THE LIVED EXPERIENCE OF SPOUSES OF PATIENTS WITH A LEFT VENTRICULAR ASSIST DEVICE BEFORE HEART TRANSPLANTATION

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• BACKGROUND No publications describe the life experience of spouses who are designated caregivers of patients with a left ventricular assist device before transplantation.

• OBJECTIVE To explore what life is like for spouses serving as caregivers of patients with a left ventricular assist device before transplantation and to assess the meaning of such experience to them.

• METHODS This phenomenological study included 3 women 38 to 52 years old who were designated caregivers of patients with a left ventricular assist device while the patients were waiting at home for a heart transplant.

• RESULTS Three major themes emerged—emotional distress, determination, and optimism: a new lease on life. The identified themes were elucidated by 8 subthemes: guilt and realization of severity of illness, fear and anxiety, recognition that being a caregiver is an overwhelming experience and a burden, coping, living with hope, realization of loving relationship, adaptation to a new life, and joyful feeling.

• CONCLUSION The spouses who served as caregivers had strong emotions as they entered each stage of this life experience. The stages were characterized by the identified themes and subthemes, which otherwise might not have been revealed or might have remained private to the study participants. Critical care nurses should recognize and anticipate challenges for these stages of life experienced by the spouses as caregivers. Heightened awareness of this phenomenon will guide nurses in individualizing plans of care, educating patients and patients’ families, and evaluating outcomes of care. (American Journal of Critical Care. 2005;14:145-151)

The left ventricular assist device (LVAD) is a mechanical heart used to augment or take over the function of a failing left ventricle.1 The HeartMate XVE LVAS (Thoratec, Pleasanton, Calif) is one of the commercially available LVADs intended for use as a bridge to transplantation in candidates for cardiac transplantation who are at risk of imminent death from irreversible left ventricular failure. The LVAD is intended for use both inside and outside the hospital.2 This device is implantable, pneumatically driven, and powered by either electricity or batteries (Figure 1).

The number of articles describing the use, efficacy, and effectiveness of LVAD therapy as a bridge to transplantation in patients with end-stage heart failure have increased in recent years.3-5 However, few publications describe the life experience of spouses who are designated caregivers of patients with a LVAD before transplantation.6,7

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to transplantation and for long-term use has multiplied in the past decade. Compared with patients who are treated medically, patients with an LVAD have a higher survival rate and superior quality of life.4,5 Because of the shortage of donor organs and the promising outcomes when LVADs were used in patients with end-stage heart failure, the US Food and Drug Administration in 2002 and Medicare in 2003 approved the HeartMate XVE LVAS for permanent use or as destination therapy for patients who are ineligible for heart transplantation.6

In the context of nursing practice, several journal articles and textbooks have delineated the nursing diagnoses and management of patients with an LVAD. Reports of research on psychosocial issues and long-term quality of life among LVAD patients have been published in recent years.6,7 Further, Dew et al8 explored the perceptions, issues, and concerns of both patients with an LVAD and the patients’ caregivers outside the hospital.

It is a standard practice in many heart transplant/mechanical heart programs in the United States to designate a patient’s family member as a caregiver for a patient with an LVAD who is waiting at home for a heart transplant. The designated caregiver is expected to be available to the patient 24 hours a day and to perform specific tasks and take on responsibilities related to the care of the patient. Extensive education and training of patients and their family members/caregivers is usually provided by an LVAD coordinator. The education and training include performance of basic nursing procedures such as care of the LVAD exit site/wound, observation for signs and symptoms of infection, monitoring the functionality of the LVAD, and responding to alarms and emergency situations.

In my previous role as an LVAD coordinator, I had observed that most caregivers were the spouses of patients with an LVAD. All of these caregiver spouses were dedicated and determined to perform the role just described. One of these spouses asked me about other spouses’ overall experience as caregivers for patients with an LVAD. I responded that most of the patients’ spouses that I had known had performed satisfactorily in the caregiver role. However, my response was based solely on anecdotal evidence acquired through my encounters with LVAD patients and the patients’ families. That conversation stimulated my interest in exploring the lived experience of spouses as caregivers of patients with LVADs and the meaning of that experience during the period before implantation.

To the best of my knowledge, the lived experience of spouses as caregivers of patients with an LVAD and the meaning of that experience have not been the focus of any qualitative inquiry. Thus, this study was designed to answer the following research questions: What is the life experience of spouses of LVAD patients in the role of designated caregivers during the period before heart transplantation? What is the meaning of this experience to the caregiver spouses?

Method
Design

Interpretive phenomenology was the methodological basis for this study. This type of inquiry is the most appropriate for understanding the meaning of the experiences of spouses as designated caregivers from the insiders’ perspectives.9 According to Van Manen,10 the aim of interpretive phenomenology is to gain a deeper understanding of the nature or meaning of our everyday experiences. The foundations of phenomenology are rooted in the work of German philosopher Husserl, and later Heidegger, who described the basic structure of the lived world, focusing on the lived experience. Experience is considered to be an individual’s perceptions of his or her presence in the world at the moment when things, truths, or values are constituted.11 People’s experience, as lived, remains private, but its meaning becomes available to others through interpretation. Using this method, researchers try to explain and understand the meaning of experience by interpreting interviews in which the narratives are fixed as a text. Interpretation of the text means seeing something new in what is already given, a step that discloses possible aspects of being in the world.12

Study Participants and Procedure

A purposive, convenient sample of 3 female spouses participated in this study. The participants were recipients of care I provided while I was an LVAD coordinator. The inclusion criteria for participation in the study were completion of LVAD education and training; having lived with the LVAD patient before, during, and after implantation of the LVAD and until the time for transplantation; being a designated family caregiver; transplantation having occurred within the past 6 months to ensure a fresh recollection of the experience; and willingness to participate voluntarily and provide consent for the interview. I telephoned potential subjects and invited them to participate in the study. Privacy and confidentiality of study participants were strictly protected throughout the study. The Table summarizes the demographic characteristics of the study participants.
Data Collection

Semistructured, face-to-face tape-recorded interviews were use to collect data. Before the interview, I mentally prepared myself to be objective and free from preconceived notions about the topic. All interviews were conducted in June 2004 in the participants’ living rooms (quiet, comfortable, and free from distractions) and lasted approximately 40 minutes. I asked each participant to tell me about being a spouse and a designated caregiver for her husband during the time he was waiting for a heart transplant and prompted her to fully describe the experience. In addition, I asked probing questions to clarify the participants’ responses. Immediately after the interview, I transcribed the tapes verbatim. Field notes were maintained to contain data that were not obtained from the interview, such as emotional reactions.

Analysis

The sententious and highlighting method of Van Manen was the approach used for data analysis. Analysis of the text was ongoing throughout data collection, transcription, and repeated readings of the text. Analysis proceeded from an initial overview of each participant’s experience to more focused reflection and then to preliminary coding of the data and identification of themes. Data were coded according to words and phrases describing the participants’ experiences. Once individual thematic summaries were written, recurrent aspects of the experience common to all participants were identified, described, and interpreted. I reflected on these aspects and the identified preliminary themes for approximately 4 weeks and then constructed themes and subthemes.

Trustworthiness of the Data

The method used for thematic analysis was reviewed by a professor familiar with qualitative research methods. I reviewed the themes and subthemes constructed from data analysis with the study participants through telephone interviews and with another colleague who is currently an LVAD coordinator and who has extensive clinical experience and expertise related to LVAD therapy. In addition, an “audit trail” was maintained throughout the study.

Results

The findings in this study are presented as themes and subthemes identified from participants’ stories. Figure 2 illustrates the 3 major themes and eight subthemes. The themes and subthemes are presented in the text below and illustrated by quotations from the interview text.

Emotional Distress

The theme emotional distress comprises 3 subthemes: guilt and realization of severity of illness, fear and anxiety, and caregiver’s role: an overwhelming experience and a burden.

Guilt and Realization of Severity of Illness. Participants described the time they were told about the need for LVAD support for their sick spouses and said that occasion was when they immediately realized how poor the health status of their spouse was. One study participant said, “I didn’t know if he was gonna die, he look[ed] like he was dead.” Upon implantation of the LVAD, participants’ realization of their sick spouses’ illness became deeper. One participant exclaimed, “Once the machine came, I realized how serious the sickness was!” Although not all participants expressed guilt related to the onset and deterioration of their spouses’ conditions, one participant remarked, “I was feeling guilty about it [husband’s illness]. What did I do? How did he get sick? Is it a curse? What did I do to deserve this? What did I do to deserve this?”

Fear and Anxiety. All participants described their experiences with strong emotional reactions. The feeling of guilt and the realization of the severity of the illness were layered by fear and anxiety about the LVAD itself and about living with the LVAD. Once they accepted the facts presented to them by the heart transplant team, participants began preparing themselves to face the reality that they would be living with a spouse with an LVAD until a donor heart became

Demographic characteristics of participants in study

<table>
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<th>Characteristic</th>
<th>Participant 1</th>
<th>Participant 2</th>
<th>Participant 3</th>
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<td>Education completed, years</td>
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<td>Diet aide</td>
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<td></td>
<td>(full-time)</td>
<td>(full-time)</td>
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<td>5</td>
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<td>1 (teen)</td>
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<td>26</td>
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<td>assist device</td>
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available. Common to all of the participants was fear of the surgery, such as the nature of the surgical procedure and the associated complications that might arise postoperatively, including bleeding, stroke, and death. Furthermore, after implantation of the LVAD, especially during the immediate postoperative period, an expression of fear was still apparent. This fear was evident despite the explanations and education participants received about what to expect after surgery:

I was scared to death because when I saw him come out of surgery the very first time with the LVAD, I was there when he came out; with these tubes and all this stuff, the vacuum from his chest, what’s going on . . . and there was so much blood. It was frightening seeing my husband like that.

After several days, while their husbands were still in the hospital, the caregiver spouses began to show readiness to learn about the details of caring for a patient with an LVAD (eg, interest in knowing the mechanics of the LVAD, long-term complications such as infection, what to do during emergency situations such as device failure, living arrangements):

We were scared. It was a machine that’s gonna be in him, and I didn’t know and understand how the machine would keep him alive, how long would it last. . . . I was afraid of the infection part and I was afraid if it’s gonna fail. . . . How long’s this LVAD gonna stay inside the body working up to par with anything going wrong with it; if something goes wrong with it, we have like minutes to do something to revive him, to transport him from here to the hospital [referring to the transplant hospital]—How am I gonna do this? . . . It scared me because at that time we’d moved into a house with very bad electricity wiring. I was scared to bring him home—I would rather leave it at the hospital for the duration of the LVAD ’cause that’s how much it scared me.

All participants recalled that when they entered the initial stage of their experiences, they were frightened and overwhelmed with the situation. They did not specifically describe the levels of their anxiety. However, they described their anxiety as emotional and as simply due to being poorly prepared:

When you first told us, it was very upsetting. At first, I was nervous, frightened, and afraid. Like at first it was very difficult. I didn’t know what to expect, that you know, that I had to do with the LVAD and that I didn’t really know what it entail[ed]. . . . I was very nervous when it comes to cleaning it [referring to LVAD site/wound], how to use the pump, especially when it used to beep.

During the first few days after discharge from the hospital, living with their partners with LVADs was a “new life” to them. Adapting to the new home situation, being a spouse and a caregiver, and yet still building...
the knowledge and skills to become proficient or con-
fident as caregivers was difficult for them. One partici-
pant said, “Those first few days [at home] I didn’t 
sleep a lot [laughing], and I was constantly watching 
the machine just to check the flows you know. At first, 
at home, we were both kind of like in a state of alert.”

Furthermore, engaging in sexual activity was a 
concern. As part of the adjustment to this new life and 
not being knowledgeable about the details of the func-
tionality of the LVAD, one participant recalled, “First, 
it [sexual intercourse] was a concern: the flow, the rate 
of the LVAD, we were watching it. I was afraid it was 
too much, and I was concerned.” Another participant 
remarked, “It’s with all that stuff [referring to LVAD 
cables and connectors] it’s kind of hard. We never had 
sex when he had the LVAD.”

Caregiver’s Role: An Overwhelming Experience 
and a Burden. All participants asserted that being a 
caregiver to a sick spouse is expected by society, and as 
wives, they were bound to take care of their husbands’ 
needs, such as having an LVAD. A participant said, 
“That’s my husband I took my vows to him, just sim-
ple.” All participants have expressed “being protective” 
of their husbands both emotionally and physically:

I’m his wife, it’s expected. I’m his wife, that’s 
my job and that’s the way I accepted it [very 
sincere]. I was just pretty much taking it all 
in. I’m his wife, I’m not gonna trust anybody 
else to be the designated caregiver, I mean it’s 
just the way I felt about it. I had to keep his 
spirits up, because at that time I don’t think 
he had much hope of living [crying].

Despite the unwavering acceptance of their role as 
caregivers, all participants described the tasks and 
responsibilities of a caregiver as overwhelming, diffi-
cult, and to some extent a burden. Particularly, being a 
caregiver interfered with their sleep and work schedule:

It was kind of overwhelming, the whole expe-
rience: I have to be changing the bandages 
and stuff and make sure he wouldn’t get an 
infection. It was hard to see, it was hard to do, 
you know it was hard . . . I was working, it’s 
hard, it was very hard, very, very hard. You 
know I have a full 8-hour job and then I have 
to come to the hospital. . . . It was a horrible 
experience. Living hell, trying to work, trying 
to do the classes [LVAD education and train-
ing] . . . The first couple of weeks I couldn’t 
sleep in the room with my husband, it [LVAD] 
was too loud, and I said, “Oh my God, this is 
what I got to go through?”

One participant stressed, “It’s one of the hardest 
things I had to deal with, and I think [it was one of the 
hardest things] I ever had to deal with. It was very hard 
for me.”

Determination 
The theme of determination comprises 2 sub-
themes: coping and living with hope.

Coping. Participants described their struggle to 
“keep on going.” Each participant expressed her own 
ways of coping, often manifested by crying: “I had my 
little cry.” Two participants said that the “sick condi-
tion” of their spouses gave them the perseverance to 
overcome the overwhelming challenges and burden 
imposed on their lives as wives and caregivers. All 
participants were grateful and emphasized that the 
supports they received from the healthcare providers 
were the most significant ways of helping them cope. 
Specifically, they appreciated the education and training 
and the psychological support they received, which 
pacified their fears and anxieties. This support assisted 
them in building their confidence and eased the transi-
tion from the hospital to the home:

I couldn’t explain the encouragement I got 
from you [LVAD coordinator], not only from 
my husband, but from you too. Those visits, 
coming in you know once a week, knowing 
from you guys that I was doing a good job 
cleaning it [LVAD site/wound], it make me 
feel more comfortable doing it, and say, “Hey 
this is what we got to do!” . . . You’re really 
good, you taught us everything, you know, me 
and his mother. You started teaching us, and 
the little classes and stuff, it got a little better 
as what to expect. You taught me everything 
before he came home, so I knew what to 
expect when I came home, and then if I felt 
something wasn’t right, I could call you . . . 
and you made me positive. Everything you 
explained to me was very clear, you made me 
feel confident in it. I was prepared.

Living With Hope. Participants stated that they 
knew the associated risks involved with having an 
LVAD. However, they all felt that “surviving with the 
LVAD” outweighed the risks of not having the LVAD. 
The LVAD had given them the hope for their partners’ 
being alive:

I just accepted it that he had the LVAD and 
that’s the only thing that would keep him 
alive. It was either to get the LVAD to stay
alive or die, and you just have to go with your plan and go on. . . . Even though my husband has a grayish tint on his skin where he had it and lost a lot of weight with the LVAD, he didn’t look very healthy, but he was still here. The LVAD had given me the comfort that he’s still here [crying].

**Optimism: A New Lease on Life**

The theme of optimism comprises 3 subthemes: realization of a loving relationship, adaptation to a “new life,” and joyful feeling.

*Realization of a Loving Relationship.* Participants described their experiences as a means of realization or reflection of the love between them and their spouses, intimacy, togetherness, and the marital relationship. Participants said that “love” is the foundation of “being together” as well as a strong marital relationship. Furthermore, all participants asserted that the essence of being together enhanced their confidence as caregivers:

I really never knew how much I loved my husband until it came down to something like this [having the LVAD]. It brought us together. Because we really expressed how much we loved each other, because we did everything together as a team. It wasn’t one-sided. He’s my inspiration, and I’m an inspiration to him too. Doing the classes together with you [LVAD coordinator] and doing it together with him, it made a difference. We would go through the lessons with the LVAD, we hooked ’em up together, we do these together. To this day, we still do everything together, he doesn’t really go anywhere without me, I’m like his shadow mirror.

*Adaptation to a “New Life.”* Participants described the facts of facing the reality of living a new way of life such as having a husband with an LVAD. Although they described the sense of feeling overwhelmed as caregivers, all participants expressed that they really had no other choice. Thus, they “moved on” and took the initiative, motivated to learn their roles as caregivers. One participant said, “I will just learn as much as I can, I have to be strong. I have to take care of him.” Moreover, participants described their ways of accommodating the new life by their willingness to modify their lifestyle and family dynamics:

I said, and look, we can go home and we could still go out, put battery packs on, we could still live a normal life, we just have to go slowly. It was gonna be a new way of life: slow, easy going, no excitement. It’s gonna be peaceful. No arguments between family members, not bringing that into the house.

Participants also described the defining characteristics of being acclimated as caregivers, such as becoming knowledgeable and confident with the LVAD and overcoming the burden:

You know, over time, you get to kind of know everything about it [referring to the LVAD], you know it gets to be a part of the routine, it’s just made a part of your routine. You know the machine; you know it’s just a part of my background noise. But you get to know the noise, and if the noise changes and you realize what that noise change is, so you know, you can plan. It took about a couple of weeks to really get used to the noise and everything, and then you start kind of knowing what it really sounds like and if the sound was different, you know, you look at the flow. That book [LVAD patient’s manual] became my real best friend. . . . As long as I could hear the machine and see him moving, I would say he’s alright.

One participant described an example of an activity that pertains to having adjusted to the new life, “We go out shopping and whatever you had, it becomes your normal, because you got used to do it. You just get used to it—at a point in time, I was able to sleep.” Another participant described the comfort level of intimacy with her spouse: “We had sex. It was great. You can live almost like a normal life with the LVAD. It’s OK to have sex and it’s safe. If a patient has to do this [referring to overall experience], it’s not really [something] to be afraid of.”

*Joyful Feeling.* Participants described the time they received the call for transplantation as the ultimate feeling of “relief,” happiness, and satisfaction with their experiences as spouses and caregivers of LVAD patients. Participants summarized their experiences as follows:

It was one of the hardest things I ever had to deal with, but amazing.

It came from a horrible experience to a wonderful experience.

It was a joyous experience. To me it’s like a project. It was a small project and became a
big project, and then at the end, the glory of the Lord, the project was beautiful.

Discussion

This study was the first qualitative inquiry to describe and explain this type of phenomenon. I elucidated the experiences of spouses providing care to patients with an LVAD awaiting a heart transplant and the meaning of these experiences to the caregiver spouses. I have reported solely what was going on in the lives of the study participants. Findings in this study unveiled the participants’ personal perspectives at each stage of events: from the time they were told about the need to have the LVAD, when the LVAD was implanted, after implantation (postoperative recovery and rehabilitation), discharge to home while waiting for a heart transplant, and the time to transplantation. These events transformed the participants to become more resilient, and thus, they were prepared to encounter a different stage of their lives, such as living with a spouse who is a heart transplant recipient. Figure 2 illustrates the stages of life, with the emerging themes and subthemes, for LVAD patients’ spouses before heart transplantation.

Because no primary or secondary source is available to validate the data, the findings in this study are purely my interpretation, based on my extensive experience in the care of patients with LVADs and the patients’ families and caregivers. Thus, the themes constructed cannot be generalized, and they are subject for further reflections as well as research.

Inherent limitations of this study include the small sample size and the nondiverse sample. Future studies on this type should include the following:

- a large and diverse sample, with male and female spouses, same-sex partners, various age groups, educational levels, occupations, incomes, and other members of the family;
- interviews that coincide with the continuum of the experience of patients with an LVAD (from hospital to home); and
- a mixed-method methodology, with adequate samples so that inferences can be made, specifically the time line or duration of each of the life stages for LVAD patients’ spouses during the period before transplantation.

Conclusion and Implications

In this study, I determined the lived experience and the meaning of the experience of spouses who served as caregivers for patients with an LVAD before heart transplantation. These caregiver spouses underwent several stages of life experience while their partners were living with an LVAD and waiting for a donor heart. The caregivers had strong emotions during each stage, emotions that otherwise might not have been revealed or might have remained private to the caregivers.

Despite the inherent limitations, several implications could be derived from this study specific to healthcare providers, who provide direct care to patients and are not intimately involved in the care of family caregivers of patients with LVADs, such as spouses. Healthcare providers such as critical care nurses should recognize and anticipate challenges for the events experienced by patients’ spouses who act as caregivers. The heightened awareness of this phenomenon will guide healthcare providers to individualize the plan of care and the education of patients and patients’ families and to evaluate outcomes of care.

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The Lived Experience of Spouses of Patients With a Left Ventricular Assist Device Before Heart Transplantation
Jessie Casida

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