Purpose: Body mass index (BMI) is thought to have an important impact on waitlist and post-transplant mortality in children. Our aim was to investigate whether the impact of BMI varies by the etiology of the heart failure.

Methods: UNOS has 3,254 listings for primary, isolated heart transplant in patients 3-18 yrs old (1995-2012) with either congenital heart disease (CHD) or dilated cardiomyopathy (DCM). Patients were stratified into 4 groups based on BMI%ile-for-age (BMI%): underweight (BMI% < 5), normal weight (5-84), overweight (85-94), or obese (≥ 95). Waitlist and post-transplant outcomes were assessed.

Results: Obesity was more common among DCM patients (18.7% vs. 9.91%) while underweight was more common in CHD patients (20.0% vs. 15.7%, p<0.0001). Waitlist survival was unaffected by BMI% category among CHD patients; underweight (HR 1.3, 1.0-1.6) and obese (1.2, 1.0-1.5) DCM patients had higher risk-adjusted mortality prior to discharge. Overweight (HR 1.8, 0.8-4.2) and obese (1.9, 0.9-4.0) patients had higher risk-adjusted mortality than CHD patients with normal BMI. Higher BMI% was a significant predictor of coronary allograft vasculopathy (p=0.02), and diabetes (p=0.0006) in DCM (but not CHD) patients (Figure).

Conclusion: The impact of BMI% on waitlist and post-transplant mortality varies by diagnosis. Analyses of weight and nutritional status in heart failure and transplantation need to examine CHD and DCM patients separately. BMI alone is insufficient, and better measures of nutrition, causes of increased BMI (obesity vs fluid retention), and physical conditioning are required to better estimate risk.

36 United Stated Trends in Pediatric Heart Transplantation: Are We Busier or Does It Just Feel That Way?

Purpose: It is a common notion that the number of pediatric heart transplants (HT) performed annually in the US has remained constant. Real growth is difficult to estimate better without the by etiology of the heart failure.

Methods: UNOS has 3,254 listings for primary, isolated heart transplant in patients 3-18 yrs old (1995-2012) with either congenital heart disease (CHD) or dilated cardiomyopathy (DCM). Patients were stratified into 4 groups based on BMI%ile-for-age (BMI%): underweight (BMI% < 5), normal weight (5-84), overweight (85-94), or obese (≥ 95). Waitlist and post-transplant outcomes were assessed.

Results: Obesity was more common among DCM patients (18.7% vs. 9.91%) while underweight was more common in CHD patients (20.0% vs. 15.7%, p<0.0001). Waitlist survival was unaffected by BMI% category among CHD patients; underweight (HR 1.3, 1.0-1.6) and obese (1.2, 1.0-1.5) DCM patients had higher risk-adjusted mortality prior to discharge. Overweight (HR 1.8, 0.8-4.2) and obese (1.9, 0.9-4.0) patients had higher risk-adjusted mortality than CHD patients with normal BMI. Higher BMI% was a significant predictor of coronary allograft vasculopathy (p=0.02), and diabetes (p=0.0006) in DCM (but not CHD) patients (Figure).

Conclusion: The impact of BMI% on waitlist and post-transplant mortality varies by diagnosis. Analyses of weight and nutritional status in heart failure and transplantation need to examine CHD and DCM patients separately. BMI alone is insufficient, and better measures of nutrition, causes of increased BMI (obesity vs fluid retention), and physical conditioning are required to better estimate risk.

37 Quality of Life and Burden in Caregivers at 3 Months After Left Ventricular Assist Device Implantation
N. Kato, T. Jaarsma, I. Okada, Y. Kagami, M. Endo, M. Ono, K. Kinugawa, S. Norrköping, Sweden; 2Therapeutic Strategy for Heart Failure, The University of Tokyo Graduate School of Medicine, Tokyo, Japan; 3Organ Transplantation, The University of Tokyo Hospital, Tokyo, Japan; 4Cardiovascular Surgery, The University of Tokyo Graduate School of Medicine, Tokyo, Japan.

Purpose: The role of caregivers is important for the successful long-term support of patients with a Left Ventricular Assist Device (LVAD). Such long-term support can impact well-being of these caregivers. We aimed (1) to evaluate quality of life (QoL) of caregivers, and (2) to identify factors associated with caregivers’ QoL at 3 months after patients’ LVAD implantation.

Methods: Patients and their caregivers were recruited from a university hospital in Japan between December 2011 and August 2014. The QoL of patients and their caregivers was assessed with SF-8. The physical and mental component summary score (PCS and MCS) were calculated, with higher scores indicating better QoL (range, 0-100). Caregiver burden was evaluated by the 8-item Zarit Caregiver Burden Interview, with higher scores indicating higher burden (range, 0-32). These outcomes were evaluated preoperatively and 3 months after LVAD implantation. We performed Student’s t-test to evaluate difference of QoL before and after implantation. Pearson’s correlation coefficient and multivariate regression analysis with backward selection were used to identify factors related to caregivers QoL.

Results: Data was collected in 56 LVAD patients and caregivers (patients, 40±12 years, male 78%; caregivers, 47±14 years, male 25%). Implanted LVADs were 8 HeartMateII (29%), 12 EV AHEART (42%), and 8 DuraHeart (20%). Compared with the preoperative period, caregiver’s MCS at 3 months after LVAD implantation improved (n=26, 40.0±6.9 vs. n=28, 44.2±8.0, p=0.06), but it was still lower than that in Japanese national norms (49.4±6.8, p<0.01). Meanwhile, PCS was comparable to that in Japanese national norms (49.9±6.9 vs. 48.6±7.2). Five caregivers (18%) had mild to moderate burden of caregiving after discharge (the caregiver burden score ≥16) and the median score of the overall sample was low (4.0) (Q1-Q3, 2-9). Multivariate analysis showed that caregiver’s gender (female, β=–6.1, p=0.01) and higher...
caring burden ($\beta = -0.90, p < 0.01$) were independently related to MCS, and only higher caring burden ($\beta = -0.50, p = 0.01$) was independent factor associated with lower QoL.

**Conclusion:** Some caregivers experienced the burden of caring their family with LVAD, which influenced caregivers’ physical and mental QoL. Support and counseling for reducing caregivers’ burden is necessary to improve their QoL.

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

**M.G. Petry, D. Christensen** 1, 2 University of Minnesota Medical Center, Minneapolis, MN; 2Innovative Program Solutions, LLC, Pine Grove, PA.

**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 MyLVAD.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%, $p = 0.02$) 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%, $p = 0.002$) 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?

**K.R. Powell, M.P. Flattery, L.F. Cei, S.P. Pinney, M. Peberdy** 1, K.B. Shah** 2, 1Division of Cardiology, Mount Sinai Hospital, New York, NY; 2Pauley Heart Center, Va Commonwealth Univ, Richmond, VA.

**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 CVAD/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

**B. Boldin, A. Hart, T. Halcomb, F. El-Mallakh**, University of Kentucky UK HealthCare, Lexington, KY.

**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.