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Experiences of Mechanical Circulatory Support Patients with Primary Implant Education

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Walden University

College of Nursing

This is to certify that the doctoral dissertation by

Dawn M. Lebid Christensen

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
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Walden University
2022

Abstract

Experiences of Mechanical Circulatory Support Patients With Primary Implant Education

by

Dawn M. Lebid Christensen

MS, The Pennsylvania State University, 1996

BS, Temple University, 1992

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing

Walden University

May 2022

Abstract

Advancement in mechanical circulatory support (MCS) device therapy has led to increased use in heart failure therapy and relies on optimized patient education for successful support. The purpose of this 3-manuscript study, guided by the Husserlian transcendental phenomenological method, was to explore the lived experiences of (a) patients with primary mechanical circulatory support education (PMCSE), (b) patients who undergo unplanned MCS implantation with PMCSE, and (c) patients who undergo planned MCS implantation with PMCSE. Eleven participants were recruited (eight planned, three unplanned) from MCS targeted social media sites and interviewed using a semistructured open-ended question format. Data were analyzed using principles of thematic analysis. Three themes were derived from the data to describe the patient experience with PMCSE and included (a) process, the participant's experience of the mechanics of the PMCSE, (b) disposition, the mindset of the participant related to PMCSE at discharge, and (c) adjustment, the participants general outlook as it relates to PMCSE. Theme descriptions differed among the planned vs. unplanned groups suggesting differences in the PMCSE experience based on timing of implant. Future research should include additional exploratory studies as well as multicenter comparisons of PMCSE practices and their effect on the patient experience taking implant strategy into consideration. Understanding differences in patient experiences surrounding MCS implantation strategy affects positive social change by providing foundational knowledge for optimizing MCS patient knowledge transfer practices, potentially improving outcomes while decreasing cost in this resource intensive therapy.

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Part 1: Overview

Introduction

Heart failure (HF) is a syndrome that results in the inability of a person's heart to meet the metabolic needs of their body and is one of the leading causes of morbidity and mortality throughout the world (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017; Seferovic et al., 2019; Trindade et al., 2019; van der Meer et al., 2019). HF affects approximately 12.4 people per 1000 in the world population including 6.2 million adult Americans and is projected to increase by 46% in the next ten years (Lesyuk et al., 2018; Savarese & Lund, 2017; Virani et al., 2020). The annual cost for HF treatment in the United States is estimated to increase 127% from $30.7 billion to $69.8 billion by 2030 (Virani et al., 2020). When HF progresses to the point where symptom management is no longer possible with oral medications it is considered advanced HF and must be treated with invasive therapies for patient survival (Crespo-Leiro et al., 2018; Fang et al., 2015). Mechanical circulatory support (MCS) is a surgical therapy used to support patients with advanced HF and is now recommended by the American Heart Association (AHA) and the American College of Cardiology (ACC) as standard of care for advanced HF patients (Potapov et al., 2019; van der Meer et al., 2019). Over 25,000 MCS devices have been implanted since 2006, improving 1 year survival rates for those patients from 63% to 83% (Estep et al., 2015; Virani et al., 2020).

HF can occur as a progressive decline or as an acute decompensation necessitating the need for initiation of MCS for patient survival (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017). Successful MCS therapy requires the patient to learn specialized medical knowledge and technical skills for safe home device/self-care (Feldman et al., 2013; Kato et al., 2014; Smedira et al., 2013). Targeted education is identified as crucial for successful outcomes involving MCS therapy, yet only a limited number of studies exist describing current practices. (Feldman et al., 2013; Kato et al., 2014; Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Variation in rate of progression of HF among patients results in a disparity in patients' knowledge surrounding their individual disease state at the time of MCS implant (Barsuk et al., 2020). Additional factors including age and cognitive performance contribute to differences in a patient's ability to assimilate the knowledge required for successful device/self-care after MCS implantation (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018).

There is a lack of evidence focusing on the patient's experience during MCS education or educational best practices for the MCS patient (Feldman et al., 2013; Smedira et al., 2013). Developing optimized educational approaches for MCS patients has the potential to improve patient outcomes making a positive impact on social change by serving as an integral role in reduction of MCS patient morbidity and mortality, decreased resource requirements through increased patient empowerment and autonomy, and decreased costs related to MCS therapy.

Background

MCS is a long-term surgical therapy used to treat advanced HF that involves implanting a mechanical pump to circulate blood within a patient's body (Potapov et al., 2019; van der Meer et al., 2019). Although MCS therapy is successful, it continues to be resource intensive and requires specialized training for successful outcomes (Starling et al., 2017; Thompson et al., 2019). Primary mechanical circulatory support education (PMCSE) is provided to an MCS patient in the perioperative period surrounding MCS device implantation prior to hospital discharge. It involves learning device/self-care which includes changes in circulatory physiology that occur with MCS therapy, care of the MCS device (battery changes and maintenance, power source changes, controller changes, driveline care, dressing change and showering procedures, alarm troubleshooting, and emergency recognition), medication management, dietary changes, and home monitoring requirements (heart failure symptoms, heightened stroke, infection, and bleeding recognition, daily device parameter recording, home INR measurement, blood pressure monitoring in non-pulsatile state; (Barsuk et al., 2020; Kato et al., 2014; Widmar et al., 2014). Despite the completion of PMCSE, newly discharged MCS-dependent patients continue to seek peer guidance for essential topics involving MCS device/self-care indicating an insufficient patient knowledge base and a disconnect in device/self-care knowledge transfer or assimilation (Boling et al., 2015). Unsafe device/self-care practices contribute to the alarming rate of complications related to MCS therapy that may be impacted through optimization of patient educational practices (Lemor et al., 2020; RobatSarpooshi et al., 2020; Smedira et al., 2013).

MCS-specific education is identified as crucial for successful outcomes involving this therapy, yet only a limited number of studies exist describing current practices. (Feldman et al., 2013; Kato et al., 2014; Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Additionally, recommendations have been made for adjustment of education of scheduled MCS patients to maximize effective patient self-care with no research basis related to optimal content or practice (Faulkner et al., 2020). The lack of inquiry exposes the deficiencies that exist in knowledge involving the patient's experience. For patient educational materials to be truly effective, the design of those materials must take into account the patient experience and the context in which the experience occurs (Meloncon, 2017). Optimization of PMCSE requires the exploration of the patient experience so that design of those materials is tailored to fit the needs of the population that is served. The overarching problem that I addressed in this research is a lack of understanding of the MCS patient experience with PMCSE.

Qualitative research methods are used to develop a deeper understanding of patient perceptions and can be used to identify gaps, gain insights, redesign and innovate practices to better deliver patient care, streamline processes, and save costs (LaVela & Gallan, 2014; Sundler et al., 2019). To explore differences that may be affected by MCS implant timing, I used a three-manuscript approach to elucidate the current patient experience and expose differences in the experiences of patients based on timing of their MCS implant. By employing transcendental phenomenological qualitative methods using purposive sampling, I recruited 11 volunteers from MCS targeted social media platforms to explore the lived experience of MCS patients with PMCSE.

Heart Failure

The syndrome of HF is the result of multiple acute and chronic pathological processes whose outcomes lead to the inability of the patients' heart to provide enough blood flow to supply the needs of their body (Crespo-Leiro et al., 2018; Fang et al., 2015). There are two broad classifications of HF. Advanced chronic HF is defined as a progressive state involving declining cardiovascular clinical criteria despite optimal medical management (OMM) resulting in extracardiac organ dysfunction (Crespo-Leiro et al., 2018; Fang et al., 2015). Advanced acute HF is a rapid onset low cardiac output syndrome typically associated with acute coronary syndrome (ACS) that presents with clinical signs of organ hypoperfusion (Harjola et al., 2017). Clinical care of the advanced HF patient involves multiple therapies including lifestyle changes, aggressive oral and intravenous medication management, and in refractory cases, implantation of an MCS device to provide augmented blood circulation when the heart is no longer able to support the body's needs (van der Meer et al., 2019).

MCS Therapy

MCS therapy was initially developed as a short term therapy for use in patients with cardiogenic shock after coronary artery bypass grafting (CABG; Kirklin & Frazier, 2006). After U.S. Food and Drug Administration (FDA) approval in 1996, indications for use expanded to include patients waiting for cardiac transplant and the therapy evolved from large paracorporial pneumatically driven devices to implantable pulsatile devices that allowed for greater patient ambulation and subsequent discharge from the hospital. Kirklin & Frazier, 2006). Further development of axial flow devices and completion of the REMATCH trial in 2001 allowed for MCS therapy to be considered for long term or destination therapy support for patients who did not qualify for cardiac transplant (Rose et al., 2001). Advancements in MCS device designs over the last 10 years have resulted in increasing use of implanted centrifugal pumps regulated and powered by external controllers and batteries (Teuteberg et al., 2020). Miniaturization and portability of device components allows for largely outpatient therapy as long-term circulatory support with or without progression to cardiac transplant (Kirklin et al., 2020; Kormos et al., 2019). Successful support requires that patients have adequate understanding and knowledge of device/self-care involving their HF chronic disease state as well as adequate knowledge, cognitive function, and skill concerning the principles of pump operation to provide routine and emergency care (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020).

Implant Timing

MCS implantation is indicated for patients with heart failure resulting in end organ dysfunction despite optimal medical management (OMM) and can be the result of advanced acute or chronic HF (Teuteberg et al., 2020). Unplanned MCS implantation for advanced acute HF typically occurs after an unexpected event resulting in cardiogenic shock requiring immediate assistance of circulation to restore organ perfusion (Grady & Dew, 2020). Patient knowledge and discussion of MCS therapy is limited to the timing of the event which resulted in the necessity for initiation of MCS support. Consent for MCS implant frequently comes from a family member and the patient may not be aware of initiation of therapy until after device implantation. It frequently involves use of a temporary device to restore circulation prior to implantation of a long term MCS device (Grady & Dew, 2020). Planned implantation of an MCS device typically occurs in patients with advanced chronic HF (Barsuk et al., 2020). The patient has had experience in self-care practices throughout the progression of their HF and has had discussion of MCS therapy prior to initiation of MCS. The difference in groups is prior exposure to education, experience, and knowledge of MCS therapy before initiation of MCS. There is a lack of evidence describing the differing educational needs of MCS patient based on timing of implant although experience and pretraining are beneficial to both HF and MCS device/self-care practices (Barsuk et al., 2020; Dickson et al., 2008). Targeted patient education and early discharge planning are recommended to increase QOL and reduce readmission rates in heart failure patients (Mai Ba et al., 2020).

Cognitive Impairment

MCS support has been increasingly used as HF treatment for patients of all age groups and can successfully provide additional years of meaningful life (Ciarka et al., 2017; Goldstein et al., 2019; Lemor et al., 2020). Cognitive performance plays an integral role in a person’s ability to learn and provide self-care (Cocchieri et al., 2015). Decreased cognitive performance or cognitive impairment (CI) has been identified as a predictor of poor outcomes and decreased quality of life (QOL) in MCS patients (Bhat et al., 2015; Casida et al., 2017; Faulkner et al., 2020; Pavol et al., 2020). A person’s cognitive performance plays an integral role in their ability to learn and provide self-care

(Cocchieri et al., 2015). Cognitive impairment (CI) is accelerated in chronic heart failure patients resulting in deficits in executive function, episodic memory, psychomotor speed, language and visio-spatial abilities but appears to improve after MCS implantation (Bhat et al., 2015; Doehner et al., 2018). CI with ACS has been identified as having an effect on both short and long term outcomes with deficits in attention and memory impacting a patient's post ACS ability to learn self-care and changes in lifestyle behaviors (Zhao et al., 2020). Life stage differences, levels of CI, and differences in HF etiology have all been identified as issues affecting adjustment after MCS implant which suggests multiple factors that may impact the patient's ability to assimilate the knowledge required for successful care after MCS implantation (Abshire et al., 2016, 2018; Casida et al., 2017)

Discharge Education

Patients who have undergone MCS implant complete PMCSE involving the care of themselves and their life-sustaining device before discharge. Despite that education, they continue to rely on outside sources of information, such as social media outlets, for advice surrounding device care, troubleshooting and management of their chronic condition (Boling et al., 2015). Outside sources of information are beneficial as substantiation of knowledge, but when patients seek outside sources of information as a primary source, a disconnect exists in the knowledge transfer process involving PMCSE which merits exploration. Prior research in hospital discharge education has demonstrated the efficacy of using patient experience data to redesign and improve discharge paperwork provided to patients (Hahn-Goldberg et al., 2015). The quality (presentation, timing, and frequency) of surgical discharge education influences the patient's ability to provide self-care in the postoperative period (Kang et al., 2018). A lack of evidence exists describing optimal methods for providing discharge education to post-surgical patients in general (Kang et al., 2018). Despite the growing number of patients requiring MCS support, very little knowledge exists surrounding the patient's lived experience with PMCSE which is the foundational knowledge necessary for developing optimized educational practices for this population (Barsuk et al., 2020; Lemor et al., 2020; Widmar et al., 2014).

Theoretical Framework

Transcendental phenomenological research is a qualitative methodology constructed by Edmund Husserl (Husserl, 2001; Peoples, 2020). The primary focus of this methodology surrounds description and understanding of the unfiltered meaning of a person's lived experience (Husserl, 2001; Peoples, 2020; Sundler et al., 2019). To be able to achieve this end, the researcher must practice phenomenological reduction, the process of questioning and dismissing any pre-understanding or judgement, in order to describe the phenomenon in its purest form (Peoples, 2020; Sundler et al., 2019). Husserl's methodology as described by Sundler et al. (2020) is used by the researcher to exercise phenomenological reduction consciously and intentionally by using an open and reflexive approach to acknowledge their existing understanding and suppositions surrounding the phenomenon (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in the present experience (horizon) of exploration, analysis, and description. By intentionally separating the researcher's judgements from the data, the true essence of the phenomenon is captured (Peoples, 2020; Sundler et al., 2019). The research approach described by Sundler et al. (2020), is a concise and practical approach to the transcendental phenomenological research process intended for novice qualitative researchers.

I chose to use transcendental phenomenology as the methodology behind this research because I have extensive experience in the MCS field. Although this experience led me to suspect deficits in knowledge within the MCS field, it created a potential bias in research which was addressed using this methodology. I used Husserl's methodology to address my concerns regarding my bias surrounding my previous experience in the MCS field as it provided guidance to acknowledge and bracket it, supporting the research goal of exploration of the patient experience with PMCSE.

This research fills the gap surrounding the understanding of patient's lived experience with PMCSE. With this research, I have provided foundational knowledge necessary to inform future studies addressing MCS patient educational content and delivery methods with a goal of optimization of PMCSE.

Overview of the Manuscripts

Although MCS therapy is successful, it continues to be resource intensive and requires the patient to receive, recall, and perform specialized training for successful outcomes (Starling et al., 2017; Thompson et al., 2019). The need for educational interventions has been identified by MCS patients as a necessary for mastery of daily self-care routines (Alonso et al., 2019). Individual circumstances surrounding HF etiology, progression, and MCS implant timing may produce unique contexts for PMCSE that have yet to be identified necessitating differences in educational methods (Abshire et al., 2016, 2018; Casida et al., 2017; Meloncon, 2017). I used a transcendental phenomenological approach to explore the patients' lived experiences with PMCSE by allowing participants to describe their experience using their own words. I used phenomenological reduction and bracketing to create an unfiltered environment for subsequent data analysis, discovery of differences in experience, and identification of common themes. I used this methodological process because it was designed to promote understanding by describing the patient's experience in its richest form (Sundler et al., 2019).

The purpose of this three-manuscript dissertation was to explore the lived experiences of (a) patients with PMCSE, (b) patients who undergo unplanned MCS implantation with PMCSE, and (c) patients who undergo planned MCS implantation with PMCSE. I used the parallel areas of study for this three-manuscript dissertation to address the gap in knowledge surrounding the experiences of MCS patients with PMCSE in relationship to the timing of their implant procedure.

Manuscript 1

Specific Problem

There is a lack of evidence focusing on the patient's experience during MCS education and educational best practices for the MCS patient (Feldman et al., 2013; Smedira et al., 2013). MCS-specific education is identified as crucial for successful outcomes involving this therapy, yet only a limited number of studies exist describing current practices. (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013;

Teuteberg et al., 2020; Widmar et al., 2014). Additionally, recommendations have been made for adjustment of education of scheduled MCS patients to maximize effective patient self-care with no research related to optimal practice suggestions (Faulkner et al., 2020). The lack of inquiry exposes deficiencies that exist in medical providers' knowledge involving the patient's experience and the optimization of MCS educational practices.

Research Question

What are the lived experiences of MCS patients with PMCSE?

Nature of Study and Design

I explored PMCSE from the patient's perspective using transcendental phenomenological qualitative methods as described by Sundler et al. (2020), based on the original philosophy of Husserl. The primary focus of this methodology surrounds description and understanding the unfiltered meaning of a person's lived experience (Peoples, 2020; Sundler et al., 2019). In order to achieve this end, the researcher must question and set aside (bracket) any preunderstanding or judgement involving the phenomenon of interest in order allow for its description in its purest form (Peoples, 2020; Sundler et al., 2019). This methodology is used by the researcher to consciously and intentionally use an open and reflexive approach while seeking to understand a phenomenon, which Husserl terms phenomenological reduction (Peoples, 2020). Transcendental phenomenological research in this form requires the researcher to acknowledge their existing understanding and suppositions (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in the present experience (horizon) of exploration, analysis, and description of the phenomenon being studied (Peoples, 2020). By intentionally separating the researcher's judgements from the data, the true essence of the phenomenon emerges (Peoples, 2020; Sundler et al., 2019). In consideration of my extensive history and experience within the MCS field, this approach, based on Husserl's methodology, aligned well with the research question exploring the patient's lived experience related to PMCSE

Source(s) of data

Qualitative researchers use an inductive approach to collect subjective forms of data, including words or images (Ravitch & Carl, 2016). I interviewed 11 MCS patients using a semistructured, open-ended question format. I recruited participants from MCS targeted social media platforms (Boling et al., 2015). I used an online video interface (Google Meet) for interviews, which I audio recorded (Notability) and transcribed verbatim (rev.com) for further analysis and identification of patterns and themes within the data (Jowitt, 2020). I used my observations, reflections, and notes as sources of data to bracket my influence in an attempt to obtain the purest description of the participant's PMCSE experience.

Manuscript 2

Specific Problem

Variation in rate of progression of HF syndrome among patients results in a disparity in patients' knowledge surrounding their individual disease state at the time of MCS implant (Barsuk et al., 2020). Additional factors including cognitive performance, HF etiology, and rate of progression contribute to patient differences in the ability to assimilate the knowledge required for successful device/self-care after MCS implantation (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018). Additionally, the quality (presentation, timing, and frequency) of surgical discharge education influences the patient's ability to provide self-care post-operatively (Kang et al., 2018).

Planned implantation of an MCS device typically occurs in patients with a medical history of chronic HF that has progressively worsened despite OMM (Grady & Dew, 2020). The patient has been previously introduced to many of the self-care requirements related to management of their chronic disease and participated in discussion of MCS therapy prior to their MCS device implantation. The difference in groups is prior exposure to HF education and knowledge of MCS therapy. There is a lack of evidence describing the differing educational needs of MCS patient based on timing of implant although prior experience and pretraining are beneficial to both HF and MCS device/self-care practices (Barsuk et al., 2020; Dickson et al., 2008).

Research Question

What are the lived experiences of patients undergoing unplanned MCS device implantation with PMCSE?

Nature of Study and Design

I explored PMCSE from the patient's perspective using transcendental phenomenological qualitative methods as described by Sundler et al. (2020), based on the original philosophy of Husserl. The primary focus of this methodology surrounds description and understanding the unfiltered meaning of a person's lived experience

(Peoples, 2020; Sundler et al., 2019). To achieve this end, the researcher must question and set aside (bracket) any pre-understanding or judgement involving the phenomenon of interest in order allow for its description in its purest form (Peoples, 2020; Sundler et al., 2019). This methodology is used by the researcher to consciously and intentionally use an open and reflexive approach while seeking to understand a phenomenon, which Husserl terms phenomenological reduction (Peoples, 2020). Transcendental phenomenological research is used by the researcher to acknowledge their existing understanding and suppositions (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in the present experience (horizon) of exploration, analysis, and description of the phenomenon being studied (Peoples, 2020). By intentionally separating the researcher’s judgements from the data, the true essence of the phenomenon emerges (Peoples, 2020; Sundler et al., 2019). In consideration of my extensive history and experience within the MCS field, this approach aligned well with the posed research question exploring the patient's lived experience related to PMCSE.

Source(s) of Data

Qualitative researchers use an inductive approach to collect subjective forms of data, including words or images (Ravitch & Carl, 2016). I interviewed 11 MCS patients using a semistructured, open-ended question format. Participants were recruited from MCS targeted social media platforms (Boling et al., 2015). I used an online video interface (Google Meet) for interviews, which I audio recorded (Notability) and transcribed verbatim (rev.com) for further analysis and identification of patterns and themes within the data. I used my observations, reflections, and notes as sources of data to bracket my influence in an attempt to obtain the purest description of the participant's PMCSE experience.

Manuscript 3

Specific Problem

Unplanned MCS implantation frequently occurs after an acute event resulting in acute advanced HF and cardiogenic shock requiring emergent implantation of the MCS device to restore organ perfusion (Grady & Dew, 2020). Patient knowledge and discussion of MCS therapy is limited to the timing of the event which resulted in the necessity for initiation of MCS support. CI after acute coronary syndrome has been identified as having an effect on both short and long term outcomes with deficits in attention and memory impacting a patient's post ACS ability to learn self-care and changes in lifestyle behaviors (Zhao et al., 2020). Life stage differences, levels of CI, and differences in HF etiology have all been identified as issues affecting adjustment after MCS implant which suggests multiple factors that may impact the patient's ability to assimilate the knowledge required for successful care after MCS implantation (Abshire et al., 2016, 2018; Casida et al., 2017). There is a lack of evidence describing the differing educational needs of MCS patient based on timing of implant although prior experience and pretraining are beneficial to both HF and MCS device/self-care practices (Barsuk et al., 2020; Dickson et al., 2008).

Research Question

What are the lived experiences of patients undergoing planned implantation of a Mechanical Circulatory Support (MCS) device with PMCSE?

Nature of Study and Design

I explored PMCSE from the patient's perspective using transcendental phenomenological qualitative methods as described by Sundler et al. (2020) based on the original philosophy of Husserl. The primary focus of this methodology surrounds description and understanding the unfiltered meaning of a person's lived experience (Peoples, 2020; Sundler et al., 2019). To be able to achieve this end, the researcher must question and set aside (bracket) any pre-understanding or judgement involving the phenomenon of interest in order allow for its description in its purest form (Peoples, 2020; Sundler et al., 2019). This methodology implores the researcher to consciously and intentionally use an open and reflexive approach while seeking to understand a phenomenon, which Husserl terms phenomenological reduction (Peoples, 2020). Transcendental phenomenological research requires the researcher to acknowledge their existing understanding and suppositions (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in the present experience (horizon) of exploration, analysis, and description of the phenomenon being studied (Peoples, 2020). By intentionally separating the researcher's judgements from the data, the true essence of the phenomenon emerges (Peoples, 2020; Sundler et al., 2019). In consideration of my extensive history and experience within the MCS field, this approach aligned well with the posed research question exploring the patient's lived experience related to PMCSE.

Source(s) of Data

Qualitative inquiry utilizes an inductive approach to collect subjective forms of data, including words or images (Ravitch & Carl, 2016). I interviewed 11 MCS patients using a semistructured, open-ended question format. Participants were recruited from MCS targeted social media platforms (Facebook) (Boling et al., 2015). Interviews took place using an online video interface (Google Meet) and were audio recorded (Notability) and transcribed verbatim (rev.com) for further analysis and identification of patterns and themes within the data (Jowitt, 2020). I used my observations, reflections, and notes as sources of data to bracket my influence in an attempt to obtain the purest description of the participant's PMCSE experience.

Significance

Patients who have undergone MCS implant complete PMCSE involving the care of themselves and their life-sustaining device to be deemed safe for discharge. Despite that education, they continue to rely on outside sources of information, such as social media outlets, for advice surrounding their device's care, troubleshooting, and their chronic condition (Boling et al., 2015). Outside sources of information are beneficial as substantiation of knowledge, but when patients seek outside sources of information due to a disconnect in the knowledge transfer process, that process needs to be re-examined to determine where deficiencies exist (Zhang et al., 2009). Prior research in hospital discharge education has demonstrated the efficacy of using patient experience data to redesign and improve discharge paperwork provided to patients (Hahn-Goldberg et al., 2015). The quality (presentation, timing, and frequency) of surgical discharge education influences the patient's ability to provide self-care post-operative period (Kang et al., 2018). A lack of evidence exists describing optimal methods for providing discharge education to post-surgical patients in general (Kang et al., 2018). Correspondingly, despite the growing number of patients requiring MCS support, very little knowledge exists surrounding MCS post-operative education or the MCS patient’s educational experience (Lemor et al., 2020; Widmar et al., 2014). Understanding the educational experience, from the patient’s perspective, provides a foundation for future design of optimized patient centered MCS educational practices and materials (Gouge, 2017; Meloncon, 2017). Optimization of PMCSE is a foundational step in promoting increased MCS patient autonomy and potentially decreasing the incidence of device related complications (Gouge, 2017; Meloncon, 2017). Increased autonomy, prevention, and early identification of complications can support positive social change by decreasing complications, readmission rates, and cost associated with this highly resource intensive therapy.

Summary

HF is one of the leading causes of morbidity and mortality globally. Advanced HF has multiple etiologies and is most simply characterized by a progressive or acute presentation. MCS is a standard of care surgical treatment for advanced HF that has progressed despite OMM. It is a resource intensive therapy that requires extensive patient training for successful outcomes. PMCSE is necessary prior to patient discharge from the hospital and can be affected by multiple issues including the timing of MCS implant. Very little evidence exists surrounding the patient’s lived experience PMCSE resulting in a gap in knowledge that directly impacts the optimization of vital patient training. Successful MCS therapy requires patients to understand and perform routine and emergency device/self-care independently. The purpose of this three-manuscript dissertation was to explore the lived experiences of (a) patients with PMCSE, (b) patients who undergo unplanned MSC implantation with PMCSE, and (c) patients who undergo planned MCS implantation with PMCSE. I used a transcendental phenomenological qualitative approach as described by Sundler, et al. based on Husserl’s methodology as a theoretical framework to guide the design and analysis of this research. By using a parallel design I used three manuscripts aimed to explore the patient's experience to provide the foundational insight for future research and optimization of MCS educational practices.

Part 2: Manuscripts

Experiences of Mechanical Circulatory Support Patients With Primary Implant Education

by

Dawn M. Lebid Christensen

MS, The Pennsylvania State University, 1996

BS, Temple University, 1992

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Nursing

Walden University

Outlet for Manuscript

The Journal of Heart and Lung Transplantation (JHLT): This scholarly, peer-reviewed journal is the Official Publication of the International Society for Heart and Lung Transplantation. The focus is as a primary forum for timely information involving pre-clinical and clinical science of the failing heart and lung including mechanical and biological support of the failing heart with a target audience of specialist medical providers in these areas. Types of manuscripts accepted include original studies involving clinical, translational, or basic science, innovation articles, brief communications, case anecdotes, state of the art revies and perspectives. JHLT submission requirements include:

- Structure of original science manuscripts in the following order: Title page, Abstract, Introduction, Materials and Methods, Results, Discussion, Author Contributions, Acknowledgments, Financial Disclosure Statement, Figures with Legends, References.
- Style and formatting as outlined in the American Medical Association (AMA) Manual of Style, 10th edition.
- Maximum length restrictions include overall manuscript of eight journal pages, with an abstract of 250-words, and main text of 3000-words (excluding tables, figures, and references). Tables and figures are limited to 8 per manuscript and 50 references.

Information about JHLT can be accessed at the following URL: https://www.jhltonline.org/content/aims. Guidelines for submission of manuscripts to

JHLT can be accessed at the following URL:

https://www.jhltonline.org/content/authorinfo.

Abstract

Advancement in mechanical circulatory support (MCS) device therapy has led to increased use in heart failure therapy and relies on optimized patient education for successful support. The purpose of this Husserlian guided transcendental phenomenological study was to explore the lived experiences of patients with PMCSE. A purposive sample of 11 participants recruited (eight planned, three unplanned) from MCS targeted social media sites were interviewed using a semistructured open-ended question format and data analyzed using principles of thematic analysis. Three themes were derived from the data to describe the patient experience with PMCSE and included (a) process, the participant's experience of the mechanics of the PMCSE, (b) disposition, the mindset of the participant related to PMCSE at discharge, and (c) adjustment, the participants general outlook as it relates to PMCSE. Theme descriptions related to disposition and adjustment differed among the planned vs. unplanned groups suggesting differences in the PMCSE experience based on timing of implant that may have patient educational implications. Future research should include additional exploratory studies as well as multicenter comparisons of PMCSE practices and their effect on the patient experience taking implant strategy into consideration. Understanding differences in patient experiences surrounding MCS implantation strategy affects positive social change by providing foundational knowledge for optimizing MCS patient knowledge transfer practices, potentially improving outcomes while decreasing cost in this resource intensive therapy.

Introduction

Heart failure (HF) is one of the leading causes of morbidity and mortality throughout the world (Seferovic et al., 2019; Trindade et al., 2019; van der Meer et al., 2019). It affects approximately 12.4 people per 1000 in the world population including 6.2 million adult Americans and is projected to increase by 46% in the next ten years (Lesyuk et al., 2018; Savarese & Lund, 2017; Virani et al., 2020). Annual cost for HF treatment in the United States is estimated to increase 127% from $30.7 billion to $69.8 billion by 2030 (Virani et al., 2020). HF can have multiple etiologies ultimately resulting in a syndrome that results in the inability of the person's heart to meet the metabolic needs of the body (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017). Advanced HF is the worsening progression of HF in which symptom management is no longer possible with oral medications (Crespo-Leiro et al., 2018; Fang et al., 2015). Mechanical circulatory support (MCS) therapy is a surgical therapy used to support patients with advanced HF and is now recommended by the American Heart Association (AHA) and the American College of Cardiology (ACC) as standard of care for advanced heart failure patients (Potapov et al., 2019; van der Meer et al., 2019). Over 25,000 MCS devices have been implanted since 2006 improving one year survival rates for those patients from 63% to 83% (Estep et al., 2015; Virani et al., 2020).

Advanced HF has multiple causes and can occur as a progressive decline or as an acute decompensation necessitating the need for initiation of MCS for patient survival (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017). For successful support patients must have an adequate understanding and knowledge of device/self-care to independently provide routine and emergency care (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020). Variation in rate of progression of HF among patients results in a disparity in patients' knowledge surrounding their individual disease state at the time of MCS implant (Barsuk et al., 2020). Primary mechanical circulatory support education (PMCSE) is provided to an MCS patient in the prior to hospital discharge but additional factors including cognitive performance, timing, individual circumstance, and the quality of educational practices contribute to patient differences in the ability to assimilate the knowledge required for successful self-care after MCS implantation (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018). MCS-specific education is identified as crucial for successful outcomes involving this therapy, yet only a limited number of studies exist describing current practices or recommendations for best practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). The lack of inquiry exposes the knowledge deficiencies that exist involving understanding the patient experience with PMCSE. For design and optimization of effective patient educational materials and practices an understanding of the patient experience in the context in which the experience occurs is crucial (Meloncon, 2017). The fundamental problem that I addressed in this research is the lack of understanding of the lived experience of the MCS patient with PMCSE.

Significance/Importance

MCS therapy is resource intensive. To be successful, it requires the patient to possess specialized knowledge and technical skills in order to safely provide home device/self-care (Feldman et al., 2013; Kato et al., 2014; Smedira et al., 2013). PMCSE is provided to an MCS patient in the perioperative period surrounding the patient’s surgical implant procedure prior to hospital discharge. It involves learning device/self-care which includes changes in circulatory physiology that occur with MCS therapy, care of the MCS device (battery changes and maintenance, power source changes, controller changes, driveline care, dressing change and showering procedures, alarm troubleshooting, and emergency recognition), medication management, dietary changes, and home monitoring requirements (heart failure symptoms, heightened stroke, infection, and bleeding recognition, daily device parameter recording, home INR measurement, blood pressure monitoring in non-pulsatile state; Barsuk et al., 2020; Kato et al., 2014; Widmar et al., 2014). Despite the completion of PMCSE, newly discharged MCS patients continue to seek device/self-care guidance from peers using social media outlets (Boling et al., 2015). Outside sources of information are beneficial as substantiation of knowledge, but when patients use these outlets as a primary source of knowledge a disconnect exists in the knowledge transfer process involving PMCSE which merits exploration (Zhang et al., 2009). Exploration of the patient experience with PMCSE provides foundational knowledge that is necessary for future research in its optimization. Optimizing PMCSE and improving patient knowledge surrounding device/self-care has the potential to affect the morbidity currently related to MCS therapy providing overall benefit in patient outcomes as well as a means of mitigating costs associated with this therapy (Lemor et al., 2020; Smedira et al., 2013).

I explored PMCSE from the patient's perspective using transcendental phenomenological qualitative methods described by Sundler et al. (2020), based on the original philosophy of Husserl. I used this methodology to guide throughout the research process seeking a description and understanding the unfiltered meaning of a person’s lived experience (Peoples, 2020; Sundler et al., 2019). To achieve this end I was required to question and set aside (bracket) any pre-understanding or judgement involving the phenomenon of interest in order allow for its description in its purest form (Peoples, 2020; Sundler et al., 2019). Following this methodology, I was required to consciously and intentionally use an open and reflexive approach while seeking to understand the phenomenon (phenomenological reduction), by acknowledging my existing understanding and suppositions (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in the present experience (horizon) of exploration, analysis, and description of the phenomenon being studied (Peoples, 2020). By intentionally separating my judgements from the data, the true essence of the phenomenon emerged (Peoples, 2020; Sundler et al., 2019). In consideration of my extensive history and experience within the MCS field, this approach aligned well with the research question: What is the patient's lived experience related to PMCSE?

The purpose of this research was to provide a foundational understanding by describing the lived experiences of MCS patients with PMCSE to inform future research and design of PMCSE practices. Using a transcendental phenomenological approach, the purpose of this study was to explore the lived experiences of MCS patients with PMCSE.

Relevant Scholarship

Successful MCS support requires that patients have adequate understanding and knowledge of device/self-care to provide routine and emergency care (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020). Multiple factors contribute to patient differences in the ability to assimilate the knowledge required for successful device/self-care after MCS implantation. These factors include individual circumstance, cognitive performance, timing, the quality of educational materials, and appropriate delivery practices (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018).

Individual circumstance and cognitive performance play an integral role in successful acquisition of knowledge in the MCS patient. Etiology of and rate of HF progression are factors that contribute to the knowledge a patient has mastered prior to MCS implantation. Prior experience and knowledge of HF self-care and MCS therapeutic options is available to the chronic HF patient but frequently missing in patients who have undergone an acute cardiac event necessitating initiation of MCS support (Barsuk et al., 2020). Experience, pretraining, targeted education, and early discharge planning are beneficial to HF and MCS device/self-care practices reducing readmission rates and increasing quality of life (QOL; Barsuk et al., 2020; Dickson et al., 2008; Mai Ba et al., 2020). Cognitive performance plays an integral role in a patient’s ability to learn and provide self-care and is a predictor of poor outcomes in MCS patients (Abshire et al., 2016, 2018; Bhat et al., 2015; Casida et al., 2017; Faulkner et al., 2020; Pavol et al., 2018). Cognitive impairment (CI) is accelerated in chronic HF affecting executive function, episodic memory, psychomotor speed, language and visio-spatial abilities but appears to improve after MCS implantation (Bhat et al., 2015; Doehner et al., 2018). CI in patients who have experienced an acute cardiac event has effects on both short and long term outcomes with deficits in attention and memory impacting a patient's post-event ability to learn self-care and changes in lifestyle behaviors (Zhao et al., 2020).

Timing, quality of educational materials, and appropriate educational delivery methods can have an impact on patient acquisition of knowledge. Prior research in hospital discharge education has demonstrated the efficacy of using patient experience data to redesign and improve discharge paperwork provided to patients (Hahn-Goldberg et al., 2015). The quality (presentation, timing, and frequency) of surgical discharge education influences the patient's ability to provide self-care in the post-operative period (Kang et al., 2018). A lack of evidence exists describing optimal methods for providing discharge education to post-surgical patients in general (Kang et al., 2018). Prior research describing MCS related patient experience has lacked in capturing the essence of the patient's lived experiences within their individual circumstances. Barsuk et al. (2020) was the first group to describe the patient, caregiver, VAD coordinator, and physician perspectives and perceptions of existing VAD self-care training using a qualitative interview format which provides basic insights into the patient perspective with the goal of development of simulation based educational methods. Although a basic description of current educational methods and patient satisfaction has emerged, lack of an in depth description and understanding of the patient's experience within the context of their individual circumstances has limited their value in guiding educational optimization

(Barsuk et al., 2020; Casida et al., 2018, 2017; Lemor et al., 2020; Spielmann et al., 2021; Widmar et al., 2014).

With this research I focused on description and exploration of the patient's experience with PMCSE. Understanding the patient's experience provides foundational knowledge for future research and design of optimized patient centered MCS educational practices. It is the first step toward increasing MCS patient autonomy and potentially decreasing complications, readmission rates, and their associated costs (Gouge, 2017; Meloncon, 2017).

Research Questions and Design

I used qualitative research methods to provide a deeper understanding of patient experiences and to identify gaps, gain insights, redesign, and innovate practices to better deliver patient care, streamline processes, and save costs (LaVela & Gallan, 2014). I have worked with MCS patients extensively and have observed self-management issues that provoked questions surrounding the effectiveness of MCS patient education. Through literature review, I identified a gap in foundational knowledge necessary in the development of optimized MCS patient educational practices.

There currently are no recommended practice guidelines for PMCSE, each implant center has developed their version of PMCSE resulting in inconsistent educational practices. A broader viewpoint was necessary to accurately explore the patient experience with PMCSE to develop a strong foundation, one not based on single center experiences, for patient focused educational practices. My unique position in this field has given me access to patients from multiple centers allowing for description of

PMCSE practices from a broader viewpoint. Transcendental phenomenological inquiry is a qualitative study approach that focuses on description of person's experiences in its truest form to describe a human phenomenon and requires the researcher to identify, consider, and bracket (set aside) their experiences to achieve this goal (LaVela & Gallan, 2014). Using Husserl’s methodology, a I used a transcendental phenomenological approach to address the research question: What are the lived experiences of MCS patients with PMCSE?

Methods

Participants and Context

Participants were recruited from Facebook groups targeted toward MCS patient support using electronic flyers (Appendix A). A purposive sample of 11 participants, based on sampling methods developed by Francis et al. (2010), was obtained at which time data saturation was achieved. Participants who were included in the study were provided with a link to an online study consent form (Jotform, 2021) which once completed provided an option to schedule an interview day and time. A copy of their consent and verification of their interview time and joining instructions was sent to the participant for documentation and reference. Participant inclusion requirements were (a) support by an FDA approved MCS device, (b) age 18 years and older, (c) the ability to understand and speak English, and (d) no barriers to participating independently in an online interview.

Instrumentation

Transcendental qualitative inquiry utilizes an inductive approach to collect subjective forms of data, including words or images (Galdas, 2017; Peoples, 2020; Ravitch & Mittenfelner Carl, 2015). Participants were interviewed using a semistructured open-ended question format which allowed the patients to describe their experience using their own words (Rudestam & Newton, 2015). An interview guide was developed following methods described by Bevan (Bevan, 2014) guided by Husserl's methodology (Appendix B). My notes and reflective journals were also be used to allow for bracketing of my previous experience.

Data Collection

Jowett endorsed the use of online video conferencing tools as acceptable methods for qualitative data collection during a pandemic (Jowitt, 2020). In consideration of current social distancing requirements, Google Meet (Google, 2021) a password secured online video conferencing system was used to conduct individual interviews with study participants. Interviews were audio recorded using Notability (Ginger Labs, 2020), transcribed verbatim using REV an online speech to text service (*Rev Speech-to-Text Services*, n.d.) which I verified for accuracy. A copy of the transcript was provided to the participant for their review via email along with additional questions for clarification with a request to be returned, with amendments, within one week. All recordings, transcriptions, and data were deidentified and given a unique ID to ensure participant confidentiality. The key for the participant IDs was stored in a password protected file and available only to me as the primary researcher. All written correspondence with participants occurred using email on google workspace for business and employed password-protected encryption (Google, 2021c).

Participant recruitment drew volunteers from a social media platform targeted to MCS patients and caregivers (Facebook groups). This platform exists using both open and closed group classifications. Although I am a member of the closed groups, I did not have a professional relationship with any of the study participants. Infrequently I have provided comments to aid in group discussion, but all comments were informational in nature and not given in any professional capacity.

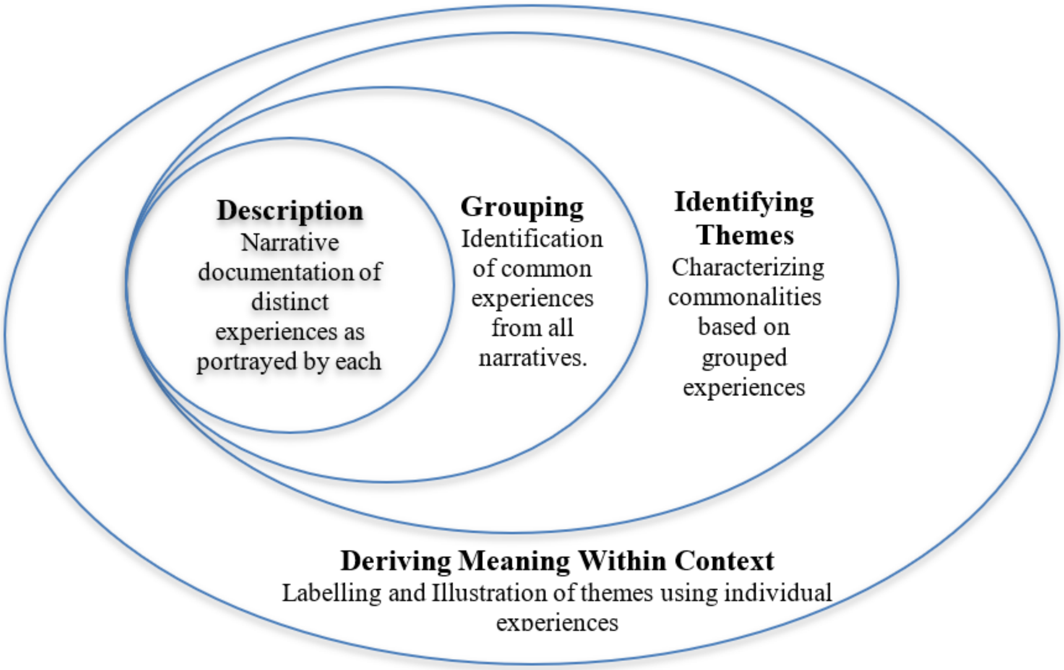
I acknowledge a long history of working with MCS patients and used reflexive journaling to bracket my interpretations of the patient experience. Transcriptions and field notes were provided to the participant for review and revision before data analysis to verify that the thoughts, statements, and themes identified accurately represented the participant's experience. Identified themes were provided to participants after data analysis for review and comment to verify accurate representation of their experiences.

Data Analysis

I analyzed the data using qualitative thematic analysis (Sundler et al., 2019). Sundler et al. described the methodological principles of thematic analysis as emphasizing openness, questioning pre-understanding, and adopting a reflective attitude and contend that these principles guide all aspects of the research process (Sundler et al., 2019). Thematic analysis as described by Sundler et al (2019) is an inductive approach that aims to understand the complexity of data meanings by searching for patterns in the data that can be organized into patterns and then themes to understand meaning (Figure 1).

Figure 1

Process of Thematic Analysis



Note. Based on Sundler et al. (2019)

I extracted data from the transcripts by breaking down the participant's responses into unique topical statements. I entered and organized the topical statements into an online database management program to assist in data analysis (Airtable, 2020). I chose this program because of my familiarity with its use as well as the flexibility it provides in visually manipulating the data into different formats efficiently. I grouped the topical statements into broad categories based on their relevancy to the participant's MCS educational experiences. Topical statements that were not related to the participant's educational experiences were excluded. I then conducted a first pass review of the educational related topical statements and created descriptive categories based on identified events as well as the participant’s description of their experiences related to those events. When possible, I separated participant accounts that spanned multiple topics into statements that reflected only one topic. On second pass analysis of the categories of data, specific themes emerged surrounding educational formatting and perceptions of each participant’s educational experience. On third pass analysis of the unplanned themes, I grouped similar themes into broad topic which became final themes. Finally, I emailed each participant a link to an online spreadsheet containing the extracted statements and thematic development and asked for a response indicating their agreement or disagreement with the analysis to verify that the derived themes represented the experiences they conveyed in the interview process.

Trustworthiness/Validity

Trustworthiness in phenomenological research involves conducting research using processes that support the quality of the work in terms of credibility, transferability, dependability, and confirmability (Peoples, 2020). In developing my original research question, I wanted to address the deficiencies with current MCS education. The deficiencies that I felt needed to be addressed were based on my interpretation of patient need through my observations and interactions with MCS patients. Because there is very little research involving the patient experience with MCS in general, I struggled with how to appropriately address describing the deficiencies in PMCSE, based on my perception of patient need, through credible research procedures. In further discussion with faculty, personal reflection, and literature review, I was able to recognize that the struggle I was having was a result of a disparity between my perception of patient needs and patients' perception of patient needs based on their lived experience. I had to concede that despite my extensive experience working with this population of patients, I lacked the personal experience of living with an MCS device. To identify and explore deficiencies in PMCSE based on actual patient needs, I realized that I needed to remove my perceptions from the equation. Focusing on exploration of the problem from the patient perspective allowed me to identify transcendental phenomenological methodology as the most appropriate way to align my research approach with my research goals. Using this methodology, I was required to approach the research process with an open, unfiltered stance, using a broad open ended question format for patient interviews and data collection, phenomenological reduction and researcher bracketing for data analysis, and development of themes based on the descriptions of actual patient experiences using the patient's perspective as the central grounding point and guide for all aspects of the research process.

Credibility in qualitative research encompasses the plausibility of research findings within the context of accurate portrayal by the researcher (Sundler et al., 2019). One method of insuring credibility is through member checking or participant validation of findings (Birt et al., 2016). I utilized member checking twice throughout this research study. First member check was performed immediately after interview transcription and served as a venue for phenomenological reduction. The second member check occurred after final theme development requesting participants to review and agree or disagree with the identified themes.

Transferability refers to the relevancy of research findings outside of the confines of the study (Sundler et al., 2019). Transferability is optimized through meticulous communication of study procedures and clear presentation of findings so that the reader has the information to be able to determine whether the data are applicable in their setting (Sundler et al., 2019).

Dependability in qualitative research is how reliable the data is and has its basis in study design (Ravitch & Carl, 2015). It is grounded in appropriate study design with rationales for methods clearly communicated and rationalized (Ravitch & Carl, 2015).

Confirmability refers to the efforts engaged by the researcher to reduce their influence or bias on the study findings (Ravitch & Carl, 2015). Following the principles of thematic analysis outlined by Sundler et al. (2018) of openness, questioning pre-understanding, and taking a reflective attitude, I have addressed confirmability of this study through study design and utilization of reflective journals and interview notes allowing for initial review of the interview transcriptions and implementation researcher bracketing and phenomenological reduction.

Results

Execution

Despite meticulous planning, conducting qualitative research often requires some deviation from the original research plan. CohenMiller, et al. (2020) term deviation from a research plan as “research failure” and contend that what is considered to be a failure in qualitative inquiry can help to uncover previously unidentified opportunities for exploration and discovery. There were three areas where execution of this research did not follow the original plan. These were exclusion of MyLVAD.com as a source for participant recruitment, issues with the sampling strategy related to participant study completion, and difficulties recruiting participants who had undergone unplanned MCS implantation.

Exclusion of MyLVAD.com

My original plan for participant recruitment involved placement of electronic recruitment flyers on both Facebook targeted MCS groups as well as on MyLVAD.com. Participant response using the Facebook platform allowed for sufficient study enrollment making cross posting on MyLVAD.com unnecessary. On further reflection, I felt that the choice to not use MyLVAD.com for recruitment strengthened the validity of the study removing any questions surrounding recruitment and bias related to my professional role as managing director of MyLVAD.com.

Issues with Sampling Strategy

My original plan for sampling did not account for participants not appearing for their scheduled research interviews. (Sauro, n.d.) reports a “no show” rate of participants in user experience research of 10-50% and recommends strategies to decrease rates. Strategies were included in the recruitment plan for to increase ease and convenience of volunteer participation but multiple participant’s failure to attend interviews extended the time length of study recruitment to achieve data saturation. There were 49 potential participants screened of which 22 progressed to signing consent and scheduling an interview. Of the 22 who scheduled interviews, only 11attended and completed an interview. Despite multiple attempts to contact and reschedule interviews, there were 11 participants who consented but did not complete the interview and were subsequently excluded from data analysis.

Lack of Unplanned Implant Participants

When developing my original research plan, the problem that I sought to address was the patient's experience with primary MCS education. Through a literature review, it became apparent that patients who underwent MCS implantation could be separated into two groups, those who experienced progressive heart failure and those who experienced an acute event resulting in heart failure. This resulted in a fundamental difference in patients' previous experience with heart failure management and self-care practices that could be distinguished based on MCS implant strategy. The data that I collected needed to be sufficient to capture the experiences of participants in both groups. To achieve that end, screening procedures were used to help identify the implant strategy of potential participants (Appendix A). There were 41 potential participants who completed the screening form. On screening, 6 self-identified as unplanned and completed consent, with 3 moving on to complete an interview. Two of the three did not fit the definition of unplanned after interview and were placed in the planned group. To achieve data saturation, study enrollment was extended to recruit additional volunteers resulting in eight additional screenings, five additional participants signing consent, and two additional participants completing the interview process. Of the two participants who completed interviews, one had already undergone transplant and was not actively supported by an MCS device. Because the participant had been recently transplanted (<1 year), I decided to make an exception to the inclusion criteria for current MCS device support and include the volunteer in the study. Data saturation was achieved in both groups and study recruitment was closed.

Results

This study explored the patient's experience with primary MCS education to inform future research surrounding MCS patient education practices.

Participant Demographics

Demographic information for study participants is described in Table 1.

Table 1

Participant Demographics

	Planned *(n=8)*	Unplanned *(n=3)*
Age(years)		
Mean	71	57.3
Range	52-86	53-61
Gender:		
Male	7	3
Female	1	0
Implant Duration:		
12 months – 2 years	0	2
>2 years	8	1

Derived Themes

I identified three main themes present within the data that describe the patient's experience with PMCSE: process descriptions, disposition, and adjustment.

Process Descriptions. Process descriptions of PMCSE were described by all participants and provided context and insight into the instructional methods that were used throughout their individual educational processes. Process descriptions included characteristics of instructional methods as well as accounts of experiences and needs. Common subthemes that were described include consistent instructor, demonstration, reverse demonstration, independent study, testing, setting goals, and family training/testing. Participant narratives describing their experiences with PMCSE are listed in Appendix C.

Process descriptions were illustrated by all the participants and set a backdrop for further exploration into their experience. Process descriptions characterized both instructional methods (demonstration, reverse demonstration, independent study, testing, family training/testing) and overall characteristics (consistent instructor, goal setting) of the PMCSE process.

Participants described instructional methods using both third-person accounts and first-person narratives of their experiences. One participant describes his experience with demonstration/reverse demonstration and how he was able to joke with hospital personnel who had not previously dealt with MCS patients as a form of reverse demonstration. Participant 0033 stated,

> …And now you do it. Okay, now disconnect. Now you do it, now disconnect. Now you do it. Now, disconnect, now you do it. Okay, and let me show you, you know, you got eight batteries and you got to rotate them…Yeah, and they had these, I forgot what they call them. There was a model they had to practice on. To

> change the dressing…Yeah, a mannequin. Yeah. Yeah, so she gave, you know, she gave a bunch of expired kits and said, take these home, do it five or six times you know, she gave everybody five of them and they all did it, so they all know how to do it if you know, it comes down to it.

Participant 0033 also stated,

> Also, you know, [I was] in physical therapy [and the] therapists unplugged my monitor, you know? All of a sudden all of the alarms are going like crazy, like there's no on/off switch and I went (pretended to faint) and like played dead. And [I said] "what are you doing? You know, you unplugged me, you know, I'm gonna die." "Oh sorry, I'm sorry," you know, because they never, PT never had an LVAD patient.

Participants had similar descriptions of independent study, setting goals, testing, and family training/testing. PMCSE processes described included “hands-on” and “written” testing with many describing “going home” as their end goal. The following quotes illustrate comments representative of these topics. Participant 0062 stated,

> But then they made me, I had to do a thing where I had to study and learn all the parts of my controller stuff and know how all the stuff functioned. That was before I could be released from the hospital.

Participant 0037 stated,

> By training, I mean, it was hands on. So, like I said, I could not leave until I passed their tests and some of these tests were written and some of them was hands on actually showing me. So, I did everything correct and I was discharged.

> But that added notes that I read…. And my caregiver also had to be tested on the device before we left the hospital. Just in case I was unconscious or anything like that. My caregiver would understand everything that was going on with the device itself.

Disposition. Participant disposition at the time of hospital discharge emerged as a theme surrounding PMCSE and describes the mindset of the participant in relation to their PMCSE at implant hospital discharge. Sub-themes that emerged from participant narratives include insecurity – understanding, cognitive impairment, confidence, frustration with inconsistent center messages, insecurity – outside medical provider knowledge, and suggestions/reflections. Appendix D lists participant narratives related to disposition.

Participant disposition at discharge accounts were also similar among participants. Insecurity and frustration were conveyed when describing the knowledge they felt they needed for device/self-care on discharge. Descriptions also included insecurities related to cognitive impairment impacting their ability to retain knowledge, lack of outside medical provider knowledge about their care, and frustration with inconsistent inter-center protocols. They also described a need for continuing education to reinforce the training that they received with PMCSE. Participant 0042 stated,

> Well, I think what overwhelms people is the fact that it tends to be a cram course. I mean, there's two hours set aside. You bring them into the clinic, and they say, "You do this, this and this. You got that?" "Oh, yeah. Okay. Got it." And then an hour later you don't remember half of it... They just need repetition. We the

> patient and the caregiver need a lot of repetition, especially since a lot of us are older, our health has been compromised. Our mental faculties may not be quite what they were years ago. Who knows, we may have lost some brain cells in surgery under anesthesia.

Participant 0044 stated,

> I was pretty whacked out. I was really not getting it all. I didn't remember people who came and saw me and that whole ... I was there for almost a month. I think the information they gave me during that time was not ... it wasn't processing with me because I didn't know what the hell was going on.

Participant 0042 also stated,

> What's interesting and what perhaps you're doing can play a role in, just from being involved in LVAD type websites or most recently in my case Facebook, the protocols vary a lot from center to center. So, there's really a lack of uniformity because as far as I can tell there's no central authority that says, "Okay, here's the best practice." It's all very personalized and it's based on people's education level and that area of experience, personality. So, if you have 150 centers, you've got 150 different ways of doing things. Even the dressing process.

Adjustment. Adjustment after MCS implant is the final theme that emerged during data analysis. I used adjustment as an encompassing term to describe participants' general mental outlook after implant as it related to their implant education. Subthemes that emerged include trust, misunderstood – feeling alone, adjustment, and not enough explanation – meanings. Appendix E lists participant narratives related to adjustment.

Participant descriptions of adjustment differed based on implant strategy. None of the participants who underwent planned implantation expressed issues with adjustment after MCS implant or PMCSE. All three of the participants who underwent unplanned implantation expressed issues with adjustment to their device after implant and PMCSE. Adjustment issues included developing trust, feeling misunderstood, general adjustment to their new normal life and frustration with not fully understanding the process or future options. The following examples describe adjustment issues that the participants expressed. Participant 0061 stated,

> You wake up your whole your whole life just changed, and you don't know. I mean, and people don't get it. There are days you go, "Nah, screw this. I've had enough. Turn this thing off." It's hard. It's a lot of work…So I was my own business. Yeah. I went from making 300 grand a year to welfare. It is tough. When people say lost everything, they don't even know what that means. I mean I do. I lost everything. My vehicles everything. Anything I had a payment on. Yeah. So yeah, if you compound everything, yup it's tough. You just kind of have to every day, put everything in perspective and say, "Hey, it's getting better.

Participant 0062 stated,

> Yeah. So yeah, that's the hardest part for me, though, is getting... They tell me all the time, "You got to get used to your new normal," and two years later, I just keep trying to push it back. Because I want my old normal back. I want to be able

> to go. I want to be able to do what I did, and it's not easy. It's hard. It's always hard.

Participant 0061 also stated,

> Even before I left hospital, one of the consultants, one of the doctors said, "All the cards are on the table," and I'm thinking what does that mean? I asked one of the nurses. Apparently, she said ‘The doctors play their cards close to their chest.’ [What does] that phrase [mean] because that threw me. Because they had told me you'll have the LVAD until you get a transplant. But then when [the doctor] said that ‘all the cards are on the table’…what does that mean?

Discussion

Interpretation

The goal of this study was to explore the patient’s experiences with PMCSE to understand their perceptions of the PMCSE process. Through literature review, I highlighted previously identified factors that have been described largely by medical personnel to influence successful MCS patient device/self-care. These include individual circumstance, cognitive performance, timing, quality of materials, and appropriate delivery. Overall themes involving participant descriptions of their PMCSE experience within this study show some parallels as well as areas requiring future exploration.

Process descriptions largely mirrored those documented in the literature. Similar to that described by (Barsuk et al., 2020) and (Kato et al., 2014), the process of PMCSE was largely described by participants as demonstration – reverse demonstration instruction with independent study and a form of verbal or written testing.

Disposition of the participants was described as the mindset of the participants at discharge in relation to their PMCSE. The participants described both confidence in their training and insecurity in their understanding and ability of device/self-care. Insecurity was attributed to factors such as cognitive impairment and rapid rate of instruction. Insecurity has been previously described by (Casida et al., 2018) but not previously described from the patient’s perspective in terms of cognitive abilities or rate of instruction. Comments included the need for continuing education, added testing, and a deeper understanding of the mechanics of the device. These results suggest areas for further study to determine appropriate types and timing of education to maximize patient outcomes. Additional comments highlight participant’s frustration with inconsistent center messages as well as insecurity with outside (non-MCS trained) medical providers’ knowledge which both of which, to my knowledge have not been previously discussed or studied.

Adjustment was defined as the participant’s general mental outlook as related to PMCSE. Adjustment issues were only identified by the unplanned group and included developing a “blind trust,” feeling misunderstood and alone, adjustment to a new normal and feelings of not enough explanation or understanding the meanings of what they were told. (Abshire et al., 2016) described issues with coping and adaptation in LVAD patients describing a need to address strategies to mitigate common issues. Participant experiences described by this research align with Abshire’s, et al. observations and identify patients with an unplanned implants strategy as a specific cohort in which to focus further research.

Limitations

As with all research studies, there were limitations. Participant recruitment took place using postings on the Facebook groups platform. Recruitment from one online source can introduce bias in terms of the type of participants who use Facebook groups vs. those who do not. Subsequently the narratives obtained may not be transferable to the greater MCS patient population.

Difficulties with interview completion after obtaining participant consent highlighted issues with the recruitment process that may have limited the scope of descriptions obtained based on unrecognized issues related to the participants who did not "show up" for their interview. Although I employed member checking and use of reflexive journaling to bracket my experience with this population, researcher bias is also a possibility and therefore a limitation.

Implications

PMCSE is an integral part of preparing the MCS patient for independent device/self-care after initial hospital discharge. Understanding the patient's experience, from their perspective, is the first of many steps in developing effective educational practices. This study is the first to describe the patient experience with PMCSE using their own words to better understand their experience from their perspective. Novel information obtained from this research includes international multi-center process descriptions of PMCSE by patients who are on the receiving side of PMCSE knowledge transfer, patient descriptions of their disposition at discharge as well as descriptions of adjustment all which impact and are impacted by the PMCSE process. Because successful MCS device support relies on the ability of the patient to perform device/self-care, this research provides a foundational start to inform future research surrounding and development of effective PMCSE practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Patient disposition and adjustment descriptions have been previously addressed in the literature but not in terms of the PMCSE process. As with process descriptions, understanding the patient's experiences with disposition and adjustment contribute to development of more effective PMCSE practices (Johansson et al., 2006; Levelink & Brütt, 2021).

Social change that may occur because of the findings of my study reveal that the individual patient needs of a higher quality of patient training and understanding of device/self-care principles which effects positive social change. Individuals with optimized PMCSE may obtain a higher level of education and understanding of device and self-care and may have the ability to independently recognize and intervene earlier when issues arise thereby potentially reducing the cost burden of this therapy in terms of personnel and financial resources (Levelink & Brütt, 2021).

Recommendations

Recommendations for future research include additional studies to further explore the patient experience as it relates to their PMCSE. Additional research is also needed to provide multicenter accounts of PMCSE processes to identify commonalities and differences in current design and execution. Comparison studies involving the patient experience and provider descriptions will also be necessary next steps in evaluation of current PMCSE processes as well as in the design of improved methods in the future.

Conclusion

This study is the first to address the foundational knowledge necessary to inform development of optimized PMCSE processes. Descriptions of the PMCSE process, disposition, and adjustment as experienced by the patient were presented. This study serves as a starting point for directing future research focused on fundamental knowledge necessary to optimize PMCSE practice ultimately effecting MCS patient outcomes.

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Lived Experiences of Individuals With Education After Unplanned MCS Implantation

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Abstract

Advancement in mechanical circulatory support (MCS) device therapy has led to increased use as an unplanned implant in acute heart failure therapy and relies on optimized patient education for successful support. The purpose of this Husserlian guided transcendental phenomenological study was to explore the lived experiences of patients undergoing unplanned MCS implant with PMCSE. A purposive sample of three participants recruited from MCS targeted social media sites were interviewed using a semistructured open-ended question format and data analyzed using principles of thematic analysis. Three themes describe the patient experience with PMCSE and included (a) process, the participant's experience of the mechanics of the PMCSE, (b) disposition, the mindset of the participant related to PMCSE at discharge, and (c) adjustment, the participants general outlook as it relates to PMCSE. Future research should include additional exploratory studies as well as multicenter comparisons of PMCSE practices as it pertains specifically to patients with an unplanned implant strategy and its effect on the patient experience Understanding the patient experience with PMCSE having undergone unplanned MCS implantation affects positive social change by providing foundational knowledge for optimizing MCS patient knowledge transfer practices, potentially improving outcomes while decreasing cost in this resource intensive therapy.

Introduction

Heart failure (HF) is a syndrome that results in the inability of the person's heart to meet the metabolic needs of the body and is one of the leading causes of morbidity and mortality throughout the world (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017; Seferovic et al., 2019; Trindade et al., 2019; van der Meer et al., 2019). Incidence is projected to increase by 46% with an estimated cost for treatment in the United States of $69.8 billion by 2030 (Lesyuk et al., 2018; Savarese & Lund, 2017; Virani et al., 2020) Mechanical circulatory support (MCS) therapy is a proven surgical treatment that is used to support patients with advanced (HF) and is considered standard of care by both the American Heart Association (AHA) and the American College of Cardiology (ACC) (Potapov et al., 2019; van der Meer et al., 2019).

HF has multiple etiologies and can occur as a progressive decline of a chronic condition or as an acute decompensation after a sudden cardiac event necessitating the need for initiation of MCS for patient survival (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017). Current MCS devices are designed for long term use and can safely provide additional years to a person's life provided they have the knowledge and skills to provide routine and emergency device/self-care at home (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020).

Successful MCS support requires the patient possess a minimum level of knowledge and skill to perform routine and emergency device/self-care. Primary mechanical circulatory support education (PMCSE) is provided to the patient after MCS implantation and although it is considered crucial for successful support there are a limited number of studies describing current or recommendations for best practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Etiology and trajectory of HF among patients results in a baseline disparity in knowledge surrounding HF self-care at the time of MCS implant (Barsuk et al., 2020). In addition, multiple factors can affect the patient's ability to assimilate MCS device/self-care information including cognitive performance, timing, individual circumstance, and the quality of educational practices (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018). The existing paucity of inquiry exposes the knowledge deficiency in understanding the patient experience with PMCSE. Without this basic understanding, optimization of educational practices for this population cannot be achieved (Meloncon, 2017). With this research, I addressed the lack of understanding from the patient's perspective of their experience with PMCSE after unplanned MCS implant.

Significance/Importance

The cost of MCS therapy is significant and to be successful requires the recipient to have a certain level of knowledge and skill for safety (Feldman et al., 2013; Kato et al., 2014; Smedira et al., 2013). MCS supported patients receive PMCSE prior to being discharged from the hospital after implant. PMCSE is used to teach patients device/self-care and includes monitoring, recognition, and management of heart failure symptoms, recognition of potential complications, operation of and basic changes in physiology that occur the MCS support pump, care of the MCS device (battery maintenance, power source management, controller operation and troubleshooting, driveline care, and emergency procedures), dietary changes, and medication concerns (Barsuk et al., 2020; Kato et al., 2014; Widmar et al., 2014).

Newly discharged MCS patients rely on social networking sites (SNS) as a reliable source of information for peer advice surrounding device care and troubleshooting as well as management of their chronic illness (Boling et al., 2015). These interactions are beneficial as a source of affirmation of knowledge but when basic device/self-care knowledge is sought because of a deficiency in knowledge transfer, reexamination of the basic components of the educational process is warranted in order to identify areas for improvement (Kennedy et al., 2017). The continued presence of unacceptable rates of MCS complications is another area that has the potential to be impacted through optimization of PMCSE. Earlier detection of complications and potential reduction of readmissions can be directly impacted by increased levels of patient knowledge and awareness. The potential for decreased economic burden related to reduction of complications and readmission rates in itself warrants examination of current practices (Lemor et al., 2020; Smedira et al., 2013).

I used a transcendental phenomenological approach, a qualitative methodology, to understand a participant's lived experience in its truest form, to explore the lived experiences of patients with PMCSE who underwent an unplanned MCS device implant. Transcendental phenomenology was developed by Husserl who believed that the researcher must set aside any pre-existing judgements of a phenomenon in order to allow for an unfiltered understanding of the experience to emerge (Sundler et al., 2019). The researcher must practice phenomenological reduction by acknowledging their existing understanding and suppositions of the phenomenon of interest (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in present (horizon) exploration, analysis, and description (Peoples, 2020). In consideration of my extensive history and experience in the MCS field, Husserl's approach aligned well with the research question exploring the lived experiences of MCS patients undergoing unplanned MCS implantation with PCMSE.

Relevant Scholarship

Successful MCS support requires that patients have adequate understanding and knowledge to provide routine and emergency device/self-care (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020). Factors that impact the patient's assimilation of knowledge required for successful device/self-care after MCS implantation include timing of implant, individual circumstance, and quality of educational transactions (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018).

Individual circumstance and cognitive performance play an integral role in successful acquisition of knowledge in the MCS patient. Cause and progression rate of HF are factors that contribute to the baseline disease related knowledge a patient has prior to MCS implantation. Unlike patients with a progressive decline resulting in advanced HF, prior experience and knowledge of HF self-care and MCS therapeutic options are frequently missing in patients who have undergone an acute cardiac event necessitating initiation of MCS support (Barsuk et al., 2020). Increased quality of life (QOL) and reduced readmission rates have been associated with patient prior experience, pretraining, targeted education for HF and MCS device/self-care (Barsuk et al., 2020; Dickson et al., 2008; Mai Ba et al., 2020). A patient’s ability to learn is directly impacted by their cognitive performance (Bhat et al., 2015; Faulkner et al., 2020). This directly effects their ability to provide device/self-care and is a predictor of poor outcomes in MCS patients (Abshire et al., 2016, 2018; Bhat et al., 2015; Casida et al., 2017; Faulkner et al., 2020; Pavol et al., 2018). Chronic HF accelerates cognitive impairment (CI) affecting executive function, episodic memory, psychomotor speed, language and visio-spatial abilities but appears to improve after MCS implantation (Bhat et al., 2015; Doehner et al., 2018). CI in patients who have experienced an acute cardiac event results in attention and memory deficits impacting a patient’s post event ability to learn self-care and changes in lifestyle behaviors (Zhao et al., 2020). This suggests that different approaches to education based on differences in circumstance and CI may be warranted to maximize the patient’s ability to gain and maintain PMCSE knowledge.

Timing, quality of educational materials, and appropriate delivery of patient education can have an impact on patient acquisition of knowledge. Use of patient experience data in the redesign of discharge education materials has demonstrated measurable improvements in effectiveness of the discharge paperwork provided to patients (Hahn-Goldberg et al., 2015). Although a lack of evidence exists describing optimal surgical discharge education, the ability of a surgical patient to successfully provide self-care is influenced by the presentation, timing, and frequency of surgical discharge education (Kang et al., 2018). Prior MCS-specific research describing patient experience in the perioperative period falls short in attempting to capture the essence of the patient’s perspective within their individual circumstances. Barsuk et al. (2020) was the first group to describe the patient, caregiver, VAD coordinator, and physician perspectives and perceptions of existing VAD self-care training using a qualitative interview format to inform the development of simulation based educational process. Although a basic description of current educational methods and patient satisfaction has emerged, lack of a strictly patient focused, in depth of description of the patient’s experience within the context of their individual circumstances continues to limit PMCSE optimization (Barsuk et al., 2020; Casida et al., 2018, 2017; Lemor et al., 2020; Meloncon, 2017; Widmar et al., 2014).

Using this research, I focused solely on the patient’s experience with PMCSE, to provide foundational knowledge necessary for further research and design of optimized patient centered MCS educational practices. It is a first step in a process of increasing MCS patient autonomy, potentially decreasing complications, readmission rates, and their associated costs (Gouge, 2017; Meloncon, 2017).

Research Questions and Design

An understanding of the patient experience with PMCSE is the foundation for development of patient focused educational practices (Meloncon, 2017). I used transcendental phenomenological inquiry, a qualitative study approach, to explore the understanding of the MCS patients’ lived experience in its purest form (LaVela & Gallan, 2014; Peoples, 2020). I was required to identify, consider, and bracket (set aside) my experiences to achieve an unaltered understanding of the data (LaVela & Gallan, 2014; Peoples, 2020). Using a transcendental phenomenological qualitative research design I sought to address the research question: What are the lived experiences of MCS patients who undergo unplanned MCS implantation with PMCSE?

Methods

Participants and Context

I recruited participants from Facebook groups targeted toward MCS patient support using electronic flyers (Appendix A). A purposive sample of three participants, based on sampling methods developed by Francis et al. (Francis et al., 2010), was obtained at which time data saturation was achieved. Participants who were included in the study were provided with a link to an online study consent form which once completed provided an option to schedule an interview day and time. I sent a copy of their consent and verification of their interview time and joining instructions to the participant for documentation and reference. Participant inclusion requirements were (a) support by an FDA approved MCS device, (b) age 18 years and older, (c) the ability to understand and speak English, and (d) no barriers to participating independently in an online interview.

Instrumentation

Using transcendental qualitative inquiry, I used an inductive approach to collect subjective forms of data, including words or images (Galdas, 2017; Peoples, 2020; Ravitch & Mittenfelner Carl, 2015). I interviewed participants using a semistructured open-ended question format which allowed the patients to describe their experience using their own words. I developed an interview guide using methods as described by Bevan

(Bevan, 2014) guided by Husserl’s methodology (Appendix B). I used my notes and reflective journals to bracket of my previous experience.

Data Collection

Jowett endorsed the use of online video conferencing tools as acceptable methods for qualitative data collection during a pandemic (Jowitt, 2020). In consideration of current social distancing requirements, I used Google Meet (Google, 2021), a password secured online video conferencing system, to conduct individual interviews with study participants. I audio recorded the interviews using Notability (Ginger Labs, 2020), transcribed verbatim using REV an online speech to text service (*Rev Speech-to-Text Services*, n.d.) which I verified for accuracy. I provided a copy of the transcript to the participant for their review via email along with additional questions for clarification with a request to be returned, with amendments, within one week. I deidentified all recordings, transcriptions, and data and assigned a unique ID to ensure participant confidentiality. I stored the key for the participant IDs in a password protected file available only to me. I corresponded with participants using an encrypted email service on google workspace for business.

I recruited participant volunteers from a social media platform targeted to MCS patients and caregivers (Facebook groups). This platform exists using both open and closed group classifications. Although I am a member of the closed groups, I did not have a professional relationship with any of the study participants. Infrequently I have provided comments to aid in group discussion, but all comments were informational in nature and not given in any professional capacity.

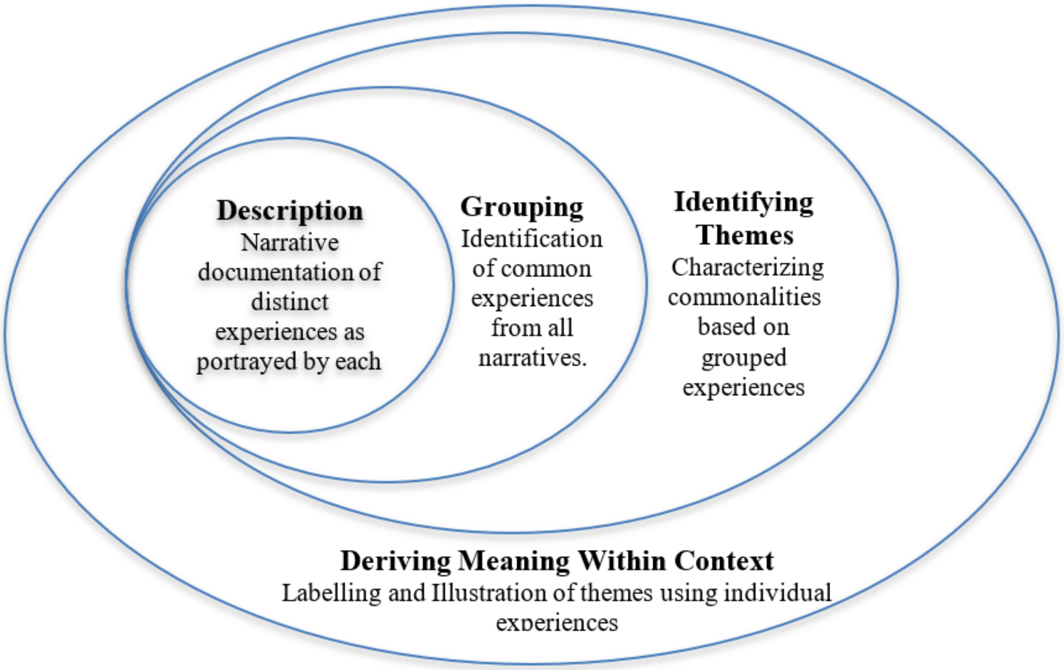
I acknowledge a long history of working with MCS patients and used reflexive journaling to bracket my interpretations of the patient experience. Transcriptions and field notes were provided to the participant for review and revision before data analysis to verify that the thoughts, statements, and themes identified accurately represented the participant's experience. I provided identified themes to participants after data analysis for their review and comment to verify accurate representation of their experiences.

Data Analysis

I analyzed the data using qualitative thematic analysis (Sundler et al., 2019). Sundler et al. described the methodological principles of thematic analysis as emphasizing openness, questioning pre-understanding, and adopting a reflective attitude and contend that these principles guide all aspects of the research process (Sundler et al., 2019). Thematic analysis as described by Sundler et al (2019) is an inductive research approach that can be used to understand the complexity of data meanings by searching for patterns in the data that can be organized into patterns and themes to understand meaning (Figure 2).

Figure 2

Process of Thematic Analysis



Note. Based on Sundler et al. (2019)

I extracted data from the transcripts by breaking down the participant's responses into unique topical statements. I entered and organized the topical statements into an online database management program to assist in data analysis (Airtable, 2020). I chose this program because of my familiarity with its use as well as the flexibility it provides in visually manipulating the data into different formats efficiently. I grouped the topical statements into broad categories based on their relevancy to the participant's MCS educational experiences. Topical statements that were not related to the participant's educational experiences were excluded. I then conducted a first pass review of the educational related topical statements and created descriptive categories based on identified events as well as the participant's description of their experiences related to those events. When possible, I separated participant accounts that spanned multiple topics into statements that reflected only one topic. On second pass analysis of the categories of data, specific themes emerged surrounding educational formatting and perceptions of each participant's educational experience. On third pass analysis of the unplanned themes, I grouped similar themes into broad topic which became final themes. Finally, I emailed each participant a link to an online spreadsheet containing the extracted statements and thematic development and asked for a response indicating their agreement or disagreement with the analysis to verify that the derived themes represented the experiences they conveyed in the interview process.

Trustworthiness/Validity

Trustworthiness in phenomenological research involves conducting research using processes that support the quality of the work in terms of credibility, transferability, dependability, and confirmability (Peoples, 2020). In developing my original research question, I wanted to address the deficiencies with current MCS education. The deficiencies that I felt needed to be addressed were based on my interpretation of patient need through my observations and interactions with MCS patients. Because there is very little research involving the patient experience with MCS in general, I struggled with how to appropriately address describing the deficiencies in PMCSE, based on my perception of patient need, through credible research procedures. In further discussion with faculty, personal reflection, and literature review, I was able to recognize that the struggle I was having was a result of a disparity between my perception of patient needs and patients' perception of patient needs based on their lived experience. I had to concede that despite my extensive experience working with this population of patients, I lacked the personal experience of living with an MCS device. To identify and explore deficiencies in PMCSE based on actual patient needs, I realized that I needed to remove my perceptions from the equation. Focusing on exploration of the problem from the patient perspective allowed me to identify transcendental phenomenological methodology as the most appropriate way to align my research approach with my research goals. Using this methodology, I was required to approach the research process with an open, unfiltered stance, using a broad open ended question format for patient interviews and data collection, phenomenological reduction and researcher bracketing for data analysis, and development of themes based on the descriptions of actual patient experiences using the patient's perspective as the central grounding point and guide for all aspects of the research process.

Credibility in qualitative research encompasses the plausibility of research findings within the context of accurate portrayal by the researcher (Sundler et al., 2019). One method of insuring credibility is through member checking or participant validation of findings (Birt et al., 2016). I utilized member checking twice throughout this research study. First member check was performed immediately after interview transcription and served as a venue for phenomenological reduction. The second member check occurred after final theme development requesting participants to review and agree or disagree with the identified themes.

Transferability refers to the relevancy of research findings outside of the confines of the study (Sundler et al., 2019). Transferability is optimized through meticulous communication of study procedures and clear presentation of findings so that the reader has the information to be able to determine whether the data are applicable in their setting (Sundler et al., 2019).

Dependability in qualitative research is how reliable the data is and has its basis in study design (Ravitch & Carl, 2015). It is grounded in appropriate study design with rationales for methods clearly communicated and rationalized (Ravitch & Carl, 2015).

Confirmability refers to the efforts engaged by the researcher to reduce their influence or bias on the study findings (Ravitch & Carl, 2015). Following the principles of thematic analysis outlined by Sundler et al. (2018) of openness, questioning pre-understanding, and taking a reflective attitude, I have addressed confirmability of this study through study design and utilization of reflective journals and interview notes allowing for initial review of the interview transcriptions and implementation researcher bracketing and phenomenological reduction.

Results

Execution

Despite meticulous planning, conducting qualitative research often requires some deviation from the original research plan. CohenMiller, et al. (2020), termed deviation from a research plan as “research failure” and contend that what is considered to be a failure in qualitative inquiry can help to uncover previously unidentified opportunities for exploration and discovery. There were three areas where execution of this research did not follow the original plan. These were exclusion of MyLVAD.com as a source for participant recruitment, issues with the sampling strategy related to participant study completion, and difficulties recruiting participants who had undergone unplanned MCS implantation.

Exclusion of MyLVAD.com

My original plan for participant recruitment involved placement of electronic recruitment flyers on both Facebook targeted MCS groups as well as on MyLVAD.com. Participant response using the Facebook platform allowed for sufficient study enrollment making cross posting on MyLVAD.com unnecessary. On further reflection, the choice to not use MyLVAD.com for recruitment strengthened the validity of the study removing any questions surrounding recruitment and bias related to my professional role as managing director of MyLVAD.com.

Issues with Sampling Strategy

My original plan for sampling did not account for participants not appearing for their scheduled research interviews. (Sauro, n.d.) reports a “no show” rate of participants in user experience research of 10-50% and recommends strategies to decrease rates. Strategies were included in the recruitment plan for to increase ease and convenience of volunteer participation but multiple participant’s failure to attend interviews extended the time length of study recruitment to achieve data saturation. There were 49 potential participants screened of which 22 progressed to signing consent and scheduling an interview. Of the 22 who scheduled interviews, 11 attended and completed an interview. Despite multiple attempts to contact and reschedule interviews, there were 11 participants who consented but did not complete the interview and were subsequently excluded from data analysis.

Lack of Unplanned Implant Participants

When developing my original research plan, the problem that I sought to address was the patient's experience with primary MCS education. Through a literature review, it became apparent that patients who underwent MCS implantation could be separated into two groups, those who experienced progressive heart failure and those who experienced an acute event resulting in heart failure. This resulted in a fundamental difference in patients' previous experience with heart failure management and self-care practices that could be distinguished based on MCS implant strategy. The data that I collected needed to be sufficient to capture the experiences of participants in both groups. To achieve that end, screening procedures were used to help identify the implant strategy of potential participants (Appendix A). There were 41 potential participants who completed the screening form. On screening, 6 self-identified as unplanned and completed consent, with 3 moving on to complete an interview. Two of the three did not fit the definition of unplanned after interview and were placed in the planned group. To achieve data saturation, study enrollment was extended to recruit additional volunteers resulting in eight additional screenings. Five additional participants signed the consent, and two additional participants completed the interview process. Of the two participants who completed interviews, one had already undergone transplant and was not actively supported by an MCS device. Because the participant had been recently transplanted (<1 year), I decided to make an exception to the inclusion criteria for current MCS device support and include the volunteer in the study. Data saturation was achieved in both groups and study recruitment was closed.

Results

I explored the patient's experience with PMCSE after unplanned MCS implantation to inform future research surrounding MCS patient education practices.

Participant Demographics

Demographic information for study participants is described in Table 2.

Table 2

Participant Demographics

	Unplanned *(n=3)*
Age(years)	
Mean	57.3
Range	53-61
Gender:	
Male	3
Female	0
Implant Duration:	
12 months – 2 years	2
>2 years	1

Derived Themes

I identified three main themes present within the data that describe the patient's experience with PMCSE: process descriptions, disposition, and adjustment.

Process descriptions. Process descriptions of PMCSE were described by all participants and provided context and insight into the instructional methods that were used throughout their individual educational processes. Process descriptions included characteristics of instructional methods as well as accounts of experiences and needs. Common subthemes that were described include demonstration, reverse demonstration, independent study, testing, setting goals, and family training/testing. Participant narratives describing their experiences with PMCSE are listed in Appendix C.

Process descriptions were illustrated by all the participants and set a backdrop for further exploration into their experience. Process descriptions characterized both instructional methods (demonstration, reverse demonstration, independent study, testing, family training/testing) and goal setting as part of the PMCSE process.

Participants described instructional methods using both third-person accounts and first-person narratives of their experiences. One participant describes his experience with demonstration/reverse demonstration and how he was able to joke with hospital personnel who had not previously dealt with MCS patients as a form of reverse demonstration. Participant 0033 stated:

> …and now you do it. Okay, now disconnect. Now you do it, now disconnect. Now you do it. Now, disconnect, now you do it. Okay, and let me show you, you know, you got eight batteries and you got to rotate them…Yeah, and they had these, I forgot what they call them. There was a model they had to practice on. To change the dressing…Yeah, a mannequin. Yeah. Yeah, so she gave, you know, she gave a bunch of expired kits and said, take these home, do it five or six times you know, she gave everybody five of them and they all did it, so they all know how to do it if you know, it comes down to it….Also, you know, [I was] in

> physical therapy [and the] therapists unplugged my monitor, you know? All of a sudden all of the alarms are going like crazy, like there's no on/off switch and I went (pretended to faint) and like played dead. And [I said] "what are you doing? You know, you unplugged me, you know, I'm gonna die." "Oh sorry, I'm sorry," you know, because they never, PT never had an LVAD patient.

Participants had similar descriptions of independent study, setting goals, testing, and family training/testing. PMCSE processes described included “hands-on” and “written” testing with many describing “going home” as their end goal. The following quotes illustrate comments representative of these topics. Participant 0062 stated:

> But then they made me, I had to do a thing where I had to study and learn all the parts of my controller stuff and know how all the stuff functioned. That was before I could be released from the hospital.

Participant 0033 stated:

> So, yeah, but they she trained me really well. She trained my family; she really trained my family. But they had daily training. XXX had daily training with my family. She even came to the house….so she gave, you know, a bunch of expired kits and said, take these home, do it five or six times you know, she gave everybody five of them and they all did it, so they all know how…

Disposition. Participant disposition at the time of hospital discharge emerged as a theme surrounding PMCSE and describes the mindset of the participant in relation to their PMCSE at implant hospital discharge. Sub-themes that emerged from participant narratives include insecurity related to their understanding, cognitive impairment, confidence, and insecurity with outside medical provider knowledge. Appendix D lists participant narratives related to disposition.

Participant disposition at discharge accounts were also similar among participants. Insecurity with knowledge was conveyed when describing the knowledge they felt they needed for device/self-care on discharge. Descriptions also included insecurities related to cognitive impairment impacting their ability to retain knowledge, lack of outside medical provider knowledge about their care, and frustration with inconsistent inter-center protocols as well as a need for continuing education to reinforce the training that they received with PMCSE. Participant 0061 stated:

> I wasn't sure that I'd be able to handle the dressing changes without any sort of guidance or anything…. But I don't know that they really could have done anything else for me in terms of the VAD training and that sort of stuff.

When discussing testing, participant 0061 stated:

> I don't know that I did it written. Because I could hardly read or focus my eyes even, let alone control pen to write when I first got onto the ward. I think it was verbal response to questions, I think. About the controller and the safety stuff like that.

When discussing outside provider knowledge, participant 0061 also stated:

> Well, and not many people knew what it was. Well, no one outside the hospital actually knew what an LVAD was. And even people at that hospital didn't know what it was. Anywhere else on the hospital, they didn't really know, they would've known what to do or anything like that.

Adjustment. Adjustment after MCS implant is the final theme that emerged during data analysis. I used adjustment as an encompassing term to describe participants' general mental outlook after implant as it related to their implant education. Subthemes that emerged include trust, misunderstood – feeling alone, adjustment, and not enough explanation – meanings. Appendix E lists participant narratives related to adjustment.

All participants expressed issues with adjustment to their device after implant and PMCSE. Adjustment issues included developing blind trust, feeling misunderstood, general adjustment to their new normal life and frustration with not fully understanding the process or future options. The following examples describe adjustment issues that the participants expressed. Participant 0061 stated:

> You wake up your whole your whole life just changed, and you don't know. I mean, and people don't get it. There are days you go, "Nah, screw this. I've had enough. Turn this thing off." It's hard. It's a lot of work…So I was my own business. Yeah. I went from making 300 grand a year to welfare. It is tough. When people say lost everything, they don't even know what that means. I mean I do. I lost everything. My vehicles everything. Anything I had a payment on. Yeah. So yeah, if you compound everything, yup it's tough. You just kind of have to every day, put everything in perspective and say, 'Hey, it's getting better.'

Participant 0062 also stated:

> Yeah. So yeah, that's the hardest part for me, though, is getting... They tell me all the time, "You got to get used to your new normal," and two years later, I just

> keep trying to push it back. Because I want my old normal back. I want to be able to go. I want to be able to do what I did, and it's not easy. It's hard. It's always hard.

Participant 0061 stated:

> Even before I left hospital, one of the consultants, one of the doctors said, "All the cards are on the table," and I'm thinking what does that mean? I asked one of the nurses. Apparently, she said ‘The doctors play their cards close to their chest.’ [What does] that phrase [mean] because that threw me. Because they had told me you'll have the LVAD until you get a transplant. But then when [the doctor] said that ‘all the cards are on the table’…what does that mean?

Discussion

Interpretation

The goal of this study was to explore the patient’s experiences with PMCSE after unplanned MCS implant to understand their perceptions of the PMCSE process. Through literature review, I highlighted previously identified factors that have been described largely by medical personnel to influence successful MCS patient device/self-care. These include individual circumstance, cognitive performance, timing, quality of materials, and appropriate delivery. Overall themes involving participant descriptions of their PMCSE experience within this study show some parallels as well as areas requiring future exploration.

Process descriptions largely mirrored those documented in the literature. Similar to that described by (Barsuk et al., 2020) and (Kato et al., 2014), the process of PMCSE was largely described by participants as demonstration – reverse demonstration instruction with independent study and a form of verbal or written testing.

Disposition of the participants was described as the mindset of the participants at discharge in relation to their PMCSE. The participants described both confidence in their training and insecurity in their understanding and ability of device/self-care. Insecurity was attributed to factors such as physical impairment and lack of real time guidance. Insecurity has been previously described by (Casida et al., 2018) but not from the patient's perspective as specific entities that could be addressed. Additional comments highlight participant's insecurity with outside (non-MCS trained) medical providers' MCS awareness which, to my knowledge, has not been previously discussed or studied from the patient's point of view.

Adjustment was defined as the participant's general mental outlook as related to PMCSE. Adjustment issues included developing a "blind trust," feeling misunderstood and alone, adjustment to a new normal and feelings of not enough explanation or understanding the meanings of what they were told. (Abshire et al., 2016) describe issues with coping and adaptation in LVAD patients identifying a need to address strategies to mitigate common issues. Participant experiences described by this research align with Abshire's, et al. observations and identify specific areas in which to focus further research.

Limitations

As with all research studies, there were limitations. Participant recruitment took place using postings on the Facebook groups platform. Recruitment from one online source can introduce bias in terms of the type of participants who use Facebook groups vs. those who do not. Subsequently the narratives obtained may not be transferable to the greater MCS patient population.

Difficulties with interview completion after obtaining participant consent highlighted issues with the recruitment process that may have limited the scope of descriptions obtained based on unrecognized issues related to the participants who did not “show up” for their interview. Although I employed member checking and use of reflexive journaling to bracket my experience with this population, researcher bias is also a possibility and therefore a limitation.

Implications

PMCSE is an integral part of preparing the MCS patient for independent device/self-care after initial hospital discharge. Understanding the patient’s experience, from their perspective, is the first of many steps in developing effective educational practices. My study is the first to describe the patient experience with PMCSE using their own words to better understand their experience from their perspective. Novel information obtained from this research includes international multi-center process descriptions of PMCSE by patients who receive PMCSE knowledge transfer, patient descriptions of their disposition at discharge as well as descriptions of adjustment all which impact and are impacted by the PMCSE process. Because successful MCS device support relies on the ability of the patient to perform device/self-care, my findings provide a foundational start to inform future research surrounding and development of effective PMCSE practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Patient disposition and adjustment descriptions have been previously addressed in the literature but not in terms of the PMCSE process. As with process descriptions, understanding the patient's experiences with disposition and adjustment contribute to development of more effective PMCSE practices (Johansson et al., 2006; Levelink & Brütt, 2021).

Positive social change is a principle aim of scientific research. Providing the foundation informing the development of more effective PMCSE processes may occur because of this research and effects the individual patient as well as the larger population. A higher level of patient training leads to better understanding of device/self-care principles. Globally, higher levels of patient understanding may eventually provide an environment whereby the patient has the ability for earlier independent recognition and intervention when issues arise. This has the potential to reduce the cost burden of this therapy in terms of personnel and financial resources (Levelink & Brütt, 2021).

Recommendations

Recommendations for future research include additional studies to further explore the patient experience as it relates to their device education and appropriate types and timing of education to maximize patient outcomes. Additional research is also needed to provide multicenter accounts of PMCSE processes to identify commonalities and differences in current design and execution. Comparison studies involving the patient experience and provider descriptions will also be necessary next steps in evaluation of current PMCSE processes.

Conclusion

This study is the first to address the foundational knowledge necessary to inform development of optimized PMCSE processes. Descriptions of the PMCSE process, disposition, and adjustment as experienced by the patient were presented. This study serves as a starting point for directing future research focused on fundamental knowledge necessary to optimize PMCSE practice ultimately effecting MCS patient outcomes.

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Lived Experiences of Individuals With Education After Planned MCS Implantation

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Abstract

Advancement in mechanical circulatory support (MCS) device therapy has led to increased use as a planned therapy in heart failure treatment and relies on optimized patient education for successful support. The purpose of this Husserlian guided transcendental phenomenological study was to explore the lived experiences of patients with PMCSE. A purposive sample of 8 participants recruited from MCS targeted social media sites were interviewed using a semistructured open-ended question format and data analyzed using principles of thematic analysis. Two themes were derived from to describe the patient experience with PMCSE and included process, the participant's experience of the mechanics of the PMCSE, and disposition, the mindset of the participant related to PMCSE at discharge. Future research should include additional exploratory studies as well as multicenter comparisons of PMCSE practices and their effect on the patient experience. Understanding patient experiences surrounding MCS implantation affects positive social change by providing foundational knowledge for optimizing MCS patient educational practices, potentially improving outcomes while decreasing cost in this resource intensive therapy.

Introduction

Heart failure (HF), a syndrome characterized by a disparity in the heart's ability to provide enough blood flow to meet the metabolic needs of the body, is a leading causes of morbidity and mortality throughout the world (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017; Seferovic et al., 2019; Trindade et al., 2019; van der Meer et al., 2019). The annual cost of HF treatment is projected to reach $69.8 billion in the United States by 2030 increasing incidence by 46% (Lesyuk et al., 2018; Savarese & Lund, 2017; Virani et al., 2020). The American Heart Association (AHA) and the American College of Cardiology (ACC) as well as their equivalent international counterparts recommend mechanical circulatory support (MCS) therapy as a proven surgical treatment to support patients with advanced HF (Potapov et al., 2019; van der Meer et al., 2019).

HF etiologies differ and result in a progressive decline in patient condition or as a sudden cardiac event resulting acute decompensation necessitating the need for initiation of MCS for patient survival (Crespo-Leiro et al., 2018; Fang et al., 2015; Harjola et al., 2017). Variation in rate of progression of HF among patients results in a disparity in knowledge surrounding individual disease state at the time of MCS implant (Barsuk et al., 2020). Designed for long term use, current MCS devices can provide additional years to a person's life but require a minimum level of patient proficiency in order to manage routine and emergency device/self-care at home (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020).

Primary mechanical circulatory support education (PMCSE) is provided to an MCS patient prior to hospital discharge after device implantation. Disparity in prior knowledge, age, and individual circumstance, and the quality of educational practices all contribute to differences in patient educational needs and ability to assimilate the knowledge required for successful self-care after MCS implantation (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018). MCS-specific education is identified as crucial for successful outcomes but a lack of inquiry exposes knowledge deficiencies that exist involving the patient perception of and experience with PMCSE (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Without a basic understanding of the patient experience and whether any differences exist, optimization of educational practices for this population cannot be achieved (Meloncon, 2017). The fundamental problem addressed by this research is the lack of understanding of the lack of understanding from the patient's perspective of their experience with PMCSE after planned MCS implant.

Significance/Importance

Successful MCS therapy requires the patient possess and maintain a minimal level of knowledge and skill for safe device/self-care outside of the hospital (Feldman et al., 2013; Kato et al., 2014; Smedira et al., 2013). PMCSE is provided to an MCS patient prior to hospital discharge after device implant. The goal of PMCSE is to provide knowledge and resources to the patient in preparation for independent care. PMCSE typically includes monitoring, recognition, and management of heart failure symptoms, recognition of potential complications (stroke, infection, bleeding), operation of and basic changes in physiology that occur the MCS support pump (non-pulsatile circulation), care of the MCS device (battery maintenance, power source management, controller operation and troubleshooting, driveline care, and emergency procedures), driveline site care, dietary changes, and medication concerns (Barsuk et al., 2020; Kato et al., 2014; Widmar et al., 2014).

Despite the completion of PMCSE, newly discharged MCS dependent patients seek peer guidance from social networking sites (SNS) for topics that are essential components of the knowledge required to maintain safe outpatient MCS therapy (Boling et al., 2015). Knowledge seeking is a healthy coping mechanism as an affirmation practice but when knowledge is sought because of a disconnect in knowledge transfer, reexamination of the process is warranted (Kennedy et al., 2017). MCS therapy continues to have an alarming rate of complications adding additional cost to a resource intensive therapy (Smedira et al., 2013). By providing the foundational knowledge necessary to optimizing patient knowledge, reduction in morbidity and cost of this therapy may be another area that can be positively impacted as a result of this research (Lemor et al., 2020; Smedira et al., 2013).

I used a transcendental phenomenological qualitative methodology with a goal of understanding the lived experience in its purest form, to explore the lived experiences of MCS patients undergoing planned MCS implantation with PCMSE. Transcendental phenomenology was developed by Husserl who stressed that the researcher must set aside any pre-existing judgements of a phenomenon in order to allow for an unaltered understanding of the lived experience to emerge (Sundler et al., 2019). Following this methodology, the researcher must practice phenomenological reduction by acknowledging their existing understanding and suppositions of the phenomenon of interest (noema), thoughtfully consider them (noesis), and intentionally exclude (bracket) them in present (horizon) exploration, analysis, and description (Peoples, 2020). In consideration of my extensive history and experience in the MCS field, Husserl's approach aligned well with the research question exploring differences that exist, if any, based on the patient's age at implant of the patient's lived experience related to PMCSE.

Relevant Scholarship

Successful MCS device/self-care mandates that the patient have adequate knowledge, understanding, and skills to perform routine and emergency care (Barsuk et al., 2020; Kato et al., 2014; Rhoades et al., 2020). Factors that contribute to a patient's ability to assimilate the knowledge and skills required for successful device/self-care include prior exposure, individual circumstance, cognitive performance, timing, the quality of educational materials, and appropriate delivery practices. (Abshire et al., 2016; Bhat et al., 2015; Casida et al., 2017; Doehner et al., 2018)

Prior exposure, individual circumstance and cognitive performance all play integral roles in successful assimilation of knowledge for the MCS patient. Etiology and progression rate of HF are factors that contribute to a patient's prior exposure to HF knowledge before to MCS implantation. Many patients experience a progressive deterioration in condition, more typically in the older population, which allows the patient to assimilate knowledge related to self-care practices required for HF management more efficiently after MCS implant (Barsuk et al., 2020). Decreased readmission rates and increased QOL are benefits of experience, pretraining, targeted education, and early discharge planning are in HF and MCS patient populations (Barsuk et al., 2020; Dickson et al., 2008; Mai Ba et al., 2020). Learning and self-care are negatively impacted by cognitive impairment (CI) and is a predictor of outcomes in MCS patients (Abshire et al., 2016, 2018; Bhat et al., 2015; Casida et al., 2017; Faulkner et al., 2020; Pavol et al., 2018). Executive function, episodic memory, psychomotor speed, language and visio-spatial abilities are all affected by chronic HF but appear to improve after MCS implantation (Bhat et al., 2015; Doehner et al., 2018).

Acquisition of knowledge can be impacted by timing, the quality of educational materials, and appropriate delivery methods (Hahn-Goldberg et al., 2015). Using patient experience data is integral to the redesign and improvement of discharge paperwork and has been demonstrated to improve the efficacy of discharge materials provided to patients and has a direct effect on the patient’s ability to provide self-care in the post-operative period (Hahn-Goldberg et al., 2015; Kang et al., 2018; Meloncon, 2017). Prior research surrounding the MCS patient experience has fallen short in capturing the essence of the patient’s perspective within their individual circumstances. Barsuk et al. (2020) was the first group to describe the perspectives and perceptions of the patient, caregiver, VAD coordinator, and physician perspectives of existing VAD self-care training using a qualitative interview format to inform development of a simulation based educational process. Although this has produced a basic characterization of the satisfaction of patients and caregivers with current educational methods, a lack of an in depth of description and understanding of the patient’s lived experience within the context of their individual circumstances remains (Barsuk et al., 2020; Casida et al., 2018, 2017; Lemor et al., 2020; Widmar et al., 2014).

I used this research to focus on the patient’s experience with PMCSE with planned MCS implantation, closing the gap in knowledge that currently exists. By providing a basic understanding the patient’s lived experience, I have provided a foundation for future research and design of optimized patient centered MCS educational practices. This is the first step toward the ultimate goal of increasing MCS patient autonomy and potentially decreasing complications, readmission rates, and their associated costs.

Research Questions and Design

An understanding of the patient experience with PMCSE is the foundation for development of patient focused educational practices (Meloncon, 2017). Using a transcendental phenomenological qualitative research design as described by Husserl, I addressed the research question: What are the lived experiences of MCS patients who have undergone planned MCS implantation with PMCSE? Transcendental phenomenological inquiry is a qualitative approach used by researchers who endeavor to provide an unfiltered understanding of a lived experience (LaVela & Gallan, 2014; Peoples, 2020). By following this methodology, as described by LaVela & Gallan (2014) and Peoples (2020), I was required to practice phenomenological reduction which is the process of identification, consideration, and bracketing (setting aside) my experiences to achieve an understanding of the data in its truest form. In consideration of my extensive history working with MCS patients, this methodology was a good fit for conducting valid and reliable research involving the MCS patient experience.

Methods

Participants and Context

I recruited participants from Facebook groups targeted toward MCS patient support using electronic flyers (Appendix A). I obtained a purposive sample of eight participants, based on sampling methods developed by Francis et al. (2010), and I achieved data saturation. Participants who were included in the study were provided with a link to an online study consent form (Jotform, 2021) which once completed provided an option to schedule an interview day and time. A copy of their consent and verification of their interview time and joining instructions was sent to the participant for documentation and reference. Participant inclusion requirements were (a) support by an FDA approved MCS device, (b) age 18 years and older, (c) the ability to understand and speak English, and (d) no barriers to participating independently in an online interview.

Instrumentation

Researchers use transcendental qualitative inquiry, an inductive approach, to collect subjective forms of data, including words or images (Galdas, 2017; Peoples, 2020; Ravitch & Mittenfelner Carl, 2015). I interviewed participants using a semistructured open-ended question format thus allowing the participants to describe their experience using their own words (Rudestam & Newton, 2015). I developed an interview guide following methods described by Bevan (2014) and guided by Husserl’s methodology

(Appendix B). I used my notes and reflective journals in order to bracket my previous experience.

Data Collection

Jowett endorsed the use of online video conferencing tools as acceptable methods for qualitative data collection during a pandemic (Jowitt, 2020). In consideration of current social distancing requirements, I used Google Meet (Google, 2021), a password secured online video conferencing system, to conduct individual interviews with study participants. I audio recorded the interviews using Notability (Ginger Labs, 2020), and used REV, an online speech to text service for verbatim transcriptions which I verified for accuracy (*Rev Speech-to-Text Services*, n.d.). I provided a copy of the transcript to the participant for their review via email along with additional questions for clarification with a request to be returned, with amendments, within 1 week. All recordings, transcriptions, and data were deidentified and given a unique ID to ensure participant confidentiality. The key for the participant IDs was stored in a password protected file and available only to me as the primary researcher. I corresponded with participants through encrypted email on Google Workspace for business (Google, 2021c).

For Participant recruitment, I drew volunteers from a social media platform targeted to MCS patients and caregivers (Facebook groups). This platform exists using both open and closed group classifications. Although I am a member of the closed groups, I did not have a professional relationship with any of the study participants. Infrequently I have provided comments to aid in group discussion, but all comments were informational in nature and not given in any professional capacity.

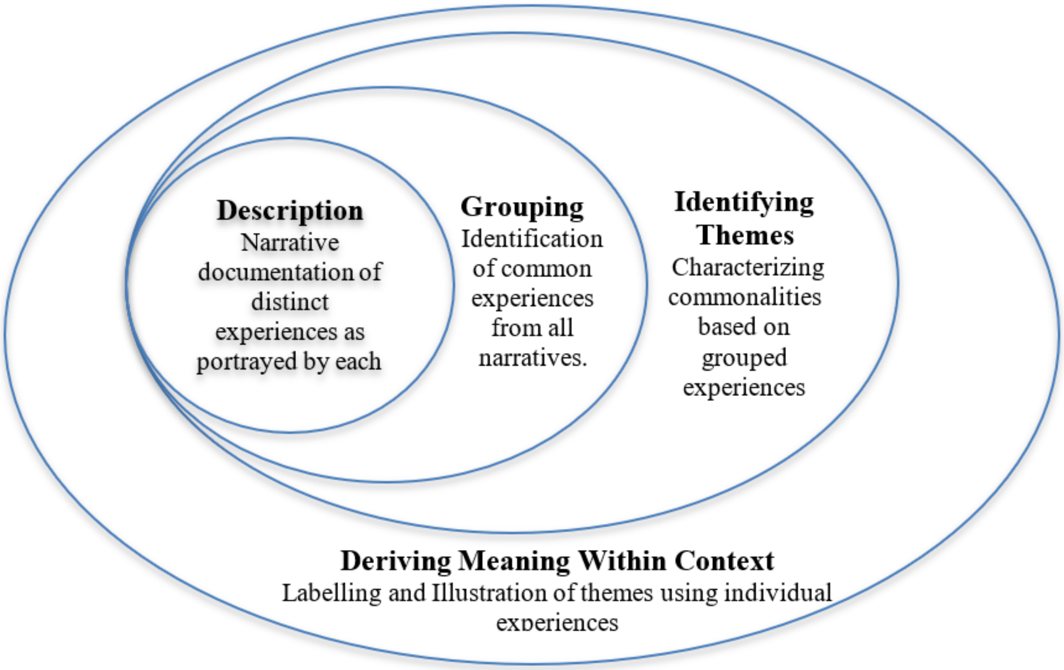
I acknowledge a long history of working with MCS patients and used reflexive journaling to bracket my interpretations of the patient experience. Transcriptions and field notes were provided to the participant for review and revision before data analysis to verify that the thoughts, statements, and themes identified accurately represented the participant's experience. Identified themes were provided to participants after data analysis for review and comment to verify accurate representation of their experiences.

Data Analysis

I analyzed the data using qualitative thematic analysis (Sundler et al., 2019). Sundler et al. described the methodological principles of thematic analysis as emphasizing openness, questioning pre-understanding, and adopting a reflective attitude and contend that these principles guide all aspects of the research process (Sundler et al., 2019). Thematic analysis as described by Sundler et al (2019) is an inductive approach that aims to understand the complexity of data meanings by searching for patterns in the data that can be organized into patterns and then themes to understand meaning (Figure 3).

Figure3

Process of Thematic Analysis



Note. Based on Sundler et al. (2019)

I extracted data from the transcripts by breaking down the participant's responses into unique topical statements. I entered and organized the topical statements into an online database management program to assist in data analysis (Airtable, 2020). I chose this program because of my familiarity with its use as well as the flexibility it provides in visually manipulating the data into different formats efficiently. I grouped the topical statements into broad categories based on their relevancy to the participant's MCS educational experiences. Topical statements that were not related to the participant's educational experiences were excluded. I then conducted a first pass review of the educational related topical statements and created descriptive categories based on identified events as well as the participant’s description of their experiences related to those events. When possible, I separated participant accounts that spanned multiple topics into statements that reflected only one topic. On second pass analysis of the categories of data, specific themes emerged surrounding educational formatting and perceptions of each participant’s educational experience. On third pass analysis of the unplanned themes, I grouped similar themes into broad topic which became final themes. Finally, I emailed each participant a link to an online spreadsheet containing the extracted statements and thematic development and asked for a response indicating their agreement or disagreement with the analysis to verify that the derived themes represented the experiences they conveyed in the interview process.

Trustworthiness/Validity

Trustworthiness in phenomenological research involves conducting research using processes that support the quality of the work in terms of credibility, transferability, dependability, and confirmability (Peoples, 2020). In developing my original research question, I wanted to address the deficiencies with current MCS education. The deficiencies that I felt needed to be addressed were based on my interpretation of patient need through my observations and interactions with MCS patients. Because there is very little research involving the patient experience with MCS in general, I struggled with how to appropriately address describing the deficiencies in PMCSE, based on my perception of patient need, through credible research procedures. In further discussion with faculty, personal reflection, and literature review, I was able to recognize that the struggle I was having was a result of a disparity between my perception of patient needs and patients' perception of patient needs based on their lived experience. I had to concede that despite my extensive experience working with this population of patients, I lacked the personal experience of living with an MCS device. To identify and explore deficiencies in PMCSE based on actual patient needs, I realized that I needed to remove my perceptions from the equation. Focusing on exploration of the problem from the patient perspective allowed me to identify transcendental phenomenological methodology as the most appropriate way to align my research approach with my research goals. Using this methodology, I was required to approach the research process with an open, unfiltered stance, using a broad open ended question format for patient interviews and data collection, phenomenological reduction and researcher bracketing for data analysis, and development of themes based on the descriptions of actual patient experiences using the patient's perspective as the central grounding point and guide for all aspects of the research process.

Credibility in qualitative research encompasses the plausibility of research findings within the context of accurate portrayal by the researcher (Sundler et al., 2019). One method of insuring credibility is through member checking or participant validation of findings (Birt et al., 2016). I utilized member checking twice throughout this research study. First member check was performed immediately after interview transcription and served as a venue for phenomenological reduction. The second member check occurred after final theme development requesting participants to review and agree or disagree with the identified themes.

Transferability refers to the relevancy of research findings outside of the confines of the study (Sundler et al., 2019). Transferability is optimized through meticulous communication of study procedures and clear presentation of findings so that the reader has the information to be able to determine whether the data are applicable in their setting (Sundler et al., 2019).

Dependability in qualitative research is how reliable the data is and has its basis in study design (Ravitch & Carl, 2015). It is grounded in appropriate study design with rationales for methods clearly communicated and rationalized (Ravitch & Carl, 2015).

Confirmability refers to the efforts engaged by the researcher to reduce their influence or bias on the study findings (Ravitch & Carl, 2015). Following the principles of thematic analysis outlined by Sundler et al. (2018) of openness, questioning pre-understanding, and taking a reflective attitude, I have addressed confirmability of this study through study design and utilization of reflective journals and interview notes allowing for initial review of the interview transcriptions and implementation researcher bracketing and phenomenological reduction.

Execution

Despite meticulous planning, conducting qualitative research often requires some deviation from the original research plan. (CohenMiller et al., 2020) termed deviation from a research plan as “research failure” and contend that what is considered to be a failure in qualitative inquiry can help to uncover previously unidentified opportunities for exploration and discovery. There were three areas where execution of this research did not follow the original plan. These were exclusion of MyLVAD.com as a source for participant recruitment, issues with the sampling strategy related to participant study completion, and difficulties recruiting participants who had undergone unplanned MCS implantation.

Exclusion of MyLVAD.com

My original plan for participant recruitment involved placement of electronic recruitment flyers on both Facebook targeted MCS groups as well as on MyLVAD.com. Participant response using the Facebook platform allowed for sufficient study enrollment making cross posting on MyLVAD.com unnecessary. On further reflection, the choice to not use MyLVAD.com for recruitment strengthened the validity of the study removing any questions surrounding recruitment and bias related to my professional role as managing director of MyLVAD.com.

Issues with Sampling Strategy

My original plan for sampling did not account for participants not appearing for their scheduled research interviews. (Sauro, n.d.) reports a “no show” rate of participants in user experience research of 10-50% and recommends strategies to decrease rates. Strategies were included in the recruitment plan for to increase ease and convenience of volunteer participation but multiple participant’s failure to attend interviews extended the time length of study recruitment to achieve data saturation. There were 49 potential participants screened of which 22 progressed to signing consent and scheduling an interview. Of the 22 who scheduled interviews, only 11 attended and completed an interview. Despite multiple attempts to contact and reschedule interviews, there were 11 participants who consented but did not complete the interview and were subsequently excluded from data analysis.

Results

This study explored the patient's experience with primary MCS education to inform future research surrounding MCS patient education practices.

Participant Demographics

Demographic information for study participants is described in Table 3.

Table 3

Participant Demographics

	Planned *(n=8)*
Age(years)	
Mean	71
Range	52-86
Gender:	
Male	7
Female	1
Implant Duration:	
12 months – 2 years	0
>2 years	8

Derived Themes

I identified two main themes present within the data that describe the patient's experience with PMCSE: process descriptions, disposition, and adjustment.

Process descriptions. Process descriptions of PMCSE were described by all participants and provided context and insight into the instructional methods that were used throughout their individual educational processes. Process descriptions included characteristics of instructional methods as well as accounts of experiences and needs. Common subthemes that were described include consistent instructor, demonstration, reverse demonstration, independent study, testing, setting goals, and family training/testing. Participant narratives describing their experiences with PMCSE are listed in Appendix C.

Process descriptions were illustrated by all the participants and set a backdrop for further exploration into their experience. Process descriptions characterized both instructional methods (demonstration, reverse demonstration, independent study, testing, family training/testing) and overall characteristics (consistent instructor, goal setting) of the PMCSE process. Examples of process descriptions include:

> "It was bedside. It was all at my bedside. OK, you figure, I've spent like six weeks in the hospital so they would come all the time and sit and talk to me about it" – Participant 0031
>
> "They would bring in groups of student nurses for me to talk about my LVAD." – Participant 0042

> “I read the whole loose-leaf binder cover to cover and always had questions for her and so on...I think the content of the binder had Abbott stuff in there. It was a slew of stuff that they added and the manufacturer (manuals).” – Participant 0039
>
> “And my caregiver also had to be tested on the device before we left the hospital. Just in case I was unconscious or anything like that. My caregiver would understand everything that was going on with the device itself.” – Participant 0037

Disposition. Participant disposition at the time of hospital discharge emerged as a theme surrounding PMCSE and describes the mindset of the participant in relation to their PMCSE at implant hospital discharge. Sub-themes that emerged from participant narratives include insecurity – understanding, cognitive impairment, confidence, frustration with inconsistent center messages, insecurity – outside medical provider knowledge, and suggestions/reflections. Appendix D lists participant narratives related to disposition.

Participant disposition at discharge accounts were also similar among participants. Insecurity and frustration were conveyed when describing the knowledge they felt they needed for device/self-care on discharge. Descriptions also included insecurities related to cognitive impairment impacting their ability to retain knowledge, lack of outside medical provider knowledge about their care, and frustration with inconsistent inter-center protocols. They also described a need for continuing education to reinforce the training that they received with PMCSE. Examples of participant disposition descriptions include:

> “Well, I think what overwhelms people is the fact that it tends to be a cram course. I mean, there's two hours set aside. You bring them into the clinic and they say, "You do this, this and this. You got that?" "Oh, yeah. Okay. Got it." And then an hour later you don't remember half of it... They just need repetition. We the patient and the caregiver need a lot of repetition, especially since a lot of us are older, our health has been compromised. Our mental faculties may not be quite what they were years ago. Who knows, we may have lost some brain cells in surgery under anesthesia.” – Participant 0042

> “I was pretty whacked out. I was really not getting it all. I didn't remember people who came and saw me and that whole ... I was there for almost a month. I think the information they gave me during that time was not ... it wasn't processing with me because I didn't know what the hell was going on.” – Participant 0044

> “What's interesting and what perhaps you're doing can play a role in, just from being involved in LVAD type websites or most recently in my case Facebook, the protocols vary a lot from center to center. So, there's really a lack of uniformity because as far as I can tell there's no central authority that says, "Okay, here's the best practice." It's all very personalized and it's based on people's education level

> and that area of experience, personality. So, if you have 150 centers, you've got 150 different ways of doing things. Even the dressing process." – Participant 0042

Discussion

Interpretation

The goal of this study was to explore the patient's experiences with PMCSE to understand their perceptions of the PMCSE process. Through literature review, I highlighted previously identified factors that have been described largely by medical personnel to influence successful MCS patient device/self-care. These include individual circumstance, cognitive performance, timing, quality of materials, and appropriate delivery. Overall themes involving participant descriptions of their PMCSE experience within this study show some parallels as well as areas requiring future exploration.

Process descriptions largely mirrored those documented in the literature. Similar to that described by (Barsuk et al., 2020) and (Kato et al., 2014), the process of PMCSE was largely described by participants as demonstration – reverse demonstration instruction with independent study and a form of verbal or written testing.

Disposition of the participants was described as the mindset of the participants at discharge in relation to their PMCSE. The participants described both confidence in their training and insecurity in their understanding and ability of device/self-care. Insecurity was attributed to factors such as cognitive impairment and rapid rate of instruction. Insecurity has been previously described by (Casida et al., 2018) but not previously described from the patient's perspective in terms of cognitive abilities or rate of instruction. Comments included the need for continuing education, added testing, and a deeper understanding of the mechanics of the device. Additional comments highlight participant's frustration with inconsistent center messages as well as insecurity with outside (non-MCS trained) medical providers' knowledge which both of which, to my knowledge have not been previously discussed or studied.

Limitations

As with all research studies, there were limitations. Participant recruitment took place using postings on the Facebook groups platform. Recruitment from one online source can introduce bias in terms of the type of participants who use Facebook groups vs. those who do not. Subsequently the narratives obtained may not be transferable to the greater MCS patient population.

Difficulties with interview completion after obtaining participant consent highlighted issues with the recruitment process that may have limited the scope of descriptions obtained based on unrecognized issues related to the participants who did not "show up" for their interview. Although I employed member checking and use of reflexive journaling to bracket my experience with this population, researcher bias is also a possibility and therefore a limitation.

Implications

PMCSE is an integral part of preparing the MCS patient for independent device/self-care after initial hospital discharge. Understanding the patient's experience, from their perspective, is the first of many steps in developing effective educational practices. My study is the first to describe the patient experience with PMCSE using their own words to better understand their experience from their perspective. Novel information obtained from this research includes international multi-center process descriptions of PMCSE by patients who are on the receiving side of PMCSE knowledge transfer, patient descriptions of their disposition at discharge as well as descriptions of adjustment all which impact and are impacted by the PMCSE process. Because successful MCS device support relies on the ability of the patient to perform device/self-care, this research provides a foundational start to inform future research surrounding and development of effective PMCSE practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). Patient disposition and adjustment descriptions have been previously addressed in the literature but not in terms of the PMCSE process. As with process descriptions, understanding the patient's experiences with disposition and adjustment contribute to development of more effective PMCSE practices (Johansson et al., 2006; Levelink & Brütt, 2021).

Positive social change for individuals as well as greater society is one of many goals of research. This research effects the individual patient by informing the development of more effective PMCSE processes, subsequently providing a foundation for development of a higher quality of patient training methods and understanding of device/self-care principles. Potential global effects include fostering an environment for patients to have the ability for earlier recognition and intervention with device/self-care issues decreasing complication rates and potentially reducing the cost burden of this therapy in terms of personnel and financial resources (Levelink & Brütt, 2021).

Recommendations

Recommendations for future research include additional studies to further explore the patient experience as it relates to their device education, and appropriate types and timing of education to maximize patient outcomes. Additional research is also needed to provide multicenter accounts of their PMCSE processes to identify commonalities and differences in current design and execution. Comparison studies involving the patient experience and provider descriptions will also be necessary next steps in evaluation of current PMCSE processes as well as in the design of improved methods in the future.

Conclusion

This study is the first to address the foundational knowledge necessary to inform development of optimized PMCSE processes. Descriptions of the PMCSE process, disposition, and adjustment as experienced by the patient were presented. This study serves as a starting point for directing future research focused on fundamental knowledge necessary to optimize PMCSE practice ultimately effecting MCS patient outcomes.

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Part 3: Summary

Integration of the Studies

The use of MCS therapy to treat HF has become standard of practice in the international medical community (Potapov et al., 2019, van der Meer et al., 2019). Success of MCS therapy relies on a specialized cohort of highly trained medical providers while the patient remains hospitalized. However, once the patient is discharged, the patient must possess specialized knowledge and skills to perform device/self-care (Feldman et al., 2013; Kato et al., 2014; Smedira et al., 2013). Patient education is a critical component of successful outcomes involving MCS therapy, yet only a limited number of studies exist describing current practices (Feldman et al., 2013; Kato et al., 2014; J. K. Kirklin et al., 2020; Kormos et al., 2019; LaBuhn et al., 2020; Rhoades et al., 2020; Smedira et al., 2013; Teuteberg et al., 2020; Widmar et al., 2014). There is a lack of evidence focusing on the patient experience as well as educational best practices for optimization of content, timing, delivery of education on PMCSE, which includes verification of successful knowledge transfer and retention (Feldman et al., 2013; Smedira et al., 2013). Foundational knowledge on PMCSE is necessary to inform and develop optimal educational processes for MCS patients (Meloncon, 2017).

To explore the patient's lived experience with PMCSE, I interviewed participants who were supported by MCS devices. I grouped participants by implant strategy to ensure representation of patients who had a history of chronic heart failure as well as those who experienced acute events. I used grouping to conduct a parallel exploration of any differences that existed in the patient experience based on whether they received an

MCS device as a planned HF intervention or as an unplanned emergent procedure. The purpose of this three-manuscript dissertation was to explore the lived experiences of (a) patients with PMCSE, (b) patients who undergo unplanned MCS implantation with PMCSE, and (c) patients who undergo planned MCS implantation with PMCSE.

Three main themes emerged from the interviews conducted. Two themes, process and disposition, were similar in both the planned and unplanned groups with participant descriptions giving insight into the mechanics and delivery of PMCSE as well as the mindset of the participant at the time of implant hospital discharge in relation to PMCSE experiences and subsequent device/self-care. PMCSE process and disposition has been previously described using data obtained from standardized questionnaires involving medical professional responses and reviews of quality-of-life survey results (Kato et al., 2014, Widmar et al. 2014, Casida et al., 2018, Barsuk et al., 2020). The addition of these data expands the depth of previous findings while highlighting new subthemes surrounding disposition related to patient concerns with cognitive impairment, inconsistent inter-center protocols, and lack of knowledge of outside medical providers about their care.

The third theme that emerged, adjustment, was unique to the unplanned group of participants and described their general mental outlook after discharge in relation to their PMCSE experience. This theme encompassed feelings related to developing a blind trust in the technology and providers, feelings of isolation being misunderstood and feeling alone, adjustment issues to their unexpected new normal, and issues with not understanding the meanings and connotations behind provider statements regarding their medical plan. Rhoades (2020) explored adjustment in LVAD patients at two LVAD centers in relation to their designation as destination therapy (DT) or bridge to transplant (BTT). With this study I have added to Rhoades (2020) findings incorporating a more diverse sample of participants, different definitions of implant strategy, and focuses on the experiences specifically surrounding the PMCSE process.

Implications for Positive Social Change

An understanding of the patient experience is crucial for development of optimized educational practices. Optimization of PMCSE provides the most effective patient educational environment giving patients the knowledge that they need for safe and effective device/self-care at home. Optimization of patient knowledge maximizes patient autonomy and understanding allowing for earlier recognition and intervention of potential issues that need to be addressed both independently and with provider assistance. Earlier intervention has the potential to moderate device complication occurrence and severity thereby reducing the cost burden of this therapy in terms of personnel and financial resources and effect positive social change (Levelink & Brütt, 2021).

Future Research

Future research is needed to further identify, explore, and expand on the three themes of process, disposition, and adjustment from my study to more fully describe optimal educational practices from the patients' perspective. Additional research is also needed to provide multicenter accounts of their PMCSE processes to identify commonalities and differences in current design and execution. Comparison studies integrating the patient experience and provider descriptions of the patient education process will also be necessary next steps to evaluate the effectiveness of current PMCSE processes and identify new best practices in an effort to inform the design of improved methods in the future.

Lessons Learned

I have learned several lessons while conducting this research. Most importantly, that no matter how much time one spends meticulously planning a study, there are always things that get missed and go wrong. Flexibility and critical thinking skills are necessary in every aspect of research to be able to stay within the boundaries established through the research plan while accommodating the issues that were not anticipated while creating it.

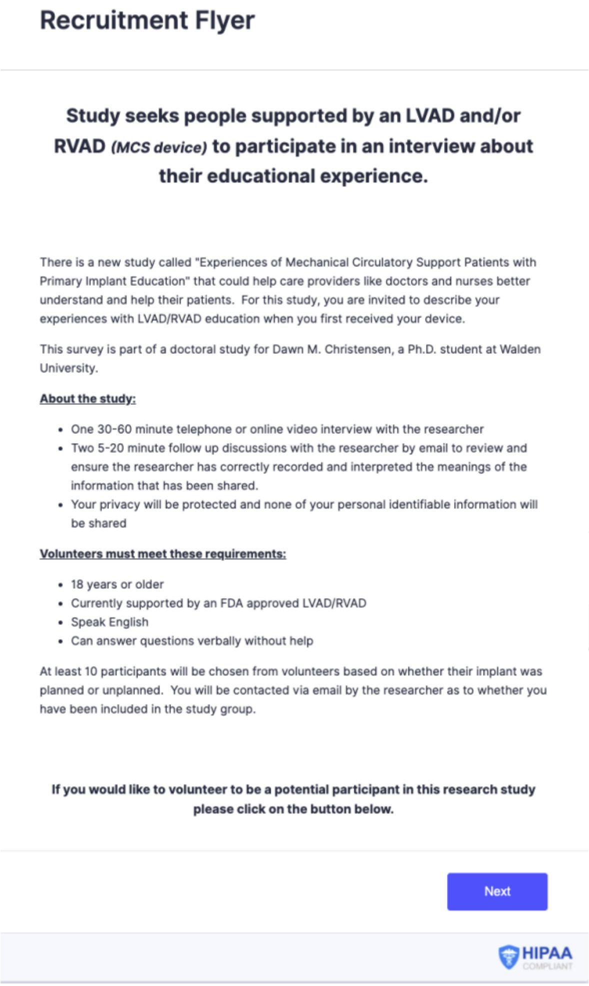
MCS patient education has implications at every level of care. Despite the routine procedures that appear to be good enough or developing the next greatest method of instruction, the implications for examining the origins and background of current processes are merited.

Finally, throughout the many years that I have worked with MCS patients, I have had what I thought was an understanding of their wishes to lead a normal life whatever they define it to be. This research has given me more insight of what it is like for them to live on a life sustaining device while trying to fit into the world around them. It has reinforced, for me, the importance of promoting their voice into every decision made within the MCS field. The minimal insights provided through the stories that the participants have generously shared emphatically reinforce my inability and the inability of anyone who has not personally undergone MCS device support to empathize at any level with their experiences. For that small amount of insight, I will be forever grateful.

Conclusion

With this study, I have been the first to explore the foundational knowledge necessary to inform development of optimized PMCSE processes from the patient's perspective. Two descriptive themes surrounding the PMCSE experience, process, and disposition, emerged as commonalities among patients in both the planned and unplanned groups. Themes surrounding adjustment emerged as unique to the unplanned group meriting further inquiry. This study serves as a starting point for directing future research focused on inclusion of the patient perspective as fundamental knowledge necessary in optimization of PMCSE practices with the ultimate goal of positively effecting MCS patient outcomes.

Appendix A: Recruitment Flyer



Recruitment Flyer

Study seeks people supported by an LVAD and/or RVAD *(MCS device)* to participate in an interview about their educational experience.

There is a new study called "Experiences of Mechanical Circulatory Support Patients with Primary Implant Education" that could help care providers like doctors and nurses better understand and help their patients. For this study, you are invited to describe your experiences with LVAD/RVAD education when you first received your device.

This survey is part of a doctoral study for Dawn M. Christensen, a Ph.D. student at Walden University.

About the study:

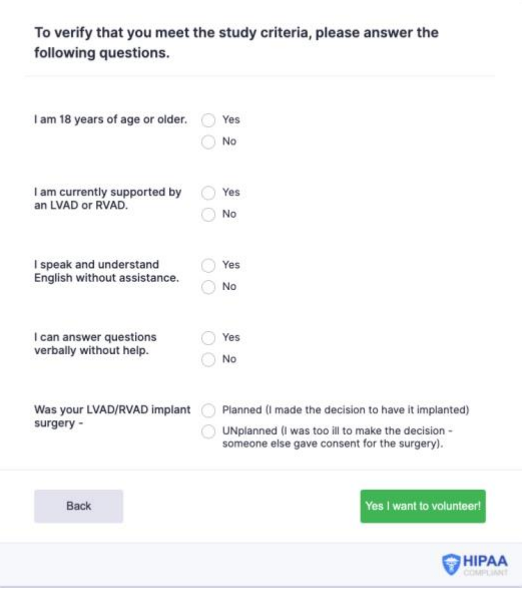
- One 30-60 minute telephone or online video interview with the researcher
- Two 5-20 minute follow up discussions with the researcher by email to review and ensure the researcher has correctly recorded and interpreted the meanings of the information that has been shared.
- Your privacy will be protected and none of your personal identifiable information will be shared

Volunteers must meet these requirements:

- 18 years or older
- Currently supported by an FDA approved LVAD/RVAD
- Speak English
- Can answer questions verbally without help

At least 10 participants will be chosen from volunteers based on whether their implant was planned or unplanned. You will be contacted via email by the researcher as to whether you have been included in the study group.

If you would like to volunteer to be a potential participant in this research study please click on the button below.



To verify that you meet the study criteria, please answer the following questions.

I am 18 years of age or older.	○ Yes ○ No
I am currently supported by an LVAD or RVAD.	○ Yes ○ No
I speak and understand English without assistance.	○ Yes ○ No
I can answer questions verbally without help.	○ Yes ○ No
Was your LVAD/RVAD implant surgery -	○ Planned (I made the decision to have it implanted) ○ UNplanned (I was too ill to make the decision - someone else gave consent for the surgery).

Appendix B: Interview Guide

Introductory Statement

Hello, my name is Dawn Christensen, and I am a Ph.D. student at Walden University. Thank you for agreeing to participate in this research project. To give you a little background about myself, I have been a nurse for 30 years and a nurse practitioner for the last 25 years. I have spent most of my career taking care of MCS patients both as an MCS coordinator for 12 years subsequently as the director of a website that is designed to provide information and support to MCS patients. It has been my privilege to work with end stage heart failure and MCS patients and would like to make sure that their experiences are heard. I believe that it is imperative that there is an understanding of your experiences so that the therapy can be improved to allow you to lead as normal of a life as possible.

For this research, you were provided with a consent form which you signed in agreement to participate in this interview. As a reminder, you have the right to decide to stop participation at any time prior to, during, or after the interview. The interview will be audio recorded and transcribed verbatim for your review. This ensures that I have correctly received your story, in your words, and allows you to add to or correct anything that may have been misunderstood. Your personal information will be kept confidential, and all of your responses will be identified with a unique identifier that will be assigned to you and known only to myself. None of the information will be given to your implanting team or current providers outside of the published results of the research study. No identifying information will be used in any publication resulting from this study. The questions that I have for you are designed to let you tell your story. You may take as much time to answer the questions as you wish, with the goal being to give us as much detail of your experience as possible.

Interview Questions

Please describe for me about becoming ill with heart failure and receiving an LVAD/RVAD/MCS Device.

Can you describe for me about learning how to take care of yourself and your LVAD/RVAD/MCSD after implant.

Reminder: Interpretive statement = ask structural question

“You mentioned…. Could you please describe what you mean by…?”

Reminder: Determine if there are opportunities for use of imaginative variation.

“If there was…., would that change….”

Closing Statement

I want to thank you for participating in this research project. As we discussed earlier, the aim of the study is to explore your experiences with MCS education. I will email you a transcript of this interview for your review. The transcript may include additional questions in order to clarify your experiences. You are welcome to add or remove any information that you provided during the interview. I will ask that you return the transcript within one week so that we are able to start analyzing the information. After analysis I will again send you a copy of the themes that have been identified to get your comments as to whether or not I was able to capture your experience accurately. If you have any further questions, please feel free to contact me at (email address inserted here) and as always, if you decide that you would like to withdraw from the research study, your interview recording, and transcription will be removed from the data analysis and destroyed. Thank you again, your participation is appreciated and will hopefully help future MCS patients with their care.

Appendix C: Process Narratives

UID	Quote	Strategy
	Consistent Instructor	
43	I had one person who was the LVAD coordinator in the hospital and she was awesome. She’s still in the team now, the person that was the beginning one. That’s the only one I think I remember during that time. Maybe they do it that way, stuck with the one person, and she was a teacher, basically.	Planned
	Demonstration	
31	It was bedside. It was all at my bedside. OK, you figure, I’ve spent like six weeks in the hospital so they would come all the time and sit and talk to me about it.	Planned
37	Okay. How do I put it, like alarms that set off in the LVAD. There are different alarms. They mean different things. The controller does explain a lot of things, but they wanted to make sure I knew what each indicator light coincides with, each function of the device. Like I said, they were hands on showing me.	Planned
45	So they did... they would come in and show you.	Planned
45	Since I was still in the hospital, it was all very hands on.	Planned

45	So they did that and they showed us hands on how to take a map, blood pressure and everything like that.	Planned
33	They showed me how to do everything.	Unplanned
33	Then she had to train all the nurses. Then all the nurses had to come in and see me and learn how my battery works, and learn how all this stuff works, and how to connect and disconnect while I was in there, you know.	Unplanned
	Reverse Demonstration	
42	They would bring in groups of student nurses for me to talk about my LVAD.	Planned
62	They were teaching me all the time how to work my VAD, how to understand my VAD, the dos and don’ts, don’t let your cord get pulled. Don’t do this. Don’t do that. Be on top of knowing where that cord’s at that.	Unplanned
33	Also, you know, they’re in physical therapy therapists unplugged my monitor, you know? All of a sudden all of the alarms are going like crazy, like there’s no on/off switch and I went (pretended to faint) and like played dead…And “what are you doing? You know, you unplugged me, you know, I’m gonna die.” “Oh sorry, I’m sorry,” you know, because they never, PT never had an LVAD patient	Unplanned

33	…and now you do it. Okay, now disconnect. Now you do it, now disconnect. Now you do it. Now, disconnect, now you do it. Okay, and let me show you, you know, you got eight batteries and you got to rotate them."	Unplanned
33	Yeah, and they had these, I forgot what they call them. There was a model they had to practice on. To change the dressing… a mannequin. Yeah. Yeah, so she gave, you know, she gave a bunch of expired kits and said, take these home, do it five or six times you know, she gave everybody five of them and they all did it so they all know how to do it if you know, it comes down to it.	Unplanned
	Independent Study	
31	Basically, I went online and learned everything I possibly could do. They gave me a lot of pamphlets and leaflets and stuff like that to read up on, you know the the warning signs and the signals and the alarms and everything. So I literally read them over and over and over till they were stuck in my brain and I, you know, I knew exactly what they all meant and everything.	Planned
37	...also the manuals that they provided, I read the manuals. So I pretty much knew everything about this machine.	Planned

39	I read the whole loose-leaf binder cover to cover and always had questions for her and so on... I think the content of the binder had Abbott stuff in there. It was a slew of stuff that they added and the manufacturer (manuals).	Planned
62	But then they made me, I had to do a thing where I had to study and learn all the parts of my controller stuff and know how all the stuff functioned. That was before I could be released from the hospital.	Unplanned
61	They had a folder and they have a different folder for a transplant as well and you got to read through that.	Unplanned
62	I did. I did. And it helped because they also were the ones who told me about like getting in an LVAD group online. And I’ll tell you right now, the group helps immense.	Unplanned
31	they also gave me a lot of CDs from previous patients who had the LVAD implanted and how it has changed their lives from what they were doing and how moving forward	Planned
	Testing	

	Oh. And the rest of her team. We had to do certain things and we got tested on them repeatedly.	
39	Yeah. Let’s follow the procedures to swap your controller. Let me see you do it, even though you’re not really doing it. You’re doing it on (a dummy).	Planned
62	Yeah, I mean they put me through, I had to know how to work everything.	Unplanned
61	I don’t know that I did it written. Because I could hardly read or focus my eyes even, let alone control pen to write when I first got onto the ward. I think it was verbal response to questions, I think. About the controller and the safety stuff like that.	Unplanned
37	By training, I mean, it was hands on. So like I said, I could not leave until I passed their tests and some of these tests were written and some of them was hands on actually showing me. So I did everything correct and I was discharged. But that added notes that I read.	Planned
45	They had us take a test, like a multiple choice test that I had to pass and fill out and pass before I could be discharged.	Planned

	Setting Goals	
61	And to get out of hospital with my team, you have to be able to basically take care of yourself. Yes, you have to have someone with you, but you have to do the dressing changes yourself. I tried to see if my wife could do it, but no, she wasn't allowed to do it. I had to learn to do that in the hospital. I had to learn what all the different alarm codes were and stuff like that. I think most of which I've forgotten now.	Unplanned
62	And I said, "Oh no, I ain't staying until..." "What do I got to do?" "Well, you got to be able to walk. You got to be able to do this. You have to be able to get up some stairs." I had to be able to walk two steps. Oh my God. That about killed me when I finally did it.	Unplanned

	Family Training/Testing	
31	Yeah, myself and my son. We both did written tests as well.	Planned
48	My wife has been so important and so instrumental in all this because she is an expert at the dressing change and just sort of paying attention. So I didn't have to learn as much as maybe some other recipients do because she's on it	Planned

37	And my caregiver also had to be tested on the device before we left the hospital. Just in case I was unconscious or anything like that. My caregiver would understand everything that was going on with the device itself.	Planned
33	So, yeah, but they she trained me really well. She trained my family, she really trained my family. But they had daily training. Edith had daily training with my family. She even came to the house.	Unplanned

Appendix D: Disposition Narratives

UID	***Quote***	***Strategy***
	Insecurity - Understanding	
39	I believe that there is a need for continuing education and continuing reminders of certain things like what are the five steps required to change your controller, for example,	Planned
42	Well, I think what overwhelms people is the fact that it tends to be a cram course. I mean, there's two hours set aside. You bring them into the clinic and they say, "You do this, this and this. You got that?" "Oh, yeah. Okay. Got it." And then an hour later you don't remember half of it... They just need repetition. We the patient and the caregiver needs a lot of repetition, especially since a lot of us are older, our health has been compromised. Our mental faculties may not be quite what they were years ago. Who knows, we may have lost some brain cells in surgery under anesthesia.	Planned
42	So I think that the teaching needs to be reinforced by testing. And then retesting if necessary. Verbal quiz, written quiz, whatever, to reinforce procedures.	Planned

44	But I think that would have been better if they would have got me back there and so ... excuse me, and take me through it. What I'm going to experience, yada, yada, all that.	Planned
48	I thought they did a good job with what I'll call the mechanics of the operation, how to do these [inaudible 00:18:08] Which was most important. I don't think they did a good job of helping the patient understand the system.	Planned
61	Q: Did you feel comfortable once you went home? A:I wasn't entirely sure about it. And my wife and kids had to go up to a wedding, so they weren't actually home that time. My parents were over. My dad actually drove up and brought me home. But I just hung around home for the first few days and I wasn't even walking 500 meters for a few days afterwards, but then I was doing 500 meters or so, and just gradually built up.	UNplanned
61	I wasn't sure that I'd be able to handle the dressing changes without any sort of guidance or anything, but after that, I got locked up in hospital again a few times while on the VAD. And I had to go up to that hospital on that ward and sometimes I was a bit lazy and asked for them to do the dressing changes, but sometimes I was doing it myself. It didn't really bother me and I didn't have to have someone with me and all that sort of stuff.	UNplanned

	Confidence	
45	No, I felt very confident. Yeah. I think my parents and I all felt very good about the education we've been given.	Planned
31	I knew it all basically.	Planned
61	But I don't know that they really could have done anything else for me in terms of the VAD training and that sort of stuff.	UNplanned
62	Okay? Call your team. I found this out. I didn't know this, but I said something about, I called the other day and I got some guy, I didn't know who the heck it was that answered the phone and stuff. And they said, "You're lucky." And I said, "Why?" "Because if you were just a regular heart patient, that phone ring and ring and ring and ring and you wouldn't get nobody." He says, "But you're LVAD. So therefore we have people to answer that phone just for LVAD no matter what." I said, "Oh really? So I'm still a little special."	UNplanned
45	They did it really well at university of Colorado. They really, that was like the most important thing was making sure we knew what to do and who to call when to call.	Planned
	Frustration with Inconsistent Center Messages	

39	Never taught me how to do it. They never brought it up, even though I would say, Kevin, the PA, showers guy, how do I ... Well, we got to make sure that you're ... I mean it's looking good but we'll talk about it. Finally, I, hearing about people's experience across the country, said, okay, so I'm going to buy some Tegaderm from Amazon- (Referring to Showering Procedures)	Planned
42	What's interesting and what perhaps you're doing can play a role in, just from being involved in LVAD type websites or most recently in my case Facebook, the protocols vary a lot from center to center. So, there's really a lack of uniformity because as far as I can tell there's no central authority that says, "Okay, here's the best practice." It's all very personalized and it's based on people's education level and that area of experience, personality. So if you have 150 centers, you've got 150 different ways of doing things. Even the dressing process.	Planned
	Insecurity - Outside. Medical Provider Knowledge	
61	Well, and not many people knew what it was. Well, no one outside the hospital actually knew what an LVAD was. And even people at that hospital didn't know what it was. Anywhere else on the hospital, they didn't really know, they would've known what to do or anything like that.	UNplanned

	Cognitive Impairment	
44	I was pretty whacked out. I was really not getting it all. I didn't remember people who came and saw me and that whole ... I was there for almost a month. I think the information they gave me during that time was not ... it wasn't processing with me because I didn't know what the hell was going on.	Planned
42	Well, I think what overwhelms people is the fact that it tends to be a cram course. I mean, there's two hours set aside. You bring them into the clinic and they say, "You do this, this and this. You got that?" "Oh, yeah. Okay. Got it." And then an hour later you don't remember half of it... They just need repetition. We the patient and the caregiver needs a lot of repetition, especially since a lot of us are older, our health has been compromised. Our mental faculties may not be quite what they were years ago. Who knows, we may have lost some brain cells in surgery under anesthesia.	Planned
62	It took a while because the month in a coma I had to relearn. I had to literally relearn how to walk, how to use most of my motor functions. As a matter of fact.	UNplanned
61	I don't know that I did it written. Because I could hardly read or focus my eyes even, let alone control pen to write when I first got onto the	UNplanned

ward. I think it was verbal response to questions, I think. About the controller and the safety stuff like that.

Appendix E: Adjustment Narratives

UID	*Quote*	*Strategy*
	Blind Trust	
33	If you say I know what I'm doing, I have no idea. You know I leave it to those guys. I just know. I feel good, I can't sleep because this thing doesn't slow down. It's always pumping four liters. So I got to be a sleeping pills which I don't mind it, I don't like it but you know if it's what I got to do, I don't care, you know, it's not a big deal.	UNplanned
	Misunderstood - Feeling Alone	
62	You wake up your whole your whole life just changed and you don't know. I mean, and people don't get it.	UNplanned
	Adjustment	
61	But in my case, there was no time for me to talk to any of those people while I was still conscious. It's different, but no one likes having the VAD, ultimately. You got to try to make the best of it you can. ...Well, I found it very difficult to adjust to actually having the VAD, but see that was because it was, and they agree	UNplanned

	with me, it's more difficult to adjust if you're not expecting it. It was all very surreal.	
62	They tell me all the time, "You got to get used to your new normal," and two years later, I just keep trying to push it back. Because I want my old normal back. I want to be able to go. I want to be able to do what I did, and it's not easy. It's hard. It's always hard. And it's like anything. You have your bad days. You got to keep telling yourself don't live there. It's just a bad day.	UNplanned
	Not enough Explanation - Meanings	
61	Because I always had a heartbeat. Once I had the LVAD, I think maybe from early March, my heart started to recover. It got back to a normal level. Even before I left hospital, one of the consultants, one of the doctors said, "All the cards are on the table," and I'm thinking what does that mean? I asked one of the nurses. Apparently, she was... The doctors play their cards close to their chest. That phrase because that threw me. Because they had told me you'll have the LVAD until you get a transplant. But then when XXX said that, all the cards are on the table, then I'm thinking, what does that mean?	UNplanned

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