



WHAT IS THE MEANING OF OCCUPATIONAL THERAPY FOR PATIENTS WITH LEFT VENTRICULAR ASSIST DEVICES IN ACUTE CARE?

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Abstract

Patients with end-stage heart failure may rely on left ventricular assist devices (LVADs) when heart transplant is delayed or not an option. Growing numbers of patients with LVADs has led to more research being performed to discover what services and support they need. None of this research has examined these patients' experiences with occupational therapy in the hospital. Using the interpretative phenomenological approach (IPA) of qualitative study, semi-structured interviews of seven questions were conducted to extract the meaning of the occupational therapy services received in acute care for participants. Nine participants were recruited in a convenience sample. They were within six months of LVAD implantation, as bridge to transplant or destination therapy, and ranged from 19-78 years of age. Data analysis established four major themes: lifestyle change, caregiver support, physiological process, and occupational therapy relevance: hospital to home. The participants all viewed occupational therapy services and having an actual shower in the hospital as beneficial to their preparation for returning home. This study demonstrates that patients with LVADs perceive occupational therapy services meaningful, as they provide positive caregiving, beneficial interventions, and education during hospitalization after LVAD implantation, facilitating life change. As the number of individuals with LVADs continues to grow, occupational therapy educators, students, and practitioners need to be aware of the services they can offer patients with LVADs and the meaning these patients ascribe to occupational therapy. Increased awareness and education regarding the LVAD and support occupational therapy services offer to patients with LVADs will improve the quality of care provided.

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What is the Meaning of Occupational Therapy for Patients with Left Ventricular Assist Devices in Acute Care?

A heart transplant is the most desirable treatment for end stage congestive heart failure. However, a heart is not always available to a patient right away, nor is it always an appropriate solution for a patient, especially if a patient has other co-morbidities. If quality of life has decreased and/or death is imminent, a left ventricular assist device (LVAD), is often considered, making it a more common option for patients with end stage heart failure (Iseler & Hadzic, 2015). The LVAD has improved technology with a smaller sized, continuous flow pump compared to the earlier, larger pulsatile pump, allowing for increased implantation of the device into patients as bridge to transplant (BTT) or destination therapy (DT) (Lietz, 2010). With the elevated number of LVADs being placed, occupational therapy practitioners are expected to treat an increasing number of patients following their LVAD surgery. Thus, as the number of patients with LVADs increases, occupational therapy practitioners could benefit from discipline specific research involving these patients. Occupational therapy practitioners need to increase their knowledge of patients with LVADs, including analysis of appropriate interventions addressing the changing needs of these patients which could result in regaining functional independence.

As the number of patients with LVADs has risen, there has been an increase in the body of research regarding this population. One area of study for patients receiving LVADs is therapeutic exercise, which is also an area of focus for occupational therapy. Prior studies have identified the importance of exercise for increasing functional independence for patients implanted with a LVAD (Bogaev et al., 2011; Hayes, Leet, Bradley, & Holland, 2012). Other areas of interest for occupational therapy practitioners identified by previous literature are self-care and community re-entry. Prior investigators examined adjustment with transitioning back

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into the home environment and the difficulties encountered on discharge, including the ability to perform activities of daily living (ADLs) (Casida, Maruccilli, Peters, & Wright, 2011). While other disciplines have performed research applicable to occupational therapy practice, they lacked occupational therapy specific information when working with patients with LVADs. The research that exists was focused from other discipline perspectives, or comprised of case studies in inpatient rehabilitation settings, and was not focused on discharge preparation (Abramson, Harvey, Greenfield, Lauman, & Metzler, 2016; Nissinoff, Tian, Therattil, Salvarrey, & Lee, 2011).

In addition, there has been some qualitative research, using a phenomenological approach, addressing self-care needs and home adjustment needs of patients with LVADs, such as dressing, showering, and socializing. However, those studies have been primarily interested in the nursing or caregiver perspective. Few studies involved the patient perspective, nor did they address occupational therapy (Baker, Flattery, Salyer, Haugh, & Maltby, 2012; Casida et al., 2011; Marcucilli, Casida, Bakas, & Pagani, 2014). While those studies have contributed to qualitative knowledge regarding the patients with LVADs population, a deeper understanding of the post-operative experience from the patient's perspective is needed. In addition, there are few occupational or physical therapy publications regarding patients with LVADs and those that do exist suggest that further research is needed to understand what is important to patients after LVAD surgery and how occupational therapy practitioners can help them achieve their goals (Abramson et al., 2016).

The purpose of this study was to investigate the experience of hospital-based occupational therapy, from the perspective of patients who had recently been implanted with a LVAD. Current scientific literature has revealed a knowledge gap regarding patients'

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perceptions of how occupational therapy practitioners can assist with their transition from hospital to home after LVAD placement. By filling the gap, occupational therapy practitioners could have a better understanding of the services they might provide to assist this population. The current study sought to answer the following question using an interpretative phenomenological approach: What is the meaning of occupational therapy for patients with LVADs in acute care?

Literature Review

A literature search was performed, by way of multiple online databases, regarding occupational therapy services for patients with implanted LVADs. The results of the literature search demonstrated at least 14 articles supporting exercise for increased function and quality of life (QOL) for patients with LVADs (Abshire, Dennison Himmelfarb, & Russell, 2014; Ben Gal et al., 2015; Bogaev et al., 2011; Buck, 1998; Evans et al., 2011; Fernandez & Ford, 2014; Freeman & Maley, 2013; Hayes et al., 2012; Humphrey, Buck, Cahalin, & Morrone, 1998; McGarrigle & Caunt, 2016; Nicholson & Paz, 2010; Perme et al., 2006; Rogers et al., 2010; Shoemaker et al., 2014). In addition, literature was found regarding the caregiver experience post LVAD implantation (Abshire et al., 2014; Baker et al., 2010; Brouwers et al., 2011; Casida, 2005; Casida et al., 2009; Casida et al., 2011; Iseler & Hadzic, 2015; Marcuccilli et al., 2014). There was also a noted increase, as compared to five years ago, in literature involving case studies and retrospective analyses involving physical therapists and focusing on functional independence measure (FIM) scores (Alsara et al., 2014; Chu, McCormick, Hwang, Sliwa, & Rydberg, 2014; English & Speed, 2013; Hollander et al., 2014; Nguyen & Stein, 2013; Nissinoff et al., 2011; Norton, Kuhar, & Poduri, 2015; Yost, Coyle, Milkevitch, Adair, Tatooles, & Bhat, 2017). Through the course of the search there appeared to be a significant gap in the literature

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regarding occupational therapy intervention for patients with LVADs, with no research in the literature demonstrating a deep understanding of the patient's hospital experience following LVAD implantation. The current review was intended to further identify areas of need in the research which were beginning to develop for occupational therapy practitioners and to provide insight into what was needed from a patient perspective.

History

The first LVAD was implanted in the 1980's as a BTT. (Stewart & Givertz, 2012). At that time the LVAD consisted of an implanted pulsatile device into the heart that was connected via external line to a large power module on wheels. The patient was able to get out of bed to chair and may or may not have been able to walk-in the hallway. No shower was permitted, only sponge bathing, for the patient's safety. The patient was not able to be discharged home and remained in the hospital until an available heart could be found. Physical limitations persisted with this large device implanted in the pre-peritoneal space, affecting pain, mobility, and food consumption. In 1998, the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) study trials were initiated. This study continued until 2001 and led to the US Food and Drug Administration (FDA) approval of a modified LVAD, which was created by Thoratec to be used for DT, or as an alternative treatment to a heart transplant (Lietz, 2010). The LVAD in the REMATCH trials, though smaller and no longer pulsatile, still put great limitations on the patient's functional independence. The medical and therapeutic focus for the patient with a LVAD at that time was not independence in function, but preventing deconditioning while awaiting a heart or other form of treatment (Humphrey et al., 1998). Case studies published by Buck (1998) demonstrated the importance of exercise and

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mobility as part of the physical therapy treatment for patients receiving LVADs at the researcher's facility.

Ventricular assist device technology continued to evolve, with the development of several models of circulatory support devices, including the Thoratec HeartMate II. The HeartMate II was a smaller, continuous flow LVAD, with device implantation into the heart. It was attached to either a smaller power-based unit or battery powered by way of an external drive line and smaller controller, which could be worn on the person. Trials of this mechanical circulatory support system were completed in 2007, with FDA approval for BTT in 2008 and DT in 2010 (Lietz, 2010). Since the FDA approval of the HeartMate II, different manufacturers have designed similar devices with some variations, such as the centrifugal force HeartWare HVAD, which was also approved by the FDA for BTT (Slaughter, et al, 2013). The smaller size of the VADs allowed for increased mobility and functional independence for patients receiving the device. However, the initial investigations of patients with LVADs postoperatively remained focused on exercise capacity and mobility, with minimal or no mention of occupational therapy services (Abshire et al., 2014; Ben Gal et al., 2015; Bogaev et al., 2011; Evans et al., 2011; Freeman & Maley, 2013; Hayes et al., 2012; Nicholson & Paz, 2010; Rogers et al., 2010; Shoemaker et al., 2014).

Exercise Post LVAD

Therapeutic exercise has always been identified as beneficial to patients with LVADs (Ben Gal et al., 2015; Bogaev et al., 2011; Evans et al., 2011; Hayes et al., 2012; Rogers et al., 2010). Several investigations examined exercise capacity, based on data from the HeartMate trials (Bogaev et al., 2011; Rogers et al., 2010). Exercise capacity was evaluated with 6-minute walk tests, lab values, cardiac functional status measures, and cardiac QOL measures at varying

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timeframes, both pre and post implantation. Findings demonstrated that while some patients could not walk prior to LVAD implantation, they had improved activity tolerance, walked increased distances, and had improved QOL scores after LVAD implantation. The researchers' results highlighted the importance of exercise and mobility after LVAD implantation for improving functional independence and QOL. However, the studies did not report from the patient's perspective and did not mention exercise in relation to occupational therapy services, though this is an area within their scope of practice as it relates to the performance skills of patients (American Occupational Therapy Association [AOTA], 2014).

Later studies included physical therapists and nurses along with physicians performing the research (Ben Gal et al., 2015; Evans et al., 2011; Hayes et al., 2012). With the inclusion of physical therapists and nurses, there began to be an emphasis on exercise protocols post LVAD placement and on the types of exercise performed. Exercises included cycling, treadmill ambulation, and strengthening of the upper and lower extremities. The exercises varied in the frequency of daily performance and number of repetitions. Findings of the studies demonstrated that despite the varied exercises and exercise protocols that patients experienced after LVAD surgery, increased strength, endurance, and gait distance were observed (Ben Gal et al., 2015; Hayes et al., 2012). An analysis of the current research conducted by physical therapy and nursing professionals indicated that patients with LVADs who exercised had shorter lengths of stay in the hospital (Evans et al., 2011). The above studies demonstrated the positive effect of exercise for patients with LVADs and the importance of interdisciplinary involvement during patient care. Researchers also began to recognize the importance of earlier mobility, QOL, and improved functional independence, for easier re-entry into the community after discharge. However, the investigations lacked occupational therapy and patient perspective, instead

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researchers based their findings on observation, professional surveys, or retrospective chart analyses (Ben Gal et al., 2015; Evans et al., 2011; Hayes et al., 2012).

Quality of Life Post LVAD

In the earlier REMATCH trials, improved QOL was observed, which prompted more studies looking at overall wellbeing of patients and caregivers following LVAD implantation (Lietz, 2010). Quality of life, especially with regards to maintaining independence with self-care and home or community management were identified areas within the occupational therapy scope of practice (AOTA, 2014). As researchers became more focused on the QOL for patients with LVADs, more qualitative findings were published and concerns about the effects on caregivers came to light (Baker et al., 2010; Brouwers et al., 2011; Casida et al., 2011; Casida et al., 2009; Iseler & Hadzic, 2015; Marcuccilli et al., 2014). For example, stress of adaptation to a new way of life after the patient was implanted with a ventricular assist device was identified by caregivers (Marcuccilli et al., 2014). In particular they voiced their commitment to the patient, as well as their sacrifices. Caregiver sacrifice included leaving their jobs and incurring financial strain, as well as decreased time with friends, and decreased attention to their own health (Baker et al., 2010). In general, it appeared that LVAD implantation was a serious life change requiring time for the whole family to fully adapt (Marcuccilli et al., 2014).

Casida et al. (2011), found that patients with LVADs identified the importance of hospital staff assisting patients and caregivers with the transition from life before LVAD implantation, to returning home after implantation. Transitional assistance was not just for physical changes, but also for social and emotional needs of the patient and family. Though nursing focused, the study touched on areas within occupational therapy scope of practice, including home modification, which consisted of rearranging furniture to fit the power-based

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unit, and to make moving with the power cord safe. In addition, self-care was addressed, especially fear of the first shower at home, post LVAD placement. The AOTA (2014) described one of the goals of occupational therapy as aiding patients and families with the transition and adaptation to life changes after a significant health event. Perhaps occupational therapy practitioners could provide this service for patients with LVADs and their families or caregivers. An in-depth understanding of the needs of these patients during hospitalization, aftercare, and on discharge would provide a guide for occupational therapy practitioners to help patients and caregivers with these transitions.

Interdisciplinary Approach Post LVAD

In recent years, a multidisciplinary, evidence-based approach to the treatment of patients receiving LVADs has been emphasized. (Alsara et al., 2014; Chu et al., 2014; English & Speed, 2013; Fernandez & Ford, 2014; Hollander et al., 2014; McGarrigle & Caunt, 2016; Murray et al., 2009; Nguyen & Stein, 2013; Nicholson & Paz, 2010; Norton, Kuhar, & Poduri, 2015; Shoemaker et al., 2014; Yost et al., 2017). The majority of these studies occurred in an inpatient acute rehabilitation setting and were published as case studies or retrospective analyses of patient charts. Some studies were physical therapy focused, looking at the benefits of exercise and mobility for patients with LVADs and other assistive heart devices (Fernandez & Ford, 2014; McGarrigle & Caunt, 2016; Nicholson, & Paz, 2010), while other studies looked at FIM score comparisons (Alsara et al., 2014; Chu et al., 2014; English, & Speed, 2013; Nguyen, & Stein, 2013; Norton, Kuhar, & Poduri, 2015; Yost et al., 2017). The FIM is the most commonly used assessment in the inpatient rehabilitation setting, and measures daily living skills and mobility independence on a seven point scale with one being total assistance and seven being independent (Alsara et al., 2014). The patients reviewed in the studies received standard care appropriate to

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an inpatient rehabilitation unit, with daily occupational, physical, and speech therapies, in addition to nursing and physician care. The results of the investigations demonstrated significant functional gains during inpatient rehabilitation stays, according to higher FIM scores at discharge as compared to admission scores (Alsara et al., 2014; Chu et al., 2014; English & Speed, 2013; Nguyen & Stein, 2013; Norton, Kuhar, & Poduri, 2015; Yost et al., 2017). The studies involved single-group cohorts who received inpatient acute rehabilitation services. There was no comparison to groups not receiving the acute rehabilitation services, therefore limiting the reliability of the studies' assumptions that this setting was more effective for improving patient function than another setting. Comparison of differing treatment and non-treatment groups would be important for future evidence-based practice. The investigations highlighted the importance of the interdisciplinary team, explaining that the patients benefited from the services provided. However, they did not give any detail regarding the scope of occupational therapy services involved. These studies did not give any insight into the patients' perceptions of their rehabilitation and no information was provided regarding the care that occurred in the acute care setting prior to inpatient rehabilitation admission.

Occupational Therapy Post LVAD

In 2004, Shepherd and Wilding published not a research study, but a discussion regarding what occupational therapy could possibly offer patients implanted with LVADs. The authors discussed the role of occupational therapy, involving exercise through purposeful activity, LVAD equipment safety, self-care, and education of patients and caregivers. They identified patients with ventricular assist devices as a growing population, needing occupational therapy support for functional living. While these topics are still applicable, this article was published prior to the HeartMate II trials and the technology referenced in the article would not be relevant

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to current healthcare practice. Other narratives, such as that of Abramson et al. (2012) and McIntyre (2007) provided general overviews of mechanical circulatory system technology and occupational therapy considerations and interventions. The authors provided general information regarding occupational therapy services across healthcare settings and reported that the occupational therapy intervention appeared beneficial to patients. However, the McIntyre (2007) article had inaccuracies with regard to self-care interventions, possibly due to out of date information. Both articles ended by requesting that evidence-based research be conducted to support occupational therapy services, for patients receiving mechanical circulatory support.

More recently, Padmanabhan and Thankachan (2011) published a discussion of the phases of occupational therapy treatment provided throughout the healthcare continuum for patients with LVADs. The authors described their own protocols used in acute care, inpatient rehabilitation, home health, and outpatient services. Their protocol was a six-phase intervention, including routine occupational therapy activities such as the initial evaluation, positioning, range of motion, splinting, ADLs, energy conservation, upper extremity coordination, and endurance building. The focus on ADLs began at bedside with feeding and grooming, and then moved to advanced self-care tasks, such as shower kit training, including the equipment and precautions needed for the LVAD. Upper extremity coordination was important for general LVAD management, involving manipulation of the power connectors and moving from the power-based unit to battery power. Occupational therapy also assisted with the discharge planning for the patient and family. The patients remained in the hospital or inpatient rehabilitation setting until they were independent with their LVAD and daily living skills, or they moved on to another level of care. The final phases of care involved moving the patient to long-term acute care, a skilled nursing facility, outpatient setting, or home health. Throughout all phases, education was

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provided to patients and caregivers (Padmanabhan & Thankachan, 2011). The authors reported successes, with patients achieving improved function and caregiver satisfaction with the described methods of occupational therapy intervention. However, the reported successes are the authors' opinions of the results of interventions they believed are best practice. Their protocols had not been studied for their effectiveness by a quality research design, nor had they been compared to other possible interventions. The authors discussed gaps in evidence-based literature demonstrating the benefits of occupational therapy for individuals with a ventricular assist device, as well as the need to further explore how occupational therapy practitioners could assist patients and their families transition from hospital to home.

Summary

Overall, there appeared to be agreement among researchers that the number of patients with LVADs was growing and that healthcare professionals, including occupational therapy practitioners, needed to know more about these patients and their care (Abramson et al., 2012; Alsara et al., 2014; Chu et al., 2014; English & Speed, 2013; Evans et al., 2011; Hollander et al., 2014; McIntyre, 2007; Murray et al., 2009; Nicholson & Paz, 2010; Nguyen & Stein, 2013; Norton, Kuhar, & Poduri, 2015; Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004; Shoemaker et al., 2014, Yost et al., 2017). Interventions such as exercise and improving performance in ADLs have been analyzed for the LVAD population, but lacked occupational therapy specific guidelines (Ben Gal et al., 2015; Bogaev et al., 2011; Casida et al., 2011; Evans et al., 2011; Hayes et al., 2012; Rogers e. al., 2010). In addition, many case study presentations and retrospective studies focused on FIM scores achieved in inpatient rehabilitation settings (Alsara et al., 2014; Chu et al., 2014; English & Speed, 2013; Nguyen & Stein, 2013; Nissinoff et al., 2011; Norton, Kuhar, & Poduri, 2015; Yost et al., 2017), while other case studies were

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concerned with physical therapy and early mobility (Fernandez & Ford, 2014; Nicholson & Paz, 2010; Perme et al., 2006). These studies provided no support for occupational therapy services, nor did they describe the patient's in-depth experience during the interventions.

Current literature demonstrates a lack of "patient-reported outcomes" for patients with LVADs (Brouwers et al., 2011). Many studies related to the post-operative patient with a LVAD are quantitative in nature (Alsara et al., 2014; Bogaev et al., 2011; Chu et al., 2014; Hayes et al., 2012; Murray et al., 2008; Nguyen & Stein, 2013; Norton, Kuhar, & Poduri, 2015; Rogers et al., 2010; Shoemaker et al., 2014; Yost et al., 2017). Quantitative studies lack the deeper inquiry and understanding that can be derived from a qualitative research study. The few published qualitative studies are typically related to QOL, they are from the caregiver or family perspective, and the authors failed to provide insight that could have been offered from the patient, particularly directly after LVAD implantation, while the patient remained in the hospital (Baker et al., 2010; Brouwers et al., 2011; Casida et al., 2011; Casida et al., 2009; Iseler & Hadzic, 2015; Marcuccilli et al., 2014). There is clearly a need for additional patient-reported research from the individuals receiving LVADs.

A gap in the literature exists for demonstrating the services and benefits occupational therapy could offer for LVAD intervention in the acute care setting. Further qualitative research delving into the in-depth patient perspective of occupational therapy services should be pursued in order to better understand and serve the growing numbers of patients being implanted with LVADs. A qualitative investigation would provide occupational therapy practitioners with the insight needed to meaningfully assist patients who were adapting to the significant life change that occurs post LVAD implantation. To this end, the investigator of the current study

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utilized interpretative phenomenology to answer the research question, “What is the meaning of occupational therapy for patients with LVADs in acute care?”

Method

Study Design

Interpretative phenomenological approach (IPA) was the qualitative approach used in this study. With its psychological focus, Smith, Flowers, & Larkin (2009) described IPA as analyzing the experience of a major occurrence in someone’s life and his or her view of its significance. Specifically, IPA addresses a time of major change in one’s life; for example, the researcher may want to understand the process relating to the placement of a LVAD and the changes that occurred postoperatively in a patient’s life. Interpretative phenomenology is said to be “double hermeneutic” because the researcher was attempting to find meaning in the participant’s meaning of their experience (Smith et al., 2009). Interpretative phenomenology based on Van Manen’s hermeneutic phenomenological approach (Van Manen, 1990) has been used to describe the experience of spousal caregivers for patients receiving LVADs (Casida, 2005) and the experience of LVAD patients during sex and intimacy (Casida, Marcuccilli, Peters, & Wright, 2011). It was anticipated that the deeper meaning derived from IPA would provide greater insight for occupational therapy practitioners regarding the significant life change endured by patients with LVADs, after being implanted with the device. This would help occupational therapy practitioners understand what was important to these patients, and provide insight into how they could better serve patients who had been implanted with a LVAD. The current study explored the meaning of occupational therapy for patients with a LVAD in the acute care setting.

Sample Selection and Recruitment

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Participants

In keeping with a qualitative approach (specifically IPA) a convenience sample of nine participants were selected, with the goal of finding common themes in the data. The study incorporated the following inclusion criteria, which was in keeping with prior studies by Casida (2005) and Casida et al. (2011):

- Male or female
- Able to follow 3-step commands
- 18 years of age or older
- Received a left ventricular assist device as either BTT or DT within the last 6 months
- Received occupational therapy, including shower kit training in the acute care setting, prior to discharge home.

As the tenets of IPA emphasize a concentrated focus on receiving detailed accounts of the patient experience, with quality, not quantity being the primary goal, a sample of nine participants is appropriate for this study (Smith et al., 2009).

Interviews were conducted with nine participants, including four women and five men. Participants had an age range of 19 – 78 years, with a mean age of 52 years. Six participants were African American and three participants were Caucasian. Seven participants had received HeartWare LVADs, while two had been implanted with HeartMate II devices. Four patients received LVADs as BTT, while five were designated as DT. The mean number of days post LVAD implantation was 85. While not all participants were married, they all had family support. Characteristic information is summarized in Table 1 (see Appendix E).

Recruitment

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Institutional Review Board approval was obtained prior to recruitment, and data collection from both Emory Saint Joseph's Hospital (ESJH) and the University of Indianapolis. Recruitment and data collection took place in the outpatient Congestive Heart Failure Clinic at ESJH during or after a follow up visit for patients who were post LVAD placement.

Recruitment proceeded as follows:

The primary investigator developed a flyer which included a short description of the study, general inclusion criteria, the nature of the procedures, estimated time commitment, location, and a short description of the investigator and her contact information (see Appendix A). The primary investigator provided copies of the flyer to the LVAD nurse/coordinator performing follow-up visits with patients. During the course of regularly scheduled heart failure clinic appointments, the LVAD nurse/coordinator gave the flyer to patients who potentially met the inclusion criteria. She provided limited information to the participant by way of a written script (see Appendix B).

Patients who met the inclusion criteria were identified by the LVAD nurse/coordinator. The LVAD nurse/coordinator received permission from these patients for their contact information to be provided to the primary investigator, and told them that they would be contacted by the primary investigator (see Appendix B). The LVAD nurse/coordinator provided this information to the primary investigator using a password protected email account within the ESJH secure network. The LVAD nurse/coordinator made it clear to the patients that participation in the research study was voluntary.

The primary investigator contacted these patients by telephone, to confirm their eligibility for the study and to answer any questions. When a patient expressed interest in participating in the research study, the primary investigator and patient set up a time to meet at the clinic to

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complete the informed consent process and conduct the interview. The primary investigator then mailed a hardcopy of the informed consent document to the patient for review prior to the face-to-face informed consent process and interview.

Data Collection

Data collection consisted of one face-to-face semi-structured interview with each participant. Informed consent (see Appendix C) was obtained when the patients and primary investigator came together for the interview meeting. During the informed consent process, the primary investigator read through the informed consent document with the patients and responded to any questions or concerns. The primary investigator verbally reviewed the study title, purpose, information regarding how the patients' information would be used, and included an explanation of how the patients' confidentiality would be maintained. If the patients agreed to participate in the study, they signed the consent, along with primary investigator.

For each participant, the semi-structured interviews took place in one of the heart failure clinic's private consultation rooms at a time convenient to the patients. The interviews, which lasted an average of 30 minutes each, were face-to-face, audio-recorded, and consisted of a predetermined set of questions (See Appendix D). During the interviews, the primary investigator asked the participants for further clarification as needed, and asked probing questions to facilitate better understanding of the participants' experiences. These procedures were consistent with those recommended by Smith et al. (2009) for an interpretative phenomenological analysis, and were similar to those utilized by researchers examining similar phenomenon (Casida, 2005; Casida et al., 2011).

Participants began the interviews by reflecting on their experience in the acute care hospital setting. They all discussed their experiences just after surgery, with some reporting

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difficulty remembering everything due to medications received or temporary altered mental status. In general the participants focused on interactions with hospital staff, the processes surrounding getting accustomed to their new LVADs, and the education and preparation they received prior to going home. Interviews were concluded with the participants' descriptions of the transition and experience upon returning home.

Prior to, and in between interviews, the primary investigator used bracketing procedures consisting of journaling, to express her own thoughts, opinions, reactions, and feelings in reaction to the interview process and content. Bracketing is considered hermeneutic or interpretive, as it helps to decrease the possibility of biases and assumptions regarding the experiences being studied, although a basic tenant of qualitative research is that some level of bias is to be expected when in-depth, personal information is sought from participants (Fischer, 2009). Bracketing, including journaling, allows researchers to acknowledge their opinions on a subject and then "reflexively" examine and interpret them as part of an ongoing process during data collection and analysis. By bracketing and reflecting on his or her assumptions, a researcher becomes more self-aware and is able to see different meanings in assumptions or perceptions, which may change one's viewpoint (Fischer, 2009). In this study, bracketing and disclosure of the investigator's and colleagues' backgrounds were used throughout data collection, analysis, and documentation of the findings.

Data Analysis

A coding system was used to identify participants on all transcripts and demographic characteristic logs in order to maintain confidentiality. After the interview data was collected in each session, the audio recordings were then transcribed verbatim into a word document, on a password protected computer, by the primary investigator. The accuracy of the transcribed data

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was verified by the primary investigator by reading the transcripts and comparing them to the original recordings. The transcriptions were then immediately forwarded to two additional therapists (one occupational and one physical therapist) working at Emory Saint Joseph's Hospital, who performed data analysis along with the primary investigator. The process of data analysis, which took place immediately after each interview and again after all interviews had occurred, was based on the sequence recommended by Smith et al. (2009) and included the following steps:

The primary investigator and colleagues independently read and re-read the transcripts, which were de-identified, using numbers instead of participant names. The primary investigator and colleagues independently made written notes during the reading and re-reading of the transcripts, describing initial interpretations regarding the content, a practice referred to as "memoing" (Creswell, 2014).

In keeping with IPA recommendations the analysts then highlighted emergent themes in the individual interviews by reading over initial notes and identifying concepts, categories, and patterns between comments made (abstraction) (Smith, et al., 2009). This finding of "first level" concepts and developing categories was also part of the open coding process frequently used in qualitative research (Biddix, 2009).

The primary investigator and colleagues then searched in the individual interviews for connections across emergent themes for "super-ordinate" themes, exploratory comments, and emergent themes (subsumption). This was done by creating written category listings taken from the text of the original transcripts and written on pages of legal pads. To explore the relationships between themes (to garner all the important facets) the process of axial coding was used and allowed the qualitative researchers to expound on, or revise original themes that were

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identified (Biddix, 2009). They looked for opposing relationships between themes (polarization), temporal or cultural themes (contextualization), the frequency of occurrence of emergent themes (numeration), and the positive or negative presentation of themes (function) (Smith, et al., 2009).

After individually going through each case to highlight themes (within-case coding), the primary investigator and colleagues moved on to individual analysis of themes across cases (cross-case coding). Therefore, initial themes (open coding) and relationships between themes (axial coding) were identified for both within-case and cross-case coding. Looking at individual participants allowed for deeper understanding of the individual, but looking at multiple participants to find common themes allowed for a deeper understanding of the experience (Ayres, Kavanaugh, & Knafl, 2003). The primary investigator and colleagues performed bracketing (journaling and discussion) throughout the analysis in order to limit possible biases brought out by the data collection and analysis processes (Fischer, 2009).

The primary investigator and colleagues then came together to look for patterns across cases by laying out the individual case theme lists and analyzing themes side by side, looking for connections, relationships, and frequency, in a categorizing list format. Re-labeling or re-naming of the themes occurred. This process allowed for triangulation of the data analysis to increase the trustworthiness of findings (Curtin & Fossey, 2007). This step of interpretation, allowed for a deeper analysis of the emergent themes for further interpretation and comparison. By reading the transcripts and going through the process of analysis, while bracketing and discussing the themes with each other, the primary investigator and colleagues were able to follow the double hermeneutic philosophy of IPA. This philosophy involved the analysts gaining their own perspective of the participants' opinions of the care they received after LVAD implantation in

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acute care. The benefit of this process is a better understanding and interpretation of the lived experience (Smith, et al., 2009).

"Member checking" was performed after the initial data analysis via phone contact between each participant and the primary investigator. Member checking is one method by which to increase the trustworthiness of a study's data analysis because it allows for the most accurate presentation of the participants' experiences, even after analysis by others (Curtin & Fossey, 2007). During member checks with the participants, the primary investigator described the themes identified in each participant's own case and how they were determined. The participants had the opportunity to offer clarification or correction on the findings for better understanding of emergent themes. Member checking was performed with seven participants upon completion of the data analysis and identification of the themes. Member checking could not be performed with two participants, as they could not be reached over the phone and did not return voice messages left on voicemail.

Results

Themes

The findings in this study are presented as themes identified from participants' descriptions of their experiences after being implanted with LVADs. Through the analysis of participants' descriptions, four major themes emerged from the data: lifestyle change, caregiver support, physiological process, and occupational therapy relevance: hospital to home. The themes are presented below and illustrated by quotations from interview transcripts.

Lifestyle Change

All participants expressed having experienced a lifestyle change due to an awareness of the LVAD as part of their person, at all times. This new awareness started in the hospital and

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continued through to their life at home. They described the feeling of the bags they were carrying around and the management of the bags. In addition, they discussed use of the equipment at home and when out in the community. One participant stated:

...It's just a, a total new lifestyle. With, you know, maintaining and taking care of all the equipment, making sure that I have my spare battery and chargers with me when I go out. It's, it's a new lifestyle that you just have to adapt to. Always having equipment hanging around your neck, around your waist, and remembering to take the spare with you.

Another participant remarked:

Well, you've got this bag hanging around your neck everywhere you go and its, its 10 pounds, so it's, it's very heavy. I've learned how to separate it into two separate bags so that I can distribute the load a little better, but it's cumbersome. It's in the way and sleeping the bed with all this equipment, and having to make sure it doesn't fall off as you're turning over. It's harder to find clothes that fit around the drive line and that look decent to go out in public (laughs)...you know that it's, it's just a trial and error thing to, to find out what I can wear and what I can't...it's just a change.

Through the transition from hospital to home, all participants expressed coming to terms with the LVAD as part of getting back to their lives. One study participant said "It's with me til death do me part..." A few participants gave thanks for having the LVAD in order to spend more time with family and live life. Several participants also described moving through the fear and overwhelming knowledge of having the new equipment responsible for their lives. A participant explained "...I mean I was terrified...but now I'm okay and that's part of the process...getting to the point where you feel comfortable with your life change...and what you have to do, because it has to be automatic." Another participant said, "I was just scared...my

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wife she was there with me, and I was like “baby are we, we gonna do, be able to do this?”...It only lasted for a couple of days, and after that...we were good.”

As a whole, the participants expressed the importance of regaining their independence with their new LVAD lifestyle. The participants expressed that the teaching and preparation about the use of the LVAD at home was an important part of regaining their independence. One participant, when asked what was meaningful during the hospitalization after the LVAD was implanted said, “...The teaching process...they taught us how to change our lifestyle and live with the LVAD.” To some participants, the teaching involved the LVAD equipment and components, “...Ah well it’s a lot to take in all at once... swapping batteries and bags, and wall charger to battery and battery to wall charger...stuff that you for sure gotta do.”

Occupational therapy practitioners were identified as meaningful contributors in providing the teaching and preparation leading to increased independence for the participants, thus assisting the participants and families in their life change. Education regarding function and maintenance of LVAD equipment, exercises, home furniture adaptation, ADLs (specifically the shower process), and use of adaptive equipment in the hospital and then at home were mentioned by all participants. A participant and his spouse described some of the occupational therapy treatments received as, “[the occupational therapist] helped you in your daily life, like...how to situate like you get your little table and how to transfer your bags and how to get ready for showers...well I mean its stuff I had to learn...” Other participants discussed the occupational therapy teaching in regards to daily living skills:

...What you all do here is prepare me strength-wise and mentally-wise, as much as you can for going home...you have to, you know, take care of yourself, have to make that its plugged in, you have to make sure, at night sometimes I have problems with pluggin into

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the cord because there's, I have to go to the bathroom, its plugged in, unplug, plug in, unplug, but, um...I realize that and it's something I've accepted by accepting the LVAD in the first place...

When asked about his experience with occupational therapy in the hospital, another participant stated, "...[the occupational therapy] got me back on track, as far as getting my dependency, doing for myself, and I think that, that was pretty much needed."

As a group, the participants described a positive lifestyle change with the LVAD, expressing happiness with the care received in the hospital and their ability to return home to their lives. Even though they described some difficulty at the start, the education and preparation in the hospital, including that provided by occupational therapy practitioners, was a crucial identified element of the successful transition home to a new life.

Caregiver Support

Every participant that was interviewed, acknowledged that the caregiver support they received in the hospital and at home was meaningful for them. Caregivers were identified as healthcare professionals, including occupational therapy practitioners, and family members assisting in the care of the patients with LVADs.

Family was identified as a big part of the caregiving experience by all participants. Support from family was described as "just being there" and "going through the experience with the participant," to actual physical assistance while in the hospital following LVAD implantation. All but one participant described receiving help from family members of all ages in managing the new LVAD equipment and dressing. One study participant noted, "My grandbabies run and get the batteries, they just think that's the most adorable thing to do to take care of mamaw." Other participants discussed family support with daily living skills, either

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basic or instrumental, first in the hospital, then at home. A participant remarked, “[my wife] assisted me too with the shower...well she washed my back and you know soaped me up...”

Throughout the interviews, family support was mentioned with appreciation for their help, with some participants acknowledging the added burden to family members now that the participant had received an LVAD. Regarding the effects of the transition from hospital to home, one participant said, “...I don’t think hard for me...it might be a little difficult on my wife, cause I was a little bit, you know, I guess babyfied...” All participants expressed the importance of having family members involved in the training and preparation received from all healthcare professionals, including occupational therapy practitioners, during hospitalization.

Characteristics of the healthcare professionals providing caregiver support in the hospital, as reported by the participants included caring, understanding, attentiveness, encouragement, motivation, and patience. One participant said, “...I went through the surgery and it’s that they cared, they would give um, advice on the things that I should, you know, I can do... to better help myself... everyone, every, everyone was helpful.” All participants described positive caregiver experiences in the hospital setting, from the ICU to the telemetry floor. One participant stated, “I mean actually cried, a cried a couple of times when ah, a couple of nurses I wouldn’t see again, because they...were a big impact on me...and my recovery.” The participants were all able to name nurses, physicians, dietitians, psychologists, LVAD coordinators, therapists, social workers, and even environmental services technicians who assisted them while in the hospital. Seven participants expressed that the therapists or nurses understood the needs of the patients, therefore the patients needed to be open and receptive to what the caregiver was telling them. One participant remarked:

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...Even though some of your patients, like me, could be grouchy and don't want to do it...thinking you know "I know how to do this..." No, let [the healthcare professional] help you, cause...your thing was to get me out of here so I wouldn't come back worse than I was before...and it helped...

Occupational therapy practitioners were also identified as positive caregivers by all participants. Caregiving behaviors for occupational therapy practitioners were described by participants as being encouraging, caring, motivating, guiding, and professional. The occupational therapy practitioners' caregiving abilities were described in regard to the education or training they provided to the participants, with one commenting:

...the [occupational therapist] that worked with us was very professional, you know he took his time with us and showed us...what we need to do, you know, in, in the showers, and a how to take care of this [points to LVAD], um the do's and don'ts, the can's and cant's, because it's what motivates [pats the LVAD bag], you know keeps us going, so it was, it very professional...

Other participants remarked on the general support, consistency, and caring the occupational therapy practitioner provided them. One participant stated:

... [the occupational therapist] was very positive for me, um, and I hope the rest of the team is like that, and people can feel that because that's what we need, more than, than I think the doctors coming in and telling you everything is alright, is more of a comfort of everyday, and that's what the occupant, occupational therapist, um brings to the table, I feel.

Physiological Process

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Physical recovery and activity immediately after LVAD implantation was a focus of all participants in the interviews. All participants described the general recovery process immediately after LVAD implantation, particularly when dealing with the successes and frustrations of the body healing. They also described physical activity they performed following surgery and the challenges they faced when trying to become active again. Some participants discussed issues with tape allergies, continued intravenous (IV) medication use, peripherally inserted central catheters, other IV line issues, or body pain. A participant stated:

...It's a ordeal and for me it's a really big one because I'm allergic to the adhesive and I have to have it from here on out, trying to keep my skin protected is, is a chore, um, I look like I've been in a fight and I lost, but on the other hand, you know I'm, I've been told six months and it be good and that this point it's getting better...

Another participant remarked, "...I had a lot of stuff, um, hooked up to my, hooked up to me, um, I couldn't do a lot of arm, arm exercise...it was more, more of a pushing my little [IV pole]...and walking the halls." Other participants acknowledged challenges associated with loss of appetite and adapting sleeping behaviors for the LVAD. One participant stated, "...So, I had to kinda get myself, make myself, pump myself up to kinda eat, like cause I didn't have a appetite."

Physical strength of upper and lower extremities and overall activity endurance were other areas of focus for participants, particularly when getting out of bed. Many described the process of getting up from their bed as particularly challenging because they had to deal with the new equipment, which added weight to their already weakened bodies, and then the lack of strength in the upper and lower limbs making the task more difficult. They described sitting on

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the edge of the bed, moving to the recliner chair, and finally ambulating out into the hall and navigating stairs. One participant described this experience:

...I was able to go up steps, not like I wanted to, it, you know, before all this got started I was able to run up the steps and run it down. No. Ah, when I go up the steps I'm gonna stay up there for a while, when I come down, then I stay downstairs...

Despite just having undergone surgery, many participants expressed surprise that their bodies could not do more, as they felt better overall than prior to LVAD implantation. A younger participant said "...Cause I actually thought that I was like 'I'm so ready to get out of bed, I'm so ready to do this,' but you try to get up and you feel like an old man..."

Almost all participants mentioned occupational therapy's role in providing exercise programs to increase strength. Occupational therapy practitioners were seen as teachers providing information on regaining strength, but also motivating the participants to move more and be active with the new LVAD. In addition to strengthening, occupational therapy practitioners were noted as providing activities for range of motion, fine motor coordination, and pain relief. One participant reported "[the occupational therapist] had gave me all these things to do my strength with, like the little clay stuff, and...tied some stuff to my bed where I can like, do like reps or something [mimicked using theraband attached to bed for arm exercises]." Another participant stated:

... [the occupational therapist] gave me a sponge and told me to squeeze it, and even though I was squeezing it, I wasn't doing it all the time and the first thing... [the occupational therapist] said was see this is why, because actually, um putting the buckles on the bags and doing certain things you really needed the strength in your hands.

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Several participants reported neck, body, or shoulder pain and soreness following surgery and while in the hospital. They described how the exercises given by the occupational therapy practitioner helped with pain relief, with one participant saying, "...with having the shoulder pain, that it can get stiff, so with me doing the exercises, it, it keeps me from having to take the pain medicine... to where I can, you know, go about my day." Another participant explained:

...the first thing [the occupational therapist] taught me, that I loved, was about my neck, because this bag [points to LVAD bag] is so heavy, so [the occupational therapist] had me do the turns and the ups and downs and those things really helped, um because in the beginning it weighs about 10 pounds and you feel it...and now it's not as bad, and the funny thing is (chuckles), um that when it starts bothering me I start doing those exercises and it still helps.

Occupational Therapy Relevance: Hospital to Home

As described through the other themes identified above, occupational therapy services played a role in the hospital process of preparing the participants for their new lives and the transition to home. Positive experiences were described, and all participants commented that the guidance and education provided by the occupational therapy practitioners was beneficial, when incorporating the LVAD equipment and accessories (power-based unit, batteries, driveline, controller, bags) into their daily routine. All participants agreed that the occupational therapy services provided in the hospital were applicable to their daily lives and were useful for them once they returned home. When asked their opinion of the applicability of occupational therapy services received in the hospital to their daily life, one participant remarked:

Oh absolutely, yeah, ah absolutely. I had to know how to operate my equipment, how to take a shower, and, um, needed to be able to function, um to do my daily routine. [The

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occupational therapist] had goals set up for you and you had to check each one off before you could go. I was able to meet mine...

Some participants referred to the benefit of occupational therapy as assisting in regaining independence with their basic ADLs, including dressing alternatives and safety. One participant said “[The occupational therapist] showed me some good stuff too, how to get my sock on with the puller upper [sock aide] and the grabber thing [reacher]... I still need the reacher since I’m not supposed to bend over.”

All participants remembered the shower process with the LVAD and related it as part of occupational therapy experience they had in the hospital. They were all able to give a description of the training required to protect the LVAD and batteries and discuss the precautions for taking a shower. Detailed descriptions for covering the drive line and dressing were given by a few participants. In addition, all participants told of the process of transferring the LVAD controller and batteries from the “Go Bag” to the “Shower bag”. Many reported that this change in shower preparation added increased time to the daily routine. One participant noted, “It’s a bit of an ordeal to have to do all that just to take a shower, but its well worth it.” Most participants reported the use of adaptive equipment in the shower (most commonly the shower chair) and the use of a hand held shower for increased ease and independence. The use of these pieces of equipment and having overall larger showers or tub/showers at home, with the shower preparation in the hospital, increased the comfort of the participants once they returned to the home environment.

As a group, the participants were effusive in their praise for the first shower taken in the hospital. Comments included, “...it was wonderful...,” “...it was nice to just feel clean again,” “I felt normal...,” “I was like ‘yes!’,” and “I was fired up.” All participants also agreed that it

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was important to experience the actual shower at the hospital prior to going home. One participant expressed the view of a few others, by explaining that the shower taken in the hospital helped in decreasing the anxiety of the shower process, "...I thought the shower bag was not gonna work and stuff was going to get wet and all that, but after I took the shower I didn't have any more fear." Another participant summarized the importance of the actual hospital shower occurring:

...that's why it's so important to, to get that shower, you, it, it takes away your fear of everything getting wet, it lets you know that 'hey, you can take a shower,' ... and be okay, and all you have to do is cover thoroughly...it's just like the LVAD they tell you all about it, but until you get into it, it's still not the same...

The participants as a whole viewed occupational therapy services and having an actual shower in the hospital as contributing to their success on returning home. All participants considered occupational therapy services a meaningful part of each of the identified themes discussed above lifestyle change, caregiver support, physiological process, and general preparation for home, including the shower process.

Discussion

Using the interpretative phenomenological approach, this study expounded on prior literature and served as the first qualitative study to explore the patients' with LVADs perspectives on the afore-mentioned themes with regard to occupational therapy services in the acute care setting. All participants reported that occupational therapy services meant providing support to patients and families through positive caregiving, involving education and training of LVAD equipment and processes, and including interventions involving physical activity and ADLs, assisting with the new life change (see Appendix F). Through the use of in-depth

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interviews, the results from this study provide an increased understanding of the role occupational therapy plays when caring for patients after they have been implanted with LVADs. Patients with LVADs see occupational therapy practitioners as offering caregiving support through the teaching and physiological interventions they provide, starting in the hospital setting. These occupational therapy interventions and preparations for home, including shower training, were identified as beneficial to those wishing to regain their independence and return home safely after device implantation. Specifically, the participants' perspectives provided information regarding occupational therapy interventions they deemed important to helping patients regain their function and return to their lives at home.

Participants in the current study, as a whole, identified numerous lifestyle changes they had to undergo as a part of receiving the LVAD. Awareness of surroundings, awareness and maintenance of the equipment, the effect of the equipment on ADLs and sleep, the anxiety of managing the new equipment, home modification, the importance of regaining independence with the LVAD, and the importance of education and preparation for home, were all identified areas of lifestyle change by the participants. The current study findings were consistent with prior literature addressing lifestyle change (Baker et al., 2010; Brouwers et al., 2011; Casida et al., 2011; Casida et al., 2009; Iseler & Hadzic, 2015; Marcuccilli et al., 2014). However, the prior studies were primarily caregiver-reported perceptions and focused mostly on changes that were needed once the participants were at home. The findings of this study add to the prior literature by demonstrating specifically how occupational therapy practitioners assisted the participants while in the hospital, with crucial education regarding the LVAD and its components. This occupational therapy intervention eased the life changes of participants, by letting them and their families know what to expect upon return home. The occupational therapy

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practitioners were able to train the participants and family members regarding the adaptation of ADLs and adaptations within the home environment, facilitating a safe return to independence. Specifically, occupational therapy services addressed management of the LVAD power-based unit and its batteries, use of adaptive equipment for ADLs, alternate clothing choices and safe dressing. A discussion of possible alterations to the home environment and suggestions of furniture for equipment storage and safe maneuvering within the home were also reviewed.

Prior qualitative studies have discussed caregivers in regard to “caregiver burden” following the return home after a patient received a LVAD (Baker et al., 2010; Brouwers et al., 2011; Iseler & Hadzic, 2015). One such study even touched on the importance of hospital caregivers supporting patients and families with the transition home after LVAD implantation (Casida et al., 2011). However, this was again discussed in relation to relieving caregiver burden. Other studies discussed the importance of the interdisciplinary team to support patients and families after LVAD implantation (English & Speed, 2013; Nguyen & Stein, 2013; Shoemaker et al., 2014). However, these studies primarily just named the healthcare team members involved in the care of patients with LVADs, provided a general description of services offered to the patients, or focused on the services provided to the patients and families by the primary researchers’ discipline, none of which were occupational therapy.

In the current study participants corroborated prior research, which focused on the importance of family as caregivers (Baker et al., 2010; Marcuccilli et al., 2014). Family caregiving was described as playing a major role in the successful re-integration of patients with LVADs into their homes and communities. However, building on previous research, this study yields information from the patients’ perspectives regarding the type of caregiver support, in the hospital setting with collaborative training from occupational therapy practitioners, which is

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meaningful to patients receiving LVADs. In this study, all of the participants stressed the importance of the quality of caregiving and instruction provided by various healthcare providers, in the acute care environment. The participants described the characteristics that the hospital caregivers demonstrated, which led to their added comfort and ability to overcome new challenges presented after LVAD implantation.

In addition, the current study provides new information to the LVAD literature regarding the important role that occupational therapy practitioners play as one of the caregivers on the interdisciplinary team. All participants described the positive feelings and experiences the occupational therapy practitioners inspired, along with their effectual characteristics. Guidance with the new LVAD equipment and ADLs, coupled with the consistency of personnel with daily visits, were key factors identified as contributing to a successful occupational therapy experience for the patients, their families, and the occupational therapy practitioners. In addition, participants discussed beneficial interventions provided by occupational therapy services including strengthening, fine motor coordination, range of motion, and home modification and adaptive equipment recommendations, which were important to their new lives. Participant identification of the importance of the occupational therapy caregiver experience provides evidence to support occupational therapy as one of the critical services involved in caring for patients with LVADs, which is in keeping with existing research (Abramson et al., 2012; McIntyre, 2007; Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004).

Physical activity and the physiological process following LVAD implantation have been addressed in numerous prior studies (Abshire et al., 2014; Ben Gal et al., 2015; Bogaev et al., 2011; Evans et al., 2011; Freeman & Maley, 2013; Hayes et al., 2012; Nicholson & Paz, 2010; Rogers et al., 2010; Shoemaker et al., 2014). Whereas the prior research was primarily

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quantitative and did not report on patients' perceptions of physical processes after LVAD placement, the current study adds to this prior knowledge with the addition of new participant-reported information. All participants in the current study referenced their physical state while in the hospital. They expressed the importance of mobilization and increasing strength, endurance, and range of motion to enable their independence with the new LVAD and its components. These findings provide additional support to prior quantitative findings (Ben Gal et al., 2015; Bogaev et al., 2011; Evans et al., 2011; Hayes et al., 2012; Rogers et al., 2010), which demonstrated the benefit of exercise following LVAD implantation, by adding the lived experience of the benefits of physical activity, as reported by these patient participants.

New information regarding the benefits of exercise and physical activity intervention provided by occupational therapy services, for patients with LVADs, was brought to light by this study. Prior occupational therapy publications included exercise or physical activity as recommendations for *possible* occupational therapy intervention with these patients (Abramson et al., 2012; McIntyre, 2007; Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004). The participant reports in the current study provide evidence to substantiate those recommendations. Occupational therapy exercise and physical activity interventions cited as being beneficial by participants in this study, included range of motion of upper and lower extremities and the neck, fine motor coordination tasks, and upper extremity strengthening with various forms of resistance; the purpose being to assist with the manipulation of the LVAD components, relieve pain, and improve energy levels for increased independence with daily life. Once the participants were able to see the results of these interventions with regard to purposeful activity, they better understood the need for the interventions and were more motivated to perform them. These specific treatments and their purposes support the interventions used with

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the LVAD population in prior occupational therapy publications (Abramson et al., 2012; McIntyre, 2007; Padmanabhan & Thankachan, 2011). Though therapists may be reluctant to use exercise alone, due to its lacking as an occupation-based activity, exercise used therapeutically as a preparatory intervention, can enhance body functions and performance skills, enabling the patient's participation in meaningful occupations (AOTA, 2014). The therapeutic exercises described by the participants in the current study are in keeping with the AOTA's (2014), definition of preparatory interventions, improving the motor skills of coordination, manipulation, moves, and endurance, allowing for the patients to manipulate and use the LVAD equipment needed to function in daily life.

Prior literature published for occupational therapy practitioners stressed the importance of occupational therapy interventions, including ADLs, when working with patients receiving LVADs (Abramson et al., 2012; McIntyre, 2007; Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004). In addition, Casida et al. (2011) reported that caregivers of patients with LVADs described that ADLs required a lot of adjustment following implantation and the return home. The current study supports prior literature, with positive descriptions from patients regarding their experience with working on their ADLS and developing new performance patterns with occupational therapy in the hospital setting. Participants described the beneficial education provided by occupational therapy practitioners, developing new routines and habits to use adaptive equipment for dressing and showering, in order to reach lower body parts and for safety. This is similar to interventions described in prior occupational therapy publications (McIntyre, 2007; Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004).

The current study demonstrated that the participants highly valued being able to participate in a real shower while they were in the hospital, as opposed to a simulated shower or

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sponge bathing, because it allowed them to better transfer the skill to their home environment.

This is new information from the patient-perspective that supports prior occupational therapy literature recommending an actual shower in the healthcare facility, in order to prepare patients for a safe transition home (Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004).

Participants in the current study gave descriptions of the shower process similar to that provided by Padmanabhan and Thankachan (2011), including the coverage of the dressing and use of the shower bag to protect the LVAD components. The new discovery of the importance of the actual shower in the hospital for adequate preparation to return to ADL occupations within the home, and for reducing concerns regarding protection of the LVAD and dressing when wet, provides evidence to support the interventions described by prior occupational therapy literature (Padmanabhan & Thankachan, 2011; Shepherd & Wilding, 2004).

Limitations

Although the participants in this study provided an in-depth look into their experiences in the hospital with occupational therapy services, following their LVAD implantation, the sample consisted of patients recruited from a single medical center, limiting the generalizability to other recipients of LVADs. Study participants responded to questions about their experiences in the hospital following LVAD implantation and their interaction with occupational therapy in a single interview. An attempt was made to limit the effects of memory by including only participants who had received LVADs within the last six months. However, these retrospective accounts were dependent on participants' memories of the activities in the hospital and any issues that these individuals were experiencing at the time of interview. Participant responses could also be skewed toward positive responses, given that the primary investigator was identified as an

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occupational therapy practitioner and represented the rehabilitation department from which the participants received services.

(Though it should be noted that the primary investigator was not involved in the care of any of the participants who were interviewed.)

Implications for Practice and Future Research

Despite the limitations listed above, the findings of the present study begin to bridge the gap of knowledge on the meaning of occupational therapy services for patients with LVADs in the acute care setting. These study findings demonstrate the need for occupational therapy intervention in the hospital setting to include beneficial patient and family education, strengthening, fine motor coordination, range of motion, home modification recommendations, and adaptive equipment recommendations, when working with patients receiving LVADs. These interventions, addressing body functions and improving performance motor skills, or assisting in the creation of new performance patterns, allow patients with LVADs to return to their meaningful occupations of health management and maintenance, and ADLs using the LVAD equipment and accessories.

Participant reporting in this study demonstrates the need for occupational therapy practitioners to work with patients with LVADs, in order to address ADLs (and specifically to perform actual showers) prior to discharge home, for improved patient preparation and independence. Further empirical research is warranted to examine the effectiveness of occupational therapy interventions in general. In particular, studies comparing the outcomes for those receiving showers prior to discharge from the hospital, versus those only simulating the shower process would help understanding of patients' needs and abilities post LVAD implantation. Accordingly, it would be beneficial for the experience of patients with LVADs

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who did not receive an actual shower in the acute care setting prior to discharging home to be further understood from a qualitative perspective. In addition, further research into the benefit of home health occupational therapy services, to aid the transition from hospital to home, is needed to inform occupational therapy practitioners of long-term management needs for patients post LVAD implantation. Future research comparing drive-line dressing infection rates for those receiving shower training versus those that do not could be useful in possibly decreasing hospital readmission rates for individuals with LVADs. Future research could also be performed with retrospective analyses of patients with LVADs who received occupational therapy services versus those that did not and the effects on length of stay and readmission rates. From a patient perspective, the study shows that occupational therapy is an important part of the interdisciplinary team, working with patients with LVADs early after implantation. Occupational therapy governing organizations, education programs, students, and practitioners should be aware of this growing patient population and the specific occupational therapy services that can be offered to support them.

Conclusion

This study addresses the lack of knowledge regarding the experience of patients with LVADs, who have received occupational therapy services as part of their hospitalization, post implantation. The study expands our understanding of the processes and preparations required to ensure a successful return home for these patients. LVAD implantation is a significant, life changing event affecting patients' body functions and performance skills. Lifestyle changes are required following LVAD implantation, and the education and training prior to discharge from the hospital, including that provided by occupational therapy practitioners, are important pieces in the journey of getting back to daily occupations.

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These study participants identified occupational therapy practitioners as an important member of the caregiver and interdisciplinary team, serving patients receiving LVADs and preparing them for the changing performance patterns of their lives. The study also highlights the patient-perceived, beneficial interventions provided by occupational therapy services in the acute care environment. Occupational therapy practitioners, educators, and students can use this information to recognize and anticipate the challenges experienced by patients receiving LVADs. An increased awareness of the LVAD experience will allow for quality patient-centered care and improved outcomes for these patients going forward.

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Appendix A

RESEARCH PARTICIPANTS NEEDED

*Have you or an immediate family member been implanted with a **LVAD** in the last **6 months**?*

We are conducting a study about persons' with LVADs perceptions of the care they received following LVAD placement. In particular we are looking for persons' with LVADs views about the occupational therapy they received while in the hospital.

As a participant in the study, you will be asked to participate in:

- A 45-90 minute face-to-face, audio recorded interview, directly after a Heart Failure Clinic visit.

Elizabeth Wyble, OTR/L and Doctoral Student in Health Sciences will be conducting this study. If you are interested in participating or have more questions, please notify your LVAD nurse/coordinator or contact Elizabeth at (678) 843-5791 to confirm eligibility for the research.

This study is being conducted in collaboration with Emory Saint Joseph's Hospital and the University of Indianapolis.

This study has been approved by the Emory Saint Joseph's Hospital and University of Indianapolis Institutional Review Boards, study # 051-16-2.

Your personal information will be kept confidential.

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Appendix B

Consent for Primary Investigator Contact

One of the occupational therapists at Emory Saint Joseph's Hospital is performing a study regarding patients with LVADs. She is looking for participants. If you are interested in participating, please provide your contact information below and sign to provide your consent for her to contact you. We will pass your contact information onto her by way of a phone call. Your participation is voluntary and is not a requirement for your continued treatment at the Emory Saint Joseph's Heart Failure Clinic.

Name: _____

Address: _____

Phone Number: _____

Email: _____

Print Name

Signature

Date

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Appendix C

Institutional Review Board of Emory Saint Joseph's Hospital**Consent Form to Participate In Research**

(Do Not Sign Unless You Have Read The Document And Are In The Presence Of The Primary Investigator).

Study Title: What is the Meaning of Occupational Therapy for Patients Receiving a Left Ventricular Assist Device in the Acute Care Setting?

Principal Investigators: Elizabeth Wyble, OTR/L

Experts/Colleagues: Lisa Borrero, PhD., Jennifer Fogo, PhD, OTR, Cheryl Bittel, MSN, APRN-CCNS, NP-C, CCRN, Katie Caldwell, MS, OTR/L, Deborah Mann, BS, PT

I. Introduction to Participate:

You are being invited to participate in the study titled "What is the Meaning of Occupational Therapy for Patients Receiving a Left Ventricular Assist Device in the Acute Care Setting?" because:

- You have received a left ventricular assist device (LVAD) in the last six months
- Received occupational therapy during your hospitalization at Emory Saint Joseph's Hospital

Occupational therapy (OT) is commonly received post-operatively after LVAD placement, in the hospital setting. The goal of the OT is to improve functional independence with daily living skills in preparation for return to the home and community for the patient receiving a LVAD. The investigators know that OT is provided to each patient, but the experiences of each patient are different. Therefore the goal of the current study is to determine the meaning of occupational therapy for those implanted with a left ventricular assist device.

The research is being conducted by Elizabeth Wyble, OTR/L in coordination with Katie Caldwell, MS, OTR/L, Deborah Mann, BS, PT, and Cheryl Bittel, MSN, APRN-CCNS, NP-C, CCRN at Emory Saint Joseph's Hospital and in coordination with Lisa Borrero, PhD. and Jennifer Fogo, PhD, OTR at the University of Indianapolis. More information about the research study can be received from the principal research investigator.

II. Research Study Description

To participate you will be asked to provide a signature of agreement to determine if you will take part in a private, audio recorded, interview session of approximately 45-90 minutes. You will be asked questions regarding your hospitalization after your LVAD was implanted.

III. Risks

There is no identified risk by participating in the study.

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IV. Voluntary Participation and Withdrawal

Your decision as to whether to participate in this Research Study is entirely voluntary and you are under no obligation to consent or participate in this Research Study. If you choose to participate in this Research Study, you have the right to withdraw from participation at any time for any reason. Your decision not to participate or to withdraw from participation will not result in any penalty to you, loss of benefits to which you are otherwise entitled, or adversely affect your access to health care or treatment by your physician, nurse, or therapist. You may ask questions about the Research Study at any time.

You may receive information about your rights as a research participant from the Institutional Review Board (“IRB”) of Emory Saint Joseph’s Hospital of Atlanta, Inc. at (678) 843-7767. The investigator may withdraw you from the study at any time.

V. Benefit(s)

No benefit from your participation is guaranteed. The results of the Research Study may help to improve patients’ care after LVAD implantation, in the hospital setting.

VI. Compensation

You will not receive payment and/or compensation for participating in this Research Study. Information about any research related risks can be received from the principal investigator.

CONFIDENTIALITY AND AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION

Any information obtained as a result of your participation in this research will be kept as confidential as legally possible. A copy of your signed Research Consent form and the Study data will be subject to Emory Saint Joseph’s Hospital confidentiality policies. Federal law requires that your privacy, security, and unauthorized access to your health information will be protected.

You may change your mind and revoke (take back or withdraw) this Authorization at any time and for any reasons. To revoke this Authorization, you must write to: Elizabeth Wyble, OTR/L, Rehabilitation Services Department, Emory Saint Joseph’s Hospital, 5665 Peachtree Dunwoody Rd., NE, 5th Floor, Room 5C, Atlanta, GA 30342. However, if you revoke this Authorization, the researchers and other parties listed may continue to use and disclose the information they previously collected as permitted by the Informed Consent Form. Information that has already been de-identified cannot be taken back.

To maintain the integrity of this Research Study, you generally will not have access to results related to this research until the Study is complete.

If all other information that does not or can identify you is removed from your health information, the remaining information will no longer be subject to this Authorization and may be used or disclosed for other purpose.

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- Your health information will be used or disclosed when required by law.
- If you have questions about the use of your information, you can call Elizabeth Wyble, OTR/L at (678) 843-5791 or the Emory Saint Joseph's Hospital Privacy Officer at (404) 778-2757.

This Authorization does not have an expiration (ending) date.

You will be given a copy of this Authorization after you have signed it.

Signature of Participant

Date

Signature of Person Obtaining Consent

Date

I hereby acknowledge that the informed consent process has been completed prior to initializing any research procedures.

Signature of Investigator

Date

Print Name of Investigator

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Appendix D

Interview Questions

1. What was your experience in the hospital after your LVAD was implanted?
2. What was or was not meaningful to you during your hospital stay after your LVAD was implanted?
3. What was your experience upon returning home after your LVAD was implanted?
4. What was your experience with occupational therapy in the hospital?
5. What is your opinion of the applicability of the occupational therapy you received to your daily life?
6. What was your experience when showering with the LVAD in the hospital?
7. What was the difference between showering in the hospital versus at home?

Probing or clarification questions:

- 1) Could you say more about that?
- 2) Could you explain that further?
- 3) Are you talking about or do you mean _____?
- 4) Could you talk more about _____?

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Appendix E

Characteristics of Participants in Study

Table 1

Characteristics of Participants in Study

Participant	Age	Marital Status	Sex	Race	Reason for LVAD	Type of LVAD	Time with LVAD
1	56	Single	F	Black	DT	HeartWare	106 days
2	47	Married	M	Black	BTT	HeartWare	68 days
3	45	Married	M	Black	DT	HeartMateII	120 days
4	70	Married	M	Black	DT	HeartWare	124 days
5	70	Married	F	White	DT	HeartWare	131 days
6	19	Single	M	Black	BTT	HeartWare	155 days
7	78	Widow	F	White	DT	HeartMateII	22 days
8	50	Married	M	White	BTT	HeartWare	27 days
9	31	Married	F	Black	BTT	HeartWare	15 days

Abbreviations: F, female; M, male; DT, destination therapy; BTT, bridge to transplant; LVAD, left ventricular assist device.

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Appendix F

The Meaning of Occupational Therapy for Patients with Left Ventricular Assist Devices

Facilitating Life Change: Hospital to Home



Figure 1. The meaning of occupational therapy (OT) for patients with left ventricular assist devices (LVADs). Demonstrates the different services provided by OT (and their relationship to each other) that assist patients with LVADs affect successful life change after implantation.