Journal of Cardiac Failure Vol. 21 No. 10 2015

Caregivers and Left Ventricular Assist Devices as a Destination, Not a Journey

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ABSTRACT

Background: The quality of life (QOL) of caregivers of patients with LVAD-DT (Left Ventricular Assist Device as Destination Therapy) has not been well explored.
Methods: We used a concurrent mixed methods design. Caregivers (n = 42; average 60 years old, 82% female, 75% white) of patients (n = 39; average 68.3 years old, 83% male, 90% white) and providers (n = 27) from 6 LVAD-DT programs were recruited. We used the City of Hope Quality of Life Family Caregiver instrument, modified for LVAD-DT. Lower scores indicate poorer QOL. We analyzed open-ended questions with the use of Nvivo 10.0, using a modified grounded theory approach.
Results: The Psychologic subscale had the lowest average QOL score, followed by Social, Spiritual, and then Physical subscales. The composite mean average QOL score across the subscales was highest in caregivers <40 years of age and ≥ 70 years of age. There was a nonsignificant trend toward better QOL in male caregivers ($P = .06$). We sorted QOL items into tertiles based on the percentage of responses <5 (10-point Likert scale). Scores <5 in the 2nd tertile (items from Social and Spiritual subscales) were reported by many fewer respondents than the 1st tertile (items from the Psychologic subscale). In the 3rd tertile, $<10\%$ of respondents scored <5 on 15 of the items. In qualitative interviews psychologic and social themes predominated in discussing requisites for competent caregivers, stress in pre-implantation decision making, lack of psychologic preparation, impact on freedom/independence, daily worry about pump performance, and value of psychologic and social support.
Conclusion: Support interventions for caregivers of patients with LVAD-DT should address the psychologic and social aspects that lead to poor QOL. (*J Cardiac Fail 2015;21:806–815*)
Key Words: LVAD, caregivers, quality of life, heart failure.

The remarkable success of therapies to reduce mortality from acute cardiovascular disease has resulted in a large population of patients living with chronic heart failure. An estimated 5% of these patients can be classified as having advanced heart failure, amounting to nearly 260,000 patients in the United States alone.[1] Left ventricular assist devices (LVADs) were originally designed to serve as a bridge to transplant (BTT) for the sickest patients awaiting cardiac transplants. Only 2,500 donor hearts become available each year, however, and an increasing number of patients are ineligible for transplants because of age, immunologic incompatibility, or the presence of other comorbidities.[2] The REMATCH trial in 2001[3] demonstrated the clear superiority of

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Manuscript received December 11, 2014; revised manuscript received May 28, 2015; revised manuscript accepted May 29, 2015.

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Funding: Greenwall Foundation. Part of funding was provided through The Kornfeld Program in Bioethics and Patient Care.

See page 815 for disclosure information.

1071-9164/$ - see front matter

http://dx.doi.org/10.1016/j.cardfail.2015.05.016

LVADs over medical management in reducing morbidity and mortality in patients with end-stage heart failure who were not eligible for transplants, establishing the use of LVADs as permanent ''destination therapy'' (LVAD-DT). Original LVADs were bulky and cumbersome, but the availability of smaller LVADs has expanded the number of patients eligible to receive implantable LVADs, including women who were too small for early-generation devices.[4]

The impacts of LVAD-DT on survival, quality of life (QOL), and even cost have garnered considerable attention,[5] but the impact of LVAD-DT on caregivers has not been well explored to date. Although concerns about caregiver fatigue, changes in caregiver health, and burnout are often addressed in the long-term care needs for patients with dementia or spinal cord injury,[6,7] they have only begun to be investigated in the area of cardiovascular disease.

Caregivers play important roles in the care of patients with LVAD-DT. Caregivers often perform dressing changes, battery changes, and other significant maintenance measures to prevent infection and thrombotic events. They must also recognize and troubleshoot LVAD malfunction. LVAD pump failure is often a terminal event, because patients usually have inadequate residual cardiac function to maintain cardiac output without mechanical assistance. Because LVAD dysfunction can cause reduced blood flow to the brain, patients may become incapable of realizing there is a problem with the device. Caregivers must therefore recognize device dysfunction before it is too late. Recent professional society guidelines recognize this important role for caregivers and recommend the identification of a caregiver who is competent to fill this role to allow patient discharge after implantation.[8,9] These responsibilities, in addition to others involved in caring for patients with a chronic illness, can create a significant amount of stress, even for the caregiver of a patient who otherwise has improved quality of life and functional capacity with LVAD support. Such stress can compromise the health of caregivers and the patients who rely on them. Our aims in the present study were to 1) characterize the QOL of caregivers of patients with LVAD-DT and 2) identify burdens and stressors associated with caregiving for patients with LVAD-DT.

Methods

We used a concurrent mixed methods research design[10] to investigate caregiver QOL. We used this design in an effort to capture QOL at the time of the interview so that we might be able to understand QOL in the aggregate for the sample as well as to link individual QOL scores with qualitative data provided in individual interviews. Providers, patients, and caregivers from LVAD-DT programs at 6 institutions, 2 from the Midwest and 4 from the mid-Atlantic region, were identified by a local site coordinator. Patients were eligible if they had an LVAD placed as intended DT because of ineligibility for heart transplant (owing to medical or psychosocial factors) or because their chances of receiving a heart transplant were extremely low (eg, patients whose blood type and other antibody status make it very unlikely they would ever receive a compatible donor heart). Exclusion criteria included patients with LVADs intended as bridge to therapy or bridge to recovery (patients under consideration for LVAD-DT weaning and LVAD removal) and patients with loss of decision-making capacity or inability to communicate in spoken English (eg, after a stroke). Caregivers were eligible if they were identified by the local site coordinator as the caregiver of a patient with LVAD-DT who met the inclusion criteria listed above. Caregivers were not excluded if not listed as the primary caregiver.

Eligible providers included cardiologists, surgeons, LVAD coordinators, nurses, and any social workers, counselors, and other mental health personnel who were the official providers in 1 of the 6 LVAD-DT programs. A $10 gift card was provided to each of the patient and caregiver participants. Institutional Review Board approval was obtained for the study from the University of Pennsylvania and all participating sites.

We conducted patient interviews to establish patient-level demographic and background characteristics and to establish the permissibility of contacting caregivers. We conducted provider interviews to investigate their perspectives on caregiver burden and explore what they thought about the role and qualifications of caregivers. Neither patients nor providers were interviewed about the quality of life of specific caregivers. After patients provided informed consent, their caregivers were contacted by the central study team and participated in telephone interviews. We used a survey instrument—the City of Hope Quality of Life Family Caregiver instrument (Appendix A)—that was developed and validated for use with caregivers of people with cancer and modified for use in caregivers of patients with LVAD-DT (Appendix B). This instrument is a 37-item tool containing 4 subscales assessing physical, psychologic, social, and spiritual well-being. A response to each item on the respective subscale is given on a 10-point Likert scale. Lower scores indicate poorer QOL. The test-retest reliability in the cancer population for the instrument is $r = 0.89$, and internal consistency is alpha $r = 0.69$. For use in this study, 5 items on this instrument were adjusted to be relevant and appropriate to the experiences of caregivers of patients with LVAD-DT. For example, ''How distressing has the time been since your family member's treatment ended?'' became ''How distressing has the time been since your family member's LVAD was placed?'' These modifications were developed by consensus of the study team.

An average score was calculated for each individual for each of the four subscales. Additionally, a composite score was constructed by calculating the mean score for each of the averaged subscales to provide a measure of overall QOL giving equal weighting to each subscale (mean of average scores). Comparisons for each averaged subscale and the mean average score were conducted by means of 1-way analysis of variance (ANOVA). A 2-way ANOVA was used to explore the relationship between participant sex, years since LVAD implantation (<2 or ≥ 2 years) and presence or absence of caregiver advance directive. Two years was chosen as a cutoff because 2-year survival with an LVAD-DT is an important clinical outcome measure, and caregivers would have had significant experience with LVAD-DT after this period of time. All analyses were conducted with the use of Stata 13 software.