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CAREGIVERS' EXPERIENCES CARING FOR SPOUSES WITH LEFT
VENTRICULAR ASSIST DEVICES-DESTINATION THERAPY

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ABSTRACT

Background: Heart Failure is one of the most expensive diagnoses in the world, and there is not treatment, to date. More and more, Left Ventricular Assistive Devices (LVADs) are used as destination therapy to help increase patients' quality of life in end-stage heart failure. There is not much information on how caregivers experience this change when their spouses receive an LVAD.

Purpose: To understand the informal caregivers' experiences of taking care of heart failure patients with Left Ventricular Assistive Devices.

Methods: This was a descriptive, exploratory study, and a secondary thematic analysis of data. The final sample size was 10 caregivers who took surveys and completed a semi-structured phone interview lasting 45-60 minutes.

Results: There were eight themes that emerged from the interviews. These themes were: burden placed on the caregiver, caregivers' perception of improved health after the LVAD was placed in the patient, increased family support, reference to life in the long-term context, caregiver's preparedness for care, change in caregiver role, sacrifice on the end of the caregiver, and religious beliefs helping the caregiver.

Conclusions: It was concluded from this secondary analysis that the placement of an LVAD improves patient outcomes and caregivers feel better the patients health. Patient education should include teaching about long-term expectations of LVAD therapy.

Table of Contents

Chapter 1	1
Introduction	1
Problem.....	3
Purpose.....	4
Definitions	4
Chapter 2	6
Caregivers' Perceived Sacrifice.....	6
Burden Experienced by Caregivers.....	8
Positive Experience	10
Caregivers' Experiences Coping and Adapting	12
Chapter 3	15
Methods	15
Study Design.....	15
Sample.....	16
Procedures of Data Collection and Analysis.....	17
Chapter 4	19
Chapter 5	28
Discussion.....	28
Implications for Nursing Practice	32
Future Research	32
Limitations.....	33
Appendix A	34
Appendix B.....	36
References.....	37

LIST OF TABLES

Table 1 Demographics of participants in study.....	19
Table 2 List of themes identified in interviews.....	20

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Chapter 1

Introduction

Heart failure is defined as “a syndrome characterized by the heart’s inability to pump blood to meet the metabolic demands of the body” (Maxwell & Jenkins, 2011, p.1791), and is one of the most expensive diagnoses in the world, costing the United States a direct estimate of 37 billion dollars in 2009 alone. The incidence of heart failure has remained the same since 1995, suggesting that this is a long lasting epidemic (Maxwell & Jenkins, 2011). There needs to be a change in how heart failure is treated in order to decrease both the incidence of the condition and the costs associated with it.

Both pharmacological and non-pharmacological treatments are utilized to reduce the incidence of acute symptom exacerbations in heart failure (Vitali, Lanfranconi, Bruschi, Russo, Colombo, Ribera, 2003). Pharmacological interventions such as Angiotension Converting Enzyme-inhibitors and loop-diuretics have been well developed for many years, but only work to an extent. Despite these pharmacological interventions there is only a 16% survival rate after one year of diagnosis, and a negligible rate five years after (Vitali et al., 2003). These patients end up paying considerable amounts of money on prescriptions that end up prolonging their life a year or two at best. A study done in 2007 with participants who had heart failure found they spent an average of almost 55,000 dollars, over the course of their treatment, on the medications for heart failure (Lawrence et al., 2007). The non-pharmacological interventions, which include reducing sodium in the diet, getting more exercise, and bed rest, do not reverse the damage (Jaarsma, 2006). They simply help to prevent further

damage to the heart. Consequently, additional interventions are needed to help people with heart failure.

Because there is no actual cure for heart failure, the only option to surgically manage heart failure is heart transplantation. There are approximately 80,000-150,000 patients that would currently benefit from a heart transplant (Lietz, 2011). However, there are very few hearts actually available for transplant, with hundreds of people waiting for one every day (Lietz, 2011). Therefore, other treatments have been developed. A type of therapy that is becoming more prevalent in this population is a left ventricular assist device (LVAD). An LVAD is a mechanical device that essentially pumps blood to the patient's body, working for the heart that cannot adequately pump the blood itself (Mayo Clinic Staff, 2012, Definition section, para. 1). These devices are used when someone's heart needs assistance pumping the blood throughout the body. They can be implanted in either side of the heart (Mayo Clinic Staff, 2012). Although many LVADS are used as bridge-therapy to sustain the patient until a transplant becomes available, they are increasingly used as destination therapy at the end of life to decrease burden and improve quality of life (Lietz, 2011). Since LVAD therapy is one of the newest treatments for heart failure, the majority of studies conducted have looked at the actual efficacy of the devices. These types of studies were important (or essential) when the LVAD was first used in heart failure patients. Now that their efficacy has been established the lived experience needs to be explored.

One important factor in destination therapy is the role the informal caregiver plays in caring for the patient with heart failure and an LVAD. An informal caregiver is anyone caring for someone, usually a family member or spouse of the ill person. It is

already known that caregivers of patients with heart failure exhibit significant levels of stress and emotional burden (Makdessi, Harkness, Luttik, McKelvie, 2011). However, few studies have addressed caregiving when patients have newer devices (or therapies) such as an LVAD. The specific effects of these particular therapies on the patients with HF and caregivers need to be studied.

Problem

The quality of a person's life after an LVAD is implanted can be greatly changed for the better, allowing them more energy and better ability to complete everyday tasks (Marcuccilli & Casida, 2011). Likewise, a caregiver's life can greatly change when the LVAD is implanted in a spouse or family member including; less time for work, friends and family, and completing hobbies (Baker, Flattery, Salyer, Haugh, Maltby, 2010). Little is known, however, about the actual experiences of informal caregivers who are taking care of patients with LVADs. A large portion of research on LVADs focus on the physiological uses and effects of the device on the patient, while there are very few studies on the psychological effects the device has on the caregiver. Because studies have already shown that caregivers are greatly affected by heart failure, more information is needed about the experiences of caring for someone with both HF and an LVAD, specifically when implanted as destination therapy.

Purpose

The purpose of this study is to understand the informal caregivers', specifically spouses, experiences of caring for patients with LVADs. This study aimed to answer the question:

What are the experiences of spousal caregivers caring for persons with heart failure and a left ventricular assist device?

Definitions

- 1) *Caregiver*: Merriam-Webster defines caregiver as “a person who provides direct care” (Merriam-Webster, 2013). For this study, caregiver refers to a spouse who has taken over the role of caregiver in the relationship with his or her partner. All caregivers in this study are informal, meaning they did not choose to take on the role and they were simply put in the role because of their intimate relationship with the patient.
- 2) *Destination Therapy*: Destination is defined by Merriam Webster as “a place to which one is journeying”, and therapy is defined as “remedial treatment of mental or bodily disorder” (Merriam-Webster, 2013). In the case of this study, destination therapy refers to the LVAD. This type of therapy will serve the patient only to get them to their final destination, which is death. LVAD therapy is used to increase their quality of life in the end, but is by no means meant to prolong their life or fix their heart failure.

- 3) *Burden*: In Merriam Webster, burden is defined as “something oppressive or worrisome” (Merriam-Webster, 2013). In this study burden can mean different things for the different caregivers. Most commonly, the caregivers’ definition of burden is emotional or financial, and when they explain burden, they explain it in the context of the LVAD and their spouses’ heart failure. It is a negative emotion, and it results in some way from caring for a spouse with heart failure and an LVAD.
- 4) *Sacrifice*: Sacrifice is defined as “something given up or lost” according to the Merriam Webster Dictionary (Merriam-Webster, 2013). Again, caregivers are the ones discussing sacrifice. They describe it as giving up something, related to their spouses’ heart failure or the placement of the LVAD. There are many different things caregivers discuss sacrificing throughout this study, although all pertain to the heart failure and LVAD.

Chapter 2

Review of Literature

The purpose of this literature review is to review the current knowledge on experiences of caregivers caring for someone with a left ventricular assistant device (LVAD). For the literature review on caregivers' experiences the databases CINAHL, MEDLINE (PubMed), and Google Scholar were utilized. Experts were also spoken with. The keywords searched included (a) caregivers, (b) experiences, (c) heart failure, (d) LVAD, and (e) left ventricular assistant device. Articles published before December 2005 were excluded, as were systematic reviews. There were very limited numbers of studies conducted in the time frame specified on caregiver experiences with a family member using an LVAD. Due to the lack of study articles on experiences of caregivers with patients who have heart failure and other end-stage organ failures were utilized. There were four key themes found throughout the review of literature: caregivers' perceived sacrifice, positive experiences, burden placed on the caregiver, and coping and adapting strategies.

Caregivers' Perceived Sacrifice

One of the common findings throughout the literature was that caregivers felt as though they had to make personal sacrifices in their lives to care for their spouses or family members. In a study by Baker et al. (2010), six participants, when interviewed using a semi-structured questionnaire, stated that sacrifice meant loss. They had to sacrifice many aspects of their lives, which included their work life and social life (Baker et al., 2010; Aldred, Gott & Gariballa, 2005). Giving up work-related obligations caused

stress and financial strain (Baker, et. al, 2010; Ferguson, Hull, Marble, Barg, & Kirkpatrick, 2011). Ferguson et al. (2011) noted that of the ten participants interviewed, six of them were employed, and of those six participants, all noted adverse experiences within their work environment. Baker et al. (2010) found participants had to put the health of their partner over their own health, despite the caregivers' being in very poor health themselves. Notably, one caregiver made a comment to the researcher that, "This year I was supposed to have my mitral valve replaced but I have put all that behind" (Baker et al., 2010, p.196).

Another study looking at the impact of heart failure on caregivers found similar experiences using focus groups (Aldred et al., 2005). Caregivers in this study explained that they felt their hobbies were no longer important, and that their energy and time needed to be solely placed in caring for their spouses. The participants also felt very alone, and they stated many times that they missed their friends and the company they used to have. Also, these caregivers said they had to sacrifice outings and holidays because the onset of symptoms and the health of their spouse were so unpredictable. Along with sacrificing holidays, another loss that was felt from caring for someone with heart failure was the loss of time with family (Aldred et al., 2005). The final common sacrifice was that participants had limited freedom after caring for a spouse with an LVAD (Akbarin & Aarts, 2012; Aldred et al., 2005). The caregivers noted that possibilities of everyday life had been greatly minimized as compared to before they were in the caregiving role (Akbarin & Aarts, 2012).

The designs of each of these four studies were very similar. They were all descriptive, phenomenological or grounded theory. Although different, these two design

types are more alike than any other two qualitative designs. The data collection methods for the four studies were all interviews. The studies by Baker et al. (2010) and Ferguson et al. (2011) both used semi-structured interviews. The study by Aldred et al. (2005) used focus groups to interview while Akbarin and Aarts (2012) used open-ended interviews with only one question, “What was it like to live with someone with an LVAD?” These studies had between six and ten caregivers as participants, so the sample was also similar among the four studies.

Sacrifice is an integral part of caring for a person with an LVAD or someone who has heart failure. The participants reported sacrificing many different parts of their lives including work, social interactions, time with family, and hobbies, in order to care for their spouses. In terms of sacrifice of caregivers, there is a gap in the literature on how they deal with this perceived sacrifice. These studies all had similar findings, and it is evident that sacrifice is a prominent theme across all four of them.

Burden Experienced by Caregivers

Another clear theme throughout the literature was the burden experienced by the caregivers. Hynes, Stokes, and McCarron (2012) explored the experiences of participants caring for family members with other chronic illnesses, and high caregiving expectations, like heart failure (HF) and advanced chronic obstructive pulmonary disease (COPD), and found that burden was a major theme. There were two types of burden experienced by caregivers, objective stressors and subjective stressors. The objective stressors included things that could clearly be seen, such as the severity of the family member’s symptoms or the extent to which they were disabled (Hynes et al., 2012). Some subjective burdens reported by caregivers included emotional burdens the disease caused (Hynes et al., 2012;

Ferguson et Al., 2011). There were also situational burdens such as sacrifices the caregivers had to make in their own lives to care for their family members and how they were not prepared for the amount of time and energy it would take (Hynes et al., 2012; Ferguson et al., 2011). Caregiving was described as a “24/7 responsibility” (Marcuccilli & Casida, 2011, p.139). Marcuccilli and Casida (2011) found that caregivers felt the burden of their spouse’s psychological state as well. The caregivers felt stress in making sure their spouse was happy and that their emotional needs were met. They also felt burdened by the stress of letting their spouse having enough independence without being in a dangerous situation. The participants that had younger children in the house had the unique burden of trying to manage taking care of a spouse with an LVAD and school-age children (Marcuccilli & Casida, 2011). With this study, however, only white women participated, so a more diverse sample should be recruited so that the results can be generalized to the population studied (Marcuccilli & Casida, 2011). Interestingly, only one of the ten caregivers in Ferguson et al.’s (2011) study mentioned the emotional burden of the deactivation of the device. This end-of-life issue is a burden that most caregivers will eventually face, but in all literature reviewed only one participant mentioned it as an issue. Because Ferguson et al.’s study was a pilot; this may have affected the results (Ferguson et al., 2011). In these studies, all used semi-structured interviews, so although they had different designs, they all had a very similar lay out (Ferguson et al., 2011; Marcuccilli & Casida, 2011; Hynes et al., 2012).

Burden has many different aspects to it and when caring for a family member with an LVAD there are numerous common themes seen in burden experienced. The majority of participants that reported burden experienced it when caring for the emotional

problems of family members, with the physical symptoms of their family member's illness, and balancing their life and their family member's illness. A definite gap in the literature is the caregivers' perceived burden in dealing with their spouses' end-of-life issues. As noted above, only one participant in all studies reviewed made a comment about the end-of-life issue, and this is something every caregiver in every study will eventually face.

Positive Experience

It is important to note that some of the literature reviewed found that caregivers experienced positive changes in their lives when taking care of their spouses. This finding may not have been expected, so it is important to look at the participants' reasons and explanations for it. Some caregivers stated that, "they knew their spouse would not be alive if the LVAD were not in place" (Marcuccilli & Casida, 2011, p.139). When looking at the different types of organ failure, such as renal failure and chronic obstructive pulmonary disease, the caregivers ranked positive experience about the same for all organ failures (Janssen et al., 2011). Another study by Hwang, Fleischmann, Howie-Esquivel, Stotts, and Dracup (2011) looked at the impact of caregiving with family members who had heart failure. This found both positive and negative caregiving experiences. Some of the caregivers reported positive experiences related to feeling satisfied that they are able to help their spouse or family member. They also identified that the fewer amount of exacerbations and hospital visits the patient had, the better the experience in caring for them was (Hwang, et. al, 2011). In addition, caregivers caring for a person with fewer co-morbidities had a more positive experience than those caring for someone who had more (Hwang, et. al, 2011).

There were some other reasons given for positive experiences in caring for patients with an LVAD. The participants also felt that caring for their family member with an LVAD was positive because of the change in lifestyle that their family member made (Marcuccilli & Casida, 2011). Another positive experience is that caregivers found that the diagnosis and surgery influenced them to become more faithful to their spouse (Marcuccilli & Casida, 2011). One study found that caregivers had relatively low stress and strain levels after the patient received their LVAD (Janssen et al., 2011). However, this particular study was different from the majority of other studies reviewed because there were no negative experiences reported. The focus was on chronic organ failure as a whole and not just in HF, therefore the different types of organ failure could have influenced the results. According to the purpose statement, they were exploring positive experiences, so this may also explain why negative ones were not found (Janssen et al., 2011). The most common finding was that caregivers had positive experiences in caring for their family members (Janssen et al., 2011; Marcuccilli & Casida, 2011). Two of the studies reviewed in this section had a very large number of participants, with 159 participants in one and 76 dyads of participants in another (Hwang et al., 2011; Janssen et al., 2011). The other study only had five participants (Marcuccilli & Casida, 2011). Most of the other studies in this review of literature had less than 15 participants, so if these exact studies were replicated with much larger numbers of participants maybe more people would report positive experience. Suggestions for future studies are similar amongst all authors reviewed in this section, and include getting a more randomized sample (Hwang et al., 2011; Marcuccilli & Casida, 2011). They also suggest getting a more diverse sample to increase generalizability of the study findings (Hwang et al.,

2011; Marcuccilli & Casida, 2011).

Positive experiences were a recurring theme throughout this literature, and although the studies that made note of it as a major theme interviewed different populations, the reasons for positive experience were all similar and well explained by the caregivers interviewed. Some of the common reasons were feeling like they could help their family member, feeling like the person got a second chance at life, and an increase in self-esteem at doing a good job (Hwang et al., 2011; Janssen et al., 2011; Marcuccilli & Casida, 2011).

Caregivers' Experiences Coping and Adapting

The final recurring theme throughout the literature reviewed was that participants felt they had to cope and adapt to the new lifestyle of providing care for a family member with heart failure and an LVAD. The caregivers identified the coping experience as being a positive one because they felt they had the tools and resources to cope well (Akbarin & Aarts, 2012; Baker et al., 2010; Marcuccilli & Casida, 2011). Some participants explained that they were thankful for their spouse's second chance at life, and this gratefulness helped them cope with the LVAD (Akbarin & Aarts, 2012). Two of the studies found that the preparation for the implantation of the LVAD gave caregivers ample time for coping and adapting to caring for the patient (Akbarin & Aarts, 2012; Baker et al., 2010). Conversely, a study by Clark et al. (2007) found that the caregivers had to continually cope and adapt to the care of their spouse with chronic heart failure. A possible reason for the differences between these studies could be the Clark et al. (2007) study was looking at patients with heart failure, and the study by Baker et al. (2010) looked at patients with LVADs. This could be attributed to a change in amount of

care needed when the LVAD is implanted. Over time the participants learned to cope and adapt to their new roles, and used different coping strategies such as positive thinking and developing a routine (Marcuccilli & Casida, 2011). The participants in this study, unlike other ones, identified religious outlets, including prayer and reading spiritual texts, as being crucial to help them cope with their family member's new LVAD (Marcuccilli & Casida, 2011). Lastly, once some of the participants were able to accept this new situation, their ability to cope was greatly improved (Akbarin & Aarts, 2012). Three of the studies reviewed in this section had between five and six participants (Akbarin & Aarts, 2012; Baker et al., 2010; Marcuccilli & Casida, 2011). It is interesting to note that these three studies had many of the same findings, so there may be a correlation with number of participants and diversity of findings. The other study had 30 participants, and had different findings than the others (Clark et al., 2007). However, this study also only used caregivers of patients with HF, so that may account for the difference in findings (Clark et al., 2007). Two of the studies stated that there is a need for further research to be conducted on the differing factors associated with positive coping skills, so this is a notable gap in the available knowledge. (Baker et al., 2010; Clark et al., 2007).

Coping and adapting was a major theme in the studies reviewed. Caregivers that participated in studies who were caring for persons with LVADS similarly had positive experiences in the end of the caregiving process. Because there are few studies on caregiving for family members with LVADs a major gap is understanding how these people cope and what exactly facilitates a positive or negative experience.

Summary

In summation, there were many common themes found throughout the review of literature. They included perceived sacrifice by the caregiver, burden, positive experience, and coping/adapting. The main gap in all of the literature found is that this topic is very new, and not many studies have looked at how caregivers caring for family members with an LVAD experience this new caregiving role. Throughout all literature reviewed, phenomenological studies are the most common type. Also, it was very difficult to find recent studies about caregivers' experiences taking care of someone with an LVAD, so other caregiver experiences had to be utilized. This may have affected the results and made it inaccurate to compare and contrast the different populations. Therefore, the main need in research on this topic, presently, is to know the overall experience of caregivers taking care of someone with an LVAD.

Chapter 3

Methods

This study was a descriptive, exploratory study, investigating the caregiver's experience of caring for a spouse with a Left Ventricular Assistant Device (LVAD) as destination therapy. There is very little known about how caregivers experience the new role of caring for someone with a LVAD, and this is a relatively new topic because the LVAD is just becoming a common therapy for patients with heart failure. The aim of the study was to better understand the experiences of spousal caregivers in order to help them transition into their new role. The way the study was conducted and how the analysis of data was completed is explained in this chapter.

Study Design

A secondary analysis of interview data with spousal caregivers for a patient with a left ventricular assist device-destination therapy (LVAD-DT) was done. The parent study took place at an LVAD-clinic and every patient and caregiver that entered over a three to four month time frame was asked to enroll and complete a short survey. A subsample of caregivers who were spouses caring for a patient with an LVAD-DT were asked to complete an interview about their experiences. The senior researchers on the original study were Dr. Judith Hupcey and Dr. Lisa Kitko, and the study was funded by Seed money from the College of Health and Human Development and School of Nursing at Penn State University. These researchers assisted in the coding and review of themes. Prior to planning this research study, approval from the Institutional Review Board (IRB) at Pennsylvania State University was granted. The steps in this thematic analysis were

followed according to the steps outlined in Silverman's *Qualitative Analysis* (2011). The first step began with becoming familiar with the dataset. This was accomplished by reading the interview transcripts. Next, the initial codes were generated. This was done without input from the senior researchers. These codes were then reviewed by the senior researchers in order to create interrater reliability. After that, themes were searched for throughout the data, and once found were then reviewed and analyzed. Lastly, the themes were refined. In a thematic analysis approach it is important to review the data collected separately from the initial researchers in an attempt to find new themes. An audit trail of all analyses and decisions was maintained.

Sample

Every patient in the LVAD-clinic was contacted and asked to enroll in the parent study based on their experiences of burden pre- and post- LVAD placement. Potential participants were asked to complete a survey. This was a visual analog scale that ranged from 0-100, with 0 indicating the least amount of burden and 100 indicating the most amount of burden. Burden was measured related to treatment, caregiving, and the disease itself. Additionally, overall health before and after the placement of the LVAD was measured. The final question was whether the patient had an LVAD for destination therapy, and if the caregiver could be called for a short interview. After distributing surveys in the clinic for four months, 12 caregivers fit the criteria to be interviewed. Of these 12, one caregiver refused because her spouse was too ill, and a second patient died prior to the spouse completing the interview. The final sample size was ten spousal caregivers, ranging in age from 52-73 years old. Within the group of caregivers that participated in the study, there were two males and eight female caregivers. Four

participants worked full-time, five were retired, and one was on disability. The patient's length of time with the LVAD ranged from five months to thirty-eight months, with the most common length of time being between six and nineteen months.

Procedures of Data Collection and Analysis

Once the caregivers filled out their surveys, confirmed that they would participate in the survey over the phone, and signed a consent form, they were interviewed via the telephone. These interviews lasted an average of 45 to 90 minutes. The researcher conducting the interviews followed a semi-structured interview guide (See Appendix A). According to Silverman (2011), semi-structured interviews are useful because they allow the researcher to gather accounts from people of their real-life experiences (pg. 75). These semi-structured interviews also provided an opportunity for the researcher to ask specific questions, but the participants were able to openly provide additional information not elicited by a question from the researcher.

After the data was recorded from the phone interview, a professional transcriptionist transcribed the interviews verbatim. In order to protect the privacy of the participants, the transcribed interviews were de-identified. All names, addresses, telephone numbers, and any other data that would make it possible to identify the participants were discarded. The data were then entered into a computer program that helped to code and sequence it. The computer program chosen for this study was called HyperRESEARCH. The main concept that was explored at that time was caregivers' experiences in caring for their spouse with an LVAD.

The next step in this secondary analysis was to review the transcribed interviews and look for themes among them. Because this is a secondary analysis, the two senior researchers had already identified themes related to the aims of the parent study. The aim for this analysis was to both confirm those themes and bring a different lens to the interviews, possibly finding new themes not identified by the senior researchers related to understanding the informal caregivers', specifically spouses, experiences of caring for patients with LVADs. In Appendix B, there is a picture of how the hand-coding of the study during the secondary analysis was completed.

In summary, ten caregivers of patients with LVADs were found at an LVAD-clinic, and participated in interviews. The participants' interviews were then transcribed and coded by the senior researchers. The resulting themes will be provided, explained, and interpreted in the following chapters.

Chapter 4

Results

In this study, the ten spousal caregivers' interviews were thoroughly read and coded as a secondary analysis of data. To better understand the sample interviewed, demographics were collected. There were two male caregivers in the sample and eight female caregivers. The mean caregiver age was 63.2. Five caregivers were retired, four worked full-time, and one caregiver was on disability. The length of time with LVAD-DT support ranged from five months to 38 months, with an average of 15.9 months. The patient's ages ranged from 58 years old to 76 years old, with an average age of 68 years old. According to the averages of this demographic data, the caregivers were generally younger than the spouse they were caring for. A full chart of the demographic information of the participants can be found in Table 1.

A total of eight themes appeared in the interviews. The most frequent themes were burden placed on the caregiver and the caregiver's perception of improved health after the LVAD was placed in the patient. Other themes included the following: increased family support, reference to life in the long-term context, caregiver's preparedness for care, change in the caregiver role, sacrifice on the end of the caregiver, and religious beliefs helping the caregiver. Listed in Table 2 are the findings with descriptions of the themes and occurrences. The different themes will be described in more detail, with illustrative quotes, in this chapter.

Table 1 Demographics of participants in study

Participant number	CG Age	CG Gender	CG Occupation	CG self-reported health status	PT age	PT's length of time with HF (years unless noted)	PT's length of time with Class III-IV symptoms (years unless noted)	PT's length of time with LVAD-DT support months
1	63	M	Retired	Good	65	10	2 months	5
2	72	M	Retired	Good	70	4	4	24
3	62	F	Retired	Fair	70	8	3	26
4	55	F	Full-Time	Good	76	15	3	38
5	52	F	Full-Time	Good	61	4	4	6
6	58	F	Full-Time	Fair	58	7	7	11
7	73	F	Retired	Fair	75	1	1	6
8	67	F	Retired	Good	69	2	2	13
9	65	F	Full-Time	Good	68	2	2	11
10	56	F	Disability	Poor	58	2 months	2 months	19

Table 2 List of themes identified in interviews

- Burden
 - Financial
 - Emotional
- Improved Health
 - Better health
 - Less hospitalizations
 - Better able to “get around”
- Sacrifice
 - Time
 - Leisure Activities
- Increased Family Support
- Better Outlook and Denial
 - Patient’s health will improve
 - Patient would not be alive without LVAD
 - Realistic about LVAD Purpose
- Well Prepared for Care
 - Adequately prepared
 - Prepared as a caregiver, but patient was not
- Change in Caregiver Role
 - Dressing changes and maintaining LVAD
 - Busy in a new way
- Religious Beliefs Helped Caregiver

Burden on the caregiver increased after the LVAD. The first theme that frequently appeared was burden on the caregiver. Throughout the interviews, eight of the ten caregivers noted some sort of burden placed on them. There were two subcategories of burden that the caregivers described. The two categories include financial burden and emotional burden.

The first type of burden, financial burden, was expressed as a concern by three of the caregivers. The cost of medications was a common stressor, one of the male caregivers stated that, “It’s a little bit tough because we don’t make that much you know.” This caregiver is explaining the financial situation after the LVAD and that it is tough to handle because of a lack of income. The cost of medications, hospitalizations, and treatment is overwhelming to some of these caregivers. One caregiver goes on to explain about the financial burdens with the LVAD and how it affects her work:

It’s difficult you know. We own our own business. When we don’t work, we don’t earn income. So you know aside from the physical we’ve had a lot of financial burdens and issues that we’ve worked through and God for some reason has blessed us that we have always kept our head above water.

This spouse is sharing that she feels the financial burden is a type of burden in caring for her spouse with an LVAD.

The other type of burden the caregivers expressed in these interviews is emotional burden. The caregivers explain that they feel their sleep is affected. One caregiver stated that, “...I had trouble sleeping at night because you know how a mother is with a baby.” Another caregiver makes reference to treating her husband like a baby when she says, “At first I was like a newborn mother, I babied him and cuddled him...” These women feel that they must approach the situation as they would approach caring for a newborn

baby. The emotional burden goes as far in one caregiver that she says she has “anxiety” as a side effect from the caring. It is evident that the LVAD placement in these ten patients causes many varying types of burden on their caregivers.

Caregivers notice improved health after the LVAD. Another very common theme found in the interviews was improved health in the patient after the LVAD, as reported by the caregiver. Most commonly, when asked how health in the patient was post-LVAD, the caregivers replied, “much better.” One caregiver even went to the extreme to say that, “...he’s like a new person.” There were two ways caregivers explained the noticed improved health. One was by a decrease in hospitalizations. A caregiver said that, as compared to before surgery, “...after the VAD surgery he hasn’t been back in or nothing.” Another more commonly reported finding of improved health was that the patient was better able to physically get around. A caregiver said, “He can take going out in public better.” There were many other examples given of improved physical activity like going shopping and on vacations. Although most of the caregivers did not go into extreme detail when asked about the health status after the LVAD surgery, eight of the ten interviewed did make note that the health status was improved in some way after the surgery.

Caregivers felt they had to make sacrifices. There were four caregivers that explained different sacrifices in their lives. There were many different things caregivers said they sacrificed. One caregiver talked about having to move because they live too far from the hospital, so she is sacrificing her house. Another sacrifice is leisure activities. One caregiver explains that she can’t make big trips anymore because of all the machinery that he has to drag along. Time is the last sacrifice a couple of caregivers

discuss. When one caregiver is asked if she feels comfortable leaving her husband alone she states, “Not really, no.” She goes on to explain that she is usually with him all the time. Another caregiver says he adjusts his schedule so his wife is never alone. Sacrifice as a theme is seen in many different ways in these caregivers.

Caregivers feel they need increased support from family members. Six of the caregivers in these interviews felt that in some way they relied on family support in the care of their spouse. Four of the caregivers mentioned that their daughters help them. Two caregivers mentioned that their spouses’ brothers helped them. One caregiver mentioned that her sons help them. The last caregiver just mentioned vaguely that her family helps them. Both male and female caregivers mentioned relying on their families for help. The two male caregivers explained that their daughters help them with the medical side of treatment, such as “riding to the hospital” and “changing the bandages”. The female caregivers, however, used their family members for more emotional support and keeping their husbands company. The female caregiver whose sons help her says she has them plow the driveway. Although the different caregivers use their family members for different reasons in the care of these patients with new LVADs, they all rely on their families. When asked if she was ready to care for her husband and his LVAD, a caregiver said, “To be honest with you, not without help.” She goes on to explain that her family has been instrumental in the care of her husband, and this seems to be the case with the other five caregivers as well.

Caregivers felt they were well prepared to give care. Although many caregivers said they needed their family members to help care for their spouses, many also felt upon discharge, that they were prepared to care for their spouse and the LVAD. When asked

simply if she was prepared, a caregiver used the pronoun 'we' instead of 'I' to respond, "Well I would say we were extremely prepared." She continued explaining how great of a job the staff did at readying the couple for discharge. It is worth noting that some caregivers felt they were prepared but their spouse with the new LVAD was not. Two caregivers mentioned that their spouses felt unprepared. Of those caregivers that felt they were prepared to care for the LVAD, four of them were women and one was a male. In this sample 50% of both genders felt they were prepared to give care to their spouses.

Caregivers felt they had a change in their caregiver role. Many caregivers described a change in their role after their spouses had the LVAD placed. All but one of these patients were chronically ill with heart failure, therefore most of the caregivers interviewed have been taking care of the patients for an average of 10.6 years. After the patients had an LVAD implanted, caregivers felt they had a huge change in their duties and had to learn to perform new tasks. The main change caregivers discussed was changing the dressings. When asked how her role as a caregiver changed, one caregiver explained:

The care post LVAD changed you know. If you want to talk about a caregiver role, I think my caregiver role previous to that was just one of management; helping him to manage his meds and doctors' visits and things like that. Post LVAD then it became of course more hands on because now I had a significant role to play in the dressing changes and maintaining the supplies and all of those things.

Many other caregivers explained the change in their role in a very similar way. One caregiver said that she simply is busy in a different way. All caregivers who identified a change in their role were females, and all but one had been caring for their spouse for at least four years.

Caregivers felt religious beliefs helped them. This theme was uncommon, only two of the ten caregivers described religion, but the ones that did, described it in great detail. One caregiver said, “My belief is what got me through all this with him.” The other that talked about her religion said, “(Husband) is very quick to tell everyone that he speaks with that you know if you don’t have faith in God before you go into this, you better find it because it is a very difficult journey to go on your own.” These caregivers are both females, but their faith and religion is mentioned numerous times throughout their interviews.

Caregivers had a change in outlook. The last theme was a change in outlook of the caregivers. There were a few different comments made. One caregiver was realistic about the LVAD and what the device implies. She said, “We don’t know if it could keep him going for 10 years of what.” This was the only caregiver that expressed she understood this LVAD is indeed destination therapy, and not a permanent fix for her husband’s heart failure. Some caregivers also realistically spoke about the LVAD keeping their spouses alive. One caregiver said, “No, I’m just happy that she has the LVAD. Otherwise we wouldn’t be around. We wouldn’t have 51 years.” Two other caregivers made similar comments. The other outlook was that the LVAD would fix the patient’s heart failure. When asked what she expects with treatment, a caregiver said, “I just expect him to keep going good like he does.” A few of these caregivers never mentioned that they understand the LVAD is for destination therapy and will not ‘fix’ the patient.

These eight themes were the most prevalent in the interviews, and the top eight coded during the secondary analysis. In the following chapter, the different themes will be discussed and compared and contrasted to both each other and others in literature.

Chapter 5

Discussion

This study looked at caregiver's experiences caring for spouses LVAD-DT. Currently, there is little research available on the caregivers' experiences, so there is a need for studies identifying their experiences and how these experiences can be improved. There were eight themes identified through interviews with spousal caregivers, and in this chapter they will be discussed in relation to previous literature, implications for practice, and future research needed based on the results of the interviews.

One of the most common findings was the caregivers felt they needed increased support from their family members. This was also a finding in other literature reviewed. In one study on patients with heart failure, it was found that increased support from family members helped the caregiver to better care for their spouse (Kang, Li & Nolan, 2011). The study also found that caregivers could not provide care by themselves, so the increase in support from family members helped them. In all of the articles used in the review of literature that focused on caregivers caring for a spouse with an LVAD, none found family support to be a relevant topic. This secondary analysis, however, found family support was a significant help in transitioning into the caregiver role for the LVAD.

Another theme found in this secondary analysis was burden placed on the caregivers. This theme was found throughout many of the interviews and throughout the previously reviewed literature. In the literature reviewed, the types of burden differed from this study. Some types of burden in this study included financial and emotional. In

the literature reviewed, the burden included the spouse's psychological state, as well as stress in making sure their spouse was happy (Marcuccilli & Casida, 2011). It seems that universally, whether it was the caregiver of a spouse with an LVAD, heart failure, or any other end-stage disease, all caregivers experienced some sort of varying burden.

Improved health was another highly reported theme. The caregivers interviewed in this secondary analysis commonly said they felt their spouse had better health after the LVAD was implanted. None of the literature reviewed found improved health as an outcome, but there was a study that found both improved health and improved sexual functioning after LVAD placement, as compared to prior to placement (Marcuccilli & Casida, 2011). Interestingly, none of the caregivers in this study mentioned anything about their sex life. The average age of this sample was 68, so the increasing age may have influenced this finding or it may be that since they were not explicitly asked about their sexual experience the caregivers did not self-disclose on this topic. Improved health was an important finding, so it is encouraging that many caregivers talked about it.

Another theme identified in the interviews was sacrifice. Many caregivers felt they had to sacrifice both their time and their leisure activities after their spouse received an LVAD. In the literature, one of the four common themes was sacrifice, as well. This theme clearly seems to affect many caregivers when their spouses have an LVAD implanted. In the literature reviewed, caregivers had to sacrifice work life and social life (Baker et al., 2010; Aldred et al., 2005). They also gave up work-related obligations, which caused subsequent stress and financial strain (Baker et al., 2010; Ferguson et al., 2011). No caregivers in the review of literature discussed sacrificing leisure activities, so this could be correlated, again, with the mean age of 68 in the caregivers of this study or

the social support that they receive from family members.

The theme of a better outlook and denial of long-term health was interesting when compared to the literature. In the reviewed literature there was no mention of how long the patient was expected to live with the new LVAD in place. One study did show that caregivers “knew their spouse would not be alive if the LVAD were not in place” (Marcuccilli & Casida, 2011, p.140). This was also mentioned in the interviews from this study. Another study found that caregivers were thankful for their spouse’s second chance at life, and this gratefulness helped them cope with the LVAD (Akbarin & Aarts, 2012). The theme of outlook and denial was very complex and it seems that caregivers mixed opinions and ideas about their spouse’s long-term health, and how their health will improve or decline going forward. Because these LVADs are all destination therapy, the outcome is not to improve long-term health but to improve end-of-life health. Very few caregivers expressed an understanding of this concept.

Caregivers reported being well prepared to care for their spouse and the LVAD, which is a positive theme found in the interviews. Likewise, in the literature reviewed some caregivers made similar comments. Two studies found that caregivers had ample time to cope with their spouse’s new LVAD because of the preparation for the implantation of the device (Akbarin & Aarts, 2012; Baker et al., 2010). This is very important in practice because as the literature and current study show, there are many negative effects on the caregiver after the LVAD placement. Since caregivers said they felt well prepared to care for their spouses, these other issues may be minimized.

Religious beliefs were another theme discussed by the caregivers in this study and the literature. Only two caregivers talked about their religious beliefs in this study, but

they focused on it and stated it was how they “got through” their change in the caregiver role. In the literature, a study also found religious beliefs to be a topic of discussion in the caregivers interviewed. In that study, caregivers explained that religious outlets, including prayer and reading spiritual texts, were crucial to help them cope with their spouses’ new LVAD device (Marcuccilli & Casida, 2011). Although this theme was not commonly discussed, it is interesting that in both literature, as well as this study, participants brought up religious beliefs. It is very possible that if asked a question about religion during the interview, more caregivers would have explained their religion helped them cope as well.

Lastly, the caregivers in this study referenced a change in their caregiver role. All of them had been caring for their spouses’ heart failure, so they all had some sort of change in the way they cared for their spouse, although not all discussed it. In the literature reviewed, caregivers more often said they felt a change in role, but regardless of the change it was a positive one (Janssen et al., 2011). None of the caregivers in the interviews for this study made comments about positive changes, so it is not clear why some caregivers had, and expressed, a positive experience in Janssen and colleagues (2011) study.

The different themes identified in this secondary analysis were all themes found in other literature. However, because of the relative newness of LVAD-DT research replication of findings such as in this study help to advance the science. The most frequent themes were improved health, burden, and a need for family support. All three of these are easy to identify in all of the literature, and seemingly more obvious experiences compared to others noted.

Implications for Nursing Practice

Based on the results of this secondary analysis, there is a need for a change in nursing practice. Teaching nurses about the caregiver's role in caring for a spouse with an LVAD is vital to help prepare the caregiver for their new role. There was little education given to the caregivers about the long-term effects and expected outcomes of the LVAD. All of these caregivers' spouses received an LVAD as destination therapy, yet only one even referenced this fact. Although discussing the implications of end of life therapy like LVAD-DT is a difficult topic, nurses need to teach spouses and caregivers that the LVAD will not cure heart failure. Also, since increased family member support was identified as helpful, nurses need to educate caregivers about this and help them identify people they can turn to for support. In general, better education on the process and emotional part of caring for a spouse with an LVAD is needed from the nurses and health care workers when educating caregivers and spouses about the device.

Future Research

There is a definite need for more research on the topic of caregivers' experiences of caring for spouses with an LVAD-DT. One of the themes that emerged and needs more research is burden. It is clear what causes the burden and what the different types are, but it is unclear about how that burden can be lessened. Another area of research that could benefit the caregiver is the involvement of religion in their recovery. Not many caregivers spoke about religion, but the ones that did speak about it emphasized it as a crucial part to the coping process. Minimally, a study with a question on spirituality

would be beneficial to establish if it is definitely a common theme. Lastly, more research on why some patients have realistic expectations would help nurses and health care workers better teach the caregivers and their spouses about what to expect long-term from destination therapy. Few patients referred to a realistic long-term plan, but it is not clear as to why they did not and why they may not have realistic expectations of the LVAD as destination therapy.

Limitations

There were some limitations in this study. Mainly, it was very difficult to obtain information on the topic of caregivers and LVADs. Research on caregivers' experiences with a person who has an LVAD is fairly recent, and because of this there are not many published studies. Studies on caregivers' experiences with a person who has end-stage organ failure were utilized because the trajectory of a patient dealing with this is very similar to that of a patient with heart failure. The review of literature may be somewhat inaccurate because there could be some differences in heart failure patients' experiences and those of end-stage organ failure patients. In addition, as a secondary analysis, it was not possible to explore some themes in greater depth. Because this study was completed in central Pennsylvania, it cannot be generalized to the nation as a whole.

Appendix A

LVAD-DT SPOUSAL CAREGIVER

Interview Guide

Insert into interview the following Short narrative-

This is interview LVAD-DT-1.0cg [caregiver, initial data collection point]), 1st phone) interview with the 52 year old wife of a 58 year old pt with heart failure. The pt was diagnosed ---, he has an implantable defibrillator (1-2 sentence summary- can be inserted after the interview is completed)

DEMOGRAPHICS:

- Age
- Ethnicity
- Marital status
- Relationship to care recipient
- Occupation
- Home location: proximity to stores, doctors, hospitals, other services
- Travel time to clinic/doctor
- Length of time since the care recipient's diagnosis with heart failure
- Characteristics of the care-recipient's health status
- Length of time caregiver has considered self caregiver
- Health status of the caregiver
- Types of assistance provided by the caregiver.
- Health Insurance of care recipient/ caregiver
- Financial Impact

INTERVIEW QUESTIONS focus on experience, caregiving tasks pre and post implant and how those have changed

Begin with description of illness capture both pre and post implant

What was your role as a caregiver before the device placement, when your spouse was living with heart failure?

What types of tasks did you do for the patient?

Tell me what it was like living with a heart failure patient before the device was implanted

Tell me what it has been like living with heart failure pt with LVAD-DT

How has your life changed since the implant of your spouse's device for you and your spouse

How would you describe the health status of your spouse since the device placement
Is it better or worse than before the device was implanted

Has the device changed your role as a caregiver? If so how

What types of caregiving tasks are you performing now that the device is implanted?
Has this changed since pre implant? If so how

What do you expect from this present treatment? Are these expectations different from
before the device was implanted?

Have there been services that you have needed as a caregiver that you felt you have not
received

What has been the impact on your finances since the device placement

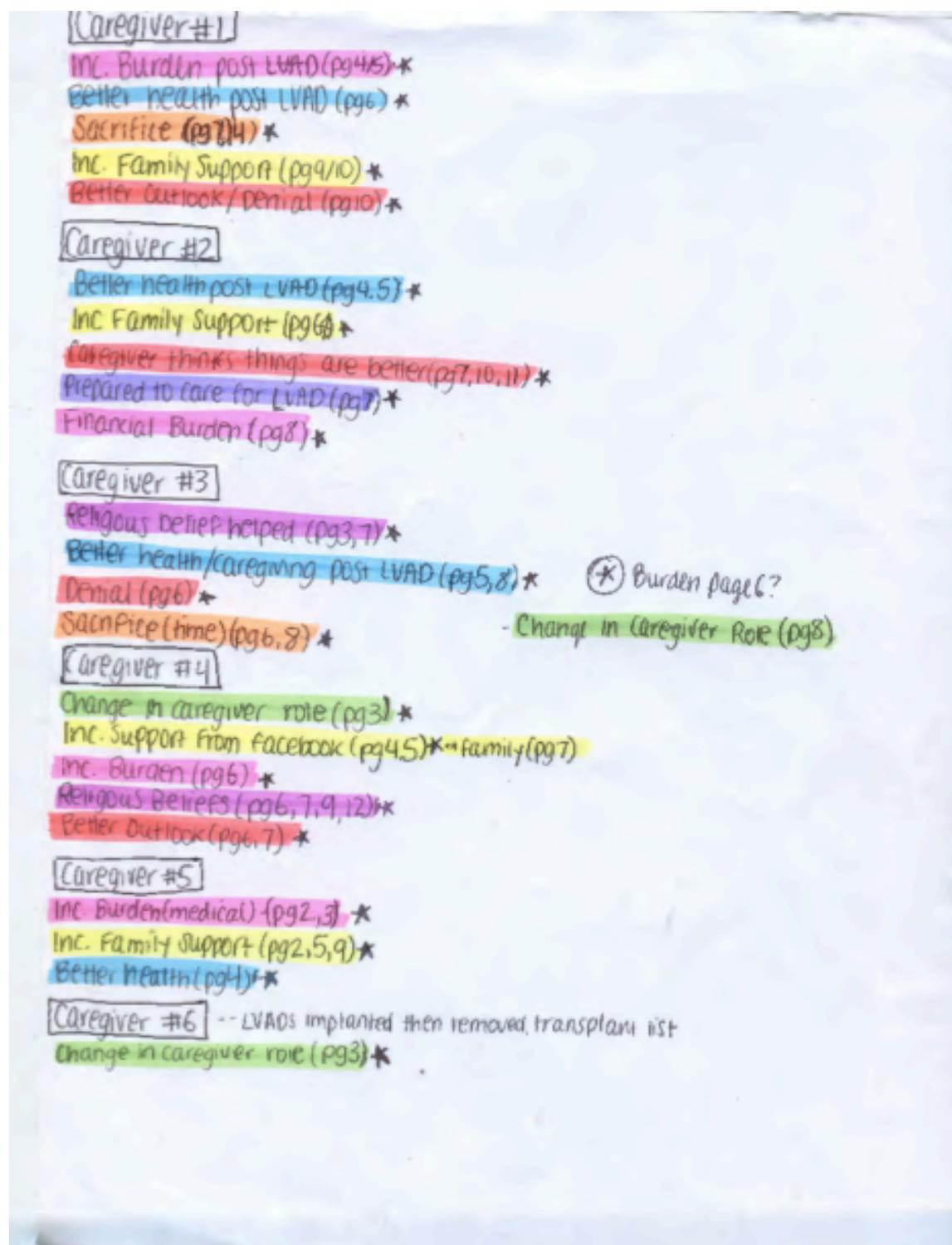
Do you feel all of your healthcare needs are being adequately addressed by the healthcare
team?

Probes:

Can you explain how you felt at that time?

Tell me more about that experience.

Appendix B



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