, H. S.,...Griffith, B. P. (2000). Human factors issues in ventricular assist device recipients and their family caregivers. *American Society for Artificial Internal Organs*, 46(3), 367-373.
- Dew, M. A., Myaskovsky, L., Dimartini, A. F., Switzer, G. E., Schulberg, H. C., & Kormos, R. L. (2004). Onset, timing, and risk for depression and anxiety in family caregivers to heart transplant recipients. *Psychological Medicine*, 34, 1065-1082.
- Dougherty, C. M., Pyper, G., Au, D. H., Levy, W. C., & Sullivan, M. D. (2007). Drifting in a shrinking future: Living with advanced heart failure. *Journal of Cardiovascular Nursing*, 22(6), 480-487.
- Dracup, K., Evangelista, L., Doering, L., Tullman, D., Moser, K. K., & Hamilton, M. (2004). Emotional well-being in spouses of patients with advanced heart failure. *Heart and Lung*, 33, 354-361. doi: 10.1016/j.hrtlng.2004.06.003.
- Dudzinski, D. M. (2006). Ethics guidelines for DT. *Annals of Thoracic Surgery*, 81, p. 1185-1188. doi: 10.1016/j.athoracsur.2005.11.002.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion*

- and Health*, 23(3), 197-203.
- Dunbar, S. B., Clark, P. C., Quinn, C., Gary, R. A., & Kaslow, N. J. (2008). Family influences on heart failure self-care and outcomes. *Journal of Cardiovascular Nursing*, 23, 258–65.
- Eggenberger, S. K., & Nelms, T. P. (2007). Being family: the family experience when an adult member is hospitalized with a critical illness. *Journal of Clinical Nursing*, 16(9), 1618-1628.
- Elkington, H., White, P., Addington-Hall, J., Higgs, R., & Edmonds, P. (2005). The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*, 19, 485-491.
- Elkington, H., White, P., Higgs, R., & Pettinari, C. J. (2001). GPs views of discussions of prognosis in severe COPD. *Family Practitioner*, 18, 611-618.
- Emanuel, L. L., von Gunten, C. F., & Ferris, F. D. (2000). Gaps in end-of-life care. *Archives of Family Medicine*, 9, 1176-80.
- Esdaile, S. A. (2009). Valuing difference: caregiving by mothers of children with disabilities. *Occupational Therapy International*, 16(2), 122-133.
- Esmore, D., Kaye, D., Spratt, P., LARBalestier, R., Ruygrok, P., Tsui, S.,... Woodard, J. (2008). A prospective, multicenter trial of the VentrAssist left ventricular assist device for BTT: safety and efficacy. *Journal of Heart and Lung Transplant*, 27, 579-88.
- Evangelista, L. S., Dracup, K., Doering, L., Westlake, C., Fonarow, G. C., & Hamilton, M. (2002). Emotional well-being of heart failure patients and their caregivers. *Journal of Cardiac Failure*, 8(5), 300-305.
- Exley, C., Field, D., Jones, L., & Stokes, T. (2005). Palliative care in the community for cancer and end-stage cardiorespiratory disease: the view of the patients, lay-caregivers, and

health care professionals. *Palliative Medicine*, 19, 76-83.

Fang, C. Y., Manne, S. L., & Pape, S. J. (2001). Functional impairment, marital quality, and patient psychological distress as predictors of psychological distress among cancer patients' spouses. *Health Psychology*, 20, 452-457.

Federal Interagency Forum on Aging-Related Statistics (2010). Older Americans 2010: Key indicators of well-being. Federal interagency forum on aging-related statistics. Washington DC: U. S. Government Printing Office. Retrieved from http://www.agingstats.gov/agingstatsdotnet/Main_Site/Data/2010_Documents/Docs/OA_2010.pdf

Foster, M., & Chaboyer, W. (2003). Family caregivers of ICU survivors: A survey of the burden they experience. *Scandinavian Journal of Caring Science*, 17, 205–214.

Fried, T. R., & O'Leary, J. (2008). Using the experiences of bereaved caregivers to inform patient- and caregiver-centered advance care planning. *Journal of General Internal Medicine*, 23(10), 1602-1607. doi: 10.1007/s11606-008-0748-0.

Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatric Society*, 58, 2315-2322. doi: 10.1111/j.1532-5415.2010.03177.x.

Gasguoine, S. E. (2005). Mothering a hospitalized child: it's the 'little things' that matter. *Journal of Child Health Care*, 9(3), 186-195.

Genovese, E. A., Dew, M. A., Teuteberg, J. J., Simon, M. A., Kay, J., Siegenthaler, M. P.,...

Kormos, R. L. (2009). Incidence and patterns of adverse event onset during the first 60 days after ventricular assist device implantation. *Annals of Thoracic Surgery*, 88, 1162-1170.

- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar M. (2004).
Burden and depression among caregivers of patients with cancer at the end of life.
Oncology Nursing Forum, 31, 1105-1115.
- Goodlin, S. J. (2009). Palliative care in congestive heart failure. *Journal of the American College of Cardiology*, 54, 386-396. doi:10.1016/j.jacc.2009.02.078.
- Goodlin, S. J., Hauptman, P. J., Arnold, R., Grady, K., Hershgerger, R. E., Kutner, J.,...
Renlund, D. G. (2004). Consensus statement: Palliative and supportive care in
advanced heart failure. *Journal of Cardiac Failure*, 10(3), 200-209.
- Gott, M., Barnes, S., Parker, C., Payne, S., Seamark, D., & Gariballa, S., et al. (2006). Predictors
of the quality of life of older people with heart failure recruited from primary care. *Age
and Ageing*, 35(2), 172-177. doi:10.1093/ageing/afj040.
- Grady, K. L., Meyer, P., Mattea, A., Dressler, Ormaza, S., & White-Williams, C. (2002).
Predictors of quality of life at 1 month after implantation of a left ventricular assist
device. *American Journal of Critical Care*, 11, 345-352.
- Grady, K. L., Meyer, P., Mattea, A., White-Williams, C., Ormaza, S., & Kaan, et al. (2001).
Improvement in quality of life outcomes 2 weeks after left ventricular assist device
implantation. *The Journal of Heart and Lung Transplantation*, 20, 657-669.
- Grady, K. L., Meyer, P. M., Mattea, A., Dressler, D., Ormaza, & White-Williams, et al. (2003).
Change in quality of life from before to after discharge following left ventricular
assist device implantation. *The Journal of Heart and Lung Transplantation*, 22(11),
1254-1267.
- Grady, K. L., Meyer, P. M., Dressler, D., Mattea, A., Chillcott, & Loo, A., et al. (2004).
Longitudinal change in quality of life and impact on survival after left ventricular assist

device implantation. *Annals of Thoracic Surgery*, 77, 1321-1327.

doi:10.1016/j.authoracsur.2003.09.089.

- Grasso, M., Fenkel, J., Sorensen, E., & Felier, E. (2007). Gastrointestinal bleeding from arteriovenous malformations in recipients of left ventricular assist devices. *Journal of Cardiac Failure*, 13(6), S115.
- Guba, E. G., & Lincoln, Y. S. (1990). The alternative paradigm dialog. In E. G. Guba (Ed.), *The paradigm dialog* (pp. 17-30). Newbury Park, California: Sage Publications.
- Gure, T. R., Kabeto, M. U., Blaum, C. S., Langa, K. M. (2008). Degree of disability and patterns of caregiving among older Americans with congestive heart failure. *Journal of General Internal Medicine*, 23, 70–76.
- Gysels, M. H., & Higginson, I. J. (2009). Caring for a person in advanced illness and suffering from breathlessness at home: Threats and resources. *Palliative and Supportive Care*, 7,153-162. doi: 10.1017/S1478951509000200.
- Harding, R., & Higgins, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness? *Palliative Medicine*, 17, 63-74.
- Heidegger, M. (1962). *Being and time*. Translated by John MacQuarrie & Edward Robinson. New York: Harper and Row.
- Heidegger, M. (1968). *What is called thinking?* New York: Harper and Row.
- Heidegger, M. (1971). *Poetry, language, thought*. Translated by Albert Hofstadter. Perennial Classics, New York: NY.
- Herbert, R. S., Arnold, R. M., & Schulz, R. (2007). Improving well-being in caregivers of terminally ill patients: Making the case for patient suffering as a focus of intervention

- research. *Journal of Pain and Symptom Management*, 34, 539-546.
- Hippocratic Oath (2002). Retrieved from http://www.nlm.nih.gov/hmd/greek/greek_oath.html
- Hogness, J. R., & VanAntwerp, Eds. (1991). The artificial heart: Prototypes, polices, and patient. Committee to evaluate the artificial heart program of the national heart, lung, and blood institute. Division of health care services, institute of medicine. National Academy Press, Washington: DC. Retrieved from http://www.nap.edu/openbook.php?record_id=1820&page=208
- Holman, W., Kormos, R., Miller, M., Pagani, F., Blume, E., Cleeton, T.,...Edwards, L. (2009). Predictors of death and transplant in patients with a mechanical circulatory support device: A multi-institutional study. *Journal of Heart & Lung Transplant*, 28(1), 44-50.
- Hopp, F. P., & Duffy, S. A. (2000). Racial variations in end-of-life care. *Journal of the American Geriatric Society*, 48(6), 658-653.
- Hudson, P. L., Remedios, C., & Thomas, K. (2010). A systematic review of psychosocial interventions for family caregivers of palliative care patients. *BMC Palliative Care*, 9(17), 1-9.
- Hunt, S. A., Abraham, W.T., Chin, M. H., Feldman, A. M., Francis, G. S., Ganiats, T. G.,... Riegel, B. (2005). ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult –summary article. *Circulation*, 112, e154-e235.
- Hupcey, J. E., Penrod, J., & Fogg, J. (2009). Heart failure and palliative care: Implications in practice. *Journal of Palliative Medicine*, 12(6), 531-536. doi: 10.1089/jpm.2009.0010.
- Husserl, E. (1970). *The idea of phenomenology*. Norwell, MA: Kluwer Academic Publishers.

- Janssen, D. J., Spruit, M. A., Schols, J. M., & Wouters, E. F. (2010). A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. *Chest*, 139(5), p. 1081-1088.
- Jessup, M., Abraham, W. T., Casey, D. E., Feldman, A. M., Francis, G. S., Ganiats, T. G.,...Yancy, C. W. (2009). 2009 focused update incorporated into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults. A report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *Journal of the American College of Cardiology*, 53, 1343-1382. doi: 10.1016/j.jacc.2008.11.009.
- John, R., Kamdar, F., Liao, K., Colvin-Adams, M., Boyle, A., & Joyce, L. (2008). Improved survival and decreasing incidence of adverse events with the HeartMate II left ventricular assist device as BTT therapy. *Annals of Thoracic Surgery*, 86, 1227-1234.
- Kaan, A., Young, Q., Cockell, S., Mackay, M. (2010). Emotional experiences of caregivers of patients with a left ventricular assist device. *Progress in Transplantation*, 20(2), 142-147.
- Karmilovich, S. E. (1994). Burden and stress associated with spousal caregiving for individuals with heart failure. *Progressive Cardiovascular Nursing*, 9(1), 33-38.
- Kierkegaard, Søren. (2000). The essential Kierkegaard. H. Hong & E. Hong (Eds.). Princeton, New Jersey: Princeton University Press.
- Kirklin, J. K., Naftel, D. C., Myers, S. L., Clark, M. L., Collum, S. C., & Zhang, S. (2011). Interagency Registry for Mechanically Assisted Circulatory Support: Quarterly Statistical Report, Implant dates: June 23, 2006 – September 30, 2011. Retrieved from [http://www.uab.edu/ctsresearch/intermacs/Document%20Library/INTERMACS%20Federal%20Partners%20Quarterly%20Report%20September%202010%20website%20\(2\).pdf](http://www.uab.edu/ctsresearch/intermacs/Document%20Library/INTERMACS%20Federal%20Partners%20Quarterly%20Report%20September%202010%20website%20(2).pdf)

- Koch, T. (1995). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21, 827-836.
- Kolanowski, A. M., Fick, D., Waller, J. L., & Shea, D. (2004). Spouses of persons with dementia: Their healthcare problems, utilization, and costs. *Research in Nursing Health*, 27, 296-306.
- Kozachik, S. L., Given, C. W., Given, B. A., Pierce, S. J., Azzouz, F., Rawl, S. M., & Champion, V. L. (2001). Improving depressive symptoms among caregivers of patients with cancer: Results of a randomized clinical trial. *Oncology Nursing Forum*, 28, 1149-1157.
- Kramer, B. J. (1997). Gain in the caregiving experience: What are we? What next? *The Gerontologist*, 37, 218-232.
- Krishnamani, R., DeNofrio, D., Konstam, M. A. (2010). Emerging ventricular assist devices for long-term cardiac support. *National Revolutions in Cardiology*, 7(2):71-6.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- LeCompte, M. D., & Schensul, J. J. (Eds.) (1997). *Designing and conducting ethnographic research*. (Volume 1 of Ethnographer's toolkit). Walnut Creek, CA: Altamira Press, a subsidiary of Sage Publications.
- Levenson, J. W., McCarthy, E. P., Lynn, J., Davis, R. B., & Phillips, R. S. (2000). The last six months of life for patients with congestive heart failure. *Journal of the American Geriatric Society*, 48(5 Suppl), S101-109.
- Lietz, K., Long, J. W., Kfoury, A. G., Slaughter, M. S., Silver, M. A., Milano, C. A.,...Miller, L. W. (2007). Outcomes of left ventricular assist device implantation as destination therapy in the post-REMATCH Era: Implications for patient selection. *Circulation*, 115, 497-505.

- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- Liotta, D., Hall, C. W., Henly, W. S., Cooley, D. A., Crawford, E. S.,... (1963). Prolonged assisted circulation during and after cardiac or aortic surgery. Prolonged partial left ventricular bypass by means of intracorporeal circulation. *American Journal of Cardiology*, 12, 399-405.
- Long, J. W., Healy, A. J., Rasmussom, B. Y., Cowley, C. G., Nelson, K. E., Kfoury, A. G.,...Renlund, D. G. (2008). Improving outcomes with long-term “destination” therapy using left ventricular assist devices. *Journal of Thoracic Cardiovascular Surgery*, 135 (6), 1353-1361. doi:10.1016/j.jtcvs.2006.09.124.
- Long, J. W., Kfoury, A. G., Slaughter, M. S., Silver, M., Milano, C., & Rogers, J., et al. (2005) Long-term DT with the HeartMate XVE left ventricular assist device: Improved outcomes since the REMATCH study. *Chronic Heart Failure*, 11, 133-138.
- Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A.,...Shekelle, P. G. (2008). Evidence for improving palliative care at the end of life: a systematic review. *Annals of Internal Medicine*, 148(2), 147-159.
- Lu, Y. Y., & Wykle, M. (2007). Relationships between caregiver stress and self-care behaviors in response to symptoms. *Clinical Nursing Residency*, 16, 29-43.
- Luttik, M. L., Blaauwbroek, A., Dijker, A., & Jaarsma, T. (2007a). Living with heart failure: Partner perspectives. *Journal of Cardiovascular Nursing*, 22(2), 131-137.
- Luttik, M. L., Jaarsma, T., Veeger, N., Tijssen, Sanderman, & van Veldhuisen, D. J. (2007b). Caregiver burden in partners of heart failure patients: limited influence of disease severity. *The European Journal of Heart Failure*, 9, 695-701.

doi:10.1016/j.eheart.2007.01.006.

- Luttik, M. L., Jaarsma, T., Veeger, N. J. G. M., & van Veldhuisen, D. J. (2005). For better and for worse: quality of life impaired in HF patients as well as in their partners. *European Journal of Cardiovascular Nursing*, 4, 11-14. doi: 10.1016/j.ejcnurse.2004.12.002.
- Lutzky, S. M., & Knight, B. G. (1994). Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychological Aging*, 9(4), 513-519.
- MacIver, J., Rao, V., Delgado, D., Desai, N., Nimesh, D., Ivanov, J.,...Ross, H. J. (2008). Choices: a study of preferences for end-of-life treatments in patients with advanced heart failure. *Journal of Heart & Lung Transplant*, 27, 1002-1007.
- Maher, T. R., Butler, K. C., Poirier, V. L., & Gernes, D. B. (2001). HeartMate left ventricular assist devices: A multigeneration of implanted blood pumps. *Artificial Organs*, 25(5), 422-426.
- Mahoney, J. S. (2001). An ethnographic approach to understanding the illness and experiences of patients with congestive heart failure and their family members. *Heart Lung*, 30(6), 429-436.
- Mancini, D., & Lietz, K. (2010). Selection of cardiac transplantation candidates in 2010. *Circulation*, 122, 173-183.
- Marcuccilli, L., & Casida, J. (2011a). Sex and intimacy among patients with implantable left-ventricular assist devices. *The Journal of Cardiovascular Nursing*, 26(6), 504-511.
- Marcuccilli, L., & Casida, J. (2011b). From insiders' perspectives: Adjusting to caregiving for patients with LVADs. *Progress in Transplantation*, 21(2), 137-143.
- Marcuccilli, L., & Casida, J. (2012). Overcoming alterations in body image imposed by the

- LVAD: A case report. *Progress in Transplantation*, in press.
- Marcuccilli, L., Casida, J., & Peters, R. M. (2012). Modification of self-concept in patients with an LVAD: An initial exploration. *Journal of Clinical Nursing*, in press.
- Martensson, J., Dracup, K., & Fridlund, B. (2001). Decisive situations influencing spouses' support of patients with heart failure: a critical incident technique analysis. *Heart Lung*, 30(5), 341-350.
- Matheny, S.C., Mehr, L. M., & Brown, G. (1997). Caregivers and HIV infection services and issues. *Primary Care*, 24, 677-690.
- Maxton, F. J. (2008). Parental presence during resuscitation in the PICU: the parents' experience. Sharing and surviving the resuscitation: a phenomenological study. *Journal of Clinical Nursing*, 17(23), 3168-3176.
- McCarthy, E. P., Pencina, M. J., Kelly-Hayes, M., Evans, J. C., Oberacker, E. J., D'Agostino, R. B.,...Murabito, J. M. (2008). Advance care planning and health care preferences of community-dwelling elders: The Framingham Heart Study. *The Journal of Gerontology. Series A, Biological Sciences and Medical Sciences*, 63(9), 951-959.
- McHorney, C. A., Ware, J. E., Jr., Lu, L. F., & Sherbourne, C. D. (1994). The MOS 36-item short form health survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care*, 32(1), 40-66.
- Mehra, M., Kobashigawa, J., Starling, R., Russell, S., Uber, P., Parameshwar, J.,...Barr, M. (2006). Listing criteria for heart transplantation: International Society for Heart and Lung Transplantation Guidelines for the care of cardiac transplant candidates. *Journal of Heart Lung Transplant*, 25, 1024-1042.
- Melnyk, B. M., & Finout-Overholt, E. (2004). *Evidence-based practice in nursing & health*

- care*. Philadelphia: Lippincott Williams & Wilkins.
- Merleau-Ponty, M. (2002). *Phenomenology of perception*. New York, NY: Routledge Classics.
- Milano, C. A., Lodge, A. J., Blue, L. J., Smith, P. K., Felker, G. M., Hernandez, A. F.,...
Rogers, A. G. (2006). Implantable left-ventricular assist devices: New hope for patients with end-stage heart failure. *North Carolina Medical Journal*, 67(2), 110-115.
- Moene, M., Bergbom, I., & Skott, C. (2006). Patients' existential situation prior to colorectal surgery. *Journal of Advanced Nursing*, 54(2), 199-207.
- Molloy, G. J., Johnston, D. W., & Whitham, M. D. (2005). Family caregiving and congestive heart failure: review and analysis. *European Journal of Heart Failure*, 7, 592-603.
- Morse, J. M., & Richards, L. (2002). *Read me first for a user's guide to qualitative methods*. Thousand Oaks, CA: Sage Publications.
- Morse, J. (1994). Designing funded qualitative research. In N. K., Denzin, & Y. S., Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 220-235). Thousand Oaks, CA: Sage.
- Moskowitz, A. J., Weinberg, M. S., Oz, M. C., & Williams, D. L. (1997). Quality of life with an implanted left ventricular assist device. *Annals of Thoracic Surgery*, 64, 1764-1769.
- Munhall, P. L. (1994). *Revisioning phenomenology: Nursing and health science research*. New York: National League for Nursing Press
- Murray, S. A., Boyd, K., Kendall, M., Worth, A., Benton, T. F., & Clausen, H. (2002). Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their caregivers in the community. *British Medical Journal*, 325(7370), 929-979.
- Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, 330, 1007-1011.
- National Consensus Project. (2004). What is palliative care? Retrieved from

<http://www.nationalconsensusproject.org/DisplayPage.aspx?Title=What%20Is%20Palliative%20Care?>

National Family Caregiver Association. (2009). Caregiving statistics. Retrieved from http://www.thefamilycaregiver.org/who_are_family_caregivers/care_giving_statistics.cfm.

National Institute of Nursing Research (2006). *The NINR strategic plan 2006-2010*. Retrieved from http://www.ninr.nih.gov/NR/rdonlyres/9021E5EB-B2BA-47EA-B5DB-1E4DB11B1289/4894/NINR_StrategicPlanWebsite.pdf.

Nguyen, D. Q., & Thourani, V. H. (2010). Third-Generation Continuous Flow Left Ventricular Assist Devices. *Innovations: Technology & Techniques in Cardiothoracic & Vascular Surgery*, 5(4), 250-258. doi: 10.1097/IMI.0b013e3181ee77a1.

Oberst, M. T., Thomas, S. E., Grass, K. A., & Ward, S. E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing*, 12, 209-215.

Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR). (2011). OPTN/SRTR 2010 Annual data report. Rockville, MD: Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation. Retrieved from http://www.srtr.org/annual_reports/2010/waitlist_outcomes.htm.

Pagani, F. D., Long, J. W., Dembitsky, W. P., Joyce, L. D., & Miller, L. W. (2006). Improved mechanical reliability of the HeartMate XVE left ventricular assist system. *Annals of Thoracic Surgery*, 82, 1413-1419.

- Pagani, F. D., Miller, L. W., Russell, S. D., Aaronson, K. D., Boyle, J. R., Conte, J. V.,...
Frazier, O. H. (2009). Extended mechanical circulatory support with a continuous flow rotary left ventricular assist device. *Journal of the American College of Cardiology*, *54*, 312-321.
- Park, S. J., Tector, A., Piccioni, W., Raines, E., Gelihns, A., Moskowitz, A.,...Dembitsky, W. (2005). Left ventricular assist devices as DT: A new look at survival. *Journal of Thoracic and Cardiovascular Surgery*, *129*, 9-17. doi:10.1016/j.jtcvs.2004.04.044.
- Pihl, E., Jacobsson, A., Fridlund, B., Strömberg, & Mårtensson, J. (2005). Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study. *European Journal of Heart Failure*, *7*(4), 583-589.
- Pinquart, M., & Sorenson, S. (2003). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Journal of Gerontology B Psychology Science Social Science*, *58*(2), P112-P128.
- Pinquart, M., & Sorenson, S. (2006). Gender differences in caregiver stressors, social resources and health: an updated meta-analysis. *Journal of Gerontology: Psychological Sciences*, *61*(1), 33-45.
- Pirraglia, P. A., Bishop, D., Herman, D. S., (2005). Caregiver burden and depression among informal caregivers of HIV-infected individuals. *Journal of General Internal Medicine*, *20*, 510-514.
- Pressler, S. J., Gradu-Pizlo, I., Chubinski, S. D., Smith, G., Wheller, S., & Wu, J., et al. (2009). Family caregiver outcomes in heart failure. *American Journal of Critical Care*, *18*(2), 149-159. doi: 10.4037/ajcc2009300.
- Quaglietti, S., Pham, M., & Froelicher, V. (2005). A palliative care approach to the advanced

- heart failure patient. *Current Cardiology Reviews*, 1, 45-52.
- QSR. (2010). *NVivo 9. Using the Software*. Cambridge, MA: QSR International.
- Rees, J., O'Boyle, C., & MacDonagh, R. (2001). Quality of life: impact of chronic illness on the partner. *Journal of the Royal Society of Medicine*, 94, 563–566.
- Rizzieri, A. G., Verheijde, J. L., Rady, M. Y., & McGregor, J. L. (2005). Ethical challenges with the left ventricular assist device as a DT. *Philosophy, Ethics, and Humanities in Medicine*, 3(20). doi: 10.1186/1747-5341-3-20.
- Rohrbaugh, M. J., Cranford, J. A., Shoham, V., Nicklas, J. M., Sonnega, J. S., & Coyne, J. C. (2002). Couples coping with congestive heart failure: role and gender differences in psychological distress. *Journal of Family Psychology*, 16(1), 3-13.
- Rose, E. A., Moskowitz, A. J., Packer, M., Sollano, J. A., Williams, D. L., Tierney, A. R.,...Gelijns, J. C. (1999). The REMATCH trial: Rationale, design, and end points. *Annals of Thoracic Surgery*, 67, 723-730.
- Rose, E. A., Gelijns, A. C., Moskowitz, A. J., Heitjan, D. F., Stevenson, L. W., Dembitsky, W.,... Meier, P. (2001) Long-term use of a left ventricular assist device for end-stage heart failure. *New England Journal of Medicine*, 345, 1435-1443.
- Roy, C. (1988). An explication of the philosophical assumptions of the Roy adaptation model. *Nursing Science Quarterly*, 1, 26-34.
- Roy, C., & Andrews, H. A. (1991). *The Roy adaptation model: The definitive statement*. Norwalk, CT: Appleton & Lange.
- Roy, C., & Andrews, H. A. (1999). *The Roy adaptation model* (2nd ed.). Norwalk, CT: Appleton & Lange.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research

- revisited. *Advances in Nursing Science*, 16(2), p. 1-8.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing and health*, 18(2), 179-183.
- Saraiya, B., Bodnar, S., Leventhal, E., & Leventhal, H. (2008). End-of-life planning and its relevance for patients' and oncologists' decisions in choosing cancer therapy. *Cancer*, 113(Suppl. 12), 3540-3547.
- Saunders, M. M. (2008). Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research*, 30(943), 943-959.
doi: 10.1188/0193945908319990.
- Saunders, M. M. (2009). Indicators of health-related quality of life in heart failure family caregivers. *Journal of Community Health Nursing*, 26, 173-182.
doi: 10.1080/07370010903259196.
- Saunders, M. M. (2010). Working and caregiving. *Holistic Nursing Practice*, 24(1), 16-22.
- Savage, L. S., & Canody, C. (1999). Life with a left ventricular assist device: the patients' perspective. *American Journal of Critical Care*, 8(5), 340-343.
- Schwarz, K. A., & Dunphy, G. (2003). An examination of perceived stress in family caregivers of older adults with heart failure. *Experimental Aging Research*, 29(2), 221-235.
- Schwarz, K. A., & Elman, C. S. (2003). Identification of factors predictive of hospital readmissions of patients with heart failure. *Heart and Lung*, 32(2), 88-99.
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 54, 240-249.
- Shumacker, H. B. Jr. (1994). A surgeon to remember: notes about Vladimir Demikhov. *The*

- Annals of Thoracic Surgery*, 58, 1196-1198.
- Schaffer, J. M., Allen, J. G., Weiss, E. S., Arnaoutakis, G. J., Patel, N. D., Russell, S. D.,...
Conte, J. V. (2010). Infectious complications after pulsatile-flow and continuous
flow left ventricular assist device implantation. *Journal of Heart Lung Transplantation*,
30(2), 164-174.
- Scott, L. D. (2000). Caregiving and care receiving among a technologically dependent heart
failure population. *Advances in Nursing Science*, 23(2), 82-97.
- Selman, L., Harding, R., Beynon, T., Hodson, F., Coady, E., Hazeldine, C.,...Higginson, I. J.
(2007). Improving end-of-life care for patients with chronic heart failure: "Let's hope
it'll get better, when I know in my heart of hearts it won't." *Heart*, 93, 963-967.
doi: 10/1136/hrt.2006.106518.
- Sharples, L. D., Cafferty, F., Demitis, N., Freeman, C., Dyer, M., Banner, N.,...Buxton, M.
(2007). Evaluation of the clinical effectiveness of the Ventricular Assist Device Program
in the United Kingdom (ELVAD UK). *Journal of Heart & Lung Transplant*, 26, 9-15.
- Simon, J. R., & Fischbach, R. L. (2008). "Doctor, will you turn off my LVAD?" *Hastings
Center Report*, 38(1), 14-15. doi: 10/1353/hcr.2008.0002.
- Slaughter, M. S., Rogers, J. G., Milano, C. A., Russell, S. D., Conte, J. V., Feldman, D.,...
Frazier, O. H. HeartMate II Investigators. (2009). Advanced heart failure treated with
continuous-flow ventricular assist device. *New England Journal of Medicine*, 361(23),
2241-2251 doi: 101056/NEHMoA0909938.
- Smith, D. W. (2011). Phenomenology. *In the stanford encyclopedia of philosophy*. E. N. Zalta,
(Ed.). Retrieved from
<http://plato.stanford.edu/archives/fall2011/entries/phenomenology/>.

- Stahovich, M., Chillcott, S., & Dembitsky, W. P. (2007). The next treatment option: Using ventricular assist devices for heart failure. *Critical Care Nurse Quarterly*, 30(4), 337-346.
- Stehlik, J., Edwards, L. B., Kuchervavava, A. Y., Aurora, P., Christie, J. D. Kirk, R.,...Hertz, M. L. (2010). The Registry of the International Society for Heart and Lung Transplantation: Twenty-seventh official adult heart transplant report—2010. *The Journal of Heart and Lung Transplantation*, 29(10), 1090-1103.
- Stevenson, L. W., Schulman, K. A., Platt, J., Pennington, D. G., Lorell, B., Klesges,...Willman, V. L. (1999). Expert panel review of the NHLBI total artificial heart (TAH) program, June 1998-November 1999. Retrieved from <http://www.nhlbi.nih.gov/resources/docs/tahrpt.pdf>
- Swetz, K. M., Freeman, M. R., AbouEzzeddine, O. F., Carter, K. A., Boilson, B. A., Ottenberg, A. L.,...Mueller, P. S. (2011a). Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as DT. *May Clinic Procedures*, 86(6), 493-500.
- Swetz, K. M., Ottenberg, A. L., Freeman, M. R., & Mueller, P. S. (2011b). Palliative care and end-of-life issues in patients treated with left ventricular assist devices as DT. *Current Heart Failure Reports*, 8, 212-218. doi: 10.1007/s11897-011-0060-x.
- Swiger, H. (2002). Hospice care and the institutional barriers to its success: An issues paper developed for NHPCO's Public Policy Committee. Retrieved from <http://www.nhpco.org>.
- Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advanced directives and quality of end-of-life care: A national study.

- Journal of the American Geriatric Society*, 55, 189-194.
- Tierney, W. M., Dexter, P. R., Gramelspacher, G. P., Perkins, A. J., Zhou, X. H., & Wolinsky, F. D. (2001). The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16, 32-40.
- Travis, S. S., Bernard, M., & Dixon et al. (2002). Obstacles to palliation and end-of-life care in a long-term care facility. *The Gerontologist*, 42(3), 342-9.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: SUNY Press.
- van Manen, M. (2010). Phenomenology online. Retrieved from <http://www.phenomenologyonline.com/>.
- von Gunten, C. F. (2002). Secondary and tertiary palliative care. *Journal of the American Medical Association*, 287(7), 875-81.
- von Guten, C. F., Ferris, F. D., & Emanuel, L. L. (2000). The patient-physician relationship. Ensuring competency in end-of-life care: communication and relational skills. *Journal of the American Medical Association*, 284(23), 3051-3057.
- Waterworth, S., & Gott, M. (2010). Decision making among older people with advanced heart failure as they transition to dependency and death. *Current Opinion in Supportive and Palliative care*, 4, 238-242.
- West, R. L., Hernandez, A. F., O'Connor, C. M., Starling, R. C., & Califf, R. M. (2010). A review of dyspnea in acute heart failure syndromes. *American Heart Journal*, 160, 209-214.
- Willette-Murphy, M., Todero, C., & Yeaworth, R. (2006). Mental health and sleep of older wife caregivers of spouses with Alzheimer's disease and related disorders. *Issues in Mental*

Health Nursing, 27, 837-852.

World Health Organization. (2010). WHO definition of palliative care. Retrieved from

<http://www.who.int/cancer/palliative/defintion/en/>.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among caregivers:

A review and analysis. *The Gerontologist, 40(2), 147-164.*

ABSTRACT**PATIENTS' AND CAREGIVERS' INSIDE PERSPECTIVES: LIVING WITH A LEFT-VENTRICULAR ASSIST DEVICE AS DT**

by

LINDA MARCUCCILLI, MSc, RN**August 2012****Advisor:** April Vallerand, PhD, RN, FAAN**Major:** Nursing**Degree:** Doctor of Philosophy

Left-ventricular assist devices (LVADs) have improved the quality of life for many patients with advanced heart failure. Past research focused on technology issues and survival rates, but patients' and caregivers' perspectives of living with an LVAD as a destination therapy (e.g., permanent alternative to transplant) was not explored. Roy's adaptation model provided a framework to guide an understanding of how participants adjusted and accepted living with destination therapy. A hermeneutic-phenomenology as described by van Manen was used to explore and describe the essence of destination therapy from patients' and caregivers' perspectives in order to understand the meaning of this experience. Data saturation was achieved with 14 participants (7 men as patients, 71-76 years old; 1 man and 6 women as caregivers, 50-74 years old), who lived with destination therapy at home. Data was collected using open-ended interviews, thematic analysis was ongoing, and final themes were consensually validated. Procedures to ensure trustworthiness are described. Themes were consistent with Roy's adaptation model. Participants illustrated a process of adjustment and eventually accepted the LVAD as part of their lives. Patients adjusted to the LVAD as part of their bodies, accepted the

device as necessary to live, and exhibited an improved quality of life. Caregivers described persistent worry and stress and accepted caregiving as part of life. Dyadic perspectives reflected gratefulness for more time to live despite uncertainties about death and dying. Findings advance the knowledge of destination therapy management. These findings may direct a holistic approach to palliative and end of life care, and can heighten nurses' awareness about the process of adaptation as a vital component for the promotion and maintenance of health and well-being among this growing population.

Key words: left-ventricular assist devices, destination therapy, caregivers, hermeneutic phenomenology, Roy Adaptation Model.

AUTOBIOGRAPHICAL STATEMENT

As I reflect upon the words set forth by van Manen in my preface, I was ‘struck with wonder,’ even ‘rendered speechless,’ as participants’ recounted their lives and experiences of living with DT. Being given the opportunity to hear the stories of participants’ experiences of living with a such a life-sustaining device has clearly affected me emotionally, but I am still Linda – a woman, a wife, a mom, a spiritual human being, and a nurse scientist. Yes, the stories of my participant struggles, thoughts, beliefs, and brushes with death, have clearly affected me in ways that are indescribable. But in the end, I learned to embrace the external forces which come our ways in unexpected ways – to turn to my family for support, believe in myself, who I am, and the work I’m going to do to help those afflicted with life-limiting illnesses and their caregivers. My new self-portrait (Figure B19) reflects an infectious enthusiasm for a life filled with unknowns and hopes for a productive and successful career in meeting the needs of those who need it most.