Mechanical Circulatory Support (MCS) Caregivers After Hospital Discharge: How Do They Want to Be Supported?

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Purpose: Caregivers play a crucial role in the successful transition of MCS patients to home. Much has been written about their experience and the burdens and challenges they face. However, nobody has reported on interventions to address burden that caregivers would regard as helpful. We surveyed caregivers to understand their currently perceived level of care involvement, social support, self care, and what kinds of assistance they would value.

Methods: We distributed an anonymous 14-item survey to MCS caregivers participating on MyLVAH.com and 10 other MCS caregiver websites.

Results: Ninety caregivers (mean age 57.9 ± 12.09 years, 89% female) completed the survey. Patients (mean age 61.8 ± 13.1 years, 84.4% with a HeartMate II for 20.19 ± 16.2 months) received a median of 10.5 hours/week of care. Importantly, 52.2% of all caregivers surveyed reported that they received no help from others with caregiving. While 22.2% endorsed receiving help in the form of respite care, 48.9% stated that they would like respite care assistance. More calls from the MCS team was endorsed by 28.9%, financial help by 44.4%, and housekeeping assistance by 43.3% as having value for the caregiver. When caregivers were divided into 2 groups: older (> 65 y.o.)(n=26); and younger (< 65 y.o., n=64), we found that older caregivers were twice as likely (92% vs. 45%, p = .022) as younger caregivers to attend support groups, but both groups reported participating in online support groups (77% vs. 80%, respectively). Younger carers were three times as likely (55% vs. 19%, p=0.022) as older carers to request financial resources as a means of support. Of concern, both groups contained a large proportion who identified no means of self-care (58% of younger, 31% of older carers, p=ns)

Conclusion: This is the first report that identifies specific methods of support requested by caregivers to reduce the burden of providing care. It also demonstrated that caregivers of different ages identified different kinds of support as valued. Further, it revealed that as many as half of caregivers do not engage in self-care. Designing trials to test the impact of support interventions is important to reduce burden and to help caregivers to optimize success, perhaps including time for self-care.

Pre-Hospital Care for VAD Patients: Where Are the Gaps?

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Purpose: Emergency medical service (EMS) providers are an important component of the continuum of care for continuous-flow left ventricular assist device (CF-LVAD) patients. To date, no standards for education for EMS providers have been established. Therefore, the purpose of this study was to determine practice patterns and content of education for EMS providers.

Methods: We studied individual behaviors and institutional policy with a survey tool created in REDCap. The questionnaire was distributed to members of the ISHLT through an email communication (survey period: 11/01/2013-11/30/2013) and participation was voluntary. The questions focused on techniques and elements for EMS education.

Results: 116 members (cardiologists: 29.3%, cardiothoracic surgeons: 22.4%, VAD coordinators: 42.2%, other: 6.0%; U.S respondents: 72.4%) responded to the survey. The majority (95.7%) reported that EMS providers receive CF-LVAD education. Teaching methods vary; most commonly employed were handouts (72.4%), oral lecture (64.7%), hands-on teaching with equipment (58.6%) and live patient demonstration (39.7%). Respondents reported different expectations for EMS providers. While more than half (53.4%) expected competency with batteries and connectivity, the majority (56.9%) of respondents do not assess whether EMS providers understand the parameters (speed, pulsatility, power, flow) of the device. Respondents do expect EMS providers understand that patients may be pulseless and they should employ other techniques to determine perfusion such as capillary refill, Doppler-derived blood pressure, color, rhythm and mental status. The complication most frequently discussed is CVA/stroke. Alarm assessment is explained less than half (45.5%) the time and other common complications (infection, GI bleed, right heart failure) are infrequently taught.

Conclusion: As the prevalence of CF-LVAD patients in the community grows, the likelihood that EMS providers will care for a CF-LVAD patient increases. Numerous gaps in education have been identified. Opportunities exist to partner with EMS providers to improve education to optimize pre-hospital care.

Use of Facebook as a Virtual Community and Support Group By Left Ventricular Assist Device (LVAD) Patients


Purpose: Left ventricular assist device (LVAD) patients may benefit from participating in a social support group; however, a number of factors limit the availability of these communities. To compensate, many patients belong to virtual communities for LVAD patients through the social media site, Facebook. There are no studies available that describe the characteristics of patients who use these communities, or how and why they use them.

Methods: An online survey of patients actively participating in LVAD Facebook groups was conducted using both multiple choice and open-ended questions. Narrative responses were categorized and percentage scores were calculated for all responses.

Results: Forty participants (65% male, 35% female) completed the survey. Respondents use Facebook LVAD groups for social/emotional support, offering support to other LVAD patients (78.9%), sharing coping strategies (76.3%), and asking other LVAD patients how they are coping (47.4%) at least once per week. Respondents also use the groups to seek medical advice; 73.7% say they get information about LVADs and 52.6% seek answers to their LVAD problems at least weekly, while a majority also offers advice to other LVAD patients (72.9%) or their spouses/family members (60.5%). Although 31.5% said there were no negative aspects of using the social media support groups, others identified an excessive focus on fear/negativity (26.3%) and confusing or misleading information (21%) as major problems. However, 100% of respondents believed the information they personally received was accurate, and 43.2% said that it was easier to get medical advice on the social media sites than from their health care providers (physicians, nurse practitioners, LVAD coordinators, etc.). The prime reason for using Facebook support groups instead of traditional groups was physical distance from such a group (33%).

Conclusion: Virtual communities meet a need for social support among LVAD patients. Although there are numerous benefits from participating in these groups, the degree to which they are utilized for medical advice, in lieu of consulting a health care professional, is concerning. The results of this study highlight the importance of a trusting relationship between practitioners and patients who can help practitioners provide for the social and educational needs of LVAD patients.

Evolution of Depressive Symptomatology and Caregiver Burden in Partners of LVAD Patients

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Purpose: Living with an LVAD might cause mental stress for patients and their partners. We sought to analyze caregiver burden and possible symptoms of depression in partners of patients living with an LVAD.

Methods: Depressive symptomatology was assessed by the Depression Anxiety and Stress Survey (DASS, 7 items) and caregiver burden by the Dutch Objective Burden Inventory (DOBI, 38 items measuring use and perceived burden of providing care, practical, motivational and emotional support to patients).

We prospectively examined the presence of depressive symptomatology and caregiver burden in 20 partners of LVAD patients at discharge, 1 and 3 months
post-discharge (75% female, median age 52.5 years). Patients themselves estimated their partner’s care burden by completing the DOBI at the same 3 time points. Differences in scores were tested by analysis of variance and paired t-tests when appropriate.

**Results:** Prevalence of depressive symptoms in partners of LVAD patients is high at discharge (75% shows signs of severe depression). This improves in time but remains significant (58% at 1 month and 33% at 3 months).

Partners very frequently provide practical and emotional support at all time points, yet do not perceive providing support as burdensome. No significant decrease in frequency and perceived burden of providing different types of support can be observed over time.

Patients significantly underestimate the practical (p=0.011), motivational (p<0.0001) and emotional support (p=0.030) provided during hospitalization, and continue to underestimate the practical support provided by their partners post-discharge. Correlations between the partners’ and patients’ perception of caregiver burden are in general weak and non-significant.

**Conclusion:** The rate of high depressive symptomatology in partners of LVAD patients both before and after discharge is worrisome. Although partners seem not to perceive providing support as burdensome, the extent of support provided is high. These innovative insights should encourage LVAD teams to consider emotional and practical support strategies for caregivers.

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### Improving Bone Health in Children Supported on Ventricular Assist Devices

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**Purpose:** Children supported with ventricular assist devices (VAD) may be at increased risk for fractures as a result of immobility, nutritional insufficiencies and medication effects. We sought to describe the incidence of fractures in children with VADs and report our multidisciplinary approach to improved bone health.

**Methods:** We retrospectively reviewed all children who underwent VAD implantation from 2005-14. Demographic data was collected. Bone fractures were identified during VAD support and up to 1-year post transplant.

**Results:** Over 10 years, 40 children (26 female), aged 6.7 ± 6.0 (median 4.6, 0.02 to 17.5 yrs) underwent implantation of 43 VADs (7 HeartWare, 25 Berlin Heart, 4 Rotaflow, 7 Abiomed BVS 5000). Diagnosis included; cardiomyopathy (27) and congenital heart disease (13). During a total of 2471 days of VAD support (median 26.5, range 1 to 342 days), 2 patients had fractures, and an additional 3 patients had 5 separate long bone fractures within the first year post transplant. Of the 5 patients who had fractures, 4 were non-weight bearing, all were on loop diuretics >3 mos and had received > 3 mos of unfractionated or low molecular weight heparin. One patient was transitioned from heparin to fondaparinux, a synthetic factor Xa inhibitor as an alternate anticoagulant to prevent bone absorption inherent to other heparins. She received a total of 60 day of heparin, 88 days of enoxaparin, and 3 days of fondaparinux, and was successfully transplanted, with no increase in clotting events after transition to fondaparinux. Dedicated assessment of bone health was instituted for all VAD recipients with focus on high risk patients; infants and toddlers, non weight bearing, failure to thrive, loop diuretic dependence and anticoagulation use >3 mos. Weekly multidisciplinary meetings with pharmacy, nutrition, physiotherapy and nursing would review modifiable risks for bone health, and develop a tailored plan to improve patient mobilization, minimize medications with effects on bone, including transition to novel anticoagulation (fondaparinux), hyper-alimentation of vitamin D and calcium, and ensure special handling precautions.

**Conclusion:** Fractures occurred in 12.5% of children supported with VADs, attributable to poor bone health. It is imperative that programs address bone health and modifiable risks as part of comprehensive VAD and post transplant care.

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### Risk Assessment for HeartWare HVAD Support as a Bridge to Transplant: Is the HeartMate II Risk Score Applicable?

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**Purpose:** The HeartMate II Risk Score (HMRS) was devised to predict 90-day mortality in patients undergoing Heartmate II support. The purpose of this study was to examine the accuracy of the HMRS in patients receiving the HeartWare HVAD as a bridge to transplant (BTT).

**Methods:** Patients receiving an HVAD as part of the BTT clinical trial and continuous access protocol (n = 382) comprised the cohort. The HMRS was calculated using preoperative serum creatinine, albumin, INR, and patient age. Institutional HVAD volume was assumed to be >15 for trial duration.

Patients were divided into risk groups according to published HMRS thresholds: low (<1.58), medium (1.58-2.48), and high (>2.48) risk. The area under the receiver operating characteristic curve (AUC-ROC) was used to assess HMRS accuracy. Kaplan-Meier survival estimates were calculated and log rank testing was used for survival comparisons across risk score groups.

**Results:** The median patient age was 56 years, creatinine 1.21 mg/dL, albumin 3.5 g/dL, and INR 1.2. The sample median HMRS was 1.31. The HMRS classified 63% (n=240) as low risk, 26% (n=99) as medium risk, and 10% (n=40) as high risk for death at 90 days after VAD. Overall sample survival was 90% and 84% at 6 and 12 months respectively. There was no overall significant difference in HVAD patient survival based on HMRS group (Figure 1, p=0.12). HMRS discrimination for 90 day survival was poor (AUC-ROC[95% CI] = 0.56[0.445- 0.682]).

**Conclusion:** In this cohort of BTT HVAD recipients, the HMRS failed to provide accurate risk stratification. Future study is needed to determine if risk models devised in VAD model-specific cohorts apply to all patients on continuous flow support.

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### Predictors of Late Survival Following Continuous-Flow Left Ventricular Assist Devices


**Purpose:** To describe the early, mid and long-term survival of the largest single-center series of patients with new-generation, totally implantable continuous-flow left ventricular assist device (CF LVADs).

**Methods:** A retrospective review of all patients (N=469) implanted with a CF LVAD at a single center between December 1999 and December 2013. Demographics, pre-operative and operative data, perioperative outcomes, echocardiographic and right heart catheterization data, and late survival were gathered. Univariate, survival, and multivariable analyses were performed.

**Results:** Patient characteristics, baseline echo and hemodynamic data, operative characteristics and clinical outcomes are summarized in Figure 1A. Patients were mainly bridge-to-transplant (BTT), with elevated creatinine, multiple comorbidities, critical INTERMACS class 1 or 2, and had advanced pulmonary vascular resistance (PVR) and pulmonary capillary wedge pressures (PCWP). Mean follow-up was 2.1±2.4 years (maximum 13.3 years). Survival is illustrated in Figure 1B (entire cohort) and stratified...