

# Emotional experiences of caregivers of patients with a ventricular assist device

**Context**—Little is known about the stresses experienced by caregivers of patients discharged home with a ventricular assist device.

**Objective**—To describe the lived experience of caregivers of patients who were discharged home with a ventricular assist device.

**Design**—The study used a phenomenological framework to conduct semistructured interviews guided by 2 psychologists using a focus group setting.

**Participants**—Interviews of 13 caregivers of 9 patients discharged to home with a ventricular assist device between March 2004 and June 2007 were recorded, transcribed, and analyzed.

**Results**—Four themes emerged during the interviews: anxiety, initially exhibited as profound shock; loss of a loved one, of their lives, of freedom and independence; burden, both the physical burden and the burden of responsibility; and finally coping through faith, acceptance, empathy, and social support.

**Conclusion**—Caregivers of patients discharged home with a ventricular assist device experienced significant pressures that changed over the duration of support with the ventricular assist device. Caregivers described their coping mechanisms in dealing with shock, loss, and burden. Understanding the fluctuating needs of caregivers will enable teams to provide interventions based on the situation. Future care guidelines should address the significant stresses placed on caregivers of recipients of a ventricular assist device. (*Progress in Transplantation*. 2010;20:142-147)

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The ventricular assist device (VAD) has been used as a bridge to transplantation, a bridge to recovery, or a substitute for transplantation—sometimes referred to as destination therapy—in carefully selected patients with end-stage heart failure.<sup>1</sup> Over time, new generations of these devices have become smaller, quieter, and more portable, thus allowing more patients to live with these devices at home.<sup>2</sup> In most cases, living at home with a VAD continues to require extensive commitment from 1 or more dedicated caregivers. Caregivers are typically a spouse, family members, or friends who provide around-the-clock help and support.

Review of the literature revealed 3 quantitative studies of VAD recipients and caregivers. In the first study,<sup>3</sup> researchers examined the burden experienced by caregivers of 6 VAD outpatients, comparing them with caregivers of VAD inpatients (n = 15), caregivers of heart transplant candidates at home (n = 30), and caregivers of heart transplant recipients (n = 87). The authors found that caregivers of VAD outpatients provided significantly more nursing care ( $P < .001$ ), felt a greater time burden ( $P < .001$ ), and were more likely to

report worsened health ( $P < .05$ ) than the other 3 groups. In the second study,<sup>4</sup> researchers found that caregivers were worried about essentially the same things that VAD recipients were worried about after discharge, namely, stroke, device malfunction, and infection. Finally, a study<sup>5</sup> of 38 VAD recipients and 27 spouses (26 women and 1 man) revealed that caregivers were more likely than the recipients themselves to have posttraumatic stress disorder, particularly if the VAD recipient displayed an avoidant coping style and hyperarousal.

Only 2 qualitative studies of caregiver experience have been published. A pilot study,<sup>6</sup> using an interpretive phenomenological framework, of 6 patients and 3 caregivers was focused primarily on interviews of patients, not caregivers. Two major themes were identified: body and self (in which feelings of shock and physical trauma were described) and trust, which included care of the device. Participants described their initial shock and trauma, and all felt the burden of the day-to-day surveillance, care, and maintenance of the device.

A similar study<sup>7</sup> that included 3 caregivers of VAD patients also used a phenomenological perspective. All

Table Demographics of participants in the study

Patient No.	Age, y	Sex	Type of VAD	Diagnosis	Implant urgency	Duration of support, days	Time at home, days	Outcome	Caregivers	Group
1	46	M	PVAD	DCM	Urgent	519	488	Alive after HTx	Female partner	B
2	22	F	IVAD	Myocarditis	Emergent	106	72	Alive after explantation	Mother Father	B
3	55	M	HM XVE	Isch	Urgent	392	325	Alive after HTx	Brother	C
4	57	F	HM XVE	Isch	Elective	248	179	Alive after HTx	Husband Daughter	C
5	66	M	IVAD	Isch	Urgent	107	40	Alive after explantation	Wife	C
6	58	M	HM XVE	Isch	Elective	228	186	Alive after HTx	Wife Daughter	C
7	61	F	PVAD	Isch	Emergent	427	300	Died on VAD	Husband	D
8	64	M	HM XVE	Isch	Elective	101	62	Died 1 week after HTx	Stepdaughter Stepdaughter's husband	D
9	49	M	HM XVE	DCM	Elective	124	48	Died day 10 after HTx	Wife	D

Abbreviations: DCM, dilated cardiomyopathy; F, Female; HTx, heart transplant; HM XVE, HeartMate XVE; Isch, ischemic cardiomyopathy; IVAD, Thoratec implantable; M, Male; PVAD, Thoratec percutaneous; VAD, ventricular assist device.

participants were women, and the mean time that their loved ones received VAD support was 6 months. The authors identified 3 themes: emotional distress, determination, and optimism. The author described the joy and “relief” that participants felt at receiving a heart transplant.

Little qualitative research has specifically examined the experiences of caregivers of VAD patients from implantation to explantation or death. The purpose of this study was to describe the lived experiences of caregivers of VAD recipients who were discharged home on support.

## Methods

### Design

The study used a phenomenological theoretical perspective, which encourages the researcher to call into question what is taken for granted (in this case, the experience of caring for a sick loved one) and to hold in abeyance presuppositions about phenomena. The aim is to attempt to capture the essence of experiences.<sup>8</sup> This perspective informed our methods: semi-structured interviews of participants in a focus group format. Use of focus groups as a means of collecting data enables participants to interact with the group and therefore exchange ideas and concepts. It is also time- and cost-efficient for the researcher.<sup>9</sup> As a limitation, Jamieson and Williams<sup>9</sup> describe the risk of “group think,” where the group seems to conform with the majority opinion. The authors recommend careful preparation of the moderator, selection of participants and selection of the site. Our study used 2 registered

psychologists with more than 10 years of experience facilitating groups in a quiet, comfortable site with adequate time to hear each patient’s response to the research questions.

Following a grounded theory method, transcriptions of each focus group interview were coded for categories independently by each investigator, and common themes among transcripts were identified. Following this, the investigative team met to carefully review their codes—and reach consensus regarding broad common themes.

### Sample

Caregivers of all VAD patients who were discharged home from hospital between September 1, 2002, and June 30, 2007, were invited to participate. Ventricular assist devices used during the study period were Thoratec implantable and percutaneous devices and the HeartMate XVE device (all manufactured by Thoratec Corp, Pleasanton, California). The indication for implantation in all patients was either a bridge to transplantation or a bridge to recovery.

### Results

During the eligible period, 30 patients had a VAD implanted, and of those, 17 were discharged to home with the VAD. Caregivers of 5 patients declined to participate, and thus 17 caregivers of the remaining 12 VAD patients were enrolled. Participants attended 1 of 4 separate group sessions. Demographic characteristics of the sample are outlined in the Table. The first 3 sessions (A, B, and C) were populated according to

the ability of the participant to attend a session. The fourth session (D) was confined to caregivers of VAD recipients who had died either while supported on VAD or shortly after transplant. The investigators thought that these participants may have wished to discuss the experience of losing their loved one in a forum where specific discussion about death could take place. Themes related specifically to the death of their loved one that were identified during this session will be reported separately.

Owing to a technical problem, the entire tape of session A was not audible and therefore could not be transcribed accurately, so the interviews of these participants were not included in the analysis. Ultimately, the final sample comprised 13 caregivers of 9 VAD patients. The mean duration of time at home with a VAD was 189 days (range, 40-488 days). During the analysis of the transcripts, 4 major themes were identified: fear and anxiety, loss, burden, and coping.

### Fear and Anxiety

Fear and anxiety was an overarching theme: it emerged not only during descriptions of all phases of the VAD experience, but also in relation to other themes. The nature of initial fear and anxiety differed among participants depending on the urgency of the VAD implantation and the relationship of the caregiver to the patient. For example, parents of a 22-year-old woman requiring emergent implantation of a VAD stated:

Well I think it's like desperation you know, you don't want to lose your child, you know this is the only thing being offered . . .

This contrasted with the brother of a 55-year-old man who had a number of days to absorb and discuss the information provided:

It was basically a no-brainer . . . we . . . talked about it as a family . . . we'll just make it work, one way or another . . .

Caregivers of patients who underwent emergent VAD implantation described extreme levels of distress in the early phase of the experience. They described a state of shock and heightened confusion and said that they had very little memory of the events:

I have no memory of time at all. I don't remember, I remember getting off the plane and calling . . . I don't remember anything else . . .

Caregivers who had more time to discuss the VAD implant with their loved one and did not have to decide on the VAD themselves described less fear and

anxiety in the early phase of the decision-making process:

[The patient] was fully aware and capable of making decisions for herself at the time so we didn't . . . have to make that decision on our own, so we decided you know, we had to go ahead and have the VAD machine.

As patients recovered, the nature of caregivers' fear and anxiety changed significantly; the new anxiety was related to what to do in an emergency and getting through each day:

One night we had to call the hospital because the numbers were going down too low and we had to get some directions . . . what happens if the pumping side fails, that was a big worry, can we get her to the hospital, can we get an ambulance on time?"

### Loss

All participants described loss of various kinds during their experience.

*Loss of "Usual" Family Roles.* Change of usual family roles such as the need to stop work, live away from their own communities, and the inability to socialize were described throughout the interviews:

We didn't have much of a social life. We couldn't travel and I wasn't working. [Patient] wasn't working. I mean that was our life.

Caregivers described their caregiving role as a full-time job:

Trying to look after the wife full-time and doing your job at the same time. You've got to have an income. I don't know what I would have done if I didn't have an employer who would accommodate.

Loss of the participant's usual role and suddenly assuming the caregiver role was difficult for some. It was frequently described as the sudden introduction of the parenting role, exemplified, in one instance, by the purchase of a baby monitor. One participant stated, "It was like having a kid." While this transition was described as difficult within the spousal relationship, not surprisingly, it seemed easier for parents to adjust to this role with an adult child supported on a VAD.

*Potential Loss of Their Loved One.* Caregivers described fear of losing their loved one.

For me, I think it was always in the back of my mind you know, something might happen and she will just die. You are constantly losing your partner over and over and over again.

Fear of loss also emerged related to neurological deterioration:

My concern was more about brain damage. That was my big fear . . . Is he going to be the same person? . . . capable of living the quality of life he would want to live?

*Loss of Independence.* The worry of loss of independence (both the patient's as well as the caregiver's) was described frequently by participants.

You totally change, from being carefree . . . Our biggest thing was the loss of independence. She was a very independent person, and with the machine, she depended on me night and day and she didn't care for that, but she had no choice.

Overall, it was clear that taking on a full-time role of VAD caregiver was perceived as a significant stressor. These caregivers tended to experience many losses in the course of caring for their loved ones.

### Burden

Participants spoke of 2 distinct types of burden: the burden of responsibility related to decision making for their critically ill family member and the burden of the actual tasks of caregiving. The burden of responsibility for making decisions was mentioned most often in relation to the early stages of the VAD experience.

I was scared, wondering if I was doing the right thing. I mean, it was for him, me, and the kids. It was like . . . either way it turned out, I was the one that was going to take the brunt of everything, which was scary.

However, some participants also referred to having this sense of burden after the initial decision:

Well yeah, I mean I know he's grateful I made the decision, but by the same token he was kind of like 'maybe you should have just let me go' . . .

The time and effort required for the tasks of caregiving was a significant theme among all participants and bears specific mention:

Just total care, looking after her 100% around the clock, you know. It changed your whole life. Showering was the other biggest issue; it was like a 2-hour ordeal . . . it was like oh my God, [by] the time we'd finished I was always exhausted.

There was a great sense of relief expressed by participants when the time came for the transplant:

Were we ever glad to pack [the power base unit] up and bring it to the hospital, my boyfriend was so happy, he was throwing it in the car (laughing)!

That was great, bringing that machine back, even though it was a lifeline and we realize it was really good and really wonderful . . .

### Coping

Several coping factors were described that mediated the impact of the stresses that were experienced. These factors included faith, acceptance, empathy, and support.

*Faith.* Before the VAD was implanted, many caregivers were asked to make life-and-death decisions on behalf of their loved one. Several participants relied on faith in the medical team to guide them: "You just put your faith into the hospital and just hope you've done everything right," said one caregiver. Others relied on their spiritual faith:

You probably have more spirituality than before . . . you have time to reflect on life . . . we were just in a rut before and this sort of thing helps you right the score . . .

*Acceptance.* One coping strategy that was repeatedly discussed was turning the mind toward acceptance. One caregiver provided a compelling image:

When a fast ball is thrown at you, you have to take it and do the best you can with it, you know, you either swing the bat or you keep the bat on your shoulder. We sort of ran with it. We knew we had to deal with it, and if we had to do it all over again, we'd probably be the same way with our emotions and everything else . . .

*Empathy.* Caregivers repeatedly expressed empathy for their loved one, especially with regards to the limitations of living with a VAD and the accompanying feelings of frustration. "When you're told you can't go somewhere, you can't drive a car, you can't

do this, you can't do that, that's like telling someone [you're] in prison," said one caregiver. Another, instead of reacting to her partner's angry outburst, added "You can't be hurt because, I mean, he's not doing it to hurt you."

*Emotional Support.* All participants expressed their need for support and obtained this support primarily from family members. The level of availability and adequacy of this support varied, however. Some caregivers described being able to share responsibilities every day, others had help a few times per week, and still others carried the responsibility almost exclusively on their own. Overall, being able to share the burden and take breaks to attend to personal needs was acknowledged as extremely helpful in managing the psychological stress and physical strain of care providing. Most caregivers, even those who had little support, agreed: "You've got to have somebody, you just can't do it all on your own."

*Cognitive Support.* Caregivers reported that they received excellent training on operation and maintenance of the VAD, and their loved one was not discharged until they felt confident. They also praised the education materials and said that they repeatedly referred to them when concerned or in doubt:

We'd go back to those books, [they were] so helpful, because there's not always somebody at the end of the phone although . . . if you looked at these things, it would help . . . and then you'd be able to phone with a reasonable amount of knowledge.

*Material Support.* Most caregivers, especially those who did not have regular help, said that they needed to take time off work. Having financial benefits, being able to work from home, or having an understanding employer who accommodated the need to work from home made the caregiving experience a little more manageable. "Fortunately I have an employer who was kind enough to let me work from home, I do my work through computers. . . ."

## Discussion

Our group has confirmed that shock, anxiety, and caregiver burden are significant in the experiences of VAD support. As with the evidence published to date, anxiety, the burden of day to day surveillance, and the stress of care and maintenance of the device were significant. Unlike Casida,<sup>7</sup> we did not identify optimism as a unique theme, but rather as a component of coping. A number of caregivers did not have a sense of optimism during their experience. Perhaps this difference can be explained by the fact that the study by

Casida had participants who were younger women (maximum age, 52 years) and the average duration of VAD support was almost 5 months (one patient for only 3 weeks), whereas our cohort was of mixed sexes and relationships to the patients, who had a mean duration with a VAD that was almost twice as long (nearly 9 months) as the patients in the study by Casida. Casida described the joy and "relief" participants felt at receiving a heart transplant, which was also expressed by our participants and described earlier.

We found that marital or family relationships were strained during the VAD experience, unlike the experiences described by Casida,<sup>7</sup> in which participants described feeling closer to their loved one as a result of the experience. However, on a positive note, in our study, participants described increased spirituality and appreciation of health and life.

Our findings highlight that responses differ according to the relationship of the VAD recipient to the caregiver. Parents described stronger feelings of desperation and loss and less burden of caregiving than did spouses, whereas spouses described greater feelings of burden in terms of caregiving than did parents. It seems an easier transition for parents of VAD recipients to assume this caregiving role than for spouses.

We did not find any major differences in responses based on sex of the caregiver. Although Casida<sup>7</sup> described 3 women who may have been more comfortable with providing nurturing support, the male participants in our study described a high level of commitment to the caregiver role and expressed similar emotions to those expressed by our female participants.

Limitations of this study include the short length of the interview. This left little time to delve into specific issues that arose as we attempted to take participants through the entire VAD experience during this time frame. Also, although the interviewers' recollections of session A (where the taping was not audible) were that the themes were similar, we could not analyze the recollections from that session.

## Implications for Practice

Results of this study reinforce the need to assess carefully the amount of information that caregivers of potential VAD recipients can absorb depending on their circumstances. Caregivers of patients undergoing emergent implantation describe having little or no memory of events. Families should receive clear, simple, and concise descriptions of the issues and the options, and there should be opportunities to repeat the information numerous times.

Caregivers of VAD patients who are discharged home undergo considerable stress, which changes in nature during the VAD experience. Indeed, published reports reveal that the experiences faced by caregivers of VAD patients in many cases may cause significant

psychiatric morbidity, including posttraumatic stress disorder.<sup>5,10</sup>

Rizzieri et al<sup>11</sup> compared the significant level of burden in VAD caregivers with other high-technology supports managed at home, such as mechanical ventilation. Guidelines published by the International Society for Heart and Lung Transplantation<sup>12</sup> recommend that evaluation of patients for VAD implantation as destination therapy should include assessment of the patients' level of social support. They go on to recommend that the dynamics of social support systems should be reviewed monthly. The guidelines do not, however, address adequately the significant toll on families of VAD recipients. Future revisions should incorporate a requirement for detailed individualized planning before implantation of a VAD related to options for providing support and respite, including active involvement of palliative care teams.

### Future Research

The narratives included a great sense of relief at receiving the call for a transplant. This finding points to the need for a study specifically of caregivers of VAD recipients who receive the device as destination therapy, to further explore how caregivers cope with little or no prospect of device explantation and/or transplantation.

We examined caregivers of patients who received pulsatile devices. Because of the decreased morbidity and mortality reported with nonpulsatile devices,<sup>2,13</sup> caregiver stress may be somewhat less during the patient's course and deserves research attention.

### Conclusion

This study is the largest qualitative study to date intended specifically to examine the experiences of caregivers of VAD recipients from admission through discharge from hospital to transplantation or death. Results of this study build on the currently available evidence and may help teams to plan for assessment of VAD candidates and provision of appropriate support

for caregivers and to recognize the intense levels of stress under which caregivers are placed.

### Financial Disclosures

None reported.

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