SATISFACTION WITH PATIENT-CENTERED CARE AND SELF-CARE EDUCATION IN LEFT VENTRICULAR ASSIST DEVICE PATIENTS

By

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This work is dedicated to Judy Widmar: a great mother, friend, and cheerleader. Thank you for believing in me, for teaching me determination and perseverance, and for always encouraging me to follow my dreams.

I miss you, Mom.

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CHAPTER I

Introduction

This chapter introduces the phenomenon of satisfaction with patient-centered care and self-care education in the ventricular assist device (VAD) patient. The PI will discuss the significance of the phenomenon and will provide its need for study. A statement of the problem relative to what is currently unknown within the phenomenon and the purpose for study will be presented. In addition, developed research questions relative to the phenomenon will be discussed.

Significance

*Significance to society***.** The significance of the phenomenon of interest to society in general is supported by (1.) the increasing indications and applications of VAD therapy to heart failure patient populations, (2.) the evolution of pump design allowing for home care and self-management, (3.) the demanding self-care requisites necessary for independence and successful self-care after hospital discharge, and (4.) the potential for psychosocial burden for both patient and caregiver relative to self-care without further exploration of patient preparation for self-care. The following discussion describes each of these elements.

1. Indications for application of VAD therapy may increase as the incidence of patients with congestive heart failure (CHF) increases. CHF is a chronic syndrome that, according to the American Heart Association (AHA), is diagnosed in approximately

670,000 new patients each year (Lloyd-Jones et al., 2010). The risk of developing heart failure increases with age, and as one of the largest cohorts of the American population, the “baby boomer” generation, ages, the potential for increase in people living with heart failure is great; the demand for heart failure care upon the US healthcare system could grow exponentially (Moser & Riegel, 2001). Every year, approximately 2,800 Americans await a life-saving heart transplant to address failing heart function, but less than 1,900 hearts are typically available (OPTN, 2011). Advanced heart failure patients who are not among those fortunate enough to be transplanted immediately must wait for life-saving surgery; the average waiting period was noted as 230 days in 2008(OPTN, 2011). These patients must rely on an alternative means of survival (Boley, Curtis, Walls, & Schmaltz, 1989; Stahovich, Chillcott, & Dembitsky, 2007).

In the US, 1,420 patients began receiving such therapy in 2010 (INTERMACS, 2011). Patients who receive VAD support are twice as likely to survive to transplant as those who receive medical management alone (Rose et al., 2001). Previous research has shown that the use of the VAD device in patients with advanced heart failure resulted in reduction of heart failure symptoms, multi-organ dysfunction, and improved quality of life (Rose et al., 2001). The United States Food and Drug Administration has been approved the VAD device for use as destination therapy (DT) – a means of chronic support for patients who may not be candidates for cardiac transplantation. The increasing numbers of individuals diagnosed with advanced heart failure now have more options for therapy.

Successful self-management and care following VAD implantation is crucial to the application of the VAD as a chronic supportive therapy in lieu of transplantation. In addition to the use of the device as a bridge to transplantation, VAD use could potentially offset the supply versus demand imbalance in patients currently waiting for suitable donor organs for transplantation, and offer an advanced option for therapy for individuals who may not be suitable for transplant. To successfully live at home on mechanical cardiac support, a patient and caregiver must demonstrate clinical competence of basic management skills in the absence of advanced healthcare providers. A measurement of patient satisfaction with self-care education processes could evaluate healthcare system efforts to assist patients in mastering self-care requisites and could support end-outcomes such as life satisfaction, quality of life, and improved heart failure symptoms and level of functioning.

2. Device manufacturers of VAD systems have evolved their designs and after implantation, patients may be successfully discharged to home. Changes in VAD pump size and pump physiology have introduced support devices that are suitable for a variety of patients. Many VAD pumps are now entirely contained within the body. The VAD pump cannulates or attaches to the heart from ventricle to aorta. The VAD is electrically activated through an external power source. The power source is a power-base unit (PBU), which connects to an electrical outlet. The VAD device may also be powered by portable battery, allowing the patient improved mobility and functionality. As a result, a greater number of CHF patients are able to be successfully discharged from hospital settings and may seek follow-up care as outpatients, maintaining and supporting

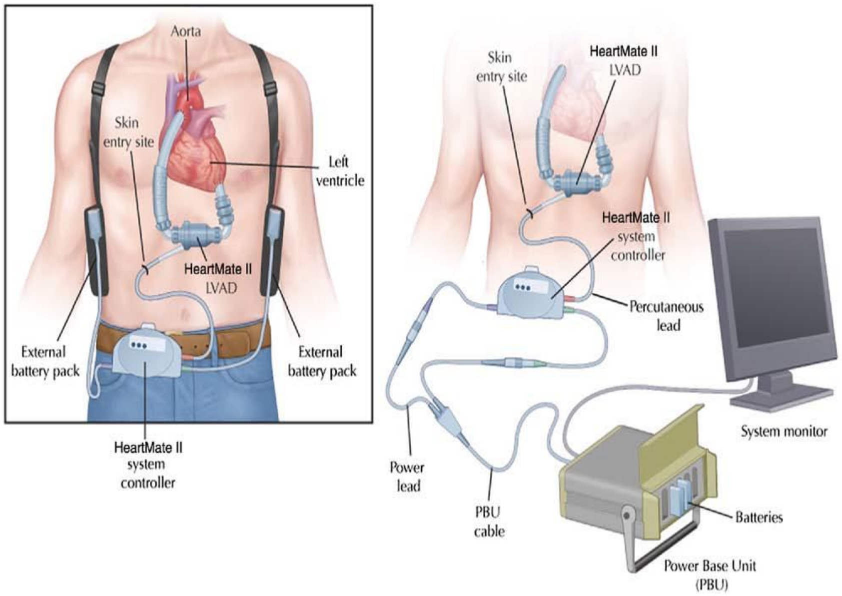
themselves and the VAD device at home. Discharge from hospital to home is contingent upon successful evaluation of self-care methods necessary for VAD maintenance. Self-care requisite education generally comprises nursing care management and self-monitoring for device complications, in addition to the continued self-management of heart failure (J. Casida, 2005).

3. Self-care requisites necessary for independence and successful self-care after hospital discharge are demanding and time-intensive. Daily maintenance and monitoring of the VAD requires psychomotor and cognitive skills in order to properly self-manage the device as well as to allow for independence and activities of daily living. Self-care behaviors required for VAD therapy include wound care of the VAD exit site, immobilization of the VAD exit site (to promote healing), exchange of power sources from battery to power-base unit (PBU), daily diagnostic self-testing and evaluation of the VAD alarm recognition system, safety precautions and emergency interventions (Mason & Konicki, 2003).

4. Self-care demands may seem daunting to the VAD patient and primary caregiver. The potential for psychosocial burden relative to self-care, without further exploration of patient preparation for self-care, may increase feelings of uncertainty and anxiety as discharge approaches. In qualitative studies of patients living with VAD therapy, patients have described experiencing emotional distress related to the device implantation. Patients noted an overwhelming feeling of helplessness after VAD implantation surgery; they realized just how severe their heart failure disease had become (J. Casida, 2005; Savage & Canody, 1999). Several patients and their family members

described feelings of fear and anxiety about the VAD device itself; patients noted a sense of worry about life changes required for living with the VAD device. Fear of the surgical procedure was also a major source of stress (J. Casida, 2005). After discharge from the hospital, patients were relieved to leave the hospital for home, though adapting to daily life with the VAD device was difficult. Continuing to apply VAD self-care knowledge and skills was stressful, as neither patients nor their primary caregivers felt proficient or confident in their abilities (J. Casida, 2005; Savage & Canody, 1999).

Figure 1. Illustration of the Heartmate II left ventricular assist device (LVAD) system. The tunneled driveline exits the abdomen in the right upper quadrant, connecting to a system controller and an external power source. Battery connections (shown on left) and power base unit (PBU) (shown on right) may be used for device power. Adapted from Wilson et al. (2009), used with permission.



*Significance to healthcare***.** The significance of the phenomenon of interest to healthcare is supported by (1.) the need to assess and improve cost-effectiveness of VAD therapy, (2.) the need to evaluate and modify organizational use of resources, (3.) the need to measure patient satisfaction with care and self-care education after VAD implantation as an assessment of patient-centered care quality, and (4.) the potential for new knowledge gained from research to be applied to like phenomena. The following discussion will describe each of these elements.

1. Cost of VAD care is an important consideration in quality improvement efforts. The estimated direct and indirect costs for heart failure care in the United States was $503.2 billion in 2010(Lloyd-Jones et al., 2010). The actual burden of heart failure is greater in elderly patients, with the majority of CHF-related hospitalizations and CHF-related deaths occurring among those 65 years of age or older (Liao et al., 2006). The financial impact of ventricular assist device therapy, both as a bridge to transplantation (BTT) or as a destination therapy (DT), is an important outcome for society, third-party payers and hospital providers to consider (Miller et al., 2006). Ethically, the cost-effectiveness analysis of a life-saving therapy is difficult, and cardiac transplantation or mechanical support requires a social, psychological and financial capability for effective therapy to be sustained (Bieniarz & Delgado, 2007). Despite ethical considerations, hospital organizations and third-party payers must continue to provide cost-effective, quality care. Bieniarz et al. (2007) state that the total Medicare cost for DT LVAD use is much smaller when compared with other means of life-supporting therapy, such as hemodialysis for renal failure. The annual cost of DT versus hemodialysis was $90

million and $12.7 billion, respectively. Most other research of cost-effectiveness of VAD therapy has concluded that VAD therapy costs, both BTT and DT, are similar to other life-saving therapeutic interventions (Miller et al., 2006; Oz et al., 2003).

There is very little research exploring the cost-effectiveness of VAD therapy. Most research has included cost summations and then compared data with costs of other treatment modalities. The absence of long-term data relating to cost implications of VADs used for DT makes it difficult to determine cost-effectiveness; most research regarding cost of VAD care have used modeled data and hypothetical situations (Hutchinson et al., 2008). In one study of destination therapy patients, a cost per quality adjusted life year (QALY) reported was approximately between $36,000 and $59,000. Considering the stated willingness to pay threshold of $59,000 per QALY, the authors supported the cost-effectiveness of VAD support as a destination therapy (Hutchinson et al., 2008). Based upon initial costs of VAD therapy and cardiac transplantation provided by Moskowitz et al. (2001), after adjustment for inflation, the average cost per patient within the first year after VAD implantation, inclusive of surgery, VAD device and supplies, and professional care costs, is $282,551.83. The adjusted cost for cardiac transplantation within the first year is approximately $269,052.03 (http://data.bls.gov/cgi-bin/cpicalc.pl).

Factors influencing cost for long-term VAD support were identified as pump longevity and device reliability, evolution of VAD support technology, hospital length of stay and readmission rates (Moskowitz, Rose, & Gelijns, 2001). By expanding the potential application of VAD support to patients waiting for or ineligible for transplantation, the market and use of VAD devices has greatly increased. Though comparable to and even less expensive than other life-sustaining therapies, it is the aggregate costs of treatment that can ultimately become high enough to have adverse effects in other areas of social welfare and reform (Douglas, Morgan, Lee, & Foster, 2004). Such aggregate costs for care may include continued outpatient VAD support, overall hospital length of stay and readmission rates attributed to device malfunction or site infection.

Though initial outcomes of VAD therapy were questionable, with considerable cost to the healthcare system with ambiguous results, the improving surgical implantation techniques, industry competition to develop more durable and efficient technology, and improved patient selection for this therapy has continued to improve clinical outcomes (Oz et al., 2003). Healthcare providers must assure third-party payers that application of the LVAD, as destination therapy, is a valuable investment. As third-party payers continue to see improvements in clinical outcomes, quality of life and efforts at cost-containment, reimbursement for DT therapies may continue to improve.

2. Two of the largest influences upon cost and use of hospital resources for VAD patient care are hospital length of stay and hospital readmissions, adding additional expense to an anticipated cost of more than $200,000 in the first year after implantation (Moskowitz et al., 2001). To reduce the duration and frequency of care, patient self-care management must be efficient and effective. Education for device management could possibly require the largest amount of resources necessary for VAD patient care. Many VAD care centers include VAD-trained surgeons, cardiologists, advanced practice

nurses, staff nurses, biomedical engineers, physical and occupational therapists, and a care coordinator that facilitates all aspects of perioperative care management (P. Blood, personal communication, November 19, 2008).

In addition, evaluation of satisfaction with care could potentially reveal deficits in care delivery and care pathways, and can identify patterns of resource utilization that may require modification or expansion to meet VAD patient-specific care needs. Such regulation of resources and identified quality improvement measures may assist patients in learning and providing self-care and manage themselves more effectively, thereby reducing hospital readmissions for infection or device failure and malfunction. As research suggests the aggregate costs of subsequent care and hospital readmission are the most expensive part of VAD patient care delivery, such study is vital to cost containment and cost-effective care (Hutchinson et al., 2008).

3. Patient satisfaction as a measure of quality has become more important to hospital directors and third-party payers as competition within the healthcare market increases. Historically, healthcare providers assumed that they understood the needs of patients based upon their own individual assessments. Several authors have noted that the majority of patient satisfaction measurements reflect issues important to providers rather than focusing on the patient’s perspective (Abdellah, 1955; Abdellah & Levine, 1957; S. Bond & Thomas, 1992).

The IOM has mandated that a patient-centered care approach to healthcare delivery is one of six aims for improving the quality of healthcare in the United States (2001). Patient-centered care is a patient-focused, individualized care delivery process that supports the building of trust within a provider-patient relationship, fosters the patient's participation in care design, and reinforces patient expectations and perceptions of quality and equity (Wolf, Lehman, Quinlin, Zullo, & Hoffman, 2008). The evaluation of patient-centered care, by measuring patient satisfaction, can identify deficits within the existing structure and processes of healthcare organization care programs currently unrecognized in existing systems. Capital input (e.g., supplies and materials used for care delivery) may be more readily scrutinized and expanded. Providers can adjust or restructure leadership structures and role delineation in order to optimize professional contributions to patient care.

Measurement and evaluation of quality related to patient care before and after VAD implantation is essential to continued improvement in care systems and cost containment. Currently both the Joint Commission (JC) and the Center for Medicare and Medicaid Services (CMS) require that ventricular assist device destination therapy programs meet criteria for program certification, including the development of performance measurement and improvement processes (Phurrough, Salive, Baldwin, & Ulrich, 2007). Measurement data must be utilized to evaluate and improve processes and outcomes, (i.e. survival rates, functional capacity), results from the national registry for destination therapy LVAD programs, the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) database is also used (Phurrough et al., 2007).

JC and CMS also recommend that hospital implant centers evaluate participant perception of care quality in addition to evaluation of processes and outcomes. A VAD program would make system structure and process changes based upon the analysis of feedback offered by participants (VAD patients) about their perception of the quality of care received. Healthcare organizations may build or improve interventions based upon by an in-depth exploration of patient satisfaction with care after VAD implantation, guided by patient recommendation. While quality of life research within this patient population has shown that self-care stress and disability is reduced after VAD implantation, patient outlook is predictive of quality of life and as such, patient education related to VAD care is crucial to postoperative stress and anxiety reduction (Grady, Meyer, Mattea, Dressler, Ormaza, White-Williams, & al., 2002; Molzahn et al., 1997).

It is unknown if hospitals are adequately preparing VAD patients for self-care. Presently, there are no VAD –specific patient satisfaction measurement tools. Currently, hospitals may only evaluate patient satisfaction relative to generic hospital care experiences. By exploration of patient satisfaction after VAD implantation, an implant hospital may develop valid and reliable tools from which to garner feedback from patients and improve or restructure processes of care and education, ultimately reinforcing skills necessary for optimal patient outcomes after discharge.

It is important to recognize that in the current literature only one article describes a detailed account of the hospital experience of training VAD patients for self-care. Future research must describe what hospitals are doing to educate VAD patients, including who provides education, what delivery methods are used and are preferred by patients, and what barriers or perceptions patients may have regarding that care training.

4. Gained knowledge could apply to similar patient populations, or like phenomena. Heart failure patients who are inotrope-dependent, transplant recipients,

cardiac defibrillator therapy patients, dialysis patients all must learn to provide self-care and monitor potentially life supportive therapies. The proposed research could provide a standard method or template for research of patient satisfaction in patient-centered care and self-care education within other similar patient populations.

The information gathered from the evaluation of self-care training in the VAD patient population could provide insight into the exploration of the self-care training of other individuals with chronic disease who must rely on a device therapy to sustain their lives. While the consequences of unrecognized therapy failure may not immediately result in a life-threatening deterioration in all cases, the advancement of disease symptoms, hospital readmissions and increased costs, and the exacerbation of complications related to primary disease may result. Chronically ill patients are often obligated to take responsibility for the daily management of their condition in order to sustain their well-being; in this instance, their participation in care is a reality and necessity rather than a choice (Coates & Boore, 1995).

*Significance to nursing***.** The significance of the phenomenon of interest to nursing is supported by (1.) the assumption that patient education is traditionally a nursing role, and that skill set mastery validation prior to discharge is completed by nursing, (2.) the need to describe how VAD patients prefer to be taught and learn basic VAD-specific care needs, (3.) the potential development of nursing interventions specific to education needs of VAD patients, and (4.) the assessment of patient satisfaction with education potentially serving as a nursing-sensitive outcome. The following discussion will describe each of these elements.

1. There is currently no standard method for providing VAD patient self-care education before initial hospital discharge. Device manufacturer recommendations clearly define educational content standards for teaching patients essential VAD self-care skills. There are currently no recommendations that suggest who should provide such education, how often providers should offer education, and at what point providers should evaluate patient competency. Education is traditionally a nursing role. Patient education of VAD self-care requisites could also fall within the domain of nursing practice. If this preparation is a nursing responsibility, post-implantation nursing care is crucial to the success of left ventricular support device therapy and long-term outcomes for VAD recipient. Skill set proficiency demonstrated by the patient could be validated by nursing prior to discharge (A. Bond, Bolton, & Nelson, 2004).

Nursing knowledge of VAD therapy directly influences patient recovery and education. Assuring patient self-care competency following VAD implantation is crucial to the prevention of postoperative complications, such as monitoring for device malfunction and site infection, as these are currently the leading causes of death or adverse event related to VAD therapy (Park et al., 2004).

2. Patient self-care education following VAD implantation is completed in the hospital, is detailed and time-intensive (Grady et al., 2003). A patient’s psychological state relative to outlook following VAD surgery has been found to be vital to quality of life after VAD implantation, reinforcing the need for healthcare providers to assure effective self-care education processes prior to initial discharge (Grady, Meyer, Mattea, Dressler, Ormaza, White-Williams, Chillcott, et al., 2002; Molzahn et al., 1997). The

evaluation of patient satisfaction with self-care education and preparation before discharge is vital to improvement of patient education pathways, VAD self-care training and ultimately patient outcomes. Feedback from patients can assist heart failure programs in developing effective and thorough guidelines for preparing both patient and family for self-management of the VAD device and continued postoperative recovery once discharged from the hospital.

3. Nursing often validates skill-set mastery, and as such, the assessment of patient satisfaction with education delivery reflects the perception of services provided by nursing during an inpatient stay. By evaluating the services provided by nursing, there is potential for development of nursing interventions specific to VAD patients' needs for education delivery. In addition, by assessment of patient satisfaction, healthcare organizations may explore previously unidentified barriers to successful education and self-care management. If patients are satisfied with nursing interventions provided that emphasize effective self-care behaviors, it is reasonable to assume that patients are more likely to continue that behavior. Nurses can identify potential resources necessary for interventions used to improve the patient's capacity for self-care. By building upon self-care agency, self-care behaviors may improve. Patient satisfaction with self-care education following VAD implantation could potentially serve as a measurable nurse-sensitive care outcome, evaluating the quality of nursing care services within the specialty patient population.

4. The evaluation of self-care education as an intervention within the domain of nursing suggests its potential for measurement as a nursing-sensitive outcome. Patient

satisfaction with nursing care is important, as the interaction between nurses and patients is the major service provided during a hospital course. Recent studies suggest that patient satisfaction with nursing is the most important predictor of satisfaction with the overall hospital experience (Mahon, 1996; Merkouris, Ifantopolous, & Lemonidou, 1999). Self-care has been regarded as a vital dimension of healthcare and the reasoning behind many health interventions, including many nursing interventions (Orem, 2003). Within the domain of nursing, self-care has been the foundation for many physical, educational, psychological, and behavioral interventions. Nursing maintains an informative and supportive role in assisting the patient in development of the ability to self-monitor, to identify significant changes in health status, to assess options for management, and to select the most appropriate action for self-care (Irvine, Sidani, & McGillis-Hall, 1998; Orem, 1991; Sidani, 2003).

Statement of Problem

Quality of care is a system priority for all healthcare organizations. Individuals who seek care want to feel confident in a healthcare system's ability to provide quality services at the specific level needed. The Institute of Medicine (IOM) has mandated that healthcare should be safe, effective, patient-centered, timely, efficient, and equitable (Institute of Medicine, 2002). A patient-centered approach to healthcare places the patient as active participants in their own healthcare. Their perspective and individual needs are important to achieving desired patient outcomes (Mead & Bower, 2000). Patient satisfaction is often viewed as a variable that is influenced by quality of care and as a predictor of future health-related behavior (Mahon, 1996). For a specialized patient population such as those with advanced heart failure who may or may not be eligible for cardiac transplantation, a left ventricular assist device (LVAD) may sustain life, reduce heart failure symptoms, and improve overall quality of life. However, self-care involving a life-supportive device can be a daunting task. A patient-centered approach to self-care education and training may be necessary to assist VAD patients and families make a successful transition from hospital to home. Evaluation of self-care training programs and measurement of patient satisfaction after self-care preparation may assist healthcare providers in improving interventions for VAD recipients.

Purpose of Study

In recent years, the majority of VAD research efforts targeted the evaluation of technological evolutions in pump design and their potential clinical applications within the heart failure patient population. To date, much is unknown regarding how patients and families are prepared to assume the burden of self-care of this life-supportive device. Although the emotional and physical impact of post-discharge VAD therapy and life has been described, how patients are trained, how they learn, and how they perform their own self-care has not been explored.

In heart failure patients that underwent internal cardiac defibrillator implantation, effective self-care behaviors were shown to contribute to a decrease in the risk of complications and hospital readmissions, to foster an improved sense of life satisfaction, quality of life and well-being, to enhance coping and adjustment to illness, and to increase a sense of personal responsibility, independence, and control (Dunbar, Jacobson, & Deaton, 1998; Slusher, 1999). To achieve desired outcomes, patients with VAD therapy must not only continue previously learned self-care behaviors required for the management of heart failure, but also effectively manage VAD pump care maintenance and evaluate potential problems via learned problem-solving strategies or by notification of a healthcare provider. The evaluation of patient satisfaction with self-care education following VAD implantation will allow patients to voice opinions and suggest improvements in training and care provided, which could potentially improve self-care requisite performance and which, in turn, would support wound healing, device functioning, autonomy, independence and health-related quality of life, in addition to timely communication with healthcare providers when problems arise.

The purpose of the proposed study is to describe VAD patient care and self-care education processes in hospitals. In addition, the primary investigator (PI) will complete an assessment of patient satisfaction with patient-centered care efforts within a selected healthcare program for VAD patients. Knowledge gathered from the assessment will support the exploration of areas of poor patient satisfaction, guided by areas of patient care and education suggested as important to the VAD patient.

Research Questions

The dissertation study applies a modified version of a proposed conceptual framework (see Figure 4). Questions addressed through this dissertation research are as follows:

1. What are the current care and self-care education structure and processes utilized in hospitals during the initial postoperative phase after VAD implantation? The actual hospital structure and care processes used for self-care education within VAD implantation centers must be described to determine if treatment fidelity exists among them. The PI will address this question first in order to effectively evaluate patient satisfaction with care delivery and self-care training after VAD implantation.
2. What elements of patient-centered care are important to VAD patients? Are VAD patients satisfied with patient-centered care within their selected healthcare facilities? The second question answered in the dissertation, measurement of satisfaction with patient-centered care, will help to evaluate how well current care methods meet VAD patients' expectations of patient-centered care during their hospital stay. Using a patient-centered care satisfaction interview, the PI will examine areas thought to be important to patients within the VAD patient population.

CHAPTER II

Literature Review

This chapter provides a review of theoretical and research literature guiding this research study. The PI identified significant concepts from this literature review, including patient satisfaction, patient-centered care, and self-care. I considered several theoretical frameworks in this review. Based upon review of the Outcome Model of Quality, the Cognitive-Affective Model of Patient Satisfaction, and the Self-Care Deficit Theory of Nursing, a conceptual framework was developed and will be used to guide the research study (Donabedian, 1966; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Orem, 1991; Smith, Schussler-Fiorenza, & Rockwood, 2006). The PI will discuss the need for study, instrument issues, methodological issues, and analysis issues, and will provide a definition of terms, including operational definitions for study variables.

Patient Satisfaction

Patient satisfaction has been often defined as the extent of agreement between what a patient expects to result or obtain from the healthcare experience and the perception of care they actually receive (LaMonica, Oberst, Madea, & Wolf, 1986). This definition implies that the individual has formed expectations prior to or during the healthcare experience, and that at some point, must consider whether or not the services received during the experience meet, do not meet, or exceed those expectations.

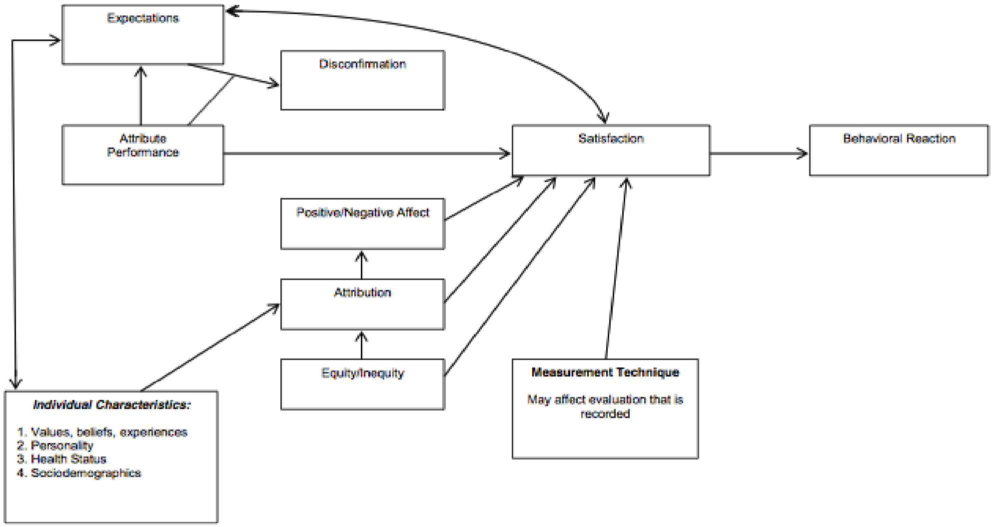
The first attempts to evaluate patient satisfaction with healthcare services originated within nursing in 1956 (Merkouris et al., 1999). Abdellah and Levine (1957) were among the first to report the positive relationship between increased hours of professional nursing availability in hospitals and overall patient satisfaction with care. Additionally, Abdellah and Levine (1957) discovered, through surveys of care providers and patients, the expectations of high quality care in hospitals were different between the two groups; healthcare providers did not necessarily know what patients wanted from their healthcare experiences. This result has also been found in other research studies of patient satisfaction with healthcare services (Minnick, Young, & Roberts, 1995).

The idea of measuring patient satisfaction by comparing expectations to perceptions was not found in the nursing literature until the late 1970s and early 1980s, when patient satisfaction was compared to consumer satisfaction (Hinshaw & Atwood, 1982). During that period, a growing interest in consumer satisfaction as a marketing strategy had evolved, and many researchers explored the possibility of an “expectancy or disconfirmation” model of satisfaction. The first study to propose and test this Expectancy-Disconfirmation Model of Satisfaction (ECD) evaluated marketing strategies and the effect of promotional claims on consumer satisfaction with services received (Anderson, 1973). Anderson’s results suggested that a consumer would not be satisfied with services if the results were not what were initially expected.

Further research has prompted refinement of the ECD model. Three variations of the ECD model have been proposed which describe the psychological underpinnings of consumer satisfaction (Pascoe, 1983). A contrast model states that a consumer will compare a current experience to a previous experience. A consumer will exaggerate a discrepancy, and in doing so, experiences deemed higher than expectations are satisfactory. The consumer considers experiences deemed lower than expectations to be unsatisfactory. An assimilation model suggests that if expectations are unmet, disconfirmation produces a psychological tension that an individual will alleviate by modifying previously held expectations to fit a present experience. Standards or expectations are adjusted so that what may have been deemed unsatisfactory is now acceptable (Pascoe, 1983). Lastly, a combination of the previously mentioned models, or an assimilation-contrast model, suggests that individuals will assimilate their expectations within a certain range above or below their present experience. This suggests that there is a range of experiences, higher or lower than a person's current expectations, an individual could deem as satisfactory. The contrast model applies when a large discrepancy exists between expectancy and experience, and a person will be either highly satisfied or dissatisfied with an experience. This "zone of tolerance" will result in consumer satisfaction with service experiences granted it falls within the boundaries set around the individual's expectations (Smith et al., 2006).

Oliver (1993) suggests that a cognitive appraisal occurs within the ECD model process. The person completes a comparative process that includes a cognitive evaluation and an emotional response to an experience. A person must decide at what point they will compare a current experience to their own expectations and consider an experience either satisfactory or unsatisfactory. An assumption of causality and equity will influence a consumer's affective response in a positively or negative manner. Essentially, an emotional response to service delivery is influenced by whether a consumer feels the provider is inherently responsible for a positive or negative outcome, and if the consumer believes they were treated equally compared to the other consumers of the same service (Oliver, 1980, 1993). Attribution is a term coined by Smith (2006) in describing the affective response within the Cognitive-Affective Model, and is a process in which the patient evaluates provider intent and effort, equitable and fair treatment, and evidence of caring. Smith (2006) proposes that if a patient believes that a provider has done his or her best and that a negative performance is out of the provider's control, the patient will still report satisfaction with care received. The Cognitive-Affective Model of Patient Satisfaction has been further refined to suggest that resultant satisfaction or dissatisfaction influences subsequent consumer behaviors and provides feedback to the service provider (Crow et al., 2002; Smith et al., 2006). Figure 2 illustrates the Cognitive-Affective Model of Patient Satisfaction as a conceptual framework describing how a patient compares their expectations with observations from care provided.

Figure 2. Model of Patient Satisfaction. Adapted from Oliver, 1993; Crow et al., 2002.



Patient-Centered Care

Patient-centered care is a patient-focused, individualized care delivery process that supports the building of trust within a provider-patient relationship, fosters the patient's participation in care design, and reinforces patient expectations and perceptions of quality and equity (Wolf et al., 2008). Mead and Bower (2000) suggest that the concept of patient-centeredness is a proxy for the quality of interpersonal aspects of care, and that those aspects of care are key determinants of patient satisfaction. This statement suggests that a patient evaluation of patient-centered care may allow providers to measure patient satisfaction with care delivery across multiple disciplines and services.

Previous patient-centered care research states that healthcare, as a whole, not only medical care per se, should be grounded in the patient's subjective experience of illness. Understanding patient experience in addition to the clinical manifestations of a disease process is essential in understanding illness experience. Healthcare providers must collaborate with patients and families, and share responsibility for defining expectations and goals, making decisions, and managing therapy.

Gerteis, Edgman-Levitan, Daley and Delblanco (1993) explored the concept of patient-centered care within the context of care delivery within medical institutions. The study sought to identify how patient interactions with healthcare providers, institutions, and systems affect subjective experiences of illness, how systems of care work or fail to work in meeting patient needs, and how providers and managers could integrate patient perspective in care delivery to improve patient satisfaction and care quality (Gerteis et al., 1993). A patient-centered care framework was introduced based upon data obtained through focus groups, survey data, hospital organization site visits, and literature reviews. Within this framework, seven domains of patient-centered care are identified: respect for values, preferences, and expressed needs, the coordination and integration of care delivery, effective delivery of information through communication and education, promotion of physical comfort, emotional support and the alleviation of fear and anxiety, involvement of family and friends in the care process, and transition and continuity of care through various levels of care. The Gerteis et al. (1993) framework of patient-centered care is included in the conceptual framework guiding this research study because it describes the most common expectations of patients during their healthcare experience.

Self-Care

Self-care is the practice of activities that persons initiate and perform on their own behalf in the interests of maintaining life, a healthful level of functioning, continuing personal development, and well-being (Orem, 1991). With a decreasing average length of hospital stay, the amount of outpatient management of chronic conditions has increased. As a result, self-care requisites have evolved over time, placing a larger responsibility upon the patient and family. In addition, with information readily available via internet and other forms of media, patients are becoming more knowledgeable and engaged in their own health, and seek to improve their well-being and level of functioning (Sidani, 2003). The patient assumes primary responsibility for executing a treatment plan, and contacts their healthcare provider if they are unsuccessful in managing any changes in their condition (Craddock, Adams, Usui, & Mitchell, 1999).

Dorothea Orem's Self-Care Deficit Theory of Nursing (SCDTN) is the most commonly used theory supporting nursing research studies involving client self-care behaviors. The theory of self-care deficit describes a balance between appraisal of self-care demands and the ability to meet those demands, as well as the action of self-care behavior (Orem, 1991). Concepts introduced in this theory include self-care agency, therapeutic self-care demand, and self-care deficit. Self-care agency is described as the power or ability of a person to engage in self-care, or a person's capability to perform self-care activities (Orem, 2003). Self-care agency is an acquired ability, a combination of motor skills, learned behaviors, and interactions with the environment. Self-care agency describes an individual's ability to initiate and perform self-care actions, and includes cognitive, physical, emotional, and behavioral domains. Motivation to achieve self-care, perceived control over motor or emotional functions, self-efficacy, and causal relevance are listed among these power components that enable the person to engage in self-care behaviors (Orem, 1991). These factors support a persons' self-care agency and links to self-care agency to self-care behaviors.

Self-care behaviors include the actual practice of self-care activity, divided into domains of universal behaviors (basic life-supporting processes), developmental (life cycle change processes), and health-deviation (health care requisites) (Orem, 1991, 2003; Sidani, 2003). Orem (1991) describes necessary health behaviors as requisites, or the therapeutic self-care demand. Healthcare requisites are defined as appropriate healthcare needs, including monitoring of health status, participating in treatment and living with chronic illness (Carlson, Riegel, & Moser, 2001).

The need for nursing care is validated by defining a potential self-care deficit. Self-care deficit results from the imbalance between a person's appraisal of self-care agency and the sum of all health-related requisites, or the therapeutic self-care demand. If a person has existing limitations which render them unable to meet the demands of self-care, a self-care deficit exists and warrants nursing intervention (Orem, 1991). Self-care education is a problem-based intervention, one that is required when self-care demand is greater than a patient's capacity to meet self-care requisites for a condition (Lorig & Holman, 2003). Nurses tailor interventions to assist the patient in meeting care needs in the setting of a self-care deficit. In this model, nursing's role is primarily described as both an educative and supportive role. Nursing actions include providing patients and families with information and resources available for effective performance of self-care behaviors and the integration of those behaviors into everyday life (Orem, 1991; Sidani, 2003).

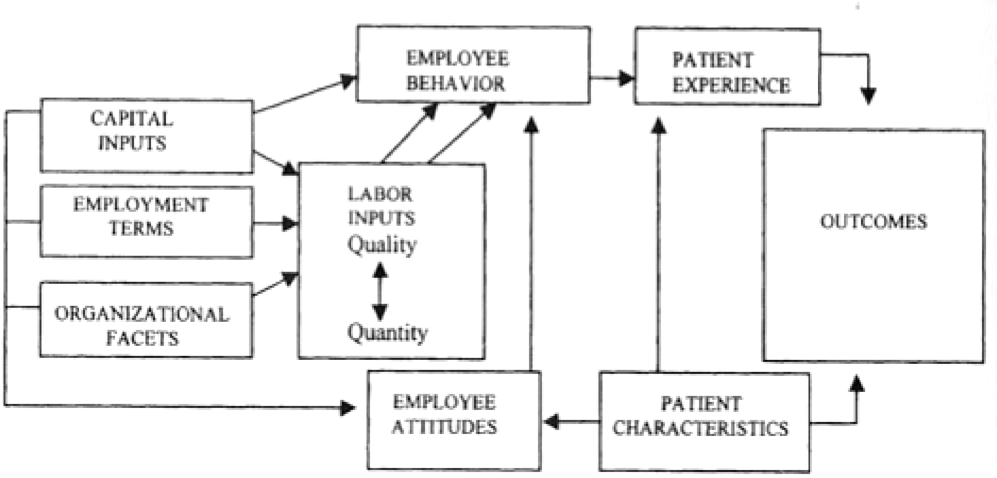
Self-care has been considered a foundational principle of nursing care (Orem, 2003). Nursing assists the patient in meeting health-related demands within a specific environment. In doing so, the nurse evaluates a relationship between what a patient is capable of doing to support themselves and their respective healthcare needs, and what additional actions are required to meet those needs effectively (Hartweg, 1990). Self-care knowledge and skills are often required for successful management of specific health states; to perform a self-care action for a specific person, one must possess knowledge of the action and its relation to a desired health response (Hartweg, 1991; Orem, 1991). Instruction for self-care may not be sufficient in achieving adequate self-care goals; assessment of self-care agency and self-care action remains an important part of education delivery (Irvine et al., 1998). Patient education for self-care has been recognized as within the domain of nursing practice, and efforts should be made to evaluate the effectiveness of that education to improve patient self-care behaviors (Irvine et al., 1998).

Conceptual Framework

No known single theoretical framework accounts for the specific contextual forces that could interfere with reception and implementation of VAD patient care education, including education content delivery and subsequent self-care management actions by the VAD patient. I developed a conceptual framework to account for organizational input, throughput of collaborative processes included in patient-provider interactions, and the output of a desired patient health outcome, as well as to illustrate the influence of patient characteristics on perception of quality and contribution to self-care. The conceptual framework shown in Figure 4 will be used in this study, and is derived from the Cognitive-Affective Model of Satisfaction, the Minnick and Roberts framework (1991) of variables influencing patient outcomes (see Figure 3), and a conceptual framework of patient-centered care (Abdellah, 1955; Gerteis et al., 1993; Minnick, 2009; Oliver, 1993; Smith et al., 2006).

The framework builds upon consumer expectancy and potential disconfirmation of service expectations and accounts for a systems analysis approach to influence of patient outcomes (Anderson, 1973; Crow et al., 2002; Oliver, 1993). The framework divides domains of patient satisfaction into components of care delivery dependent upon healthcare organizational structure and healthcare delivery processes, both of which influence resultant patient outcomes (Donabedian, 1988; Minnick, 2009).

Figure 3. A framework of variables influencing patient outcomes. (Minnick & Roberts, 1991).



In my conceptual framework, healthcare structure includes capital input, such as education delivery materials and supplies used, technology and equipment utilized in the care process, and compensation for employment. An organizational framework represents the lines of responsibility and authority within a given care team or department. Medical and business leaders can share leadership roles and lines of authority, and decision-making processes may not be clearly defined. The development of critical pathways and treatment protocols could require input and revision by multiple providers, and care process fragmentation results from unclear direction relayed to direct care providers.

Caregiver role delineation refers to who does what or performs what service within an organizational service line. The PI will describe caregiver role delineation and will evaluate the potential lack of treatment fidelity among hospital systems in the care of VAD patients. A VAD coordinator could be responsible for education delivery, or specialty-trained nurses might deliver and reinforce education while the VAD coordinator assumes responsibility for final skill validation prior to hospital discharge. Another aspect of organizational structure includes employment terms, the defined patterns of work coverage from each care provider. Different providers providing varied amounts of the same educational content could leave a patient and family with various methods for performing the same tasks, which could potentially confuse patients and families, who are seeking information regarding the “right way” to perform self-care management tasks.

Healthcare processes represent the actual services provided by care providers (nursing or medical). The actual VAD self-care training and emergency response training represents the healthcare process evaluated within this dissertation research. Medical care includes hemodynamic management and recovery through adjustment of VAD settings and drug therapy, as well as maintenance of other body system functions and comorbid conditions. Nursing care represents support for basic self-care requisites previously mentioned as described by Orem (1991), in addition to facilitating and evaluating outcomes from medical and nursing interventions and coordinating care services offered by other professionals and ancillary staff. As the education process traditionally falls within the domain of nursing, it would be fair to assume that heart failure education and the reinforcement of heart failure self-care behaviors and monitoring would be performed by nursing.

In addition to multidisciplinary management of postoperative recovery, a major focus of patient care includes VAD education and physical rehabilitation to facilitate strength building and successful performance of activities of daily living (Stahovich et al., 2007). Nursing's role in VAD self-care and management education is defined at each respective healthcare facility. Education methods among institutions are not explicitly described in the literature, and few articles describe organization pathways and role delineation. It is speculated that many VAD centers have varied methods for VAD self-care education, though guidelines pertaining to content required are defined by the VAD device manufacturer (P. Blood, personal communication, November 19, 2008).

The PI found only one article describing, in detail, the scope of postoperative education following VAD implantation. Bond et al. (2004) describes education processes and management of the VAD patient as detailed and time-intensive. In many hospital centers, the nurse to patient ratio is 1:1, even after the first 24 to 48 hours following transfer to an acute care telemetry unit. This staffing model allows for adequate monitoring and adjustment, with continued interaction with nursing to reinforce self-care education and behaviors. An initial meeting with family during the immediate postoperative period includes an introduction to the VAD device and related instructional literature. After the first meeting, a daily appointment is set up between designated caregivers and the educator (Bond et al. describes that role as performed by a nurse) during which time various VAD self-care management content is introduced. Content includes power source exchange (i.e. from base unit to battery power), travelling considerations (i.e. emergency resources and power supplies), basic daily maintenance and outpatient follow-up care. Length of time of each training session has not been described.

Of particular interest is site and wound care education, which includes teaching the patient and caregiver proper performance of required VAD dressing changes. Strict aseptic technique is necessary to prevent a VAD driveline infection (Richards & Stahl, 2007). Both the patient and family caregiver receive training for site care, and instruction could be delivered in a variety of ways. Bond et al. (2004) describes a method of instruction, which includes site care and mastery of sterile technique. The method gradually prompts the caregiver to assume care, through a tiered approach of observation, participation, and eventually self-performance with supervision. A manual or checklist is given to patient and caregiver to provider reinforcement of steps required for site care (A. Bond et al., 2004).

Self-care training continues on a daily basis, with a greater emphasis placed on self-management and daily routine as the patient continues to develop strength and greater mobility. Implementation of basic heart failure management principles (e.g., medication administration, dietary considerations, weight monitoring) is continued during the hospital stay, in addition to documentation of VAD hemodynamic measurements (e.g., Heartmate II LVAD device data includes rotations per minute, device flow, and power), and troubleshooting and safety measures in response to alarms. Bond et al. (2004) states that the patient’s bedside nurses continually reinforce education. The nurses are expected to accompany the patient off the care unit and out of the hospital if weather allows. Nursing presence is required at all times, until the patient and family caregiver are validated for emergency response in the event of device failure, after which, they are encouraged to leave the unit independently (A. Bond et al., 2004).

As the patient progresses through rehabilitation efforts and approaches a potential hospital discharge, successful coordination of community resources is vital to safe transition from hospital to home. Traditionally, a care coordinator with specialized training in device care (i.e., a VAD coordinator) completes coordination of services potentially required as the patient assumes responsibility for self-care once discharged. Obtaining emergency identification cards with information regarding the VAD device and specific contact information for the patient, and providing education to local emergency medical service (EMS) personnel and home health nurses, physical and occupational therapists are important steps to helping the patient and caregiver transition to life at home. In addition, the home's electrical supply is evaluated, and the patient's local power provider must be informed of the patient's home address, to ensure priority attention for power restoration in the event of an outage (Mason & Konicki, 2003; Stahovich et al., 2007).

Lastly, an important care interaction that may or may not be affiliated with the hospital organization could be peer support, or support groups, which could potentially provide validation of emotional response to the VAD implantation experience. Such support could provide a tangible support to the patient and family, giving the patient access to a network of individuals that share similar experiences and can offer support and reinforcement of feelings when needed (Edgman-Levitan, 1993).

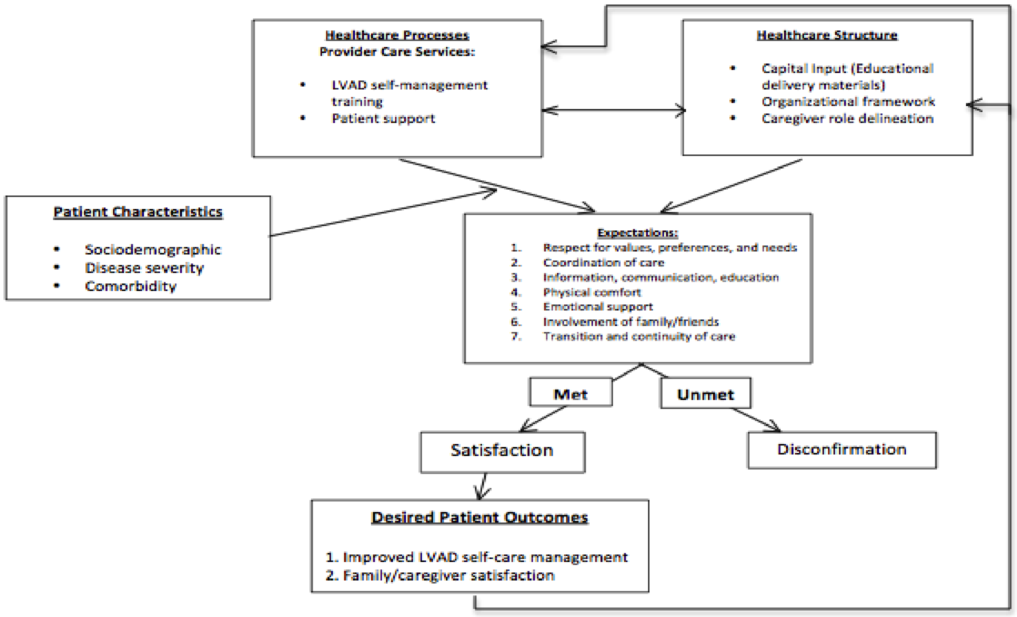
Patient characteristics and patient experiences influence patient expectations of services offered by healthcare providers before and after VAD implantation. Influential characteristics are unknown in this patient population. For the purposes of risk adjustment in health outcomes measurement, sociodemographic data, primary disease severity and comorbid conditions are included (Kane, Maciejewski, & Finch, 1997). Contextual factors that influence a patient's perception of self-care agency and ultimately influence self-care behaviors may be identified through a qualitative exploration of patient satisfaction with self-care education following VAD implantation. Though not supported through current VAD patient research, if conceptual definitions of patient-centered care are applied, patient characteristics and experiences may also include patient motivation and desire for independence and autonomy, learning style and preferred means of receiving education and information, basic understanding of implications of heart failure disease and VAD therapy (i.e. health literacy), ways of coping with illness and self-care demands and available supportive resources, and past healthcare experiences.

A patient's expectations refer to what a patient may expect when entering into a healthcare exchange. Gerteis et al. (1993) described the patient's perspective and desire of healthcare and provide a framework of concepts identified by study participants. These concepts serve as a foundation for defining patient-centered care: respect for values, preferences and needs, coordination of care, information, communication and education, physical comfort, emotional support, involvement of family and friends, and transition and continuity of care. Expectations may be influenced by patient characteristics, and individual perspectives may vary.

Patient outcomes from patient satisfaction in VAD patient populations are also unknown. If VAD patients are ultimately satisfied with their self-care and management education, and if patient satisfaction truly is a mediator to other health outcomes, then potentially satisfied patients would be more likely to remain compliant with care recommendations and learned behavior, demonstrating VAD self-care and skill set mastery. An increased independence and autonomy in self-care could allow the patient to rely less on care providers, whether hospital providers or family, and could have an increased sense of life satisfaction and improved health-related quality of life. Such improvement could improve caregiver or family satisfaction and reduce caregiver burden. If a patient can effectively manage self-care requisites, can identify worsening heart failure or VAD pump complications and can respond appropriately to emergency situations, potential health-related complications may be identified and intervened upon and decrease unnecessary hospital readmissions, decreasing readmission rates and costs for care.

If a patient's expectations are met during the hospital experience, patient satisfaction is potentially supported. If unmet, expectations are disconfirmed, and the patient is dissatisfied with the care experience. If expectations are not met, a patient perception of self-care agency may be too limited to meet a therapeutic self-care demand and inadequate self-care behaviors could potentially result, leading to VAD-related complications and hospital readmissions. In this setting, patient satisfaction could be viewed as a mediator between a patient perception of quality and could impact subsequent behaviors (e.g., learned skills, compliance) and provides feedback to the service provider that reinforces or recommends reevaluation of care delivery programs (Crow et al., 2002; Woodside, Frey, & Daly, 1989). If patient satisfaction with VAD self-care education is poor, exploring why patients are not satisfied could identify potential self-care deficits and associated nursing interventions to improve self-care strategies after hospital discharge.

Figure 4. Modified Conceptual Framework of Patient Satisfaction with Care after Left Ventricular Assist Device Implantation.



Application of Current Literature

*Need for study***.** Quality of care is a system priority for all healthcare organizations. Individuals who seek care want to feel confident in a healthcare system's ability to provide quality services at the specific level needed. The Institute of Medicine (IOM) has mandated that healthcare should be safe, effective, patient-centered, timely, efficient, and equitable (Institute of Medicine, 2002). A patient-centered approach to healthcare places the patient in a more active role: as a participant in their own healthcare, their perspective and individual needs are important to achieving desired patient outcomes (Mead & Bower, 2000). Patient satisfaction is often viewed as a variable that is influenced by quality of care and is a predictor of future health-related behavior (Mahon, 1996). For a specialized patient population such as those with advanced heart failure who may or may not be eligible for cardiac transplantation, a left ventricular assist device (LVAD) may sustain life, reduce heart failure symptoms, and improve overall quality of life. However, self-care for a life-supportive device can be a daunting task. A patient-centered approach to self-care education and training is necessary to assisting VAD patients and families make a successful transition from hospital to home. Evaluation of self-care training programs and measurement of patient satisfaction after self-care preparation may assist healthcare providers in improving self-care interventions for VAD recipients.

Health researchers have different opinions regarding the end results of studying and ultimately improving patient satisfaction ratings and reports. Consequences of patient satisfaction have implications for health promotion and business productivity and profitability. Patient satisfaction with nursing care has a strong relationship to overall satisfaction with the entire healthcare experience, and increases the likelihood that a patient will adhere to a recommended medical therapy (Abramowitz, Cote, & Berry, 1987). In addition, patients who are more satisfied with care delivery, both medical and nursing care, are more likely to reuse healthcare services and recommend those services to others (Abramowitz et al., 1987)

*Instrument issues***.** The assessment of patient satisfaction and the use of its analysis have traditionally depended upon an organization's reasoning for measurement.

Patient satisfaction is considered by many to be the ultimate outcome and validation of high quality healthcare and is an endpoint of healthcare interventions in itself (Donabedian, 1966). For others, patient satisfaction is a means to other outcomes, specifically patient compliance with healthcare recommendations, intent to reuse care services and potentially refer others to use the same service provider (Smith et al., 2006).

Patient satisfaction measurement tools appear to vary depending upon anticipated expectations and needs, the domains chosen for evaluation, and the respective dimensions of each domain (See Table 1). Pascoe (1983) suggests that expectations vary among individuals based upon multiple contextual influences that shape perceived needs. Domains may or may not be relevant to the patient, but may be deemed as important to the care provider. Dimensions of each domain may be “macro” or “micro” measures. In situations where global ratings of different domains are sought, a macro measure might evaluate access to care, availability, or communication during a hospital experience. A micro measure might be used to evaluate detailed aspects of a particular experience, such as technical quality of care or emotional support from a particular provider during a patient-provider exchange. An ideal measurement tool would build upon content recognized by patients as capturing concepts that are important to patients during a healthcare experience, and would use reporting as opposed to ratings, in order to obtain richer, objective data. An instrument should allow for evaluation of multiple dimensions of the healthcare experience and for the experience as a whole. The lack of standardized and consistent application of a theoretical foundation provides a weak basis for both conceptual and operational definitions of the patient satisfaction concept, leaving its definitions contingent upon the underlying purpose for its study.

For the purpose of this study, patient satisfaction will be evaluated as a measure of VAD care quality and its implications for successful performance of VAD self-care requisites. Though there is no universally accepted theoretical model of patient satisfaction, the Cognitive-Affective Model of Consumer Satisfaction appears to be the most widely used in consumer research and has been applied in many healthcare satisfaction surveys (Crow et al., 2002; Oliver, 1993).

*Methodological issues***.** Many social research methods are capable of measuring patient satisfaction. According to Smith et al. (2006), archives, focus groups and survey research have proven useful in data collection for assessment of patient satisfaction. Archival data would include medical records and patient complaint records. Patient complaints would specifically target areas of dissatisfaction with care processes of the health system or a particular provider, and provides an opportunity for review and potential for process and system improvement. Patient complaint records also identify various aspects of care that patients and families consider important. One disadvantage in relying on this type of data is that patients and families may not readily complain verbally about dissatisfaction, and patients are not prompted to consider different aspects of the care experience.

Open-ended interviews will provide an opportunity to collect detailed information about patient perception of the healthcare process, and may explain certain answers found on satisfaction surveys (Smith et al., 2006). The exchange of communication in open-ended interviews allows the patients to verbalize their opinions, and to describe their expectations and what they perceived from their own point of view and within the context of their health experience. Interview data can be used to develop measurement items for satisfaction surveys, as recurring themes identified in interviews suggest generalizable areas of concern that are important to a larger group of patients. Focus groups, like interviews, provide a qualitative data that can contribute to the explanation of quantitative data. Groups of participants within a particular setting may offer themes and opinions that might not be inferred to larger populations.

Survey methodology remains the most commonly used form of data collection for patient satisfaction (Laschinger & Almost, 2003; Smith et al., 2006). Closed responses standardize the survey: patients must answer the same questions by selecting only among the answers provided. The data accrued from the sample of patients surveyed are studied with the results potentially inferred to a greater population. The development and structure of questions is important to internal validity, reliability and the quality of data obtained from surveys. The choice to use questions requiring ratings or self-reporting in evaluation of services impacts the data obtained, and will be discussed as a controversy attendant to patient satisfaction. While archival data and qualitative methods have been used for data collection relative to patient satisfaction, survey methodology is the most commonly used in satisfaction research.

Several biases could potentially affect surveys of patient satisfaction. Three most commonly mentioned within satisfaction research are nonresponse bias, acquiescent response bias and sociopsychological artifact (Smith et al., 2006). Nonresponse bias can greatly impact the validity of study results, and satisfaction surveys commonly have lower response rates (Abramowitz et al., 1987). Previous studies have attempted to determine if there is a difference between respondents and nonrespondents in satisfaction surveys. Researchers have also reported that less satisfied patients are less likely to complete satisfaction surveys, and those respondents who are late to respond answer differently because they are not as interested in the subject matter (Mazor, Clauser, Field, Yood, & Gurwitz, 2002). If satisfied patients are more likely to respond, then the results of satisfaction surveys are obtained from a majority of satisfied patients, potentially overestimating results. In institutions where providers are compensated partially based upon satisfaction scores, providers with satisfied patients will have a higher number of respondents and a "higher" degree of satisfaction ratings, where the provider who may have a lower number of respondents will yield a "lower" degree of satisfaction ratings.

Acquiescent response bias is a tendency to agree with survey statements regardless of question content (Smith et al., 2006). A suggested measure taken to reduce acquiescent response bias is to include both positive and negative statements in survey content. Sociopsychological artifact refers to responses impacted by personal fear of retribution or a tendency to offer answers thought to share the same values as the investigator. This bias could potentially be significant in VAD patient satisfaction research, as most VAD patients are committed to seeking follow-up care within the hospital system in which the VAD was implanted. A patient could feel that answering honestly about their satisfaction with care delivery could be detrimental to their continued support and caring from hospital providers. Assuring patient confidentiality and potentially seeking third party administration and facilitation of satisfaction surveys could potentially reduce sociopsychological artifact bias.

Response by proxy or by other raters may be required when objective measurement or an outcome indicator of a construct does not exist, or exists but is not obtainable. Such responses are also required when a patient is unwilling to report, is unable to report, provides questionable information or cannot be reached to report information (Snow, Cook, Lin, Morgan, & Magaziner, 2005). In measuring patient satisfaction in VAD patients, the primary caregiver could be considered a proxy who would speak for the patient when the patient cannot respond or is unavailable. An example of the use of a proxy would be in the rating of perceived VAD surgical wound healing if the primary caregiver is the primary person performing scheduled dressing changes. Other external raters may be used to define an observable state that cannot be validated by proxy or the patient, such as signs of depression in an aphasic patient (Snow et al., 2005). Use of proxy in satisfaction measurement will obtain multiple perspectives of care delivery. Not recognizing the influence of proxy in measuring patient satisfaction could threaten study result validity, and lead to inferences and interpretation of results that are inaccurate and do not represent the patient experience.

The timing of survey administration is another important consideration. Timing can influence results, because a patient’s recollection and perceptions of care delivery may change over time (Smith et al., 2006). A patient’s evaluation of healthcare delivery may be reflected by their overall health outcome, due to a change in symptoms over time. Many patient satisfaction instruments contain instructions which suggest administration of surveys to patients only a few weeks after initial hospital discharge (Laschinger & Almost, 2003).

Response rates can be influenced by a variety of reasons and must be considered when measuring patient satisfaction within a subspecialty population such as VAD patients. In general, patient satisfaction survey response rates decline as time passes from the point of actual hospital discharge. In addition, less-satisfied patients are less likely to return questionnaires, leading to skewed survey results; caution is recommended in interpretation of survey results with satisfaction rates below 80% (Laschinger & Almost, 2003).

Returned satisfaction surveys generally have a high incidence of completion rates; missing data items do not generally pose a significant problem. Ware et al. (1981) noted a 65% return rate in survey administration, and among those returned, a 95% survey item completion rate was noted. Many reports describe follow-up telephone or in-person interview to obtain missing data from unanswered questions. It is interesting to note, however, that within the VAD patient cohort, missing data could pose a problem; morbidity and mortality could reduce an already small sample size (the nature of VAD therapy itself leads to small patient sample sizes per hospital setting) and skew data results. Data could be reported by patients who experience fewer complications or from those patients with more effective ways of coping, and issues important to other patients may not be recognized (Grady et al., 2001). A historical threat to study validity could also pose a problem in measuring patient satisfaction with care. Due to the increasing number of devices used for support and the fast pace of innovation in device development, researchers should be aware of which devices are used at different implant centers. Different VAD pump models require different methods of self-care and supportive therapy. Study inclusion criteria should reflect the appropriate device selected for study.

As previously mentioned, many satisfaction surveys are developed by institutional efforts to assess quality within their respective organizations. The surveys are not built upon any theoretical framework or established data. Items scored may be measured variables deemed important by hospital leadership rather than experiences viewed as important to patients. In regard to VAD patient populations, not knowing what experiences are truly important to them could lead to general assessments of satisfaction with care that do not identify areas for improvement that patients desire.

A gap in methodological knowledge involves the lack of application of satisfaction survey measures across multiple care settings. A large amount of patient satisfaction literature discusses survey item development, and in many instances the measurement tools have been used in single-site applications. These survey tools are not readily generalized to other patient populations; they lack a consistent conceptual and operational definition or theoretical foundation. The lack of use in multiple settings prevents comparison of patient satisfaction ratings across different healthcare settings.

Though methods for evaluation have improved, patient satisfaction is a conceptual outcome that can be easily influenced by subjectivity. One must be careful to identify potential sources of bias, and appreciate the potential influence of patient characteristics on satisfaction scores, the impact of survey administration timing, and the use of proxy in survey completion. Processes of care are not the only variables that determine patient satisfaction. Life satisfaction could be relative to patient perception of outcomes, whether physical, social, or psychological. Resolution or worsening of clinical symptoms may also impact how patients perceive their healthcare experience and thus their overall satisfaction with care.

*Interpretation issues***.** Most satisfaction surveys are self-administered and include Likert-type rating scales that solicit patient evaluation of a dimension of care included in subscales of selected domains. The Consumer Assessment of Health Plans (CAHPS) and Hospital Consumer Assessment of Health Providers and Systems (HCAHPS) requires patients to report experiences with different dimensions of the healthcare experience rather than rate their satisfaction with them. Asking for estimated wait times, or if a certain expectation was met or not removes the variance in expectations of care delivery among patients and the subjective nature of ratings. A global satisfaction rating, when included in this data collection, offers more objective data regarding patient care experiences (Smith et al., 2006).

A gap in methodological knowledge relative to analysis of satisfaction research findings includes the determination of a set point in which satisfaction ends and dissatisfaction begins. Though a majority of satisfaction research studies have negatively skewed scores, suggesting high levels of patient satisfaction, many satisfaction scores list ranked respondents and do not delineate between who was satisfied and who was not (Ware, Snyder, Wright, & Davies, 1984). Many instruments do not include dimensions responsible for dissatisfaction and only measure the degree of satisfaction experienced with a certain healthcare experience.

Definition of Terms

A definition of terms is provided for each research question, including an operational definition of all variables. Major concepts and sub-concepts with both conceptual and operational definitions are provided in Table 2.

*Research question 1***.** What are the care structure and VAD self-care education processes utilized in hospitals during the initial postoperative phase after VAD implantation?

Care is used in the context "to take care of", and is defined as the process of watching over, taking responsibility for, providing for; the provision of what is needed for the health, maintenance and well-being of another (Orem, 1991). Care actions which fall under the responsibility of an individual further define that care as given by a care agent: a person qualified to take care of others in limited capacity under certain conditions, described specifically by a particular profession (i.e., medical care, nursing care, etc.) (Orem, 1991). Care structure is conceptually defined through the sub-concepts of capital inputs, the organizational framework, and caregiver role delineation.

For the purpose of self-care education, capital inputs may be defined as any materials utilized in education delivery processes and basic care delivery. Operationally, this is measured as any reported capital resources or materials utilized by care providers during VAD self-care education training. The organizational framework is defined as identified lines of responsibility for administration, clinical services and budget within the healthcare service team. Administration operationally represents the organizational structure of the healthcare team, reporting structure, identifiable mission, philosophy or strategic plan, identified head of the VAD care program, identified members of the VAD team, and identified employees that report to the VAD Coordinator. Clinical service is measured by evidence of reported functions of selected VAD team members, the span and trajectory of care delivery, identified VAD coordinator role within institutions, and the span of patient management within the VAD coordinator role.

Caregiver role delineation is conceptually defined as identified service role expectations of selected individual care providers within and outside the recognized VAD care team. This sub-concept is operationally defined through identification of key care providers within respective organizational VAD care teams, reported care services provided by identified caregivers, identified components of the VAD coordinator position within subject hospital organizations, identified preferred preparation for the VAD coordinator (i.e., education, certification, and experience), and identified preferred preparation for the staff registered nurse (RN) providing inpatient care for VAD patients (i.e. VAD care education, professional certification, VAD care competency validation, clinical experience).

Self-care education refers to the instruction of practice of activities that a person must initiate and perform on their own behalf in order to maintain life, health, functioning and well-being (Orem, 1991). VAD self-care education includes the sub-concepts of education processes specifically related to VAD device management, including exit site care, mobility and power supply, and emergency procedures. VAD exit site care includes evidence of training of wound care of the VAD exit site and immobilization of the VAD exit site (to promote healing). Mobility and power supply refers to exchange of power sources from battery to power-base unit (PBU). Emergency procedures includes function surveillance actions such as daily diagnostic self-testing and evaluation of the VAD alarm recognition system, as well as safety precautions and emergency interventions such as responding to device alarms and power failure (Mason & Konicki, 2003).

These three sub-concepts will be operationally defined as reported methods for patient self-care education and skill-set training, including verbal instruction, written instruction, audio multimedia (compact disc), cassette tape or digital video disc (DVD), physical demonstration, return demonstration, internet applications or training modules, and simulation applications. In addition, self-care education processes will be measured using applicable elements relevant for a type of treatment as noted by Kane (2006): type of treatment, dosage, route, frequency, duration, onset/timing, and technical aspects/provider characteristics. These conceptual and operational definitions are also described in Table 2.

Patient support is recognized as a component of healthcare processes, and is further divided into either peer support (i.e. fellow VAD patients) or provider support (i.e. support mechanisms offered by care providers). Patient support is defined as an identified supportive mechanism or method available to assist in reinforcement of learned self-care skill sets of behaviors for VAD patients after initial hospital discharge following VAD implantation. Peer support is support mechanisms or methods provided by a patient support group or by another individual VAD patient. Provider support is provided by a healthcare organization (i.e. VAD team or VAD care provider). These support systems will be operationalized by reports of methods listed for each sub-concept. Peer support is measured by report of identified patient access to support provided by a variety of recognized methods (e.g. hospital-sponsored support group, independently facilitated support group, social networking sites, internet chat room or listserv sites, or cellular phone text messaging). Provider support is measured by reports of support methods such as coordinator triage of patient calls or concerns via telephone, e-mail communication with healthcare provider, or internet access to healthcare resources and information.

A hospital refers to the inpatient care setting in which the health exchange between LVAD patient and care provider occurs, and is an acute care facility and environment that provides advanced heart failure care, surgical implantation of the VAD device, and maintains certification for the VAD surgical procedure and provision of subsequent care.

The initial postoperative phase is the length of initial inpatient hospital stay that includes surgical implantation of the VAD device to discharge from hospital to outpatient recovery phase. It is operationally defined as the length of time (i.e. length of hospital stay in days) from the initial date of operative procedure until the date of initial hospital discharge after surgery.

VAD implantation refers to surgical implantation of a left ventricular assist device, specifically the Heartmate II LVAD system. This will be measured by medical record review and evidence of documentation of operative date and implanted pump type.

*Research question 2***.** What are VAD patients' reports of patient-centered care within their selected healthcare facilities? What patient-centered care expectations are important to VAD patients?

Patient-centered care, as previously discussed, encompasses a framework of related sub-concepts identified by interviewed patients as being important expectations of healthcare delivery (Gerteis et al., 1993). These sub-concepts are listed and conceptually and operationally defined in Table 2. Measurement of these sub-concepts is achieved through patient reporting of occurrence of events related to those sub-concepts during the patient's hospital stay. The Hospital Consumer Assessment of Healthcare Providers and Services (HCAHPS) stems from this framework, and targets several domains, including concern, or viewing the patient as an individual, provider communication, medication, nursing services, discharge information, pain control, physical environment, and global ratings of the healthcare experience.

The term "selected healthcare facilities" refers to the hospital(s) at which VAD patients have underwent VAD surgical implantation. For this research question, the concept of VAD patients is defined both conceptually and operationally as it was defined in question 1.

Patient-centered care component importance is used to describe patient-perceived importance of variables pertaining to the timeliness, thoroughness and individualization of certain areas of service delivery (Minnick et al., 1995). Minnick et al. (1995) selected variables that had been identified by patients as important and applied the identified variables to aspects of care identified by national research, clinical and administrative experts as those in which nursing makes significant contributions (Young & Minnick, 1996). It is to be noted that not all components within the patient-centered care framework are included. The aspects of patient-centered care selected are perceived to be highly-controlled by nurses and are needed by most hospitalized patients, including physical care, patient participation in care, patient teaching, and pain control (Young & Minnick, 1996). Measurement of importance of these aspects of patient-centered care include patient rating of importance of aspects using a 1-4 range Likert scale (1 = not at all important, 2 = somewhat important, 3 = important, and 4 = very important). The questions requiring rating of aspects of care were included as a supplement to the HCAHPS survey.

Summary

Through the review of existing literature relevant to the VAD patient population and patient satisfaction research, several gaps in knowledge have been identified. This research attempts to begin to examine issues currently unknown to nursing. The gaps in current knowledge are as follows:

Gap 1: There is no known or identified standard method for providing postoperative VAD patient self-care education. Self-care education as a treatment must be described among hospitals to evaluate treatment fidelity. Processes currently used in hospital VAD implant centers must be described before they can be evaluated.

Gap 2: The phenomenon of patient satisfaction with care delivery has not been explored in VAD patient populations. Using the patient-centered care framework, multiple dimensions of the healthcare experience could be evaluated and explored. We currently do not know what patients expect from the VAD implantation experience and the first transition from hospital care to life at home.

Gap 3: We do not know if VAD patients are actually satisfied with hospital self-care education delivery. Once self-care education processes have been identified and described, patient satisfaction with those processes can be evaluated. If nursing has a significant contribution in providing self-care education, it would be reasonable to explore this relationship in order to develop effective nursing interventions to improve education delivery processes.

Gap 4: The relationship between patient satisfaction and self-care practices after discharge is unknown in the VAD patient population. If patients are satisfied or are dissatisfied with self-care education during their initial hospitalization, a relationship between that outcome and subsequent self-care behaviors could exist and be defined.

Gap 5: There is a lack of a uniform method for measuring and evaluating satisfaction with self-care education in VAD patient populations across settings. If a measurement tool accurately measures satisfaction with information delivery, communication and education processes, its application to a subspecialty patient population such as VAD populations could be explored. If appropriate, VAD patients across multiple settings can be evaluated using the same measurement tool. Differences among implant centers relative to self-care education processes could be evaluated.

Table 1. Summary of selected patient satisfaction measurement tools.

Health Plans Satisfaction						
Tool	**Author(s)**	**Dimensions**	**Validity**	**Reliability**	**Administration**	**Analytic Issues**
Consumer Assessment of Health Plans (CAHPS)	Hargraves et al., 2003	1. Expedited care 2. Physician communication 3. Staff helpfulness/courtesy 4. Receiving needed care 5. Customer service 6. Global ratings: Personal doctor/nurse, quality of health care, specialist care, health plan	Construct	Plan level reliability high with 2 domains Cronbach α > 0.75, others 0.58-0.62	1. Self-administered (mail) 2. Telephone and in-person interview 3. 46 items – potential response burden 4. Estimated cost $15-$24 per completed survey 5. Available from AHRQ website	1. Multiple domains measured 2. Subscales plus global ratings 3. Uses report rather than ratings, reduces multicollinearity 4. Derived from interview and focus groups: fewer items measuring technical skill 5. Potential for bias
Consumer Satisfaction Survery (CSS)	Davies, Ware, and Kosnicki, 1991 (American Association of Health Plans)	1. Access to care 2. Communication 3. Continuity of care 4. Interpersonal care 5. Services offered 6. Information 7. Costs of care 8. General satisfaction 9. Satisfaction with outcomes 10. Plan satisfaction	Construct	Plan level reliability with Cronbach α 0.87-0.97	1. Self-administered 2. Telephone and in-person interview 3. 47 items (31 general satisfaction; 16 items on health plan coverage and demographic data)– potential response burden	1. Not designed to evaluate any particular type of care delivery 2. Likert rating scales limit data available for quality improvement, potential multicollinearity 3. Does not address provider-patient communication/relationship 4. Potential for bias

Hospital Care Satisfaction						
Tool	**Author(s)**	**Target/Dimensions**	**Validity**	**Reliability**	**Administration**	**Analytic Issues**
Hospital Consumer Assessment of Providers and Systems (HCAHPS)	Agency for Healthcare Research and Quality (AHRQ), Center for Medicare Services (CMS)	Inpatients 1. Concern; patient viewed as individual 2. Doctor communication 3. Medication 4. Nursing services 5. Discharge information 6. Pain control 7. Physical environment 8. Global ratings of care – hospital, physician and	Construct	Reliability for composites range Cronbach α 0.5-0.89	1. Self-administered 2. Telephone and in-person interview 3. 27 items – low potential for response burden 4. Estimated cost $11-$15.25 per survey completed 5. Administered 48 hours to 6 weeks after discharge 6. Available from AHRQ website	1. Data collected by CMS for public reporting. Published quarterly and allows for comparison among hospitals. 2. Aggregates individual items into 3 composites (health plan, provider, hospital) for analysis 3. No real items measuring technical skill 4. Includes global and subscale items

		nursing				5. Report scales help reduce multicollinearity 6. Potential for bias
Patient Judgments on Hospital Quality (PJHQ)	Meterko et al., 1990	Inpatients 1. Admissions process 2. Nursing care 3. Medical care 4. Hospital environment 5. Information delivery 6. Discharge process	Content, construct and predictive validity are addressed	Reliability for subscales range Cronbach α 0.87-0.95	1. Self-administered 2. Telephone and in-person interview 3. 106 items total (46 evaluate care processes; 60 include demographic data)– potential response burden 4. Considered in public domain (free for use)	1. Broad categories measured but none in detail 2. Data recruited from only 10 hospitals; results may not be readily generalizable. 3. Care process questions yield ordinal data aggregated to section total of a 0 to 100 point scale. 4. Potential for bias

Hospital Care Satisfaction

Tool	Author(s)	Target/Dimensions	Validity	Reliability	Administration	Analytic Issues
Patient Questionnaire	Abramowitz et al., 1987	Inpatient 10 subcategories of services: 1. Admissions process 2. Attending physicians 3. House staff 4. Nurses 5. Nursing aides 6. Housekeeping 7. Food services 8. Escort services 9. Other staff 10. 3 outcome measures (general satisfaction, intent to return, intent to recommend to others)	Construct, content	Reliability for subscales range Cronbach α 0.51 – 0.95. Inter-item reliability established.	1. Self-administered 2. 37 items total 3. 35 Likert-type questions with summated rating scales 4. 2-open ended questions 5. Literacy level not addressed 6. No copyright	1. Rating versus report scales limit data available, increased potential for multicollinearity 2. Includes subscales and global scores providing ordinal and continuous level data 3. Potential for response bias
Modified SERVQUAL	Babakus and Mangold, 1992	Inpatient Measured perceptions and expectations in 4 domains: a. Responsiveness b. Assurance c. Tangibles d. Empathy e. Reliability	Construct Content	Reliability for subscales range Cronbach α 0.49 to 0.90	1. Self-administered 2. 15 –pairs of matching expectation/perception items rated on 5-point Likert scales 3. Literacy level not addressed 4. No copyright	1. Two separate surveys of expectations and perceptions of care 2. Likert rating scales 3. No global measures or aggregate data 4. Ordinal level data 5. Expectations are

						compared to perceptions
Quality of Multidisicplinary Care Scale	Blegen and Goode, 1993	Maternity patients 1. Technical quality 2. Patient communication 3. Interpersonal quality 4.Outcomes of care 5. General satisfaction	No information available	Reliability for subscales range Cronbach α 0.66 – 0.86; total scale 0.86	1. Self-administered 2. 31 items total 3. No time estimation given 4. 5-point rating scale 5. No literacy level addressed 6. Copyrighted	1. Only evaluated care of maternity patient population 2. Each item rated on 5-point scale – ordinal data; items aggregated into total scores 3. No items sensitive to any one discipline of care provider 4. Potential for bias 5. Rating scales – potential for multicollinearity
Quality of Care Monitors	Carey and Seibert, 1993	Inpatient, emergency, ambulatory care settings 1. Admissions/billing 2. Courtesy of staff 3. Nursing care 4. Physician care 5. Religious care 6. Outcomes of care 7. Nutrition services 8. Comfort/cleanliness 9. General quality of care 10. Willingness to return/recommend to others	Construct, content	Reliability for subscales range Cronbach α 0.44 - 0.92 Test-retest reliability	1. Self-administered 2. Different item totals for different scales 3. No time estimation given 4. Literacy level not addressed 5. Copyrighted	1. 5-point Likert scales used 2. No aggregate data but one global score for general quality of care 3. Potential for bias 4. Potential for multicollinearity 5. Nursing scale had high correlation with overall satisfaction with care
Picker-Commonwealth Survey of Patient-Centered Care	Cleary et al., 1991	Patient experience of hospitals and ambulatory care. 1. Respect for values, preferences, needs 2. Coordination of care, service integration 3.Information, communication, education 4. Physical comfort 5. Emotional support 6. Involvement of family/friends 7. Transition and continuity	Content validity – supported by interview data obtained in previous work with patients, families, providers and administrators	Test-retest reliability assessment	1. Self-administered 2. Item number varies depending upon which survey used. 3. No time estimation given 4. Literacy level not addressed 5. Copyrighted	1. Used report rather than rating scales 2. Most responses yield dichotomous data 3. Potential for bias 4. Reduced risk of multicollinearity 5. No aggregate data

		of care				
Satisfaction with Nursing Care Questionnaire	Eriksen, 1987, 1995	Inpatients 1. Art of care 2. Technical quality of care 3. Physical environment 4. Provider availability 5. Continuity of care 6. Outcomes of care	Construct and content validity supported	Not mentioned	1. Self-administered 2. 21 total items 3. Reported 20-30 minutes to complete 4. 5-point rating scale 5. No open ended questions 6. Literacy level not addressed 7. Copyrighted	1. Rating scales used, restricted data and increased potential for multicollinearity 2. Measures patient perception of technical quality of healthcare 3. Potential for bias 4. No aggregate data
Patient Satisfaction Questionnaire	Forbes and Brown, 1995	Outpatient surgery patients 1. Caring 2. Continuity of care 3. Competency of nurses 4. Patient and family education	Content	Reliability for subscales range Cronbach α	1. Self-administered 2. 21 total items 3. Reported 20-30 minutes to complete 4. 5-point rating scale 5. No open ended questions 6. Literacy level not addressed 7. Copyrighted	1. Rating scales used, restricted data and increased potential for multicollinearity 2. Potential for bias 3. No aggregate data 4. No assessment of technical quality of care 5. No assessment of multiple disciplines 6. No global scores
Patient Satisfaction Questionnaire	Guzman et al., 1988	Inpatient 1. Nursing care 2. Admissions process 3. Other hospital services 4. Information giving 5. Interpersonal skills	Face validity established (panel experts, peers)	Reliability Cronbach α 0.83	1. Self-administered 2. 30 items 3. Reported 20 minutes to complete 4. Rating scales 5. 2 open-ended questions 6. 7th grade reading level 7. Copyrighted	1. Rating scales used, restricted data and increased potential for multicollinearity 2. Potential for bias 3. 2 open ended questions for qualitative data collection 4. 5 domains used, no global scores, no aggregate data
Patient Satisfaction Instrument	Hinshaw and Atwood, 1982	Medical-surgical acute care patients (inpatient and outpatient) 1. Technical/professional behavior 2. Patient education 3. Trusting relationship	Construct	Reliability for total survey 0.80; subscales range Cronbach α 0.44 – 0.97	1. Self-administered 2. 22 items 3. 20 minutes to complete 4. Likert-type rating scale with 3 subscales 5. No literacy level given 6. No copyright	1. Rating scales used. Increased potential for multicollinearity and limited data collection 2. Potential for bias 3. 3 subscales/domains 4. No aggregate scores or

						global scores
Press Ganey Satisfaction Measurement	Kaldenberg and Regrut, 1999	Inpatient, emergency, ambulatory care settings 1. Registration/admissions process 2. Lab/diagnostic testing/X-rays 3. Nursing and staff 4. Physicians 5. Environment/building	Content	Reliability for subscales range Cronbach α	1. Self-administered 2. Range of 26-32 items depending upon which survey used 3. Can be delivered via internet 4. No literacy level given 5. Copyrighted	1. No aggregate scores or global scores 2. Measures 5 domains with varying item numbers depending upon clinical setting 3. Potential for bias
Inpatient Nursing Service Quality	Koerner, 2000	Inpatient 1. Close relationships/trust 2. Reduction of anxiety/uncertainty 3. Individualized care 4. Compassionate care 5. Reliability	Content	Reliability for subscales range Cronbach α	1. Self-administered 2. 14 items total 3. Likert scale ratings 4. No literacy level given 5. No copyright 6. No time estimation given	1. Rating scales used, limited data collection, increased risk of multicollinearity 2. Potential for bias 3. No mention of aggregate measures of subscales; only ordinal data provided
Care/Satisfaction Questionnaire	Larson and Ferketich, 1993	Inpatients – measure of nursing behaviors: 1. Accessibility 2. Anticipation of patient need 3. Promotion of comfort 4. Trust 5. Explaining and facilitation of care 6. Monitoring/reliability	Construct, Content	Cronbach α 0.94 for total scale	1. Self-administered 2. 29 items 3. No time estimation given 4. No copyright 5. No literacy level given 6. Rating scale 0-10 scale (client places an “x” on the scale, illustrating degree of agreement/disagreement)	1. Potential issues with interrater reliability – no concise/clear rating scores with current method 2. Rating scale used, limiting quality of data and increasing risk of multicollinearity 3. Measures nursing behaviors as perceived by the patient –ultimately measures 3 domains: benign neglect, enabling and assistive behaviors.
Patients’ Perception of Quality Scale – Acute Care Version	Lynn and Moore, 1997	Inpatients 1. Professional behavior 2. Respect 3. Responsiveness 4. Mindfulness	Content	Reliability for subscales range Cronbach α	1. Self-administered 2. 54 items total – potential for response burden 3. Estimated time to completion 30-45 minutes 4. No literacy level given 5. No copyright	1. Ratings used, limiting data quality and increasing risk of multicollinearity 2. Potential for bias 3. Potential response burden 4. No appearance of sensitivity to any type of

					6. 5-point likert scale used	provider 5. No mention of aggregate data or global scores
Patient Satisfaction with Health Care Provider Scale	Marsh, 1999	Patients of nurse practitioners and physicians 1. Access to care 2. Compassion 3. Quality 4. General satisfaction	Content	Reliability for subscales range Cronbach α	1. Self-administered 2. 18 total items 3. Likert rating 5-point scale 4. No literacy level given 5. No copyright 6. No estimated time for completion	1. Ratings used, limiting data quality and increasing risk of multicollinearity 2. Potential for bias 3. Appears sensitive to patient-provider relationship only 4. No mention of aggregate data or global scores
Patient Satisfaction Scale	McGivern et al., 1972	Inpatients: 1. Patient and MD relationships 2. Patient and RN relationships 3. Information and education 4. Quality of care received	Face validity reported	No information available	1. Self-administered 2. 21 items 3. 30 minutes to complete 4. Likert-type scale 5. No literacy level given 6. No copyright	1. Ratings used, limiting data quality and increasing risk of multicollinearity 2. Potential for bias 3. Sensitive to patient-provider relationships 4. No mention of aggregate data but includes a global measure of care quality
Critical Care Patient Satisfaction Survey	McGivern et al., 1992	Critical care patients 1. Art of care, technical quality of care 2. Physical environment 3. Availability 4. Continuity of care 5. Outcomes of care 6. Respect for individual needs 7. Promotion of patient autonomy 8. Patient and family education	Construct, Content	Inter-rater reliability	1. Self-administered 2. 43 items 3. 45 minutes to complete 4. Likert type 5-point scale 5. Some items open-ended 6. No literacy level given 7. No copyright	1. Ratings used, limiting data quality and increasing potential for multicollinearity 2. Potential for bias 3. Multiple domains, no global measure of satisfaction 4. Open-ended questions improve data quality 5. No apparent sensitivity to any one provider type
Satisfaction with Nursing Care Questionnaire	Nash et al., 1994;	Inpatients 1. Art and technical quality of care 2. Physical environment 3. Availability 4. Continuity of care	Construct, Content	No information available	1. Self-administered 2. 16 items 3. No time estimation given 4. 3-point rating scales 5. Not copyrighted 6. Adaptation of Erikson (1994)	1. Ratings used, limiting data quality and increasing potential for multicollinearity 2. Potential for bias 3. Includes measure of

		5. Outcomes of care			tool.	technical quality of provider care 4. Measure of perception of outcome of care but not global measure of care experience 5. No mention of aggregate data or global measure of satisfaction
Service Quality Framework (SERVQUAL)	Zeithaml et al., 1990 Nursing Services: Scardina, 1994	Scardina (1994): Satisfaction of nursing care of inpatient cardiothoracic surgery patients 1. Evaluated expectations and perceptions of care in 4 domains: a. Tangibles – appearance of physical facilities, equipment, personnel, communication materials b. Reliability – performance of promised services dependably and accurately c. Responsiveness – . willingness to help promptly and effectively d. Assurance – knowledge and courtesy of employers and conveying of trust and confidence e. Empathy – provision of caring, individualized attention to patient needs	Face and Content validity (expert opinion and subject review)	Cronbach α for service dimensions in perception and expectation range 0.74 to 0.98; only empathy perception was 0.40	1. Self-administered 2. 44 total items (22 pairs) 3. No response time given 4. No literacy level given 5. No copyright	1. Two separate surveys of expectations and perceptions of care 2. Likert rating scales 3. No global measures or aggregate data 4. Ordinal level data 5. Expectations are compared to perceptions 6. Potential for bias 7. Potential for multicollinearity

Table 2. Major Concepts, Sub-Concepts, Definitions and Analytic Considerations

Major Concepts	Sub-Concepts	Conceptual Definition(s)	Operational Definition(s)	Survey Questions	Analytic Considerations
Research Question 1: What are the care structure and VAD self-care education processes utilized in hospitals during the initial postoperative phase after VAD implantation?					
Care Structure	1.Capital Inputs 2. Organizational Framework 3. Caregiver Role Delineation	1. Materials utilized in education delivery process and basic care delivery 2. Identified lines of responsibility for administration, clinical service, and budget 3. Identified service role expectations of selected individual care providers within and outside the recognized VAD care team.	1. Any reported capital resources/materials used by care providers in VAD self-care education training 2. Lines of responsibility include: a. Administration: organizational structure; reporting structure; identifiable mission, philosophy, strategic plan; budget and patient volume; identified head of program; identified members of the VAD team; identified employees who report to the VAD coordinator b. Clinical service: Reported functions of selected VAD team members, span/trajectory of care delivery; identified VAD coordinator role within institution, span of patient management within the VAD coordinator role 3. Reported service role expectations of identified care providers within and outside the defined VAD care team including: a. Reported members of the VAD care teams within subject hospital organizations. b. Reported care services provided by identified caregivers. c. Identified components of the VAD Coordinator position within subject hospital organizations. d. Identified preferred preparation for the VAD Coordinator including: 1. Education	VAD Services Survey: Sub-concept/Operational Definition/Survey Item Number: 1: Item: 1, 5, 6, 7 2 a. Item: 9, 10, 15, 16, 17, 18, 19, 20, 21, 22, 25 2b. Item: 11, 12, 23, 24, 26 3a. Item: 23 3b. Item: 12 3c. Item: 11, 12 3d. Item: 13 3e. Item: 14	Target population is VAD clinicians/coordinators. Target domains of: 1. Self-care Training 2. Patient Support 3. Resources 4. Provider Roles and Responsibilities 5. Education and Training (for VAD Coordinators and RNs) 6. Organizational Framework Face validity and content validity confirmed by expert opinion No further psychometric testing Administration: 1. Self-administered 2. 26 items, potential for response burden 3. Nominal level data on most questions – limited statistical testing options, descriptive statistics only Proposed Analysis by Item Number: 1. Percentage/cross tabulations of resources used or not used by resource item. 2. Percentage of facilities with dedicated time for self-care education; average time (minutes) for dedicated education 3. Percentages/cross tabulations of hospital methods of validation of self care skills 4.Percentages/cross tabulations of

			2. Certification 3. Experience e. Identified preferred preparation for the staff RN providing inpatient care for VAD patients including: 1. VAD care education 2. Professional certification 3. VAD care competency validation 4. Clinical experience		level of difficulty of self-care skill sets for both patient and primary caregiver 5. Percentage/cross tabulation of hospital organizations that have identified resources available to patient and family/caregiver 6. Percentages/ cross tabulation of hospital organization/unit resources available in ICU or step-down 7. Percentages/cross tabulation of hospital organization 8. Percentage of ICU units with restricted or unrestricted visitation policies 9. Percentage of VAD program management types 10. Percentage of VAD program with specified named heads of program 11. Percentage/cross tabulation of hospital organizations with presence or absence of role components for VAD Coordinators 12. Percentage/cross tabulation of hospital organizations' clinical services with provider assigned 13. Percentage of requirements for VAD Coordinator practice, required/not required 14. Percentage of requirements for staff RNs practice as required/ not required. Mean length of time for nursing orientation to VAD care 15. Mean number of VAD Coordinators employed in hospital organizations 16. Percentage of hospital organizations in which the VAD Coordinator reports to a specific director 17. Mean number of employees reporting to the VAD Coordinator 18. Percentage of employees reporting to VAD Coordinators within hospital organizations

					19. Percentage of VAD Programs that manage VAD patients for specific therapies 20. Percentage of VAD programs with written mission, philosophy and strategic plan 21. Percentage of VAD programs with types of organizational placement 22. Percentage of VAD programs that report to specific departments 23. Percentage/ cross tabulation of caregivers with assignment to VAD patient care 24. Percentage of hospitals with specific patient care units for VAD patient care. Average number of unit beds in hospital units that provide VAD patient care 25. Mean number of VAD implantations budgeted for and provided during the last fiscal year. Mean number of HeartMate II VAD implantations during the last fiscal year 26. Percentage of VAD programs with patient education pathways
VAD Self-Care Education Processes	Education processes related to VAD device management, including: 1.Exit site care 2.Mobility and Power Supply 3.Emergency Procedures	1. Identified methods for patient instruction of VAD percutaneous lead wound care. 2. Identified methods for patient instruction of VAD power source management, including exchange from power-base unit to battery power. 3. Identified methods for patient instruction of troubleshooting VAD system alarms and device malfunction or failure.	For each of the three educational topics: 1. Reported methods for patient self-care education and skill training: a. Verbal instruction b. Written instruction c. Audio multimedia d. Tape/DVD media e. Physical demonstration f. Return demonstration g. Internet application h. Simulation application 2. Reported difficulty of skill set mastery for patient and caregiver 3. Reported duration of VAD self-care education	VAD Services Survey: Items: 1, 2, 3, 4, 5, 26 *Item 26 requests a copy of unit protocol or education goal sheet.	Analysis for questions within this domain are mentioned above. Item 4 reflects provider perception of difficulty for skill-set mastery for patient and caregiver. It cannot serve as a proxy for patient satisfaction with self-care education.

			4. Reported provider of self-care education 5. Reported method for evaluation of VAD patient self-care and skill set performance relative to exit site care, mobility and power supply maintenance, and emergency procedures: a. Verbal demonstration b. Written examination c. Physical demonstration 6. Reported organizational process of validating self-care competency: a. Presence of protocol b. Documentation of competency c. Required number of successful demonstrations of competency d. Responsible provider who validates patient competency		
Patient Support	1.Peer Support 2. Provider Support	1. Identified supportive mechanism or method available to assist in reinforcement of learned self-care skill sets or behaviors for VAD patients after initial hospital discharge following VAD implantation a. Peer support: support mechanism or method provided by support group or another VAD patient b. Provider support: support mechanism or method provided by healthcare organization/VAD team/VAD care provider	1. Peer Support: Identified patient access to support provided by one or more methods: a. Hospital-sponsored patient support group b. Independently facilitated patient support group c. Social networking site d. Internet chatroom list serve e. Cellular phone text messaging 2. Provider support: Identified patient access to support provided by one or more healthcare organization provided service methods: a. Coordinator triage by telephone call coverage. ("On-call"). b. E-mail communication with healthcare provider c. Internet access to healthcare resources and information	VAD Services Survey: Item: 5	Same as above. 1. Only one item assessing patient support from hospitals.
Initial Postoperative		1. The length of initial inpatient hospital stay from surgical	1. Length of time (length of stay in days) from initial date of operative procedure	Patient report	No implications for this study. Length of hospital stay and

Phase		implantation of VAD to discharge from hospital to outpatient recovery phase.	until date of initial hospital discharge after surgery.		reinforcement of skill set training could impact learned behavior post-discharge.
VAD Implantation		1. Surgical implantation of left ventricular assist device therapy.	1. Operative date for VAD implantation 2. VAD pump type	Patient report	No implications for this study. Future studies could explore demand for education for different VAD devices and varying self-care demands.

Research Question 2: What are VAD patients' reports of patient-centered care within their selected healthcare facilities? What patient-centered care expectations are important to VAD patients?

Major Concepts	**Sub-Concepts**	**Conceptual Definition(s)**	**Operational Definition(s)**	**Survey Questions**	**Analytic Considerations**
LVAD Patient Reports of Patient Centered Care	A. Identified components of Patient Centered Care as described by Gerteis et al., 1993. 1. Respect for values, preferences and needs 2. Coordination of care 3. Information, communication and education 4. Physical comfort 5. Emotional support 6. Involvement of family/friends 7. Transition and continuity of care B. Overall rating of hospital care	Identified care expectations of LVAD patients relative to sub-concepts. Sub-concept 1: a. Believes care team seeks opinion. b. Identity is preserved. c. Involved in care decision-making. d. Patient believes needs and expectations are met. Sub-concept 2: a. Reported trust in healthcare team. b. Believes service is received from the right person at the right time. Sub-concept 3: a. Informed of clinical changes in timely manner b. Data is understandable and questions answered appropriately Sub-concept 4: a. Pain addressed adequately and in a timely manner.	A. Patient reports of occurrence of events as: Never Sometimes Usually Always Yes or No to questions relative to hospital stay. Sub-concept 1: a. treatment by nurses with courtesy and respect b. concerns listened to carefully by nurses c. treatment by doctors with courtesy and respect d. concerns listened to carefully by doctors Sub-concept 2: a. nurses explaining things in a way patients can understand b. doctors explaining things in a way patients can understand c. when pressing the call button, receiving help from nursing as soon as help is wanted d. obtaining help getting to bathroom or using bedpan as soon as wanted by patient	A. The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey is used as the basis for this research Survey questions added to HCAHPS questions to evaluate perceived importance, timeliness, frequency, and individualization of nurse-influenced care components (Young & Minnick, 1996). See Appendix D: *Survey of Patient Perceptions of Patient-Centered Care after Ventricular Assist Device Implantation* Domain: Survey Item Number 1.Concern; patient viewed as an individual: Items 1, 2, 3, 12, 13, 14, 15, 16, 17, 18, 29, 20 2. Communication and education: Items 4, 5, 6, 7, 8, 9, 10, 11, 25, 26, 27, 28, 29, 30, (VAD self-care education) 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45,	**HCAHPS targeted domains of Inpatient care:** 1. Concern; patient viewed as individual 2. Doctor communication 3. Medication 4. Nursing services 5. Discharge information 6. Pain control 7. Physical environment 8. Global ratings of care – hospital, physician and nursing Noted construct validity and reliability for for composites range Cronbach α 0.5-0.89. **HCAHPS Administration:** 1. Self-administered 2. Telephone or in-person interview 3. 27 items – low potential for response burden 4. Estimated cost $11-$15.25 per survey completed 5. Administered 48 hours to 6 weeks after discharge 6. Available from AHRQ website

		b. Receives appropriate help with activities of daily living. c. Hospital environment is safe and comfortable. Sub-concept 5: Healthcare team recognizes and addresses anxiety related to: a. clinical status, treatment and prognosis b. Impact of illness on self and family c. Financial impact of illness Sub-concept 6: Reports healthcare team includes identified family/friends in care process by: a. Allowing family/friends to support patient emotional needs b. Involving family in decision making c. Recognizing family needs Sub-concept 7: Healthcare team recognizes patient anxiety regarding transition and continuity of care: a. Patient is given and understands post-discharge self-care information and skills b. Coordination of outpatient care and follow-up care is given and understood. c. The patient has access to clinical, social, physical and financial support on a continuing basis as an outpatient.	Sub-concept 3: a. nurses explaining data in a way patients can understand b. doctors explaining data in a way patients can understand c. hospital staff describe what new medications are for prior to administration d. hospital staff describe side effects of new medications prior to administration Sub-concept 4: a. during the hospital stay, how often was pain well controlled b. during the hospital stay, how often was everything possible done to help patient with pain c. during the hospital stay, how often was patient room and bathroom kept clean d. during the hospital stay, how often was the area around the patient room quiet at night Sub-concept 5: Emotional support for concerns and fears of patient expressed by: a. nurses listening carefully to patient concerns b. nurses explaining things to the patient in a way they understand c. doctors listening carefully to patient concerns d. doctors explaining things to the patient in a way they understand Sub-concept 6: None listed Sub-concept 7: a. Assessment of patient post-discharge destination: own home	46, 47 3. Nursing Services: Items 7-11, 20-26, 28-55 4. Medication: Items 12, 13, 14, 15, 16, 17, 18, 5. Discharge information: 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47 Overall rating of hospital stay: Item 48 Patient Demographics: Items 49 - 57 Open-ended Questions Related to VAD Care: Items 58, 59	**Analysis:** 1. Data collected by CMS for public reporting. Published quarterly and allows for comparison among hospitals. 2. Aggregates individual items into 3 composites (health plan, provider, hospital) for analysis 3. No real items measuring technical skill 4. Includes global and subscale items 5. Report scales help reduce multicollinearity, yields objective reporting of occurrence of events 6. Potential for bias Proposed analysis by survey item number: Questions are pertaining to the hospital stay after VAD surgery -- 1. Percentage of patient reports: Frequency 2. Average reported number of times patient not treated with courtesy and respect 3. Percentage of patient reports: Importance 4. Percentage of patient reports: Frequency 5. Average reported number of times patient was not carefully listened to by providers 6. Percentage of patient reports: Importance 7. Percentage of patient reports: Frequency 8. Average reported number of times care provider did not explain things in a way the

		B, 1. The patient’s opinion of the overall hospital experience. 2. The patient’s willingness to recommend hospital to family and friends.	someone else’s home another health facility b. did doctors, nurses, or other hospital staff talk with patient about having the help needed once discharged from hospital c. did patient get information in writing about what symptoms or health problems to screen for after hospital discharge d. did patient get information in writing about what problems to screen for related to VAD exit site care e. did patient get information in writing about what problems to screen for related to mobility and VAD power supply f. did patient get information in writing about what action(s) to take in the event of a VAD emergency (e.g. pump alarm or failure) B. 1. (Using 0-10 scale: (0 = worst hospital possible, 10 = best hospital possible) Number chosen by patient to rate hospital 2. Report of possible recommendation of hospital to friends and family Using: Definitely No Probably No Probably Yes Definitely Yes		patient could understand 9. Percentage of patient reports: Thoroughness 10. Percentage of patient reports: Individualization 11. Percentage of patient reports: Importance 12. Percentage of patient reports (yes or no) 13. Percentage of patient reports: Frequency 14. Average reported number of times that pain was not well-controlled 15. Percentage of patient reports: Timeliness 16. Percentage of patient reports: Thoroughness 17. Percentage of patient reports: Individualization 18. Percentage of patient reports: Thoroughness 19. Percentage of patient reports: Importance 20. Percentage of patient reports (yes or no) 21. Percentage of patient reports: Frequency 22. Percentage of patient reports: Frequency 23. Percentage of patient reports: Timeliness 24. Percentage of patient reports: Thoroughness 25. Percentage of patient reports: Individualization 26. Percentage of patient reports: Importance 27. Percentage of patient reports: Destination after discharge 28. Percentage of patient reports (yes or no) 29. Percentage of patient reports: Timeliness (yes or no)

					30. Percentage of patient reports: Thoroughness (yes or no) 31. Percentage of patient reports: Individualization (yes or no) 32. Percentage of patient reports: Importance 33. Percentage of patient reports (yes or no) 34. Percentage of patient reports: Timeliness (yes or no) 35. Percentage of patient reports: Thoroughness (yes or no) 36. Percentage of patient reports: Individualization (yes or no) 37. Percentage of patient reports: Importance 38. Percentage of patient reports (yes or no) 39. Percentage of patient reports: Method of site care education delivery 40. Percentage of patient reports: Timeliness (yes or no) 41. Percentage of patient reports: Thoroughness (yes or no) 42. Percentage of patient reports: Individualization (yes or no) 43. Percentage of patient reports: Importance 44. Percentage of patient reports (yes or no) 45. Percentage of patient reports: Method of transfer of power source education delivery 46. Percentage of patient reports: Timeliness (yes or no)

					47. Percentage of patient reports: Thoroughness (yes or no) 48. Percentage of patient reports: Individualization (yes or no) 49. Percentage of patient reports: Importance 50. Percentage of patient reports (yes or no) 51. Percentage of patient reports: Method of response to VAD emergency education delivery 52. Percentage of patient reports: Timeliness (yes or no) 53. Percentage of patient reports: Thoroughness (yes or no) 54. Percentage of patient reports: Individualization (yes or no) 55. Percentage of patient reports: Importance 56. Percentage of patient reports: General rating of overall care received 57. Average report of age in years 58. Percentage of patient reports: gender 59.Percentage of patient reports: race 60. Percentage of patient reports: ethnicity 61. Percentage of patient reports: highest educational level 62. Percentage of patient reports: annual income level 63. Percentage of patient reports: marital status 64. Open-ended question: Patient recommendations to providers to improve VAD

					patient care. 65. Open-ended question: Patient advice to other VAD patients.
VAD Patients	1. HeartMate II LVAD Implantation	1. Patients receiving left ventricular assist device therapy for advanced heart failure. 2. Implantation of the Heartmate II LVAD device	1. Surgical implantation of a VAD device 2. Surgical implantation of the HeartMate II LVAD device	Patient report	Nominal data – presence of VAD device: Yes/No
Patient Centered Care Component Importance	1. Patient-reported importance of individual identified sub-concepts of patient-centered care (see above). 2. Aspects of patient-centered care selected are those highly controlled by nurses and needed by most hospitalized patients (Young & Minnick, 1996): a. physical care b, patient participation in care c. patient teaching d. pain control	Reports of perceived importance of actual care received relative to sub-concepts identified consistent with patient-centered care (see above).	Questions from the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey are used as a template for this research. Modified approach to evaluate perceived occurrence, timeliness, thoroughness, individualization, and importance of sub-concepts. Each concept question uses a rating scale such as: 4 = very important 3 = important 2= somewhat important 1 = not at all important 1 = Never 2 = Sometimes 3 = Usually 4 = Always 1 = Yes 2 = No Approach used for HCAHPS questions specific to domains of a. Physical care b. Patient participation in care c. Patient teaching d. Pain control	Survey questions added to HCAHPS questions to evaluate perceived importance of nurse-influenced care components (Young & Minnick, 1996). See Appendix D: *Survey of Patient Perceptions of Patient-Centered Care after Ventricular Assist Device Implantation* Domain: Perceived Importance Survey Item Number a. Item 3, 6, 11, 19, 26, 32, 37, 43, 49, 55	Modified approach to evaluate actual care received, timeliness, thoroughness, individualization, and perceived importance of sub-concepts. Analytic considerations and analysis for individual survey items listed above.

CHAPTER III

Methods

Chapter III introduces the research design, description of research setting, sample and sampling plan, data collection methods, and plans for data analysis for both phases of the dissertation research. I will present criteria for sample selection, inclusion and exclusion, methods for recruitment, strategies for human subject protection, survey design, and plan for analysis and missing data used for this research.

AIM 1/ Research Question 1

Research Design

The design used for AIM 1 of the dissertation research was a prospective, cross-sectional descriptive design. This research explored the process of VAD patient self-care education and the organizational structure and care processes that influence education delivery during the initial postoperative phase after VAD implantation (See Figure 4). AIM 1 of this dissertation research used a one-time administration of a survey in which VAD coordinators described current care structure and delivery processes relative to self-care education used at their respective institutions. The PI selected VAD coordinators rather than medical directors to complete this survey as the VAD coordinator most often has an in-depth knowledge of both medical and nursing care processes of VAD patients within hospital centers.

To obtain the highest possible level of subject participation in this research study, prior to sending the mailed survey, the PI posted an announcement to participate in the survey on an Internet virtual bulletin board used by VAD Coordinators. The announcement indicated that the survey would be mailed to all VAD coordinators at their hospitals if the hospital program in CMS or INTERMACS registered. In this announcement, the PI also asked VAD coordinators from hospitals that are not on the CMS or INTERMACS registries, so that contact information might be obtained for their participation in the study.

The PI sent a paper version of the survey to VAD Coordinators employed by identified VAD implanting hospitals. The cover letter included with the survey included instructions for accessing an electronic version of the survey. The participant could choose to complete the printed survey and return in a postage-paid return envelope, or access, complete and submit the survey online. In both the mailed and electronic versions of the survey, study participants were able to access the survey through a provided Internet web address located at the bottom of the mailed invitation letter. Study participants who chose to complete the survey could choose the method of completion most convenient for them thereby improving overall response rate (Minnick, Norman, Donaghey, Fisher, & McKirgan, 2010). Additional details for follow-up recruitment to maximize response rate are provided in the Procedures section.

Research Setting

AIM 1 of the dissertation research sought to include all respective VAD-implanting hospital organizations in the United States. The total number of hospital organizations using various types of mechanical cardiac support is unknown, though there are registries with which many of these hospitals are affiliated. To identify potential research settings for study, current listings of CMS-approved destination therapy VAD programs and organizations affiliated with the INTERMACS database registry of VAD programs were used, as these are two widely recognized listings of active VAD programs within the United States. The current total number of VAD programs is estimated to be 100.

Sample and Sampling Plan

The PI's goal was to obtain data from all U.S. VAD programs. Three methods for locating and identifying VAD coordinators were used:

1. Use of current listing of CMS-approved destination therapy VAD hospital centers, accessed through the CMS website.
2. Use of current listing of VAD programs enrolled in the INTERMACS registry. The CMS and INTERMACS listings will be compared and overlap eliminated.
3. Electronic posting of study invitation on a VAD/mechanical cardiac assist device discussion board of an identified Internet listserv.

To ensure that institutions were not sent multiple surveys, the PI cross checked the lists of currently approved CMS listing of destination therapy VAD programs, as well as with the INTERMACS registry. All destination therapy programs must be CMS-approved, and the INTERMACS registry is a commonly used registry for the recording of VAD surgical volume and outcomes data by respective VAD hospital centers.

*Nature and size of sample***.** The subject population for the AIM 1 research consisted of one group: hospital organizations that provide VAD therapy. To describe these hospital organizations, the PI recruited VAD Coordinators or clinicians employed within these organizations for survey completion. According to the ICCAC website, ICCAC membership includes VAD coordinators from over 90 hospital organizations across the United States (www.vadcoordinator.org). There are approximately 70 hospital centers approved for DT LVAD implantation by the Center for Medicare and Medicaid Services (CMS) (https://www.cms.gov/MedicareApprovedFacilitie/VAD/list.asp). It is possible that the ICCAC membership includes both VAD Coordinators who manage VAD patient populations receiving therapy as either bridge to transplantation (BTT), destination therapy (DT), or both, and by comparing lists of programs between both organizations, the PI will identify a larger number of implant centers to recruit.

Criteria for sample selection, study inclusion and exclusion. The criteria for sample selection, and study inclusion and exclusion for Phase I research were as follows:

a. The study population included all VAD-implanting hospital organizations within the United States as included in the ICCAC listserv website, INTERMACS registry, and response to the electronic posting. The final study sample included all hospital organizations represented by VAD Coordinators who completed the electronic survey.

b. The PI included all VAD hospital organizations in the study if the following criteria were met: (a) located within the United States, (b) have active programs of care for advanced heart failure including ventricular assistive device therapy, including the Heartmate II LVAD (c) employed care providers that have a primary role in care coordination and management of patients receiving VAD therapy, and (d) currently use VAD therapy for bridge to transplant or destination therapy care indications.

Procedures

Preliminary Work

The PI completed pilot testing of study instrument items. The PI reviewed the survey to ensure accuracy of concepts and terminology before utilization for this study. The PI recruited five individuals not affiliated with the study population to complete the survey. The PI corrected all identified errors in survey layout and wording. The PI reworded confusing concepts in order for the survey to be clearly understood by participants. The PI considered the survey ready for study participant dissemination.

The procedures used in AIM 1 of this dissertation research are as follows:

Month 1

1. The PI obtained Institutional Review Board (IRB) approval from Vanderbilt University Medical Center (VUMC).
2. The PI programed and activated the internet-based survey Research Electronic Data Capture (REDCap). Vanderbilt University provides the REDCap survey system free for use to any student or employee of Vanderbilt University or Vanderbilt University Medical Center through grant support from the National Institute of Health (NIH) (1UL1 RR024975 from NCRR/NIH). Surveys that are adapted for use in the REDCap system are easy to administer and are

encrypted and secure; the REDCap system is designed to protect healthcare information and any data input from a REDCap survey is stored on a database within a secure internet server at VUMC. Once data is stored within an established REDCap database, the PI can download data to several statistical software packages allowing for data analysis. At this point, the PI completed the REDCap Survey process for electronic option for survey administration. The PI created the study database at this time. The PI reviewed both the survey and generated database to ensure accurate function before study utilization. The PI corrected any survey problems identified before distribution to study participants.

Month 2-5

The PI provided VAD coordinators with two options for survey completion. VAD coordinators were allowed to choose to complete the survey process electronically or through paper survey. The PI provided recruitment for and dissemination of the survey in both forms concurrently. The PI continued recruitment for a total of 3 cycles by Internet and standard mail (See Table 3). The PI chose a 3-week interval period between cycles as not to irritate participants by sending frequent reminders for study participation. All messages sent by the PI included a disclaimer assuring that the PI will only report participant survey results as aggregate data to ensure confidentiality.

Table 3. AIM 1 Recruitment and Data Collection Timeline.

Month	**Week**	**Procedure**
2 - 5	1	Posted announcement and link to electronic survey on Listserv.
	2	Cycle 1: Standard mailing of survey.
	3	
	4	Posted announcement/reminder and link to electronic survey on Listserv.
	5	Cycle 2: Standard mailing of survey.
	6	
	7	Posted announcement/reminder and link to electronic survey on Listserv.
	8	Cycle 3: Standard mailing of survey.
	9	
	10	
	11	Closed data collection.

Recruitment procedures are as follows:

1. Listserv Recruitment – Initial Internet Posting:
    a. Prior to survey distribution, the PI posted an email to the ICCAC listserv announcing 1.) the study and its intent, 2.) when and where the survey would be mailed to participants, 3.) the importance of knowledge development and participation in the research process, 4.) the importance of describing the role of VAD care providers in VAD patient care and self-care education, 5.) a contact email address that they may access for additional information, 6.) a thank-you for their participation in the study process (Dillman, 2000). The PI also asked VAD coordinators to contact the PI directly by e-mail if CMS or INTERMACS registries do not list

their respective organizations, so that contact information may be obtained for their participation in the study.

> The ICCAC is a "professional mentorship organization of mechanical circulatory assist device clinicians whose mission includes information sharing, education, and professional support in order to obtain optimal outcomes of care for patients requiring mechanical circulatory support and support the area of device clinical research and development" (International Consortium of Circulatory Assist Clinicians, 2010). As this Consortium is the largest cohort of VAD Coordinators to organize independently, the PI recruited this group membership to increase the number of study participants. Members/participants of the ICCAC Internet Listserv receive bulletin board communications via a chosen email address selected when members initially register for access to the site. Electronic postings are delivered to the registered email account. Potential study participants are more likely to read the study invitation as it is posted through a familiar website from which they discuss topics relative to their professional roles. This avoids the potential immediate deletion of a study invitation due to receipt of the invitation by an unknown source.

b. The PI included an embedded hyperlink within the recruitment email, which directed the participant to information about the study and provides data protection information. The PI included an explanation of dissertation study and research aims within the invitation.

2. Standard Mail Recruitment – Initial Mailing:
    a. The PI mailed a printed copy of the research study invitation and survey to each identified VAD Coordinator at their listed contact address. The PI provided a postage-paid envelope with the PI's contact address in the mailing.
    b. The PI included an invitation to participate in the study attached to the first page of the survey mailing, which included information regarding 1.) the study and its intent, 2.) the survey instrument, 3.) the importance of knowledge development and participation in the research process, 4.) the importance of describing the role of VAD care providers in VAD patient care and self-care education, 5.) a contact email address that they may access for additional information, 6.) a web-address at the bottom of the page that when typed into a web-browser will allow the participants to take the survey electronically, and 7.) a thank-you for their participation in the study process (Dillman, 2000).
    c. The PI also included additional information within the invitation, including information about data protection and an explanation of dissertation study and research aims.

    d. The PI ensured that each paper-copy survey will have an ID number placed in the upper right corner of the survey document in order to identify the hospital organization described.
    e. Completion and return of the paper copy of the survey implied consent for participation in the study. Individuals who opted to take the electronic version of the survey grant consent through the completion and submission of the electronic survey.

3. <u>Listserv Recruitment – Second Internet Posting</u>: The PI posted a second e-mail to the ICCAC Listserv, thanking participants and reminding all VAD Coordinators of the implications of the study. The PI also provided all information listed in the first e-mail recruitment letter. The PI also asked again those VAD coordinators who have not participated in the survey or whose organizations are not listed within the CMS and INTERMACS registries to contact the PI directly by e-mail so that contact information may be obtained for their participation in the study.
4. <u>Standard Mail Recruitment – Second Mailing:</u> The PI mailed a second printed copy of the research study invitation and survey to each identified VAD Coordinator that had not yet participated in the study at their listed contact address. The PI provided a postage-paid envelope with the PI’s contact address in the mailing. The PI included all information provided, as mentioned above, in the first standard mailing in the second mailing cycle.
5. <u>Listserv Recruitment – Third Internet Posting</u>: The PI posted a third e-mail to the ICCAC Listserv, thanking participants and reminding all VAD Coordinators of

the implications of the study. The PI also provided all information listed in the first and second e-mail recruitment letters. The PI also asked again those VAD coordinators who had not participated in the survey or whose organizations were not listed within the CMS and INTERMACS registries to contact the PI directly by e-mail so that contact information may be obtained for their participation in the study.

6. Standard Mail Recruitment – Third Mailing: The PI mailed a third printed copy of the research study invitation and survey to each identified VAD Coordinator that had not yet participated in the study at their listed contact address. The PI provided a postage-paid envelope with the PI's contact address in the mailing. The PI included all information provided, as mentioned above, in the first standard mailing in previous mailing cycles.
7. The PI closed data collection for Phase I of the research study approximately three weeks following the third cycle of recruitment.
8. In return for participation in this research study, the PI will present an explanation of study results and implications for VAD care at an ICCAC annual consortium meeting.
9. Data was automatically populated into the established database when the survey was completed electronically. The PI entered data into the database for all completed surveys received via standard mail.
10. Background demographic information on participating implanting hospital centers was obtained through the American Hospital Association (AHA) Database and

was added into the established study database (e.g., region, ownership, bed size, and membership in the Council of Teaching Hospitals, etc.).

Month 6-7:

3. The PI downloaded REDCap data into SPSS for analysis.
4. The PI analyzed data and evaluated results.

Month 8-9

5. The PI completed writing of results of research study.
6. The PI will ensure dissemination of research results through the dissertation defense and through presentation of aggregate results to the ICCAC Annual Meeting for the following year after research is completed. The PI plans to format results into a manuscript suitable for publication, such as *Progress in Transplantation,* or *The Journal for Cardiovascular Nursing,* or for presentation at a national conference, such as The Annual Research Meeting of AcademyHealth, or the AcademyHealth Interdisciplinary Research Group on Nursing Issues (IRGNI).

Human Subjects Protection

The PI's dissertation committee reviewed the project and submitted the project to the Vanderbilt University Institutional Review Board (IRB) for evaluation.

*Potential risks***.** This AIM 1 research did not involve recording of patient identity or information and did not alter the clinical care offered to VAD patients at their respective organizations. As this was a survey administered to VAD Coordinators, there was a risk of identification of individual healthcare professionals and their relation to specific healthcare organizations and locations.

*Participant confidentiality***.** The methods used for ensuring participant confidentiality are as follows:

1. Electronic survey administration: the survey database was assigned automatic unique identifiers not related to the study participant. Automated identifiers and identifying data (name, email address) were stored on the secure server and only the PI had access to the database.
2. Mail survey administration: Once survey responses were manually entered into the database by the PI, the survey database assigned identifiers in a similar fashion as noted in part 1.
3. Identifying information for one hospital organization was used for further organizational assessment and patient perception of self-care education in Phase II of the dissertation research. Once the PI collected additional study information Phase II research and linked data to the original survey data, the individual identifiers were destroyed.

*Data monitoring***.** The PI sent a progress report to the research committee monthly and included progress relative to this study. Study participant recruitment, provision of necessary measurement tools, data obtained from completed surveys, and accuracy of the data entry were reviewed. Any difficulties encountered during the study were discussed with the committee chair. There were no protocol deviations during the AIM 1 study.

The student's dissertation committee and the Vanderbilt University Institutional Review Board (IRB) reviewed the study protocol before beginning the study.

Data Collection Methods

1. The PI obtained research data from human subjects by electronic survey and from completed paper copy survey. The PI did not use individual medical records or specimens in Phase I dissertation research.
2. The PI recorded data from human subjects including demographic information, closed-ended questions about healthcare organizational structure, VAD self-care education delivery processes, and the VAD Coordinator role.
3. The PI generated automatic linkage to study participants through creation of an identifier maintained in the survey database with the survey data. The PI removed identifiers from any file downloaded for statistical analysis, and the PI will destroy all identifiers in one year following entire study completion through deletion of electronic record or by shredding of completed paper copies of the survey. The PI will report data in aggregate only and will never attribute data to one hospital organization or VAD Coordinator.
4. The PI collected data electronically as a response to an electronic survey, or by response to a mailed survey. The PI entered data into an electronic database. The PI has not previously used this within the subject population and the PI used the survey specifically for this dissertation research.

Instrument. There were no existing instruments sufficient for use in describing the organizational structure and care processes of VAD patient self-care management education. Due to the specialized nature of self-care requisite demand placed upon VAD patients, wound care, physical rehabilitation and heart failure self-care measurement tools do not adequately address processes required by healthcare providers. The PI developed a survey to describe healthcare organizational structure and care processes involved in self-care management education within the VAD patient population.

The PI developed the survey based upon the synthesis of the conceptual framework discussed in Chapter II (See Figure 4). The survey consists of 26-items describing components of care delivery such as self-care training practices and resources used, VAD Coordinator -perceived level of difficulty of learning content of self-care skills by VAD patient and primary caregiver, patient support, capital resources, provider roles and responsibilities, provider education and training, and organizational framework.

The PI identified major concepts within the first research aim through the synthesis of previously described conceptual frameworks (See Page 27). Table 2 provides a listing of identified concepts, conceptual definitions, operational definitions, and which survey item is intended to address each concept. A narrative description of conceptual and operational definitions of identified variables is included (See Page 46).

The majority of question items in this survey require selected options resulting in nominal-level data. The purpose of this instrument is to describe current healthcare structure and care processes used in VAD self-care education by hospital organizations across the United States. The PI assured face and content validity of the survey through extensive literature review and by expert opinion of the dissertation committee.

Credibility, rigor, and validity of design and method. The dissertation research attempts to answer questions previously unanswered in the research literature. The instrument developed for this research was developed based upon conceptual frameworks applied extensively in health services research, and applies concepts reflected in those frameworks. Credibility was enhanced by the use of survey question items developed and applied in previous healthcare workforce studies evaluating administratively mediated variables (Minnick & Mion, 2009). Rigor was established through strict adherence to detailed study and recruitment procedures. Only the PI performed data entry.

Validity was supported through an adequate conceptual explication, as there are clearly stated conceptual-operational links, and conceptual definitions are established in literature. It is important to be aware that mono-operation and mono-method bias was possible; the initial exploration of this phenomenon was undertaken using one instrument and one method of measurement was used, though several items in the instrument were adapted from extensively used measurement tools.

Data Analysis

The data analysis plan for the proposed research was designed to describe the current healthcare structure and care processes used in VAD self-care education by hospital organizations across the United States. Data analysis was completed using the SPSS statistical software package (Statistical Package for the Social Sciences). Data were verified for completion prior to statistical analysis. The questions were descriptive in nature as little is known about VAD self-care education practices among U.S. hospitals.

Missing data. There was a concern for missing data. If a significant amount of missing data were found to be in a non-random pattern, or specific to one particular measured variable, then the survey item may have been poorly constructed and misunderstood by the subject, or perhaps the study subject was uncomfortable with providing that information. To minimize these risks, the PI completed preliminary work consisting of pilot testing of survey questions and rewording of confusing items, and the PI informed survey participants of their confidentiality during the research process and would only report results in the aggregate.

Missing data from the completed surveys were addressed by coding the respective missing response as 98 for “not applicable” answer options, and 99 for missing or omitted data. Many of the survey question items include a “not applicable” answer option because many of the queried care structure and processes among hospitals for the VAD patient population has not been previously described.

Research question 1: What are the care structure and VAD self-care education processes utilized in hospitals during the initial postoperative phase after VAD implantation?

The levels of measurement for the variables of Research Question 1 were nominal and continuous. Nominal data were summarized using frequency distributions, and a percentage of the total that each category represents. Continuous data were first evaluated for normality. Means and standard deviations were used if normally distributed; if not, median, interquartile range, and minimum and maximum values summarized the distributions.

To further understand and describe the care structure and VAD self-care education processes utilized in hospitals during the initial postoperative phase after VAD implantation, surveys were described and compared by geographical region, organization ownership, hospital bed size and membership in the Council of Teaching Hospitals (COTH). These characteristics were obtained from the latest American Hospital Association (AHA) Annual Survey Database (2009). Chi-square tests of independence were performed to evaluate whether any of the differences among regions, organization ownerships, hospital bed sizes and COTH membership were statistically significant.

Lastly, a cluster analysis of responding hospitals was performed in order to further describe patterns of self-care education material and resource use by VAD hospitals. The cluster analysis technique defines unknown groups within a data set by arranging groupings together in "clusters". Clusters are developed within this technique by optimizing homogeneous characteristics within groups and heterogeneous characteristics between groups. Because both categorical and continuous variables were included in the analysis, a Log-Likelihood Distance (two-step cluster algorithm) cluster analysis method was chosen. The distance between two clusters is related to the decrease in log-likelihood; the algorithm continues to combine model clusters until one cluster remains. The Schwarz Bayesian Information Criterion (BIC) is used to select the best number of clusters based on those distances. Variables chosen for inclusion in the cluster analysis included variables which represented hospital care structure and care process elements described in the conceptual framework. Those variables included materials used in education delivery, resources for patient-provider communication, labor input, and annual patient volume. PASW® Statistics 18 software was used for all of the statistical analysis conducted.

AIM 2/Question 2

Research Design

The design of AIM 2 of the dissertation research was a prospective, cross-sectional descriptive design. The PI used a one-time, telephone interview process to identify what patient-centered care expectations are important to VAD patients, and to explore VAD patient reports of patient-centered care within their hospital facility.

Research Setting

The PI used the University of Alabama at Birmingham (UAB) Hospital as the research setting for AIM 2 of the dissertation research. UAB Hospital is a large, 1,000-bed university hospital, tertiary care and teaching facility in Birmingham, Alabama. The PI selected this hospital site for convenience, as it was reasonably close to the investigator's personal residence and was both an accessible and cost-effective option. UAB Hospital also offers a well-established program for cardiothoracic transplantation and ventricular assist device implantation, and maintains a high annual surgical volume and VAD patient population. UAB Hospital is approved for both bridge to transplant (BTT) and destination therapy (DT) LVAD implantation indications (Peggy Blood, personal communication, October 2009).

The purpose of AIM 2 was to identify what patient-centered care expectations are important to VAD patients and to explore VAD patient reports of patient-centered care within their hospital facility. The PI completed a telephone interview with current VAD patients of the University of Alabama at Birmingham Hospital (UAB). The PI chose the telephone interview (TI) process, as this method appeared to have practical and financial benefits for this research when compared to other methods. The TI process offers an advantage compared to pencil-and-paper personal interviews in areas of formatting of both complex and open-ended questions, control of sequence of response to questions, supervision of the interviewer (none required as the PI personally completed interviews), and control of the length of the data collection period.

TI with concurrent computerized data entry is also advantageous for data preparation prior to analysis; the process simplifies data editing and cleaning, the imputation of missing values, and improves turnaround time. Telephone interviewing also reduces overall costs for implementation when compared to other methods (Aday & Cornelius, 2006). Personal interview response rates may decline as people may be fearful of admitting strangers into their homes, and more people reside in high-security buildings or gated communities. Though response rates for TI may be decreased as many people are reluctant to answer unrecognized phone numbers due to unwanted solicitation, the PI provided all VAD patients with survey information and the PI's contact information prior to attempting telephone contact (Aday & Cornelius, 2006). The PI completed the telephone interview process and entered survey responses into a computer database during the telephone conversation.

Sample and Sampling Plan

The PI used a convenience sampling of VAD patients from UAB Hospital for this Phase II research. The PI recruited the sample population using solicitation inviting VAD patients to participate in a telephone interview exploring perceived importance of patient-centered care.

*Nature and size of sample***.** The sample of VAD patients included current patients with care managed by the heart failure and MCSD/VAD program at UAB Hospital. At the time of study implementation, the LVAD patient cohort consisted of approximately 40 VAD outpatients, including both BTT and DT patient groups.

*Criteria for sample selection, study inclusion and exclusion***.** The criteria for sample selection, study inclusion and exclusion for AIM 2 research were as follows:

a. The sample was a convenience sample of VAD patients with care managed by UAB Hospital. The final sample included all VAD patients who agreed to participate and complete the TI.
b. The PI excluded no one adult VAD patient from the study based upon age, race, gender, or ethnic group.
c. The PI included VAD patients in the study if the following criteria were met: (a) possessed the ability to speak and understand English, (b) were 18 years old or older, (c) were currently receiving LVAD therapy as BTT or DT, (d) were receiving VAD therapy with the HeartMate II LVAD device, (e) had been successfully discharged from the hospital following initial surgical implantation, (f) had access to a telephone.

d. The PI excluded VAD patients from participation in the study if the following criteria were met: (a) did not have the ability to speak or understand English, (b) were under 18 years old, (c) were not currently receiving LVAD therapy as BTT or DT, (d) were receiving LVAD therapy with any device other than the HeartMate II LVAD system, (e) were currently a hospital inpatient or have not yet been successfully discharged from the hospital following initial surgical implantation, (f) did not have access to a telephone.

Procedures

The procedures used in AIM 2 of this dissertation research were as follows:

Month 1:

1. The PI obtained agreement for organizational support from the University of Alabama at Birmingham Hospital.
2. The PI obtained IRB approval from VUMC and IRB approval from the University of Alabama at Birmingham Hospital
3. The PI programmed and activated the internet-based survey Research Electronic Data Capture (REDCap). The PI used the REDCap system for data input during telephone interview.
4. The PI reviewed the survey and generated database to ensure accurate function prior to utilization for the study. After the computer formatted survey and

database functioned appropriately, the PI used the database for Phase II data entry.

Months 2-5:

5. The PI notified VAD patient participants of the research study prior to telephone communication.

   Recruitment procedures were as follows:

   - The PI met with and discussed Phase II research plan and implications with the VAD Coordinator of the selected healthcare facility. The PI explained and reviewed the TI process.
   - The PI provided the VAD Coordinator with study inclusion and exclusion criteria. The VAD Coordinator identified current outpatient VAD recipients who met study criteria and provided VAD patients with the study invitation flyer. The flyer included 1) the name of the PI and Vanderbilt University School of Nursing, 2) a brief description of the survey topic, 3) a description of the subject area and patient population of interest, 4) an explanation of the purpose of the research, 5) a description of the interview process, 6) an estimate of the time required to complete the interview, 7) assurance of confidentiality and anonymity, 8) an explanation of voiding of confidentiality if patient safety issues are identified during the research process, 9) explanation that there is no cost for participating in the study, 10) an assurance that

participation in the research study is voluntary and that withdrawal from consent to participate is acceptable at any time during the study, 11) an assurance that non-response to any item or question in the interview is acceptable, 12) contact information for questions regarding the research study and for concerns or complaints regarding the research study, and 13) IRB approval of the planned research. The PI also provided a contact number and e-mail address for patients to contact if they had any questions or concerns regarding the study.

- If the patient was interested in participating in the research study, they were asked to sign a release of protected health information (PHI) form per the University of Alabama at Birmingham (UAB) Hospital requirements. The PHI form permitted the release of patient name and telephone number to the PI. The signed PHI form was to be securely stored on-site at the UAB Hospital until 6 months after the date of signature.
- During the data collection period, the PI attempted to contact identified potential study participants by the telephone number provided by the patients at the time of study recruitment.
- The PI obtained a verbal consent from patients who chose to participate in the survey. The PI reviewed information included in the study recruitment flyer, as well as risks and benefits for

participating in the study. After consent was obtained for participation in the study interview, the PI began asking survey questions to the VAD patient participant.

- If subjects were not accessible in two attempted telephone calls, the PI excluded them from the study.
- If a participant was not reached prior to, or was contacted once but requested another appointment beyond the 90-day limit for data collection, the PI made no further contact.
- If a participant indicated no preferred time for telephone interview, the PI made up to 9 attempts at telephone contact during the 90-day data collection period.

6. The PI contacted study participants by telephone. During the interview process, the PI entered answers that were provided by the study participant into the REDCap database. The Patient Perceptions of Important Aspects of Care (See Appendix D) were used for reporting of patient-centered care and to measure patient perception of importance of individual aspects of care, as well as patient reports of VAD self-care education.
7. Demographic data such as age, gender, race, ethnicity, and marital status were obtained from the patient during the interview. Level of education and socioeconomic status were also asked during the interview process.

8. The maximum time allowed for data collection was 90-days from the beginning of subject recruitment. After this time, the study interview was closed to participation.

Month 6:

9. Data were downloaded to SPSS for analysis.

Months 7-9:

10. Data were analyzed and results were written for AIM 2 of the dissertation research. Conclusion sections for AIM 1 and AIM 2 were completed at this point.
11. Dissemination of results will be completed through the dissertation defense, and through presentation of aggregate results to the Department of Cardiothoracic Transplantation, University of Alabama at Birmingham Hospital. Results will also be formatted into a manuscript suitable for publication, such as *Progress in Transplantation,* or *The Journal for Cardiovascular Nursing.*

Human Subjects Protection

A collaborative agreement with the Department of Cardiothoracic Transplantation at University of Alabama at Birmingham Hospital was used to facilitate this study. Review for this study process included review by the PI’s dissertation research committee, review for protection of human subjects by the Vanderbilt University Medical Center (VUMC) Institutional Review Board (IRB), and review by the University of Alabama at Birmingham Hospital (UAB) IRB.

*Potential risks to subjects***.** There appeared to be no inherent physical risk related to participation in this study. Potential risk from participation included actual realization of potential knowledge deficits related to VAD therapy not otherwise realized by patient and primary caregiver. The standard level of care provided for these patients at their respective medical centers was not compromised. Patients and caregivers who had concerns regarding their care needs relative to VAD support were encouraged to discuss these concerns with their healthcare provider. The PI informed VAD patients who participated in the study that any information provided by the patient during the interview process that suggests a risk to health or functioning of the VAD device would be reported to the VAD Coordinator for follow-up. Another potential risk included perceived stress related to fear of retribution on the part of the healthcare team should dissatisfaction with care services be identified. As this is an extremely specialized patient population, access to specialty-trained providers could limit care options and force patients to seek care at one hospital location. There was a high potential for sociopsychological artifacts creating bias in study results.

*Participant confidentiality***.** The methods for ensuring participant confidentiality were as follows:

1. Electronic data from interviews were secured and encrypted within the established survey database. To assure patient confidentiality with the interview process, all survey data did not contain or request identifying patient information, and were coded using a random generated ID number.

2. Protected health information (PHI) forms containing patient names and telephone numbers are securely locked in a file cabinet kept on-site at the University of Alabama at Birmingham Hospital, and data will not be removed from this site, until 6 months after receiving patient signature, per UAB Hospital requirements.

3. Patient participants were informed of efforts to maintain confidentiality and right to decline or stop participation at any time without fear of repercussion by their healthcare providers.

4. Immediately following data collection, all identifying information (patient name and telephone number) was discarded by the PI, either by electronic deletion or by shredding if in paper format.

*Inclusion of gender and minorities***.** The study included both male and female study participants. The collaborating site is a large university medical center in Birmingham, Alabama. According to the 2000 United States Census, the Birmingham, AL population is approximately 46.14% male and 53.86% female. Unfortunately, due to the nature of advanced CHF and the indications for LVAD therapy, equal numbers of male and female participants could not be assured.

Efforts were made to enroll minorities into this study. However, according to the 2000 United States Census, Hispanic and Latino ethnic groups made up only 1.55% of the greater Birmingham, AL population, and the largest minority group in that region is African-American (73.46%). All other represented minority groups included less than 0.5% of the greater Birmingham population. There is evidence that disparities exist with this therapy, which supports the need for this research within minority groups. However, due to the ethnic and racial composition of the region, as well as the nature of CHF and indications for LVAD therapy, an equal distribution among participants could not be assured.

*Data and safety monitoring***.** The PI met at least monthly with the research committee or committee chair to review progress relative to this study, in similar fashion as described in AIM 1. Participant recruitment, provision of necessary measurement tools, data obtained from completed surveys, and accuracy of the data entry were reviewed. There was no protocol violation noted during this study. .

The study protocol was reviewed by a research committee within the Vanderbilt University School of Nursing, as well as by the Vanderbilt University Institutional Review Board (IRB) before beginning the study. Computer software was provided including encrypted spreadsheet software and statistical analysis packages.

Data Collection Methods

1. The PI electronically collected research data materials obtained from human subjects during a telephone interview. No specimens were used in AIM 2 dissertation research.
2. TI: During the interview process, the PI entered data obtained from patients into the REDCap database. Linkage to study participants was generated automatically through creation of an identifier that was maintained in the survey database with the survey data. The PI deleted identifiers from any file downloaded for statistical analysis. The PI

destroyed all identifiers after data collection was completed. The PI will report data in aggregate only and never attribute data to one patient.

*Instruments***.** The PI used one instrument for AIM 2 of the dissertation research. The instrument is a synthesis of two surveys: the Hospital Consumer Assessment of Healthcare Providers and Services (HCAHPS) survey, and a Patient Perceptions of Important Aspects of Care survey previously used by Young and Minnick (1996). A description of these tools relative to their application towards operational definition of identified variables and analytic considerations is provided in Table 2. The PI modified question stems to emphasize the postoperative recovery in-hospital phase of the VAD patient, and the PI chose only questions pertinent to communication and self-care education. The PI added demographic questions to describe the patient sample, and open-ended questions were included to explain patient perceptions of the care they received.

Survey of Patient Perceptions of Patient-Centered Care after Ventricular Assist Device Implantation. (Appendix D). This survey is 65-items, and is synthesized from the Hospital Consumer Assessment of Healthcare Providers and Services (HCAHPS), and from a tool previously used by Young and Minnick (1996). The HCAHPS survey tool was chosen for this study, as it is the only measurement of patient satisfaction with an inpatient hospital stay experience that has been developed upon a theoretical framework and patient opinion, rather than perceptions of care providers. Table 1 provides a general review of a majority of well-known patient satisfaction tools utilized in outcome research. The HCAHPS survey has also been endorsed nationally as a means for comparison of hospitals across the country. Additionally, as there is no disease-specific patient satisfaction measurement tool readily utilized among hospitals with VAD programs, stems were changed in the HCAHPS survey to reflect VAD patient-specific experiences.

The HCAHPS evolved from numerous patient interviews and the resulting framework providing the foundation for measurement of Patient-Centered Care, the HCAHPS tool is self-administered, and can be completed by telephone or by in-person interview. In accordance with the patient-centered care framework, the HCAHPS survey targets domains of 1.) concern for the patient as an individual 2.) physician communication, 3.) medication, 4.) nursing services, 5.) discharge information, 6.) pain control, 7.) physical environment, and 8.) global ratings of care, including hospital, physicians and nursing.

The PI did not use all questions included in the HCAHPS survey. Questions included in the domains which were directly related to education delivery were chosen for use in this research. There are no items, however, that measure perception of skill by any care provider. There is a risk of bias, as with any satisfaction measurement tool, but the use of patient reports of care rather than rating care by numerical scale yields more of an objective measurement, and reduces potential for multicollinearity. To reflect the actual experience of postoperative recovery following VAD implantation, the stems of survey questions were modified.

Several questions were combined with selected HCAHPS survey items in order to explore VAD patient perceptions of important aspects of patient-centered care, as well as patient reports of timeliness, thoroughness and individualization of care received. Based upon the work of Young and Minnick (1996), the items included follow an HCAHPS domain question with a patient rating of perceived importance (i.e., “How important was it to you that your nurses listen carefully to your concerns?”). The patient ranked the perceived importance on a 1-4 scale.

In order to enrich data obtained from VAD patients, survey, three additional questions were added in order to assess patient report of self-care education relative to VAD therapy. Those questions ask the patient to report if they were given, in writing, instructions for proper performance of an identified VAD self-management skill. The survey also included questions regarding demographic information (i.e., age, gender, race, ethnicity, level of education, annual income, and marital status). Lastly, the survey contained two open-ended questions, asking patients to provide recommendations to healthcare providers and to provide advice to future VAD patients regarding learning self-care skills.

*Credibility, rigor and validity of design and methods***.** The AIM 2 component of this dissertation research attempted to assure credibility by the use of well-established measurement tools with known validity and reliability. The HCAHPS survey tool is well-known and used widely in an effort to compare satisfaction reports across multiple hospital centers. The survey is in the public domain, available through the Agency for Healthcare Research and Quality (AHRQ). The Patient Perception of Importance of Aspects of Patient-Centered Care tool is derived from the HCAHPS survey, asking for ranked importance of sub-concepts of the HCAHPS tool. Rigor was assured through adherence to the instruments' scoring techniques and the use of appropriate statistical analysis techniques based upon level of measurement data obtained.

Data Analysis

The data analysis plan for the AIM 2 research was designed to 1.) describe LVAD patient reports of patient-centered care, and 2.) describe what patient-centered care expectations are important to LVAD patients. Data analysis was completed using the PASW® Statistics 18 software package. Data were verified for completion prior to statistical analysis through 25 random checks for data accuracy. Aims 1 and 2 are descriptive in nature as very little is known about LVAD patient preferences and perceptions of care.

*Research question 2***:** What are LVAD patients' reports of patient-centered care within their selected healthcare facilities? What patient-centered care expectations are important to LVAD patients?

AIM 1: To describe LVAD patient reports of patient-centered care.

The levels of measurement for the variables of AIM 1 in Research Question 2 were nominal, ordinal and continuous. The PI used selected items of HCAHPS survey tool, requiring report of occurrence of care events. Question stems were adjusted to reflect VAD patient specific care. AIM 1 analysis was performed using frequency distributions for nominal data. Ordinal and continuous data was described using median and minimum and maximum values.

AIM 2: To describe what patient-centered care expectations are important to LVAD patients.

The level of measurement for the variables of AIM 2 in Research Question 2 was nominal. The Patient Perceptions of Important Aspects of Care survey requires reports of events based upon degree of perceived importance. AIM 2 was addressed using frequency distributions.

The PI added two open-ended questions into the survey instrument in order to gather richer data from VAD patients. The PI asked patients to list methods of education delivery for VAD skill sets offered to them by providers. The PI added two open-ended questions to provide VAD patient advice to current care providers and to future VAD patients. Recurrent themes and methods for education delivery were identified through content analysis of the patient-reported data.

Dissertation Research Timeline

It is important to note that both Phases of the dissertation research are mutually exclusive and as such the PI completed both phases concurrently. This is reflected in the following timeline for the dissertation research, provided in Table 4.

Table 4. Dissertation Research Timeline

	Month	1-2	2-5	6-7	8-9
	Task				
AIM 1	Identify Hospital Organizations	X			
	IRB Approval(s)	X			
	Database Development	X			
	Subject Recruitment		X		
	Data Collection		X		
AIM 2	IRB Approval(s)	X			
	Train Research Support Staff	X			
	Database Development	X			
	Subject Recruitment		X		
	Data Collection		X		
	Statistical Analysis/Interpretation			X	
	Write-Up of Results/Defense				X

Note. AIM 1 and AIM 2 contains elements that may be completed concurrently.

Summary

The knowledge gained with this proposed dissertation study will be used to identify components of healthcare structure and care processes that play a major role in preparing VAD patients for successful self-management after hospital discharge. Understanding what VAD patients perceive as successful care interventions and by identifying what aspects of care that LVAD patients perceive as most important or crucial to their outpatient success, nursing may contribute a greater role in development of supportive interventions aimed at reducing fear and stress during the postoperative recovery phase, improve retention of learned self-care skill sets, and increasing numbers of support modalities available for both VAD patient and caregiver. By evaluating patient expectations, healthcare organizations may change current structure and care processes and improve patient satisfaction with care received and postoperative self-care after discharge.

CHAPTER IV

Results

Following a discussion of analytic preparation and sample characteristics, chapter IV provides the results of this study by each research question and their respective aim(s).

AIM 1: To describe care structure and VAD self-care education processes used in hospitals.

Analytic Preparation and Procedures

Completed paper survey data were loaded into the REDCap survey database by the PI. Completed electronic surveys were automatically included in the study database via REDCap. After close of data collection, the PI completed 25 random survey data checks to assure accuracy in transferring data from survey to computer database. The PI converted all data loaded into the REDCap system into SPSS for statistical analysis.

*Missing data***.** There were very little missing data in this study. There were several "Not Applicable" responses pertaining to some skill set validations and VAD coordinator perceptions of difficulty of mastery of self-care skills. Some VAD coordinators wrote on their completed surveys that their hospital programs do not allow patients to perform certain self-care skills (e.g. 25% of respondents rated patient showering with the VAD as 'N/A'), and thus the patient must rely on a primary caregiver to complete those skills. Another omitted answer (7% of respondents) concerned the question asking for the number of annually budgeted VAD implantations within the respective hospital facility. VAD coordinators who declined to answer this question often stated that they were not allowed to provide that information publicly. Due to the very low incidence of missing data (< 0.5%), cases that included some missing data were retained, and statistical analyses were completed with the total number of responses available for the respective item.

Comparison of Study Participants with Universe: Estimates of Generalizability

*Study participants***.** The PI recruited the universe of VAD-implanting hospitals. He identified these using the methods described in Chapter III. After excluding pediatric VAD programs from this study cohort, a total of 116 VAD-implanting hospitals were identified. Of the 116 hospitals identified, 5 were found to have closed their VAD surgical programs, leaving 111 VAD-implanting hospitals for potential study. All 111 identified VAD-hospitals were invited to participate via cycled electronic advertisements and standard mailings as described in Chapter III. The final response rate was 64% (71 out of 111 hospitals). Most (86%) of responders submitted a completed paper survey (n = 61); 14% of responders completed the electronic version of the survey (n = 10).

*Characteristics of responders and non-responders***.** The distribution of hospitals by region, ownership, and service are illustrated in Table 5. No significant differences were observed among regions, ownership, service, and membership in the Council of Teaching Hospitals (COTH) for the responding and non-responding hospitals ($p > .05$).

Table 5. Comparison of Hospital Responders and Non-Responders to VAD Services Survey (n, %).

Hospital Characteristics	**Responder** **n =71 (64)**	**Non-Responder** **n =40 (36)**	**All** **n =111**
REGION			
1: New England	6 (9)	0 (0)	6 (5)
2: Mid Atlantic	8 (11)	12 (30)	20 (18)
3: South Atlantic	14 (20)	6 (15)	20 (18)
4: East North Central	12 (17)	6 (15)	18 (16)
5: East South Central	4 (6)	2 (5)	6 (5)
6: West North Central	5 (7)	2 (5)	7 (6)
7: West South Central	6 (9)	8 (20)	14 (13)
8: Mountain	6 (9)	0 (0)	6 (5)
9: Pacific	9 (13)	4 (10)	13 (12)
Unassigned	1 (1)	0 (0)	1 (1)
OWNERSHIP			
12: Government – State	9 (13)	4 (10)	13 (12)
16: Government – Hospital district/authority	4 (6)	2 (5)	6 (5)
21: Nongovernment – Church operated	3 (4)	5 (13)	8 (7)
23: Nongovernment – not-for-profit	52 (73)	25 (63)	77 (69)
32: Investor-owned (for-profit) Partnership	1 (1)	1 (3)	2 (2)
33: Investor-owned (for-profit) Corporation	1 (1)	2 (5)	3 (3)
45: Government, federal – Veterans Affairs	0 (0)	1 (3)	1 (1)
Unassigned	1 (1)	0 (0)	1 (1)
SERVICE			
10: General Medical and Surgical	70 (99)	38 (95)	109 (98)
42: Heart	0 (0)	1 (3)	1 (1)
Unassigned	1 (1)	0 (0)	1 (1)

Note. Characteristics were obtained from the latest AHA Annual Survey Database available at time of study (FY 2009).

Research question 1. “What are the care structure and VAD self-care education processes utilized in hospitals during the initial postoperative phase after VAD implantation?”

Results: Care Structures

Organizational framework of VAD programs

Nearly half of responding coordinators reported VAD program placement within their hospital’s cardiac transplant program, while 25% reported a different placement within the organization (e.g., cardiothoracic surgery or heart failure departments). Despite program placement, only 40% (n = 29) of programs report to one department. The remaining 60% of VAD programs (n = 42) report to two or more departments. More than 75% of coordinators reported VAD program leadership by more than one physician director. No statistically significant differences were found in number of VAD Program reporting structures among groups in region, ownership, hospital bed size, or Council of Teaching Hospitals (COTH) status ($p > .05$).

The median number of VAD implantations reported by coordinators in 2010 was 19.5 (n = 68; IQR 10, 36; min, max = 0, 85). All VAD programs (n = 71) managed both VAD inpatient and outpatient needs. Most (85%) VAD programs provided care to patients receiving VAD therapy as bridge to transplant (BTT), as destination therapy (DT), and as bridge to recovery. The remaining 15% provided care to VAD patients receiving therapy as BTT and/or DT.

Care Providers

Most coordinators reported a multidisciplinary approach to the management of VAD patient care in which providers were either exclusively assigned to the care of VAD patients, or were regularly assigned to VAD patients but also worked with other patient populations as well. Table 6 provides a description of healthcare provider assignments in VAD hospitals.

Table 6. Healthcare Provider Assignments in VAD Hospitals (N =71).

Healthcare Provider	**Assignment Type* % of row**			
	1	**2**	**3**	**4**
Cardiac Surgeon	4	96	0	0
Heart Failure Cardiologist	6	90	3	1
Clinical Nurse Specialist	4	31	17	48
Nurse Practitioner	23	54	11	13
Discharge Planner	3	69	13	16
Biomedical Engineer	14	45	24	17
Pharmacist	7	61	27	6
Social Worker	9	86	6	0
Physical Therapist	1	70	27	1
Clinical Psychiatry	3	47	32	17
Clinical Perfusionist	4	61	24	11
Home Health Nurse	3	27	47	24
Respiratory Therapist	3	41	45	11
Dietician	4	76	20	0
Chaplain	1	45	44	10

1 = Works with VAD Program Only
2 = Same provider regularly assigned but also works with other kinds of patients
3 = Not regularly assigned to VAD program, but is available as needed
4 = Provider not currently available to VAD program

Note. Items may not add to 100% due to rounding. * Values in cells are row %s.

Caregiver Role Delineation

After identifying key members of the VAD patient care team in addition to the VAD coordinator and staff registered nurse (RN), the PI sought to determine which members of the team performed specific VAD patient care clinical services. The VAD coordinator performed most clinical services, including those services targeted toward self-care training. Advanced practice nurses (APN) performed several services as well, although only 37 coordinators noted that APNs were in a non-coordinator role within the VAD care team. Staff registered nurses (RNs) had several responsibilities, most commonly including direct patient care, medication administration, wound care and VAD self-care education delivery and evaluation. Other providers identified included attending physicians, fellows and residents (Table 7).

Table 7. Personnel Responsible for Performance of Clinical Services in VAD Implanting Hospitals (N = 71).

Clinical Service	**VAD Coordinator N = 71**	**APN (Not Coordinator) N = 37**	**Staff RN N = 71**	**Biomedical Engineer N = 71**	**Case Manager N = 71**	**Other N = 71**
	% of Hospitals Reporting Clinical Services Performed by Personnel					
Direct patient care	59	30	82	9	4	4
Order drug therapy	54	92	3	0	0	27
Administer drug therapy	20	16	90	3	0	3
Order nutritional support	61	95	11	0	1	30
Order diagnostic testing	66	86	4	0	0	27
Perform wound care	75	30	70	1	0	0
Adjust VAD Settings	89	38	7	14	0	21
Recommend social support	89	59	44	3	34	18
Order home health	63	65	4	0	30	10
Teach self care:						
VAD exit site care	96	19	63	1 1	0	1
Mobility and Power Supply	96	16	56	5	0	3
Emergency Procedures	94	19	25	9	0	1
Evaluate self-care:						
VAD exit site care	96	27	51	1	0	0
Mobility and Power Supply	96	22	41	9	0	7
Emergency Procedures	94	19	17	10	0	1
Self-care after Discharge	97	24	14	6	4	4

Note. Due to performance of clinical services by multiple personnel, rows do not add up to 100%.

VAD Coordinator and Nursing Staff Role Preparation

The education, certification and experience requirements of VAD coordinators and staff RNs were also explored in order to describe requisites for VAD patient care management in hospitals. Most hospitals (N = 44, 62%) required a Bachelor's degree in Nursing (BSN) or higher, and critical care nursing experience (N = 51, 72%). Cardiac surgery experience was required in 47% of hospitals (N = 33).

Almost one-third (N = 22, 31%) of hospitals required a VAD coordinator be certified as an Advanced Practice Nurse (Nurse Practitioner). Hospitals with 200-299 beds were more likely to require the VAD coordinator to be an Advanced Practice Nurse (APN)/Nurse Practitioner than hospitals with any other category of bed size (χ^2 (7, N = 71) = 16.00, p = .025).

Staff RN education was explored to determine how RNs received didactic content specific to VAD patient care. Experience refers to the clinical application of learned content through an on-site, preceptor-led orientation. Most coordinators reported that formal instruction was provided by the VAD coordinator (N = 64, 90%). More than half of reporting coordinators noted instruction was also provided by a device representative (N = 36, 51%), and 44% (N = 34) provided instruction delivered by a designated unit educator.

Most coordinators reported RN preceptor-led experiences included ICU VAD patient assignments (N = 64, 90%) as well as Step-down unit VAD patient assignments (N = 59, 83%). One-quarter (N = 18, 25%) of coordinators reported RNs had preceptor-led outpatient clinic VAD patient care experiences. Most hospitals (N = 54, 76%) required Staff RNs to obtain Advanced Cardiac Life Support (ACLS) certification prior to caring for VAD patients; this requirement was most commonly reported by hospitals in the South Atlantic region (24%).

VAD Coordinator Role and Responsibilities

Responding coordinators reported a median of 2 named full-time VAD coordinators within their VAD programs (N = 71, min/max: 1 – 5.5). Forty-nine percent (N = 35) of respondents provided a patient -VAD coordinator ratio, with an average patient-coordinator ratio of 16:1. Several VAD coordinator reporting structures were provided by responding hospitals. Some VAD coordinators are required to report directly to a medical (69%) or surgical (68%) director, cardiovascular service line director (42%), or nursing director (52%), which suggests that VAD coordinators may report to more than one physician or nurse leader.

Almost one-third of VAD coordinators reported to one leader (N = 19, 27%), and 21% (N = 15) report to two leaders. Over 50% of VAD coordinators (N = 37) report to more than two leaders. The largest numbers of those hospitals was located in the South Atlantic region (22%), were non-government, not-for-profit (70%), had > 500 beds (62%) and were teaching hospitals (70%). There were no statistically significant differences noted among the various AHA hospital demographic features in total number of leaders reported to (p > .05).

Responding coordinators identified several role components within the VAD coordinator position, as listed in Table 8. Most commonly identified role components included outpatient direct care nursing, development of VAD nursing education, providing and evaluating nursing staff education, training of housestaff, training of staff at subacute or rehabilitation facilities, education of emergency response (EMS) personnel, participation in research, database entry, and on-call patient care responsibilities. Roles specified as “other” components included participation in community outreach efforts with referring heart failure care providers. There was no statistically significant difference noted between the reported actual number of annual VAD implants and number of identified role components among VAD coordinators (p > .05).

Table 8. VAD Coordinator Role Components (N=71).

Role Components (N = 71)			
Role Component	**%**	**Role Component**	**%**
Development of VAD nursing education	96	Database entry of clinical data	79
On-call patient care responsibilities	95	Direct care nursing (outpatient)	75
Train staff at Subacute/Rehabilitation Facility	93	Maintain inventory of VAD equipment	74
Emergency Response Personnel (EMS) Education	93	Advanced practice nursing (inpatient)	59
Provide nursing staff education	90	Case Management	58
Evaluate nursing staff education	85	Direct care nursing (inpatient)	56
Research (Outcomes or Clinical)	85	Advanced practice nursing (outpatient)	55
Train housestaff	82	Other	17

Note. Items may not add to 100% due to rounding.

There appeared to be variability in assignment of VAD coordinator role components of direct care nursing, advanced practice nursing (inpatient), advanced practice nursing (outpatient), case management, and maintaining inventory of VAD equipment among responding coordinators. Over half of hospitals required VAD coordinators to perform direct care nursing (N = 40, 56%). Inpatient advanced practice nursing was required by 59% (N = 42) of hospitals, and outpatient advanced practice nursing was required by 55% (N = 39). Case management was included as a role component in 58% (N = 41) of hospitals, and 74% (N = 50) of hospitals required VAD coordinators to maintain inventory of VAD equipment.

There was a statistically significant difference in the likelihood that a hospital required inpatient advanced practice as a VAD coordinator role depending on the location of the hospital (χ^2 (9, N = 71) = 18.80, p = .027). The VAD coordinator role component of inpatient advanced practice nursing was reported most often by coordinators within the

New England, Mid Atlantic and West North Central regions, and least often in the East North Central, West South Central and Mountain regions (see Table 9).

Table 9. Hospital Region and VAD Coordinator Role Component of Inpatient Advanced Practice Nursing in VAD Hospitals (N= 71).

Region	**VAD Coordinator Role Component: Advanced Practice Nursing – Inpatient %**	
	NO 29 (41)	**YES 42 (59)**
New England (N = 6)	17	83
Mid Atlantic (N = 8)	12	88
South Atlantic (N =14)	36	64
East North Central (N = 12)	75	25
East South Central (N = 4)	25	75
West North Central (N = 5)	20	80
West South Central (N = 6)	83	17
Mountain (N = 6)	50	50
Pacific (N = 9)	22	78
Unassigned (N = 1)	100	0

Note. Values in cells are row %s.

Results: VAD Self-care Education Processes

Description of VAD hospital self-care education processes included provider care services (e.g., materials and methods used in VAD self-care training) and hospital resources made available for patient support, and communication between care provider and patient and primary caregiver. Patient self-care requisites were defined according to existing literature and developed conceptual framework (see page 47).

The PI asked VAD coordinators to rank their perceptions of the level of difficulty for VAD self-care skills for both patients and primary caregivers. Results are summarized in Table 10. There were statistically significant positive correlations between perceived level of difficulty for both patient and primary caregiver across all listed self-care skills ($p < .001$). The weakest correlation was observed between patient and primary caregiver regarding VAD coordinator perceptions of difficulty included the skill of care for the LVAD percutaneous driveline (r_s =0.55, $p < .001$).

Table 10. VAD Coordinator Perceptions of Self-Care Skill Level of Difficulty for Patient and Primary Caregiver (N = 71).

VAD Self-Care Skill	**Level of Difficulty* % of Row**										
	Patient					**Primary Caregiver**					***r_s***
	1	**2**	**3**	**4**	**N/A**	**1**	**2**	**3**	**4**	**N/A**	
Power Source Changes	18	61	21	1	0	20	61	19	1	0	0.76
Battery Changes	30	52	16	3	0	32	48	18	1	0	0.81
Dressing Changes	1	21	41	25	11	6	24	48	23	0	0.66
Sterile Technique	0	10	42	31	17	1	13	45	32	9	0.76
Care of the LVAD Driveline	9	42	38	10	1	9	54	28	9	0	0.55
Recognizing Infection	21	55	16	9	0	18	59	20	3	0	0.78
Patient Showering	11	45	24	7	11	10	49	21	9	11	0.83
Self-testing LVAD Controller	54	37	6	0	3	51	37	9	1	3	0.79
Hemodynamic Monitoring	16	25	23	10	25	17	34	21	4	21	0.88
CHF Symptom Management	25	47	21	7	0	23	47	27	4	0	0.80
Medication Management	16	49	27	9	0	20	47	27	7	0	0.70
Alarm Troubleshooting	6	23	45	27	0	9	24	45	23	0	0.78
Emergency Management	7	23	41	30	0	7	31	35	25	0	0.82

1 = Not difficult, easy to master without additional coaching
2 = Moderately difficult, quick to master with some additional coaching
3 = Difficult, mastery requires practice and frequent reinforcement of instruction
4 = Very difficult, mastery requires frequent practice, frequent reinforcement of instruction and outpatient follow-up

Note. All p-values are < .001. Items may not add to 100% due to rounding. *Values in cells are row %s.

Education Delivery Materials

Included in the healthcare delivery structure portion of the summary was capital input, which was defined in this study as education delivery materials, used in VAD self-care training. Responding coordinators (N = 71) were asked to select all resources used in VAD patient self-care education. Results are summarized in Table 11.

Table 11. Materials Used by Hospitals for VAD Patient Self-Care Education (N=71).

Resource	**Frequency Used** **%**
Written material developed by device manufacturer/others	96
Verbal Instruction	96
Written material developed by hospital or unit	90
DVD	89
Internet Website(s)	66
CD-ROM	21
Videotape	18
Audio CD	11
Podcasts	6
Other	17

Most commonly used delivery materials were written materials developed by the hospital or patient care unit (90%), or device manufacturer (96%), as well as verbal instruction (96%) and the use of DVD (89%). Resources categorized as “Other” included written-in resources used by hospitals. Several coordinators noted the use of simulation training for VAD self-care education. Other facilities used videos created by nursing staff, or formal mandatory classes held for patients and caregivers prior to discharge.

There was variability in the use of several of the resources listed, including the use of videotape, audio CD, internet websites, podcasts, and CD-ROM. A summing of the less often-used resources used by hospitals indicated that 73% (N = 52) of hospitals used two to five of those resources in addition to the use of written material and DVD when providing self-care training. The lowest use of additional resources occurred in the New England region (N = 3, 50%) and East North Central region (N = 50%). No statistically significant differences in self-care education resource utilization were noted among institutions by region, ownership, hospital bed size or COTH status (p > .05).

Validation of Patient Self-Care Skill Performance

The PI asked coordinators to describe the methods used to validate patient self-care skill performance prior to hospital discharge. Table 12 summarizes reports of VAD self-care skill set validation used in hospitals. There was a considerable variability in methods of validation across all listed VAD self-care requisite skills. Return physical demonstration of skills was most commonly used for battery changes (99%), dressing changes (99%), sterile technique (89%), care of the LVAD percutaneous driveline (90%), and self-testing the LVAD system controller (94%). Return verbal demonstration was most often used to validate recognizing infection (76%), alarm troubleshooting (79%), and emergency management procedures (78%).

Table 12. Methods of Validation of Patient Self-Care VAD Skill Performance (N = 71).

	Method of Validation of Patient Self-Care VAD Skill Performance %				
Skill	**Return Physical Demonstration**	**Return Verbal Demonstration**	**Written Testing**	**Oral Testing**	**Not Applicable**
Power Source Changes	54	54	44	47	0
Battery Changes	99	51	38	44	0
Dressing Changes	99	45	20	34	11
Sterile Technique	89	41	20	28	7
Care of the LVAD Percutaneous Driveline	90	61	27	41	0
Recognizing Infection	42	76	32	52	0
Patient Showering	51	59	11	31	13
Self-Testing System Controller	94	41	34	32	1
Hemodynamic Monitoring	27	54	18	37	27
CHF Symptom Management	18	66	23	52	3
Medication Management	27	65	23	55	1
Alarm Troubleshooting	59	79	54	58	0
Emergency Management	52	78	52	58	0

Note. Due to use of multiple methods by each responding hospital, rows do not add up to 100%.

VAD power source change. To appraise the potential use of multiple methods of validation, the PI evaluated each identified skill separately by validation method, and then compared across AHA hospital demographic data. More than half of hospitals (N =38, 53%) used one or two methods of validation of changing the VAD power source. Almost one-half of hospitals used three to four methods of validation (N = 32, 46%). There were no statistically significant differences among regions, ownership, hospital bed size, or COTH status in number of methods used for skill validation of power source change ($p > .05$).

VAD battery change. Several regions used multiple methods of skill validation, while no majority of hospitals was noted to use any specific number of methods. More than half of hospitals (N = 41, 57%) use one to two methods of validation, and 43% (N =30) use three or four methods. There were no statistically significant differences among regions, ownership, hospital bed size, or COTH status in number of methods used for skill validation of VAD battery change (p > .05).

VAD dressing change. Most hospitals (N = 48, 68%) used one or two methods of validation of this self-care skill. One-quarter (N = 18) of hospitals used three or more methods. The South Atlantic region (18%) was most often noted using multiple methods for skill performance validation. There were no statistically significant differences among groups according to region, ownership, hospital bed size, or COTH status in number of methods used for skill validation of VAD dressing change (p > .05).

VAD sterile technique. The performance of correct sterile technique is required during the VAD dressing change procedure. Almost half of hospitals (N = 31, 44%) used one method to validate sterile technique. There were no statistically significant differences among groups by region, ownership, hospital bed size, or COTH status in number of methods used for skill validation of VAD sterile technique (p > .05).

VAD percutaneous driveline care. The use of two validation methods was most commonly reported for this VAD self-care skill (N = 26, 37%). The East North Central (92%), West South Central (83%) and Pacific (100%) regions were more likely to use more than one additional method of validation when compared to other regions (see Table 13). There was a statistically significant difference among the hospital regions in number of methods used for skill validation of VAD percutaneous driveline care (χ^2 (18, N = 71) = 29.63, p = .041). There were no statistically significant differences noted among the institutions in terms of ownership, hospital bed size, or COTH status (p > .05).

Table 13. Hospital Region and Number of Methods Used for Validation of VAD Percutaneous Driveline Care (N = 71).

Region	**% of Hospitals by Number of Methods Used for Validation of VAD Percutaneous Driveline Care**		
	1 method 21 (30)	**2 methods 26 (37)**	**3-4 methods 24 (34)**
New England (N = 6)	33	33	33
Mid Atlantic (N = 8)	50	12	38
South Atlantic (N = 14)	29	43	28
East North Central (N = 12)	8	67	25
East South Central (N = 4)	75	25	0
West North Central (N = 5)	60	0	40
West South Central (N = 6)	17	50	33
Mountain (N = 6)	50	50	0
Pacific (N = 9)	0	22	78
Unassigned (N = 1)	0	0	100

Note. Values in cells are row %s.

Recognizing infection. The use of one method for validation was most commonly reported among hospitals (N = 26, 37%), although approximately the same number reported using two methods (N = 25, 35%). There were no significant differences among regions, ownership, hospital bed size, or COTH status in number of methods used for skill validation of recognizing infection (p > .05).

VAD patient showering. Thirteen percent of hospitals (N = 9) used no methods of validation of this skill. One method of skill validation was used most often among hospitals (N = 28, 39%), followed by the use of two methods (N = 25, 35%). There were no statistically significant differences among regions, ownership, hospital bed size, or

COTH status in number of methods used for skill validation of VAD patient showering (p > .05).

Self-testing the VAD system controller. VAD coordinators most often cited one method of validation used for self-testing of the VAD system controller (N = 31, 42%). Two methods of validation were used by 23% of hospitals (N = 16), and three or four methods were used by 34% (N = 24). There were no statistically significant differences among regions, ownership, bed size, or COTH status in number of methods used for skill validation of self-testing the VAD system controller (p > .05).

Hemodynamic monitoring. Hemodynamic monitoring refers to regular self-monitoring of blood pressure, and vital VAD settings (e.g. pump speed, flow, pulsatility index). Over one-quarter (N = 19, 27%) of responding coordinators reported no method of validation used. The most frequently reported number of methods used was one method of skill validation (N = 22, 31%), followed by the use of two methods (N =20, 28%). There were no statistically significant differences among regions, ownership, hospital bed size or COTH status in number of methods used for skill validation of hemodynamic monitoring (p > .05).

Heart failure symptom management. Over half of responding VAD coordinators (N = 40, 56%) noted either no or 1 method for validation of heart failure symptom management was used in their hospital. Thirty-one percent (N = 22) of hospitals used two methods of skill validation. There were no statistically significant differences among regions, ownership, hospital bed size or COTH status in number of methods used for skill validation of heart failure symptom management (p > .05).

Medication management. More than 50% of responding coordinators noted zero to one method used to validate effective medication management. Two methods of validation were used by 28% (N = 20) of VAD hospitals. There were no statistically significant differences among regions, ownership, bed size, or COTH status in number of methods used for skill validation of medication management (p >.05).

VAD alarm troubleshooting. Over one-third (N = 39%) of VAD hospitals use two methods of validation of VAD alarm troubleshooting. Three methods were used by 21% (N = 15) of hospitals, and four methods were used by 23% (N = 16).There were no statistically significant differences among regions, ownership, hospital bed size, or COTH status in number of methods used for skill validation of VAD alarm troubleshooting (p > .05).

VAD emergency management. Thirty-four percent (N = 24) of responding coordinators reported using two methods of skill validation in responding to a VAD emergency. Thirty percent of hospitals (N = 21) used three methods of validation. There were no statistically significant differences among regions, ownership, hospital bed size, or COTH status in number of methods used for skill validation of VAD emergency management (p > .05).

Resources for Patient Support

The PI asked VAD coordinators to list what resources were made available for use to support patients and family/primary caregivers after VAD implantation. Table 14 provides a list of the most commonly cited resources used by VAD hospitals. The most frequently reported resources included VAD support group meetings (56%), the use of the hospital website (45%), patient counseling (73%), and the use of patient-provider email correspondence (45%).

Table 14. Organizational Resources for VAD Patients and Family/Caregivers (N= 71).

Resource	**% of Hospitals with Resources Available to:**	
	Patient	**Family/Caregiver**
Patient Counseling	73	65
VAD Support Group Meetings	56	56
Hospital Website	45	45
Patient-Provider E-mail Correspondence	45	44
Patient Picnics	24	24
Facebook/Social Networking	14	14
Internet listserv/ Discussion forum	9	9
Internet Chat Rooms	6	6

There was variability in the use of several of the organizational resources listed. The PI calculated sums of less frequently reported resources to estimate the frequency of other resource use for patient and family/caregiver support in addition to the most common resources offered. The variable organizational resources were then compared to AHA hospital demographic data to assess for trends. Most coordinators (N = 55, 77%) that responded either provided no or one additional resource to VAD patients and their family/primary caregivers. There were no statistically significant differences among regions, ownership, hospital bed size, or COTH status in number of additional organizational resources available to VAD patients or family/caregiver ($p > .05$).

Cluster Analysis

The cluster analysis method used is described in Chapter III. Variables which represented elements of hospital care structure and self-care education resources according to our conceptual framework were entered into the cluster analysis (see Table 15). Several reporting coordinators stated they were unable to provide the actual number of VAD implants, and as a result, the total number of responding hospitals included in the cluster analysis was 66. Two clusters were identified by this analysis. For ease of presentation, the two groups are designated as Cluster A and Cluster B.

Table 15. Patterns of Additional Material and Resource Use, Labor Input and Quantity of VAD Programs (N = 66).

	Cluster A (N = 29)	**Cluster B (N = 37)**
Additional Materials Used for Education		
Videotape	45% reported use	0% reported use
Audio CD	21% reported use	5% reported use
Internet Websites	76% reported use	65% reported use
Podcasts	14% reported use	0% reported use
CD-ROM	14% reported use	30% reported use
Additional Resources Used for Patient and Family/Caregiver		
Patient Picnics	48% reported use	3% reported use
Internet Listserv/Discussion Forums	21% reported use	0% reported use
Internet Chat rooms	14% reported use	0% reported use
Social Networking Sites	35% reported use	0% reported use
Sum of Healthcare Providers on VAD Team	83% Same providers work regularly with VAD program, others are available as needed	81% Same providers work regularly with VAD program, others are available as needed
Actual Number of VAD Implants in Last Fiscal Year	Median = 16, IQR = 10-36	Median =21, IQR = 9-38

Cluster A (N = 29) was the smaller cluster of responding coordinators (43.9%). Cluster A tended to use a larger variety of VAD patient self-care education resources than did Cluster B. Cluster A used videotapes for training (45%), audio CDs (21%), internet websites (76%), podcasts (14%), and CD-ROM (14%) in addition to the most commonly used resources identified by most responding hospitals (i.e. written materials developed by hospital or unit, written materials developed by device manufacturer or others, DVD, or verbal instruction). Cluster A also used a larger variety of resources for patient and primary caregiver support than did Cluster B. In addition to support group meetings, patient counseling and patient-provider e-mail correspondence, Cluster A was more likely than Cluster B to use patient picnics (48%), internet listservs/discussion forums (21%), internet chat rooms (14%), and social networks (35%) for support and communication with patients following VAD implantation.

Cluster B (N = 37, 56%) tended to use fewer additional material resources for patient self-care education than Cluster A. No hospitals within Cluster B used videotaped material or podcasts for training, while 5% used audio CDs, and 39% used CD-ROM. Of additional material resources, Cluster B used internet websites almost exclusively (65%). Cluster B also used patient picnics (3%) for patient and family/caregiver support after discharge. There was no reported use of internet listserv/discussion forums, internet chat rooms, or social networking within Cluster B.

Cluster A and Cluster B had similar assignments of healthcare providers within the VAD program care team. Both clusters had multidisciplinary care teams that were regularly assigned to the management of VAD patients (Cluster A – 14%; Cluster B –

16%). The majority of both clusters indicated that several care professionals used in the care of VAD patients were not regularly assigned to VAD patient care management, but were available as needed (Cluster A – 83%; Cluster B – 81%). There were no statistically significant differences between clusters in the sum of all healthcare providers identified within respective VAD teams and in number of actual VAD implants ($p > .05$). Regardless of cluster, hospitals did between 9 and 38 implants in the previous fiscal year.

Subsequently, an exploration of possible differences in AHA hospital demographic characteristics between the clusters indicated no statistically significant differences among regions, ownership, hospital bed size or COTH membership status ($p > .05$).

AIM 2: To describe VAD patient reports of patient-centered care within their hospital facilities and to describe which patient-centered care expectations are most important.

Research question 2: "What are VAD patients' reports of patient-centered care within their selected healthcare facilities? What patient-centered care expectations are important to VAD patients?"

Results are provided by each domain specified in the patient-centered care framework (Gerteis et al., 1993). Within each domain, the PI asked patients to evaluate service quality based upon timeliness, thoroughness, and individualization, based upon previous work by Minnick et al. (1995). Lastly, two open-ended questions were asked, prompting patients to provide advice, if any, to both healthcare providers and future VAD patients, relative to learning to perform self-care while living with the VAD device.

Answers were transcribed and later reviewed for content and recurring themes were identified as described in Chapter 3.

Study Participants

The PI recruited a convenience sample of eight patients currently receiving ventricular assist device support via the HeartMate II VAD system managed through the Mechanical Circulatory Support Device program at the University of Alabama at Birmingham Hospital over a four month period, using the methods described in Chapter 3. Of the eight patients recruited, two were unable to be reached via telephone after nine call attempts. One patient declined participation in the telephone survey, resulting in a final sample size of five ventricular assist device patients who participated and completed the telephone survey.

Participant characteristics. All patients (N = 5) were receiving VAD support via the HeartMate II VAD device. One patient had recently undergone device implantation and had been discharged to home for two weeks, while the remaining participants (N = 4) had been receiving VAD support for over one year. Two patients were Black/African American race (40%); 60% were White (N =3). One patient (20%) was of Hispanic/Latino ethnicity, while the remaining patients (N = 4) were not.

Two patients reported a highest educational level of “high school or GED” (40%), two patients indicated “some college” (40%), and one patient reported completing an undergraduate degree (20%). Forty percent of patients (N = 2) indicated an annual household income level of < $20,000 per year, and three patients (60%) reported an annual household income of $25,000 - $50,000. Four patients (80%) were married, and one patient (20%) was divorced. The average age of the participants was 60.8 years (median 59 years, range 54 – 72 years).

Analytic Preparation and Procedures

The PI loaded completed telephone survey data into the REDCap survey database during the telephone interview. Data were automatically included in the study database via REDCap. After close of data collection, the PI converted all data loaded into the REDCap system into SPSS for statistical analysis.

Missing data. There were no missing data. There were several questions omitted because they were not required given the participant's response to previous question. For example, a participant who responded "always" to a question asking "how often did care provider(s) treat you with courtesy and respect?" would not be asked to estimate how many times a care provider did not treat the patient with courtesy and respect. This format of questioning occurred within each domain of the modified HCAHPS survey.

Results: VAD Patient Reports of Patient-Centered Care

Respect for Patients' Values, Preferences, and Expressed Needs

These questions asked patients about the courtesy of care providers during the hospital stay following the patient's VAD surgical implantation. All patients reported that they were always treated with courtesy and respect by their healthcare providers. Respect for patient "sleep time" and family visits were commonly noted. Staff allowing family to bring low fat and low sodium foods from home for patients was noted as important to one patient: "It was good to have something from home every now and then." All patients noted that it was very important that care providers treated them with courtesy and respect (100%).

Information, Communication and Education

Questions included in the survey asked patients to evaluate how well healthcare providers communicated with them and how information regarding their healthcare was presented to them. 100% of respondents noted that their care providers always listened carefully to them. All patients noted that it was very important that care providers listened carefully to them (100%).

Each patient noted that providers always explained things in a way they could understand (100%), though one patient noted that he “just let my wife ask the questions”. Care providers also explained information as thoroughly as patients wanted (100%) and explanation of information was individualized to patient need (100%). Provider explanation of things in a way that patients could understand was reported as “very important” to all participants (100%), and one patient noted “the way they explained everything…they covered everything really well and we didn’t have any problems.”

Several patients also noted that it was the patient’s responsibility to keep close communication with the VAD coordinator after being discharged to home. “Keep in close communication with them [the VAD coordinator] and the doctor…call if you have problems and don’t wait,” one patient said. One patient noted that she wasn’t aware of all the possible complications that could occur after the VAD implantation surgery: “They don’t tell you about all the possible complications and the slow recovery time and all that…I had to have two surgeries and wound up having to learn to walk again…I wasn't expecting that."

Experiences in the Hospital – Medications

Several questions in the HCAHPS survey focus on new medications and how they were explained to the patient. All patients reported that they had been given medications they had never taken before (100%), and that hospital staff always explained why a medication was given. 100% of patients stated that care providers usually described possible side effects of medications in a way that the patient could understand. One patient noted that he "knew what most of the medicine was for already" because he had taken the drug or something similar before. Information about new medications was always explained as soon as the patients wanted (100%), generally this information was provided when the drugs were brought to the patient. All patients reported that medication information was as thorough and as individualized as they wanted (100%). All patients also stated it was very important for care providers to explain new medications in a manner that was easy to understand (100%).

Transitions and Continuity - Discharge Information

Several questions within the HCAHPS survey ask the patient to evaluate how well they feel they were prepared for discharge from the hospital. One person (20%) was discharged to their own home, while another (20%) went to a family member's home. The family member was trained as the primary caregiver following the patient's VAD implantation. Three patients (60%) lived in cities that were in remote areas away from Birmingham prior to surgery, and for the first several weeks after discharge from the hospital, stayed at the “UAB Townhouse”, which is a residential, apartment-style building that patients and their families may pay to stay in after hospital discharge.

All patients reported that doctors, nurses and other hospital staff talked with both them and their family about the help they needed when they left the hospital (100%). Each patient thought that this exchange was necessary and as thorough as they wanted, and that it was individualized to meet their specific needs (100%). One patient reported that she was able to have two people – her husband and her neighbor – be trained as primary caregivers as her husband needed to work and would not be consistently available to help if needed. The VAD coordinator arranged for home inspection of both the patient’s home and her neighbor’s home to ensure that electrical support was adequate for the VAD device in both areas. All patients (100%) reported that talking with doctors, nurses and other staff about help needed after discharge was very important.

All patients noted they were well-prepared to monitor for symptoms or health problems after discharge and were instructed to report them to their VAD coordinator. Patients receive a discharge instructions sheet with instructions for self-monitoring and contact information in case of questions or an emergency. One patient said, “The only thing I can really say is to call your coordinator if you have any questions…follow the directions the coordinator gives you and keep in close communication with them…call if you have problems and don’t wait.” Patients felt that the information in writing was given as soon as they wanted the information (100%), and was as thorough as they wanted (100%) and was individualized for their needs (100%). All patients thought it was very important to have this information in writing prior to discharge (100%).

VAD Self-Care Education

Additional questions were added to the survey to evaluate patient perceptions of VAD self-care education prior to hospital discharge.

1. *VAD exit site care.* All patients reported receiving information in writing about how to properly assess and perform VAD exit site care (100%). Information provided to patients included written material provided by the device manufacturer, and by verbal and physical demonstrations by both VAD coordinator and staff RNs. All patients stated that this information was provided as soon as they wanted (100%), was as thorough as they wanted (100%). Three patients (60%) noted that site care education was provided each day that site care was performed, usually by the staff RN. Written material was used as a reminder once the patient was discharged home. Information provided was individualized for patient needs and preferences (100%), including changes in care protocol. One patient recalled, "Even the way they changed the protocol was good…for the first few days they did a sterile dressing change, about once or twice a day, and then before we went home they changed it to a non-sterile protocol." All patients (100%) reported that having this information in writing was very important.

2. *VAD mobility and power supply.* Patients reported that they received information in writing about how to transfer the VAD power source from wall to battery power for mobility (100%). Information in writing was provided via device manufacturer education manuals. All patients (100%) received hands-on training by physical demonstration and verbal demonstration. Patients also noted that information was provided as soon as they wanted (100%), was as thorough as needed (100%) and was

individualized for their needs (100%). One patient noted he was advised to keep his wall-powered power-base unit (PBU) in between his bed and bathroom so he could awaken and go to the restroom without having to attach to battery power for mobility. All patients (100%) stated that this information was very important.

3. *VAD emergency procedures.* VAD emergency procedures included patient responses to VAD system alarms and device malfunction or failure. All patients stated they received information in writing about what to do in case of a VAD emergency (100%). Information was delivered via written materials created by the device manufacturer, by verbal and physical demonstration. One patient reported that replacing the VAD device controller was taught by using a separate controller as a hands-on demonstration. 100% of patients reported that information was provided as soon as they wanted. Most patients (80%) believed that they received information regarding response to a VAD emergency was as thorough as they wanted, while one patient reported wanting more information about changing the VAD system controller. The possibility of changing the system controller in the event of failure was a major source of anxiety and stress for her, though she has not had to perform this skill since discharge. All patients (100%) believed information provided was individualized to their needs and preferences. All patients (100%) believed information about what to do in case of a VAD emergency was very important.

Global Ratings of Care

At the end of the survey, patients were asked to rate the hospital and overall hospital experience during the stay following their VAD implantation. Patients rated the hospital experience on a 0 to 10 scale, where 0 is the worst hospital possible and 10 is the best hospital possible. The average rating score for the hospital experience following VAD implantation was 9 out of 10, with a range of scores from 8 to 10.

Advice to Healthcare Providers

At the end of the telephone survey, patients were asked an open-ended question, "What advice would you give to healthcare providers (doctors and nurses) to improve care and self-care training for VAD patients?" Many patients mentioned a feeling of uncertainty regarding responding appropriately to emergencies. One patient was uncertain and afraid of changing the VAD system controller: "If I had a problem with the system controller…how to change it out…they could be more thorough. I was scared because I could lose power and someone else would have to do it if I couldn't." Another patient wanted hospitals in different regions to be better informed or trained to manage the VAD device in the event of an emergency: "I guess just let other hospitals know what to do when we come into their ER…I've had my VAD for a while and I've had to go to my emergency room a couple of times before they had any training…the hospital had no idea what it was or what to do, and it was a little scary…they called Birmingham and had me sent to Birmingham as soon as they could."

Advice to Future VAD Patients

Patients were also asked, “What advice would you give to other patients who are going to have VAD implant surgery regarding learning to care for themselves?” Many patients stated that learning to care for themselves and adjusting to living with the VAD was a “process” that takes time to “get into a routine.” One patient noted, “I am doing better now than I have been in 7 years…it’s not all at once – getting better is a gradual process. It will take you time to heal but it is worth it.” “If you have to have the surgery, just be patient,” one patient stated, “Take your time to adjust and heal and everything. You won’t feel better or get back to yourself overnight – it’s not an instant fix or anything. I felt nervous in the beginning but after a while you get used to it and learn to live with it and move on.” Another patient noted, “The taking care of yourself is simple once you learn it. It’s just overwhelming, you know? Once you get a feeling for what’s supposed to happen, everything else, getting into a routine, it just takes time to get used to it after that.”

Patients also frequently stated that if the VAD surgery is needed, it is worth having. “If their heart is really sick, they should consider having it. It’s worth it,” one patient said. Another patient noted that the procedure was worth it as she was looking forward to “regaining her independence” after years of being sick. A third patient stated, “I believe that if there’s nothing else that can be done then they need to have the surgery done – I think it’s worth it and can help.”

CHAPTER V

Discussion

Chapter V includes a discussion and interpretation of study results by research question and in light of previous research findings. Limitations of the research, implications for nursing, and recommendations for future research are provided.

Care Structures of Hospital VAD Programs

Organizational frameworks. The finding that almost half of VAD programs were placed within their hospital cardiac transplant programs was not surprising, because many patients receive VAD support as a bridge to cardiac transplantation, and often the VAD coordinator cross-trains to manage patient care for heart transplant patients in addition to management of VAD patient care needs. Despite program placement, almost half of responding coordinators stated that their hospital VAD programs reported to 3 or more departments. This may suggest that even though VAD programs are aligned with a hospital cardiac transplant program, there are additional internal stakeholders within other departments who could be part of decision-making processes within the VAD program (e.g., cardiac surgeons, cardiologists, etc.). The finding that 75% of VAD programs were led by more than one physician director supports this claim.

It is important to note that patient understanding of which provider is directing care is vital to the patient's perception of coordination and integration of clinical care

(Gerteis et al., 1993). Gerteis et al. (1993) also notes that one of the most important perceptions of the patient during the hospital experience was “feeling that they were in competent hands.” If a patient believes that multiple leaders do not communicate with each other or agree on patient care goals, and if coordination of clinical care, clinical support services, and patient care delivery from bedside nurses is perceived as disorganized, a patient’s trust in a provider or facility may suffer, resulting in noncompliance with recommended treatments or transfer of care to another facility (Gerteis et al., 1993).

Care providers. To date, only one study has evaluated a multidisciplinary approach to decreasing length of stay and reducing costs in ventricular assist device patient care (Murray et al., 2009). Murray et al. (2009) found that a multidisciplinary approach to VAD patient care reduced the total length of stay and associated hospital costs for care. My research explored the use of such teams across all VAD hospitals in the United States. I found that most hospital programs use a care team comprised of multiple disciplines. This finding suggests multidisciplinary collaboration in VAD teams, but because a large percentage of hospitals had several care professionals who either cared for VAD patients but were also caring for other patient populations, or were not regularly assigned to VAD patient care but were available as needed, it is possible that all identified team members not be consistently included in VAD patient care planning.

Caregiver role delineation. The majority of clinical services explored in this study were performed by the VAD coordinator, a staff nurse, or an advanced practice nurse (not coordinator) when an APN was employed as part of the VAD care team. It is unknown if services listed in Table 7 were exclusively performed by the care providers listed or if a collaborative approach is taken within hospitals. A collaborative approach to patient self-care education could prove beneficial as skill sets could be practiced more often and learned content could be reinforced, although learning multiple methods to perform specific skills could prove confusing to the patient and primary caregiver.

VAD coordinator and nursing staff role preparation. It was interesting to note that more than 30% of hospitals required VAD coordinator certification as an APN/Nurse Practitioner, and that this finding was observed more frequently in hospitals with larger bed sizes. Perhaps this is due to higher patient volumes in larger hospitals requiring more provider coverage. Staff RN training appears to be provided by more than one person – almost half of respondents noted staff RNs received formal instruction by a device representative, VAD coordinator, and unit educator. The VAD coordinator was responsible for education delivery nearly 100% of the time, so it appears that the VAD coordinator would be the primary source of nursing education and training, while device representatives and unit educators may supplement staff RN education.

VAD coordinator role and responsibilities. The average number of named full-time VAD coordinators reported is consistent with VAD coordinator staffing mentioned in other research (J. M. Casida & Ilacqua, 2011). The reported VAD coordinator-to-patient ratios included the coordination of care for all VAD patients, inpatient or outpatient, assigned to one VAD coordinator. Many VAD coordinators follow a combination of both inpatient and outpatient VAD patients, so a total patient-provider census appeared to be a reasonable estimate of labor quantity.

Several VAD coordinator reporting structures were provided by responding coordinators. Almost half of all VAD coordinators reported to each of the listed directors (e.g. medical director, nursing director, cardiovascular service line director, or nursing director), and more than half of VAD coordinators reported to more than two leaders. Perhaps a unity of command is not possible due to the nature and complexity of VAD patient care requirements because a multidisciplinary approach to care management is required. It is important to note that if numerous leaders have input into a VAD coordinator's role components, confusion regarding performance expectations and a loss of productivity may result (Marquis & Huston, 2009).

The most common role components of VAD coordinators were outpatient direct care nursing, development of, providing and evaluating staff nursing education, training of housestaff, training of staff at subacute facilities, education of EMS personnel, participation in research and database entry, and on-call patient responsibilities. Many of these role components were not surprising; the majority of nursing education was provided by the VAD coordinator, and fewer responding hospitals reported APNs in the VAD coordinator role. There was a statistically significant difference in the VAD coordinator role requirement of inpatient advanced practice nursing among hospitals when compared by region. The clinical implications of this finding are not clear, as there could be many explanations for why APN employment in VAD coordinator roles differs according to region (i.e., hospital hiring practices, budget constraints, residency/fellowship programs, state practice acts, etc.).

VAD Self-Care Education Processes

The statistically significant correlations of VAD coordinator perceptions of self-care skill level of difficulty suggest that coordinators believe each skill set is of similar difficulty for both patient and caregiver. Each skill set level of difficulty had strong positive correlations between patient and primary caregiver. Weaker correlations were found in perceptions of difficulty between patient and caregiver in performing dressing changes and care of the LVAD driveline. This could be due to some VAD programs not allowing patients to perform site care or manipulate the VAD percutaneous drivelines themselves; several hospitals scored “N/A” for the patient under both of these skill categories. Other skill sets also received an “N/A” scoring for both patient and primary caregiver, including hemodynamic monitoring. Many hospital facilities do not require blood pressure monitoring after implantation of the HeartMate II VAD device. The continuous flow of the VAD pump may make peripheral pulses difficult to palpate or auscultate, thus some at-home blood pressure monitoring systems may not be sensitive enough to measure a blood pressure accurately, while the costs for more sensitive devices could be prohibitive.

Education delivery materials. The materials most frequently used for patient self-care education were written materials developed by hospital or unit, written material developed by device manufacturer/others, DVD and verbal instruction. Thoratec

Corporation (HeartMate II LVAD) provides patient education materials including written manuals and a DVD (www.thoratec.com). Verbal instruction could possibly be the most convenient and easiest method of education delivery, and with this method, there may be more opportunities for delivery with each nurse-patient interaction.

Although there were no statistically significant differences in variable material utilization for self-care education by hospital region, ownership, bed size, or COTH membership, the finding that > 70% of hospitals used one to four additional resources for self-care training was surprising. By offering multiple options for content delivery, patients and their caregivers may choose the method best suited for their learning style and preferences. Although this does provide an individualized approach to training, providing numerous methods of content delivery could make it more difficult to evaluate the impact of self-care training on patient outcomes, both within and across VAD hospital programs. It is unknown if the use of additional materials for VAD patient self-care education is clinically feasible or cost-effective.

Validation of patient self-care skill performance. There was a wide amount of variability in most methods of validation used in hospitals. Return physical demonstration was most often used in evaluating the performance of VAD self-care skills most frequently required of the patient – battery changes, dressing changes (often requiring sterile technique), care of the percutaneous LVAD driveline, and self-testing the LVAD system controller. Return verbal demonstration was used most often for self-care skills which may not require psychomotor function (i.e. recognizing infection), or may be required in threatening or “unsafe” clinical situations (e.g. alarm troubleshooting and emergency management procedures). Several regions used multiple methods of evaluation of skill set performance; the Mid Atlantic, South Atlantic, East North Central, and Pacific regions were the most commonly identified.

Greater than 25% of hospitals reported using four methods of validation for skill performance of power source changes, battery changes, VAD dressing changes, and VAD percutaneous driveline care, recognizing infection and self-testing the VAD system controller. Among these skills, only the number of methods used for validation of VAD percutaneous driveline care was statistically significant among groups when compared by region. The clinical implications of this are not clear, but could be related to capital resources (supplies) available and used by hospitals within a region to secure drivelines to the patient, or related to practice patterns shared by VAD hospitals within a region via provider consensus.

Sterile technique was most often validated by one or two methods. The reason for this is unknown, but because sterile technique requires a combination of factual knowledge and psychomotor skill, and because the home environment is vastly different than the hospital environment (i.e. different surfaces and resources, different bacterial flora, etc.), it is understandable why clinicians may choose to evaluate performance of sterile technique by return demonstration or by return verbal demonstration overall.

The same explanation could apply to the skills of patient showering with the VAD device and hemodynamic monitoring. Several hospitals reported using no methods of skill validation for these two skills, which is congruent with reports of "N/A" in coordinator perception of difficulty for skill set performance, described earlier (Table 14). There appear to be many VAD hospitals that do not allow patients to shower after VAD implantation, and do not require or educate patients to monitor blood pressure or VAD setting and flow parameters once discharged to home.

Over half of responding hospitals reported using 0-1 methods for validation of heart failure symptom management and medication management. Heart failure symptom management was most often validated by verbal demonstration, possibly because due the nature of an acute exacerbation of heart failure, appropriate management may not be easily validated by other methods.

There were no statistically significant differences in number of methods used for skill validation of medication management by hospitals according to region, ownership, bed size or COTH status. This skill refers to recall of knowledge and accurate self-administration of required medications, so it is easily understood why return verbal demonstration and oral testing were most often used for validation. Several hospitals noted asking patients what medications were used for prior to administration, while some hospitals require medication teaching by a clinical pharmacist, followed by a return verbal demonstration of medication administration. In the latter scenario, the patient would read prescription bottle labels for required medications and instruct the pharmacist in how many tablets to administer to achieve the prescribed dose.

VAD alarm troubleshooting was most often validated by return verbal demonstration, return physical demonstration and oral testing. Almost 40% of respondents noted using two methods of validation; while as many as 23% reported using four methods. There were no statistically significant differences in number of methods used for validation of alarm troubleshooting among hospitals by region, ownership, bed size or COTH status, supporting the finding that most hospitals, regardless of demographic data, use multiple methods to validate this skill.

Return verbal demonstration, oral testing, return physical demonstration, and written testing were used to validate skill performance of VAD emergency management, suggesting a similar approach to validation as alarm troubleshooting. The majority of hospitals reported using combinations of two or three different methods to validate performance. There were no statistically significant differences in validation methods for VAD emergency management among hospitals by region, ownership, bed size or COTH status.

From a clinical perspective, identified patterns of validation of both alarm troubleshooting and VAD emergency management could represent the urgent nature of appropriate response to VAD alarms, and the need to quickly and accurately respond to correct alarms or seek help appropriately. I was surprised to find that 17% of hospitals only used one method for validating alarm troubleshooting and 21% used one method for validation of emergency management. When considering the results found in AIM 2, perhaps hospitals should consider using more than one method of evaluation for these skills in order to ensure patients and caregivers are able to appropriately respond to emergency situations should they occur.

Resources for patient support. The most commonly reported resources used for patient support were VAD support group meetings, patient counseling, hospital websites and patient-provider e-mail correspondence. Most hospitals reported using no additional resources, while more than one-third of coordinators noted using one additional resource for patient support. There were no statistically significant differences in resource use by hospitals when compared by region, ownership, bed size or teaching status. It appears that social support is encouraged by peer networks developed during support group meetings, while communication between patient and provider is supported by on-call responsibilities of the VAD coordinator, either by telephone or by e-mail correspondence.

The cluster analysis identified two groups of VAD hospitals according to variables representing elements of hospital care structure and self-care education resources according to my conceptual framework. The smaller cluster of responding hospitals, Cluster A reported using a larger variety of materials for both patient self-care education training as well as using more resources for patient and primary caregiver support. Cluster B was larger by comparison and used fewer additional resources, but almost exclusively relied on internet websites as an additional material used for self-care education. Clusters A and B had similar assignments of healthcare providers within the VAD program care team, with both clusters reporting similar numbers of several members within the care team that were not regularly assigned to care, but were available as needed. The average number of reported actual VAD implants in the previous fiscal year was similar between clusters. There were no statistically significant differences between clusters according to either the sum of all healthcare providers within VAD care teams, or by number of reported actual VAD implants. When compared by AHA hospital demographic data, no statistically significant differences were found between Cluster A and Cluster B by region, ownership, hospital bed size, or COTH membership status. This suggests that there is possibly another distinguishing demographic variable between clusters that has not been identified.

VAD Patient Reports of Patient-Centered Care

Respect for patients' values, preferences and expressed needs. "Patients are usually satisfied with the technical quality of care they receive…but somewhere in the process, their individuality is lost sight of; their personal and subjective needs remain unmet" (Gerteis et al., 1993). VAD patients may identify perceived control as a core of their cognitive evaluation of their quality of life; patients evaluate their own sense of normality, their emotional state, and feelings of uncertainty about the future (Hallas, Banner, & Wray, 2009). In our survey, each patient felt they were always treated with courtesy and respect during the hospital stay following VAD surgical implantation. Patients reported staff having respect for "sleep time" and family visits, and allowing family to bring low fat and low sodium foods from home. All patients noted this was very important to them. Some advanced heart failure patients and VAD patients are not able to be discharged home soon after surgery, and extended lengths of stay may have detrimental effects on a patient’s sense of well-being. By allowing a patient to maintain a “normal” schedule or have regular reminders of their life at home, care providers support the patient’s need to feel like a respected, “normal” individual.

Information, communication and education. “Through the patient’s eyes, communication is the essential ingredient to participation in healing and recovery” (Gerteis et al., 1993). We found that all patients believed care providers always listened carefully to them. Information delivered was always thorough and individualized.

One-third of the patients included in the study reported by Gerteis et al. (1993) stated they wanted more information than what was provided to them, most often about finances and medical insurance. Effective communication is especially important in critical care settings; most patients “regress under the stress of hospitalization and under the influence of the unfamiliar culture in the hospital” (Gerteis et al., 1993). Patients and caregivers may not effectively process or retain provided information as they progress through their hospital course. Gerteis et al (1993) also noted that patients at risk for ineffective communication included patients of lower socioeconomic status, older patients, women, and patients with a poorer self-reported health status. Most of the patients included in this study met several of these descriptors. Another interesting finding by Gerteis et al. (1993) was that patients receive information from many different sources, including physicians, nurses, social workers, dieticians, family members, and media. A risk of multidisciplinary collaboration is multiple care providers giving different, and possibly conflicting, information to the patient. If this occurs, the patient may not understand the correct methods for performing self-care.

Medications. All patients in our study reported receiving medications they had not previously taken. All patients noted that care providers “usually” described medications in a way that the patient could understand, and all patients wanted to know more about medication side effects. One patient said that he “already knew what some of the medications were for” because he had taken them previously. This reinforces the assertion by Gerteis et al. (1993): patients need different amounts and different kinds of information provided to them. Though many hospitals complete a baseline educational needs assessment upon admission in preparation for eventual discharge, optimal treatment of a chronic illness may require a long-term adherence to medical regimens as well as long-term behavioral change (Gerteis et al., 1993). Patient education should help bridge the gap between hospital to home and facilitate effective self-care in patients with chronic health needs.

Transitions and continuity – discharge information. The patient’s healthcare needs continue even after leaving the hospital. Gerteis et al (1993) notes that continuity of care for patients is often lacking once patients make the transition from hospital to home or to another healthcare facility. Fewer than 60% of the patients felt their discharge needs were being adequately met (Gerteis et al., 1993).

Three patients in this study lived in remote areas and needed to reside in closer proximity to UAB hospital for the first few months after surgery. While patients were prepared to live in temporary housing apartments after discharge, it is unclear if they were prepared to effectively perform self-care and identify resources within and near their own homes. One patient in our study noted that she felt very anxious after seeking care at her local emergency department and finding that care providers were afraid to provide care due to her having a VAD, and, on one occasion, she was transported to UAB hospital instead. Patients are often unaware of resources or fail to navigate complex health systems on their own. A multidisciplinary approach to discharge planning is necessary to coordinate the transition from hospital to home, which includes an interactive process in which caregivers communicate and collaborate with patients, families/caregivers, and referring or local care providers to ensure a seamless transition to home and effective management strategies for care needs in the future (Gerteis et al., 1993).

VAD self-care education. The PI sought to evaluate patient perceptions of how well they were trained to manage the VAD device prior to discharge to home. All patients were very satisfied with the majority of their VAD training and described receiving a variety of resource materials. Patients reported their care providers using several methods for teaching, and the most commonly used methods were verbal and physical demonstration. It appeared that self-care education was thorough and, in some cases, individualized for patient needs. For exit site care, all patients noted they were given written checklist to use as a reminder of the proper procedure once they went home. One patient was advised to position his power-base unit (PBU) between the bed and restroom in order to use the restroom without transferring to battery power in the middle of the night.

The learning experience for VAD emergency procedures varied among patients. One patient said that replacing the system controller in the event of a hardware failure was taught using a separate controller; this technique was very helpful to the patient. Another patient stated that controller failure was a big source of anxiety and they wished more “hands-on” training was offered. Individual patients have individual styles of learning and a combination of teaching methods may be more effective than any single technique alone (Gerteis et al., 1993). Overall, patients noted they were satisfied with the way they were trained to manage their VAD devices, and said they had become more independent as they had adjusted to daily life with the device.

Advice to healthcare providers. A feeling of uncertainty was commonly described by patients. Patients described a fear of the unknown, the emergency that “may” happen, and what to do once that emergency actually happens (e.g., exchanging the VAD system controller). Performance of emergency management actions was not the only concern; patients were also uncertain about whom to contact for care in an emergency if they lived a long distance from the VAD hospital. One patient noted a local emergency department was afraid to treat a health complaint that was not related to cardiac or VAD function, because the patient had a VAD and the hospital was not prepared to manage the VAD itself. Even though there was no issue with the VAD itself, the patient was referred back to the VAD hospital for assistance, which was over an hour-long drive away.

Patients need different amounts and different kinds of information – what works for one patient may not work for another (Gerteis et al., 1993). While offering more than one method of education delivery may be helpful, individualization, feedback and reinforcement have been found to be strong predictors of educational effectiveness (Gerteis et al., 1993). Hands-on practice by return demonstration of skills required for addressing VAD emergencies (i.e. by simulation experiences, practicing with an extra set of VAD equipment specifically used by hospitals for training purposes, etc.) may reinforce content provided verbally or by written material.

It is important that healthcare providers understand that patient concerns and fears do not end upon discharge from the hospital. In some circumstances, it might not be clinically or financially possible for patients to seek care at the implanting VAD hospital for all health concerns, especially if the patient lives in a remote area. Patients may also desire to travel or vacation, especially as they regain control over their everyday lives and their health continues to improve. A VAD hospital should strive to establish effective collaboration and coordination of care for patients after discharge. Perhaps VAD hospitals can establish lines of communication and contacts for outside hospital facilities to refer to in the event a VAD patient seeks urgent care at that facility. VAD hospitals may also establish communication networks with other VAD hospitals, so VAD coordinators may be alerted when patients travel to other areas of the country, and the patient may contact that other coordinator in the event of an emergency while travelling.

Advice to future VAD patients. Most patients noted that learning to care for themselves and adjusting to life with a VAD was a “process” that takes time. Patients stated that their health had improved, and that if given the choice, would probably choose to have the VAD again. Patients said that the experience was overwhelming at first, but with time and patience, they felt better and had more independence. Ultimately, the experience “was worth it”. Considering these responses, care providers should evaluate processes used to help patients and caregivers make the transition from hospital to home, including discharge teaching and efforts made for patient follow-up. The consistent use of patient and family support groups, counseling, events that foster interaction with other patients and families, and effective and open lines of communication between patient, family and care providers are important to helping patients and families overcome the feelings of uncertainty and fear experienced after discharge, and making an effective transition through the “process” of learning to live independently and comfortably with the VAD device.

Study Limitations

AIM 1. In this study, it was assumed that the VAD coordinator was the best person to describe the organizational structure and care processes used in VAD hospitals. We assumed that responders had given their best responses to survey items and that their responses were accurate.

Though extensive steps were taken to identify the universe of VAD hospitals in the U.S., there may be additional hospitals not certified for DT by CMS, not registered with the INTERMACS registry, or affiliated with the ICCAC coordinator listserv.

Many coordinators were either unaware of or restricted from providing financial or budget information of their VAD programs. This made it difficult to evaluate potential relationships between financial strain of VAD program volume and resource use by VAD programs.

There were limitations in conducting the cluster analysis as well (www.statisticshell.com/docs/cluster.pdf). Each method of cluster analysis yields different results due to different criteria for merging clusters. A two-step cluster (Log-Likelihood Distance) method was chosen because it will analyze both continuous and categorical variables, and resulted in two clusters for this study. Second, the clustering analysis is not stable when cases are dropped. This was a reason why we were unable to use a ratio of actual to budgeted annual VAD implants as a measure of program financial stress. We used the actual number of annual implants as a measure of labor quantity in the cluster analysis instead. Lastly, while cluster analysis provides information regarding differences in material and resource use among hospitals, additional measures are required to describe those differences in detail.

*AIM 2.*There were many limitations identified in this research. Limitations pertaining to the Aim 2 study are similar to those reported in other VAD research studies (Moser & Riegel, 2001). Satisfaction was measured in a small convenience sample of VAD patients within one hospital VAD program. Small sample sizes, patient resource utilization patterns and patient disease severity and comorbidity could result in skewed results if many patients have more or fewer complications or extended hospital lengths of stay (Smith et al., 2006).

The timing of survey administration was also a limitation. It is suggested that a patient's perception of satisfaction with care changes over time: a patient is more likely to measure satisfaction based on their current health status rather than health care service experience as more time passes since the experience occurred (Smith et al., 2006). In this study, most patients had been living with their VAD device for greater than one year, while only one patient had received support for less than one month.

There was a risk for sociopsychological artifacts in this research. Sociopsychological artifact is a type of bias that refers to how responses are affected as patients fear potential retribution. As a result, the patient provides the interviewer with responses the patient believes are consistent with beliefs of the interviewer (Smith et al., 2006). The nature of VAD patient care, a small patient population with care provided by a highly specialized care team not immediately available in other regions, would make patients vulnerable to sociopsychological artifact. The PI chose methods to reduce this bias, including a telephone interview led by the PI (who was not a VAD coordinator at the participating hospital) and took several steps to ensure confidentiality (e.g. de-identified data sets, verbal consent, guaranteeing patients of confidentiality, etc.).

Implications for Nursing

This research contributes to the current knowledge of self-care education of patients with ventricular assist device therapy by describing organizational care structures and self-care education delivery methods used in VAD hospitals, as well as VAD patient reports of patient-centered care and perceptions of important aspects of patient-centered care pertaining to self-care education.

Clinical practice. My findings may be of interest to VAD coordinators and to nurses who train VAD patients and caregivers essential self-care requisites after VAD implantation as it describes the materials and methods most often used in education delivery, and the resources commonly used for patient and caregiver support, across all VAD hospitals in the United States. Identification of national trends in care team structure and care delivery processes, including self-care education, may encourage an internal evaluation of existing methods used in hospitals. VAD coordinators and nurses may find patient reports of satisfaction with care, perceived importance of aspects of patient-centered care, and recommendations for care providers and future patients helpful as they facilitate a safe and effective transition from hospital to home.

By describing material, resource and workforce utilization trends across region, ownership type, hospital bed size and COTH status of all VAD hospitals in the U.S., nursing leaders and administrators who hire and organize VAD nursing care teams may use these findings to identify trends across settings, and to determine total labor input and role components of team members who provide VAD patient care.

Research. VAD care professionals may seek to build on the findings in this study by evaluating the quality of currently used self-care education processes through further exploration of patient satisfaction with their VAD care training. Patient and caregiver feedback may help care providers modify existing programs to suit patient preferences and needs. My findings note that nursing (VAD coordinator, Staff RN, APN) is almost exclusively responsible for patient self-care training after VAD implantation. Patient satisfaction with self-care training may be measured as a nurse-sensitive outcome, and then linked to outcomes such as patient service usage and health outcomes.

Education. My findings suggest there is variability in clinical and educational preparation and role requisites of VAD coordinators, as well as clinical and educational preparation of staff RNs. It is unknown if self-care education and evaluation of learned self-care skills is more effective if delivered by a coordinator with advanced training (e.g. APN). It is also unknown if current orientation methods for staff RNs are adequately preparing nurses to provide effective and sufficient education to VAD patients and caregivers after surgery.

Recommendations for Future Research

Future research may explore findings of this research in more detail and develop effective nursing interventions to improve the education delivery processes used in hospitals. Several recommendations for future studies are as follows:

- Exploration of Staff RN and VAD Coordinator orientation programs
- Exploration of patient and family caregiver perceptions of difficulty of VAD self-care skill sets
- Linkage of VAD program organizational processes with reports of patient-centered care and other outcomes (e.g. hospital length of stay, device failures, driveline infections, emergency department visits, etc.)
- Reports of patient preference of methods used in self-care training
- Reports of patient preference of methods of evaluation of self-care performance

- Exploration of patient perceptions of support resources used by hospitals to facilitate transition from hospital to home after VAD implantation

Conclusions

Ventricular assist device therapy is becoming an increasingly used treatment for patients with end-stage heart failure or as a means to sustain survival until cardiac transplantation. Self-care education processes used among implant hospital centers in the United States have not previously been described. VAD patient reports of patient-centered care and satisfaction with care have not been described.

More than half of VAD programs report to two or more departments, and more than half of VAD coordinators report to two or more administrators. VAD coordinators have the highest number of role components amongst the identified members of the VAD patient care team. Though the median patient census for VAD coordinator management was 15 patients per coordinator, reported patient census varied among hospitals, and could possibly be related to VAD patient volume. Most members of the VAD patient care team do not exclusively care for VAD patients, but also care for other patient populations. Some providers are not regularly assigned to VAD patient care but are available as needed.

There appears to be no standard method of providing postoperative VAD patient self-care education across hospitals, though a majority of hospitals use materials provided by the device manufacturer. Approximately 75% of VAD programs consistently use greater than two resources in providing self-care education. VAD self-care skill performance was most often validated by return physical demonstration, while recognizing infection, hemodynamic monitoring, medication management, and emergency management procedures were most often validated by return verbal demonstration. Approximately 50% of VAD programs consistently use greater than two methods of self-care evaluation for each skill set.

Patients appeared to be satisfied with patient-centered care and self-care education, and are ultimately grateful for regained independence and reduced heart failure symptoms after VAD implantation. Patients experienced a feeling of uncertainty regarding what to do in the event of an emergency if they lived in a remote area away from the VAD hospital, and were worried about being able to perform certain emergency management skills effectively. Patients also noted that learning to live with the VAD device and to perform self-care was a process that takes time but was ultimately worth the experience.

Understanding the processes of self-care education and patient satisfaction with patient-centered care after VAD implantation is necessary to developing or improving methods used for self-care education delivery in VAD hospitals. Further research is needed to explore relationships between hospital care processes and VAD patient outcomes.

Appendix A

Ventricular Assist Device Coordinator Participant Study Invitation

Dear Colleague,

This is to ask you to participate in an approximately 15-minute survey concerning healthcare structure and care processes of VAD patients. It is important to gain knowledge about the VAD Coordinator role, as well as the healthcare organizational structure and care delivery processes influencing self-care education, in order to continue to improve outcomes for patients receiving VAD therapy. I am a cardiothoracic surgery nurse practitioner who is currently conducting research as part of the requirements for a PhD in Nursing Science degree at Vanderbilt University School of Nursing, Nashville, TN.

Your identity, and that of your organization, will not be known to anyone except me. All data collected from this research will be secured and will be destroyed in one year following the completion of the study. To protect you and your institution, your answers will only be reported in the aggregate, not at the individual level. Your organizational affiliation will also remain confidential, and no organization will be identified from this research. This study has been approved by the Vanderbilt University IRB as Exempt (IRB# 110231).

The study results will be made available as a presentation and submitted for publication in a peer-reviewed journal following completion of the research study and dissertation defense, estimated to be within a year. An abstract will be sent to the International Consortium of Circulatory Assist Clinicians (ICCAC) for general dissemination. If you have any questions, please contact me at Brian.Widmar@Vanderbilt.Edu, or my PhD advisor, Ann Minnick PhD, RN, FAAN, at Ann.Minnick@Vanderbilt.Edu.

Thank you for your time and consideration.

Sincerely,

Brian Widmar, PhD(c), RN, ACNP-BC, CCRN
Doctoral Candidate,
Vanderbilt University School of Nursing

You may also complete the survey electronically by typing the following address into your web-browser:

http://www.nursing.vanderbilt.edu/VADservices

Appendix B

VENTRICULAR ASSIST DEVICE SERVICES SURVEY

Instructions

I am...

a. a VAD Coordinator who has a primary role in care coordination and management of patients receiving VAD therapy. **Please go to Question 1 to begin the survey.**

b. not a VAD Coordinator and do not have a primary role in care coordination and management of patients receiving VAD therapy, BUT my organization manages VAD patients and has a VAD Coordinator. **Please give to your VAD Coordinator.**

c. a VAD caregiver but there is no named coordinator. **Please attempt to complete and identify your role title here: ______________________________.**

d. none of the above. There is no VAD program in my facility. **Please refer to below to return the survey. Thank you.**

To Return the Survey:

- Please use the provided postage-paid envelope and send to the address below by DATE:

Brian Widmar

Thank you for your participation!

Note: For your convenience, you may also complete this survey online. Please type the following link into your web-browser to be directed to the survey.

http://www.nursing.vanderbilt.edu/VADservices

VENTRICULAR ASSIST DEVICE SERVICES SURVEY

Part I: Patient Self- Care Training

1. Indicate the resources used in your facility for VAD patient self-care education.

Resource	**Used**	**Not Used**
Written material developed by hospital or unit	______	______
Written material developed by device manufacturer/others	______	______
Videotape	______	______
DVD	______	______
Audio CD	______	______
Internet websites	______	______
Podcasts	______	______
Verbal instruction	______	______
CD-ROM	______	______

Other (Please specify): ____

2. Do you allot a set amount of time for VAD self-care education? (e.g., a set time for training self-care skills, dressing changes, etc.)

Yes ________ (If yes, please specify total time: ________ minutes) No _________

3. Indicate how patient performance of self-care VAD skills is validated. *Check all that apply*:

Skill	**Return physical demonstration**	**Return verbal demonstration**	**Written testing**	**Oral testing**	**N/A**
Power source changes	_______	_______	_______	_______	_______
Battery changes	_______	_______	_______	_______	_______
Dressing changes	_______	_______	_______	_______	_______
Sterile technique	_______	_______	_______	_______	_______
Care of the LVAD percutaneous driveline	_______	_______	_______	_______	_______
Recognizing infection	_______	_______	_______	_______	_______
Patient Showering	_______	_______	_______	_______	_______
Self-testing	_______	_______	_______	_______	_______
Hemodynamic monitoring	_______	_______	_______	_______	_______
CHF symptom management	_______	_______	_______	_______	_______
Medication management	_______	_______	_______	_______	_______
Alarm troubleshooting	_______	_______	_______	_______	_______
Emergency management	_______	_______	_______	_______	_______

4. Rate the following VAD skills by level of difficulty for:

	Level of Difficulty				
The Patient	**1**	**2**	**3**	**4**	**N/A**
Power source changes	__	__	__	__	__
Battery changes	__	__	__	__	__
Dressing changes	__	__	__	__	__
Sterile technique	__	__	__	__	__
Immobilization of the LVAD percutaneous driveline	__	__	__	__	__
Recognizing signs of infection	__	__	__	__	__
Patient Showering (protecting the LVAD)	__	__	__	__	__
Self-testing	__	__	__	__	__
Hemodynamic monitoring	__	__	__	__	__
Heart failure symptom management	__	__	__	__	__
Medication management	__	__	__	__	__
Alarm troubleshooting	__	__	__	__	__
Emergency management	__	__	__	__	__
The Primary Caregiver					
Power source changes	__	__	__	__	__
Battery changes	__	__	__	__	__
Dressing changes	__	__	__	__	__
Sterile technique	__	__	__	__	__
Immobilization of the LVAD percutaneous driveline	__	__	__	__	__
Recognizing signs of infection	__	__	__	__	__
Patient Showering (protecting the LVAD)	__	__	__	__	__
Self-testing	__	__	__	__	__
Hemodynamic monitoring	__	__	__	__	__
Heart failure symptom management	__	__	__	__	__
Medication management	__	__	__	__	__
Alarm troubleshooting	__	__	__	__	__
Emergency management	__	__	__	__	__

Level of Difficulty:

1 = not difficult, easy to master without additional coaching

2 = moderately difficult, quick to master with some additional coaching

3 = difficult, mastery requires practice and frequent reinforcement of instruction

4 = very difficult, mastery requires frequent practice, frequent reinforcement of instruction, and outpatient follow-up

Part II: Patient Support

5. Select all resources your organization has available to VAD patients and families/caregivers. *Check all that apply*:

	Available to:	
Resource	**Patients**	**Family/Caregivers**
LVAD support group meetings	______	______
Patient picnics	______	______
Hospital website	______	______
Patient counseling	______	______
Internet listserv/discussion forums	______	______
Internet chat rooms	______	______
Facebook/social networking	______	______
Patient-Provider email correspondence	______	______

Part III: Unit Resources

6. In your <u>ICU</u>, is there is a computerized unit accessible information system that allows for:

Service	**Yes**	**No**	**If yes, is it visible from the bedside?** Yes	No
Provider order entry	_____	_____	_____	_____
Nursing care documentation	_____	_____	_____	_____
Radiology data – order <u>and</u> retrieval	_____	_____	_____	_____
Pharmacy data	_____	_____	_____	_____
Retrieval of inpatient and outpatient hospital clinical records	_____	_____	_____	_____

7. Which of the following best describes visitation policies in your ICU?

________ Restricted visitation (Indicate <u>total</u> minutes per day: _____________ minutes)
________ Unrestricted visitation but may be restricted by nurse's judgment

Part IV: Provider Roles and Responsibilities

8. Which statement characterizes VAD program responsibility? Our VAD program:

________ a. manages VAD inpatient and outpatient care needs
________ b. has separate programs for VAD patient inpatient and outpatient care
________ c. manages VAD inpatient only (Specify how outpatient care is managed): ______________________

9. Is there a named head of the VAD program?

________ a. Yes, one MD
________ b. Yes, more than one MD (e.g., medical director and surgical director)
________ c. Yes, not a MD (write person's/s' professional credential) ____________________________
________ d. No, no one is currently named head of program

10. Which are the components of the <u>VAD Coordinator</u> position? *Check all that apply:*

Role Component	**Yes**	**No**	**Role Component**	**Yes**	**No**
Direct care nursing – inpatient	____	____	Train Staff at Subacute/Rehab Facility	____	____
Direct care nursing - outpatient	____	____	Case management	____	____
Advanced practice nursing - inpatient	____	____	Emergency Response Personnel Educator	____	____
Advanced practice nursing - outpatient	____	____	Research (Outcomes or Clinical)	____	____
Development of VAD nursing education	____	____	Database entry of clinical data	____	____
Provide nursing staff education	____	____	On-call patient care responsibilities	____	____
Evaluate nursing staff education	____	____	Maintain inventory of VAD equipment	____	____
Train Housestaff	____	____	Other: Please specify --		

____

11. Indicate who performs the following clinical services: *Check all that apply:*

Clinical Service	**VAD Coordinator**	**APN (not coordinator)**	**Staff RN**	**Biomedical Engineer**	**Case Manager (not coordinator)**	**Other (Please specify)**
Direct patient care	________	________	________	________	________	________
Order drug therapy	________	________	________	________	________	________
Administer drug therapy	________	________	________	________	________	________
Order nutritional support	________	________	________	________	________	________
Order diagnostic testing	________	________	________	________	________	________
Perform Wound Care	________	________	________	________	________	________
Adjust VAD Settings	________	________	________	________	________	________
Recommend social support	________	________	________	________	________	________
Order home health	________	________	________	________	________	________
Teach self care:						
VAD exit site care	________	________	________	________	________	________
Mobility and power supply	________	________	________	________	________	________
Emergency procedures	________	________	________	________	________	________
Evaluate self-care:						
VAD exit site care	________	________	________	________	________	________
Mobility and power supply	________	________	________	________	________	________
Emergency Procedures	________	________	________	________	________	________
Self-care after discharge	________	________	________	________	________	________

Part V: Staff Education and Training

12. Indicate requirements for VAD coordinator(s) at your institution:

Certification	**Yes**	**No**	**Experience**	**Yes**	**No**	**Education**	**Yes**	**No**
BLS	___	___	Critical care	___	___	Bachelor's Degree (Nursing)	___	___
Advanced Practice – NP (Provide specialty) ________________	___	___	Cardiac Surgery	___	___	Master's Degree (Nursing)	___	___
						Other (Please Specify): ____________________________		

- If no educational requirement, is a preference mentioned in the job description?

_____ Yes (Specify: ____)

_____ No

13. Prior to caring for VAD patients, indicate all requirements for staff RNs.

Certifications	**Yes**	**No**	**Clinical Experiences**	**Yes**	**No**	**VAD Education**	**Yes**	**No**
BLS	____	____	ICU VAD patient assignment with preceptor	____	____	Formal instruction provided by:		
ACLS	____	____	Step-down unit VAD patient assignment with preceptor	____	____	Device representative	____	____
CCRN	____	____	Outpatient Clinic VAD patient assignment with preceptor	____	____	VAD Coordinator	____	____
						Unit Educator	____	____
Other (Please specify): ___________________			Other (Please specify): ___________________			Other (Please specify): __________________		

- Approximately how long is the VAD nurses' orientation/training period? If none, specify "0".

_______________________ weeks.

Part VI: Organizational Framework

14. How many VAD Coordinators are named in your institution? _________ (If 0, indicate 0).

15. What is your average VAD Coordinator-Patient ratio?

______________ patients per VAD Coordinator.
________________no VAD Coordinator-Patient ratio specified

16 Indicate the title(s) of all people to whom the VAD Coordinator(s) report(s)?

_____ a. Medical Director
_____ b. Surgical Director
_____ c. Nursing Director
_____ d. Other (please list) ____

16. Which of the following best characterizes VAD program responsibility? Our VAD program:

_____ a. manages VAD patients who receive therapy as bridge to transplant or as destination therapy
_____ b. manages VAD patients who receive therapy as bridge to transplant only
_____ c. manages VAD patients who receive therapy as bridge to recovery only
_____ d. manages VAD patients who receive therapy as bridge to transplant, destination therapy or bridge to recovery

17. Does your VAD program have a <u>written</u>:

	Yes	**If yes, is it included in heart failure program?**	**No**
Mission	_____	_____	_____
Philosophy	_____	_____	_____
Strategic Plan	_____	_____	_____

18. Which of the following characterizes how your VAD program is placed in your organization?

_____ a. Stand-alone (i.e. staff with exception of MD are dedicated only to this program)
_____ b. Integrated with transplant program
_____ c. Integrated with cardiothoracic surgery program
_____ d. Other arrangement (specify): ____

19. Indicate all organizational structure(s)/department(s) to which your <u>VAD program</u> report(s)?

_____ a. Critical Care
_____ b. Heart Failure
_____ c. Surgery
_____ d. Transplantation
_____ e. Other (please specify) ____

20. How are the following healthcare providers assigned?

<u>Caregiver</u>	**<u>1</u>**	**<u>2</u>**	**<u>3</u>**	**<u>4</u>**
Cardiac Surgeon	_______	_______	_______	_______
Heart Failure Cardiologist	_______	_______	_______	_______
Clinical Nurse Specialist	_______	_______	_______	_______
Nurse Practitioner	_______	_______	_______	_______
Discharge Planner	_______	_______	_______	_______
Biomedical Engineer	_______	_______	_______	_______
Pharmacist	_______	_______	_______	_______
Social Worker	_______	_______	_______	_______
Physical Therapist	_______	_______	_______	_______
Clinical Psychiatry	_______	_______	_______	_______
Clinical Perfusionist	_______	_______	_______	_______
Home Health Nurse	_______	_______	_______	_______
Respiratory Therapist	_______	_______	_______	_______
Dietician	_______	_______	_______	_______
Chaplain	_______	_______	_______	_______

<u>Type of Assignment</u>

1 = Works with VAD program only

2 = Same provider regularly assigned but also works with other kinds of patients

3 = Not regularly assigned to VAD program, but is available as needed

4 = Provider not currently available to VAD program.

21. Where is postoperative care of VAD patients usually given?

Patient Care Unit	Yes	If yes, list number of total unit beds	No
VAD-designated ICU	______	______	______
VAD-designated Stepdown unit	______	______	______
Cardiac Surgery ICU	______	______	______
Cardiac Surgery Stepdown unit	______	______	______
Cardiothoracic Transplant ICU	______	______	______
Cardiothoracic Transplant Stepdown unit	______	______	______
Coronary/Cardiac ICU (CCU)	______	______	______
Cardiac Care Stepdown unit	______	______	______

Other ICU (Specify) ___________________________

Other Stepdown unit (Specify) ___________________________

22. In the last fiscal year, how many VAD implantations did your hospital

Budget for? __________

Provide? ____________

Provide via HeartMate II VAD System? ___________

23. Does your VAD team use a patient education and pathway or skill-set goals sheet? If so, **please attach a copy of the documents.**

THANK YOU FOR YOUR PARTICIPATION!

To RETURN the survey: Please use the provided postage-paid envelope and send to:

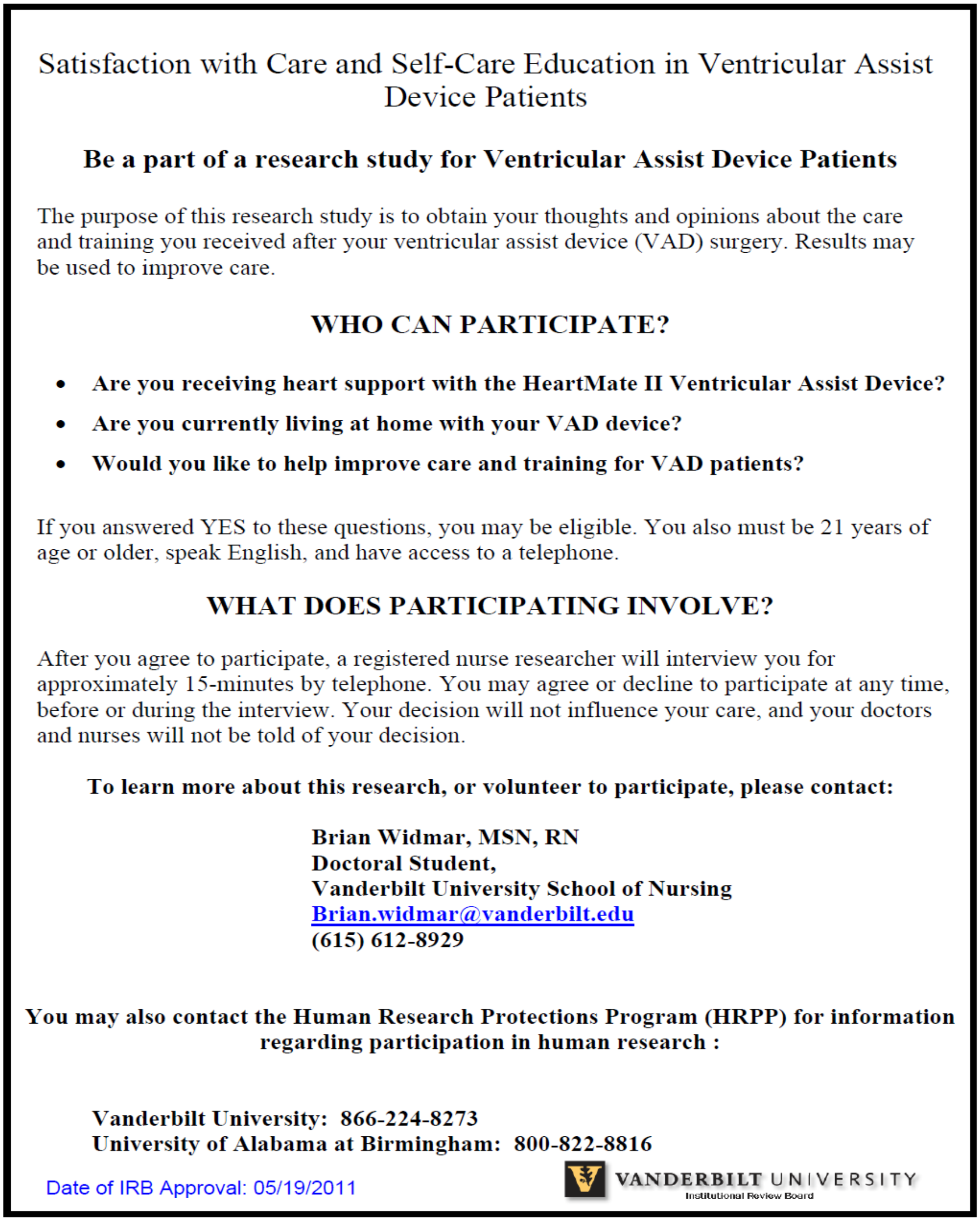
Brian Widmar PhD (c), RN, ACNP-BC

PLEASE RETURN BY: April 8, 2011

SURVEY MAY ALSO BE TAKEN ONLINE AT: http://www.nursing.vanderbilt.edu/VADservices

Appendix C

Ventricular Assist Device Patient Telephone Survey Invitation Flyer



Satisfaction with Care and Self-Care Education in Ventricular Assist Device Patients

Be a part of a research study for Ventricular Assist Device Patients

The purpose of this research study is to obtain your thoughts and opinions about the care and training you received after your ventricular assist device (VAD) surgery. Results may be used to improve care.

WHO CAN PARTICIPATE?

- **Are you receiving heart support with the HeartMate II Ventricular Assist Device?**
- **Are you currently living at home with your VAD device?**
- **Would you like to help improve care and training for VAD patients?**

If you answered YES to these questions, you may be eligible. You also must be 21 years of age or older, speak English, and have access to a telephone.

WHAT DOES PARTICIPATING INVOLVE?

After you agree to participate, a registered nurse researcher will interview you for approximately 15-minutes by telephone. You may agree or decline to participate at any time, before or during the interview. Your decision will not influence your care, and your doctors and nurses will not be told of your decision.

To learn more about this research, or volunteer to participate, please contact:

Brian Widmar, MSN, RN
Doctoral Student,
Vanderbilt University School of Nursing
Brian.widmar@vanderbilt.edu
(615) 612-8929

You may also contact the Human Research Protections Program (HRPP) for information regarding participation in human research :

Vanderbilt University: 866-224-8273
University of Alabama at Birmingham: 800-822-8816

Date of IRB Approval: 05/19/2011

VANDERBILT UNIVERSITY
Institutional Review Board

Appendix D

SURVEY OF PATIENT PERCEPTIONS OF PATIENT-CENTERED CARE AFTER VENTRICULAR ASSIST DEVICE IMPLANTATION

I. Dignity and Respect

1. During the hospital stay after your VAD surgery, how often did care provider(s) treat you with <u>courtesy and respect</u>? (If NOT always, go to question 2. If always, go to question 3).

1. Never
2. Sometimes
3. Usually
4. Always

2. Approximately how many times were you <u>not</u> treated with courtesy and respect?

____

3. How <u>important</u> was it to you that your care provider(s) treat you with courtesy and respect?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

II. Communication and Education

4. During the hospital stay after your VAD surgery, how often did care providers <u>listen carefully to you?</u> (If NOT always, go to Question 5. If always, go to Question 7).

1. Never
2. Sometimes
3. Usually
4. Always

5. Approximately how many times did a care provider <u>not</u> listen carefully to you?

____

6. How important was it to you that your care provider(s) listen carefully to you?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

7. During the hospital stay after your VAD surgery, how often did care provider(s) explain things in a way you could understand? (If NOT always, go to Question 8. If always, go to Question 9).

1. Never
2. Sometimes
3. Usually
4. Always

8. Approximately how many times did your care provider(s) not explain things in a way you could understand?

____

9. During the hospital stay after your VAD surgery, how often did care provider(s) explain information as thoroughly as you wanted?

14. Never
15. Sometimes
16. Usually
17. Always

10. During the hospital stay after your VAD surgery, how often was care provider(s) explanation of information individualized to meet your needs and preferences?

1. Never
2. Sometimes
3. Usually
4. Always

11. How <u>important</u> was it to you that your care provider(s) explain things to you in a way you could understand?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

III. Your Experiences in This Hospital

12. During the hospital stay after your VAD surgery, were you given any medicine that you had not taken before?

1. Yes
2. No → If No, GO TO QUESTION 19

13. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

1. Never
2. Sometimes
3. Usually
4. Always

14.Before giving you any new medicine, how <u>often</u> did hospital staff describe possible side effects in a way you could understand?

1. Never
2. Sometimes
3. Usually
4. Always

15. How often was information about new medications and their side effects explained to you <u>as soon as you wanted</u>?

1. Never
2. Sometimes
3. Usually
4. Always

16. How often was information about new medications and their side effects explained to you as thoroughly as you wanted?

1. Never
2. Sometimes
3. Usually
4. Always

17. How often was information about new medications and their side effects individualized to meet your needs and preferences?

1. Never
2. Sometimes
3. Usually
4. Always

18. How important was it to you that new medications and their side effects were explained to you in a way you could understand?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

IV. When You Left the Hospital

19. After you left the hospital, did you go directly to your own home, to someone else's home, or to another health facility?

1. Own home
2. Someone else's home
3. Another health facility → If Another, GO TO QUESTION 30

20. During the hospital stay after your VAD surgery, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

1. Yes
2. No

21. During the hospital stay after your VAD surgery, did doctors, nurses or other hospital staff talk with you about the help you needed when you left the hospital as soon as you wanted?

1. Yes
2. No

22. During the hospital stay after your VAD surgery, did doctors, nurses or other hospital staff talk with you about the help you needed when you left the hospital as thoroughly as you wanted?

1. Yes
2. No

23. During the hospital stay after your VAD surgery, was the discussion about the help you needed when you left the hospital individualized to your needs and preferences?

1. Yes
2. No

24. How important was it to you that doctors, nurses or other hospital staff talk with you about the help you needed when you left the hospital?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

25. During the hospital stay after your VAD surgery, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

1. Yes
2. No

26. During the hospital stay after your VAD surgery, did you get information in writing about what symptoms or health problems to look out for after you left the hospital as soon as you wanted?

1. Yes
2. No

27. During the hospital stay after your VAD surgery, was information in writing about what symptoms or health problems to look out for after you left the hospital as thorough as you wanted?

1. Yes
2. No

28. During the hospital stay after your VAD surgery, was information in writing about what symptoms or health problems to look out for after you left the hospital individualized to your needs and preferences?

1. Yes
2. No

29. How important was it to you that you got information in writing about what problems or symptoms to look out for after you left the hospital?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

30. Did you get information in writing about how to properly assess and perform VAD exit site care? (If NO, GO TO QUESTION ; IF YES, GO TO QUESTION)

1. Yes
2. No

31. How was information about how to properly assess and perform VAD exit site care provided to you?

____

32. Was information provided about how to properly assess and perform VAD exit site care as soon as you wanted?

1. Yes
2. No

33. Was information provided about how to properly assess and perform exit site care as thorough as you wanted?

1. Yes
2. No

34. Was information provided about how to properly assess and perform exit site care individualized to your needs and preferences?

1. Yes
2. No

35. How important was it to you to receive information about how to properly assess and perform VAD exit site care?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

36. Did you get information in writing about how to transfer VAD power source from wall to battery for mobility? (If NO, Go to QUESTION ; If YES, go to QUESTION)

1. Yes
2. No

37. How was information about how to transfer VAD power source from wall to battery for mobility provided to you?

____

38. Did you get information about how to transfer VAD power source from wall to battery for mobility as soon as you wanted?

1. Yes
2. No

39. Was information provided about how to transfer VAD power source from wall to battery for mobility as thorough as you wanted?

1. Yes
2. No

40. Was information provided about how to transfer VAD power source from wall to battery for mobility individualized to your needs and preferences?

1. Yes
2. No

41. How important was it to you to receive information about how to transfer VAD power source from wall to battery for mobility?

1. Not at all important
2. Somewhat important
3. Important
4. Very Important

42. Did you get information in writing about what to do in case of a VAD emergency? (If NO, go to QUESTION . If YES, go to QUESTION)

- Yes
- No

43. How was information about what to do in case of a VAD emergency provided?

____

44. Did you get information about what to do in case of a VAD emergency as soon as you wanted?

1. Yes
2. No

45. Was information provided about what to do in case of a VAD emergency as thorough as you wanted?

1. Yes
2. No

46. Was information provided about what to do in case of a VAD emergency individualized to your needs and preferences?

1. Yes
2. No

47. How important was it to you to receive information about what to do in case of a VAD emergency?

Not at all important
Somewhat important
Important
Very Important

48. Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay?

- 1 (worst hospital possible)
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 (best hospital possible)

V. Information About You

49. Age - ________ years

50. Gender

1. Male
2. Female

51. Race

1. American Indian/Alaska Native
2. Asian
3. Native Hawaiian/Pacific Islander
4. Black/African American
5. White

52. Ethnicity

1. Hispanic/Latino
2. Not Hispanic/Latino

53. Educational Level
    1. Some high school
    2. High School/GED
    3. Some college
    4. Undergraduate
    5. Graduate

54. Income Level (annual)
    1. < $20,000
    2. $25,000 – $50,000
    3. $50,000 - $75,000
    4. > $75,000

55. Marital Status
    1. Married/Marriage-like relationship
    2. Widowed
    3. Divorced
    4. Single

56. What type of VAD system did you receive?
    1. Heartmate II
    2. Hearmate XVE
    3. Thoratec TLC II (BiVAD)
    4. Other
    5. Don't know

57. How long have you had your VAD device?
    1. < 1 month
    2. 1-3 months
    3. 3-6 months
    4. 6-12 months
    5. > 12 months

V. ADDITIONAL QUESTIONS

58. What advice would you give to healthcare providers (doctors and nurses) to improve care for VAD patients?

59. What advice would you give to other patients who are going to have VAD implant surgery?

Note. This tool adapted from the Health Consumer Assessment of Healthcare Providers and Services (HCAHPS) survey and from Young & Minnick, 1996.

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