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Caregiver Burden is Low Nine to Twelve Months after Ventricular Assist Device Implantation

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Abstract

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Background

Prior studies have found that caregivers of chronically ill patients, including those with heart failure, have significant stress and burden. Ventricular Assist Devices (VADs) are a promising therapeutic modality for end stage heart failure. However, caregiver burden has not previously been studied in the caregivers of VAD patients.

Methods

We studied 31 caregivers of VAD patients receiving care at University of California, San Diego. Validated instruments tools, such as the Bakas Caregiving Outcomes scale and Oberst Caregiving Demand and Difficulty sub-scales, were used to measure the caregivers' psychological burden.

Results

Nearly half of the caregivers were the patient's spouse or partner (55%) with a mean age of 57 years. When evaluating caregiver burden difficulty, 23/31 (74.2%) of the caregivers experienced little to no difficulty, 5/31 (16.1%) had mild difficulty, and 3/31 (9.6%) noted moderate difficulty. When assessing caregiver burden demand, 17/31 (54.8%) experienced little to no demand, 8/31 (25.8%) reported mild to moderate, 5/31 (16.1%) noted moderate to severe, and 1/31 (3.2%) had severe demand. Using the Baka's scale, 27/31 (87.1%) reported that VADs were not disruptive to their lives.



Conclusions

In this single center study, we found that 80-90% of VAD caregivers had little caregiver burden difficulty or demand, which is significantly less than published studies of caregivers of patients with other chronic diseases. Further study will be required to validate these findings and compare them to other therapies for end stage heart failure, such as cardiac transplantation.

Keywords: caregiver burden, ventricular assist device, ventricular assist devices

Introduction

Caregiver burden is an all-encompassing term used to describe the physical, emotional, and financial toll of providing care. High caregiver burden is commonly seen in chronic conditions including COPD, cancer, end stage renal disease and heart failure. Caregiver burden is generally perceived to be high in patients with ventricular assist devices (VADs), but this has not been studied in the modern VAD era of continuous flow devices.

Prior studies suggest that caregivers experience significant stress and burden. Dew et al. evaluated 37 patients and 20 caregivers using an "Opinions about VAD Treatment" questionnaire. They observed significant apprehension by patients and caregivers regarding potential infection, pain related to the driveline, sleep disturbance, device noise, and device malfunction (1). A cross sectional study of 38 patients and 27 spouses also suggested that the overwhelming majority of caregivers experienced post-traumatic stress syndrome type symptoms following VAD implantation in patients (2).

These studies were limited to pulsatile flow devices which are significantly louder, prone to a higher incidence of infections and mechanical malfunction compared to contemporary continuous flow devices. Additionally, the questionnaires utilized were performed during the perioperative period, a time when complications associated with LVAD implant occur more frequently. Moreover, new comprehensive questionnaires have been validated as tools to assess caregiver burden across different disease states including caregivers of patients with heart failure. As 1 year post-VAD implant survival is nearly 90%, it is important to understand caregiver burden beyond the perioperative period.

The objective of this study was to assess long-term caregiver burden in the primary caregivers of VAD patients 9-12 months post LVAD implant. We hypothesized that caregiver burden at 9-12 months post implant will substantially lower due to the decreased incidence of VAD related complications and increased independence of the VAD patient.



Methods and Results

We enrolled 31 consecutive, English-speaking caregivers of patients who underwent VAD implantation as either a bridge to therapy or destination therapy at the University of California, San Diego 9-12 months post-LVAD implantation. We excluded patients who had emergent VAD placements without prior anticipated scheduling or education.

Caregivers were asked to complete three questionnaires at 9-12 months post-LVAD implantation: the Bakas 15-item Caregiving Outcomes Scale, Oberst Caregiving Demand Burden Scale, and Oberst Caregiving Difficulty Burden Scale. The Bakas outcomes scale assessed the caregivers' perceived change in their life since providing care to the VAD recipients. Meanwhile, the Oberst caregiver burden scale measured the emotional and physical demands/difficulty of caregiving.

Of the 31 caregivers enrolled, more than half were either the patient's spouse or partner (55%). These individuals averaged 57 years of age and about 80% were women. About 25% of the caregivers were the patient's sibling and the remaining 30% were another relative or friend. All 31 caregivers completed the three questionnaires (Table 1).

Table 1: Questionnaire Results

	Mean	Standard Deviation	Range of Total Points*
Caregiver Burden Demand	30.5	14.7	15 to 70
Caregiver Burden Difficulty	23	11.8	15 to 53*
Bakas Outcomes Scale	1.90	14	-24 to +24

* Minimum & Maximum Points for Oberst Caregiver Scale
Minimum total points= 15
Maximum total point= 75

* Minimum & Maximum Points for Bakas Outcomes Scale
Minimum total points= -24
Maximum total point= +24



When assessing caregiver burden demand, which accounted for the amount of time required to perform caregiving tasks, 17/31 (54.8%) experienced little to no demand, 8/31 (25.8%) reported mild to moderate, 5/31 (16.1%) noted moderate to severe, and 1/31 (3.2%) had severe caregiver burden demand (Graph A). When evaluating caregiver burden difficulty, which measured the level of difficulty required to perform tasks, 23/31 (74.2%) of the caregivers experienced little to no difficulty, 5/31 (16.1%) had mild difficulty and 3/31 (9.6%) noted moderate difficulty in caregiver burden (Graph B). Using the Bakas caregiving outcomes scale, which evaluates changes in the caregiver's life as a result of providing care for the patient, 22/31 (71%) reported no significant change, 4/31 (12.9%) described that it changed for the better, 4/31 (12.9%) revealed that it changed slightly for the worse, and 1/31 (3.2%) claimed that it changed significantly for the better (Graph C).

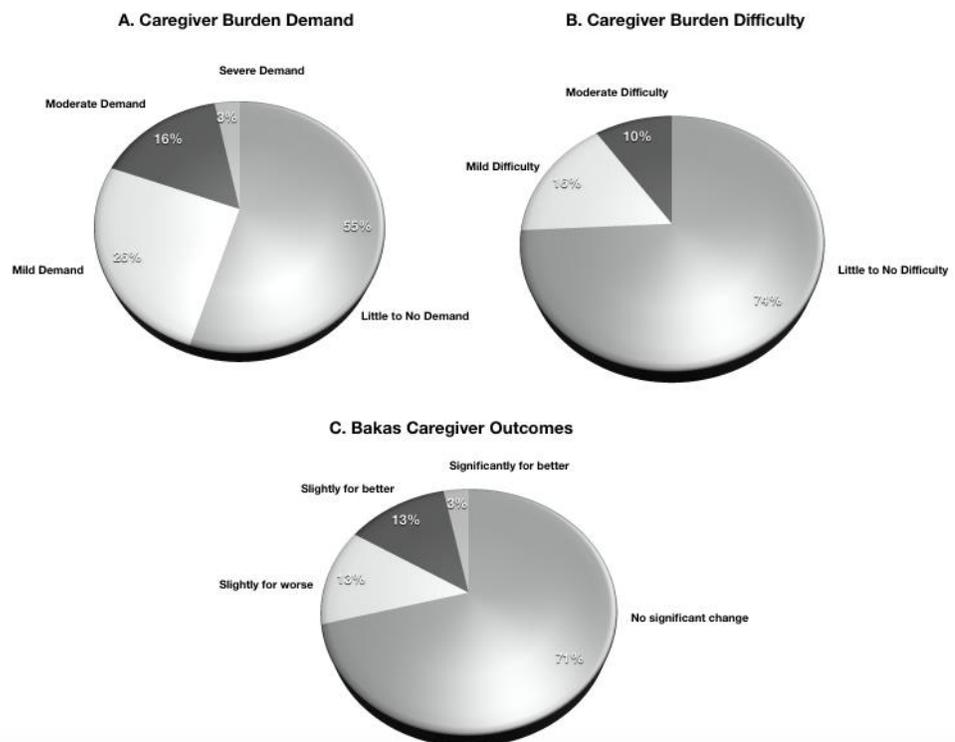


Figure 2 Graphs A&B illustrate the extent of caregiver burden demand and difficulty, respectively. Graph C depicts how the caregivers perceived a change in their quality of life as a result of providing care to the VAD recipients.

The major finding of this study was that 80-90% of VAD caregivers had relatively little caregiver burden difficulty or demand at 9-12 months post-VAD implantations, based on validated heart failure assessment tools. Additionally, the Bakas scale clearly demonstrated that there were very few, if any changes, to the caregivers' lives as a result of providing care to VAD recipients.



These numbers were lower than we hypothesized given previous studies and common perceptions about caring for patients with LVADs. Advances in technology have led to a new generation of VADs that are less prone to malfunction and infection. VADs are now also more easily programmed and have ambulatory troubleshooting mechanisms in place. Meanwhile, in tertiary referral heart failure programs, there has been widespread implementation of the medical home model which is thought to be more patient and family friendly. These factors may help explain the caregiver's perception of a lower burden when compared to previous studies. Further study is required to validate these findings and compare them to other therapies for end stage heart failure, such as cardiac transplantation.

Of note, this study was a preliminary, single center study with a modest sample size (n=31), without a control group. Also, caregiver burden was evaluated at 9-12 months post-VAD implantation. It is possible that caregiver burden will be higher immediately after VAD implantations. Finally, the patients and caregivers who were non-English speakers were excluded from the study which limits the generalizability of the findings.

In summary, this single center study demonstrates that caregiver burden is low 9-12 months post implantation of VADs. These results may help when counseling patients and caregivers contemplating LVADs and or during the perioperative experience. Larger multicenter trials examining temporal trends in caregiver burden, and comparing to other modalities (transplant, hospice) will help further define the incidence, prevalence and severity of this problem across the spectrum of Stage D heart failure.

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