

Palliative Care Engagement for Pediatric Ventricular Assist Device Patients: A Single-Center Experience

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Abstract: Outcomes in pediatric patients with ventricular assist devices (VADs) for advanced heart failure (HF) are improving, but the risk of associated morbidity and mortality remains substantial. Few data exist on the involvement of pediatric palliative care (PPC) in this high-risk patient population. We aimed to characterize the extent of palliative care involvement in the care of patients requiring VAD placement at our institution. Single-center retrospective chart review analyzing all VAD patients at a large pediatric center over a 4 year period. Timing and extent of palliative care subspecialty involvement were analyzed. Between January 2014 and December 2017, 55 HF patients underwent VAD implantation at our institution. Pediatric palliative care utilization steadily increased over consecutive years (2014: <10% of patients, 2015: 20% of patients, 2016: 50% of patients, and 2017: 65% of patients) and occurred in 42% (n = 23) of all patients. Of these, 57% (n = 13) occurred before VAD placement while 43% (n = 10) occurred after implantation. Patients who died during their VAD implant hospitalization (24%, n = 13) were nearly twice as likely to have PPC involvement (62%) as those who reached transplant (38%). Of those who died, patients who had PPC involved in their care were more likely to limit resuscitation efforts before their death. Four patients had advanced directives in place before VAD implant, of which three had PPC consultation before device placement. Three families (5%) refused PPC involvement when offered. Pediatric palliative care utilization is increasing in VAD patients at our institution. Early PPC involvement occurred in the majority of patients and appears to lead to more frequent discussion of goals-of-care and advanced directives. *ASAIO Journal* XXX; XX:00–00.

Key Words: advanced heart failure, pediatric mechanical circulatory support, pediatric palliative care, pediatric ventricular assist device

The use of ventricular assist devices (VADs) as bridge-to-transplantation has emerged over the past decade as the preferred treatment for advanced decompensated heart failure

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(ADHF) in pediatric patients refractory to medical therapy.¹ While short- and long-term outcomes are improving, pediatric patients supported by VADs must contend with substantial risk of morbidity and mortality. Serious adverse events, including neurologic injury, uncontrolled bleeding, and life-threatening infection occur in 62% of patients² and 84% of patients will require hospital readmission.^{3,4} Six-month mortality in this population approaches 30%.^{1,5}

The integration of palliative care services in pediatric subspecialty practices that care for critically ill children (oncology, neonatology) is now recognized as an important component of the care of these patients.^{6,7} Recent literature on pediatric palliative care (PPC) involvement in patients with critical congenital heart disease (CHD) suggests similar benefits in this subpopulation^{8–10} and involvement in children with ADHF has been previously described.¹¹ In adults with advanced heart failure (HF), randomized prospective trials have shown improvements in patient quality of life, anxiety, and depression when palliative care interventions combined with medical management are compared with medical management alone.¹² Despite the high burden of morbidity and mortality in pediatric VAD patients, the effect of PPC involvement in this vulnerable subpopulation is understudied.

The purpose of this analysis was to characterize the evolving integration of PPC services in the subpopulation of pediatric

Table 1. Baseline Patient Characteristics Reported as Averages and Range or Percent of Total Cohort (n = 55)

Characteristics	Median (Range) or Number (%)
Age at implant (years)	9.5 (0–21)
Weight at implant (kg)	36.9 (3–96)
Male sex	32 (58%)
Underlying diagnosis	
Dilated cardiomyopathy	30 (55%)
Congenital heart disease	14 (25%)
Other	11 (20%)
Device type	
HVAD LVAD	25 (45%)
Single ventricle HVAD	7 (13%)
HVAD BiVAD	3 (5%)
Berlin Excor LVAD	11 (20%)
Berlin Excor BiVAD	6 (11%)
Thoratec Pedimag LVAD	1 (2%)
Thoratec Pedimag SVAD	2 (4%)
ECMO use	15 (27%)
Heart transplant	42 (76%)
Died	13 (24%)

ECMO, extracorporeal membrane oxygenation; BiVAD, biventricular assist device; HVAD, Heartware Ventricular Assist Device; LVAD, left ventricular assist device; SVAD, single ventricle VAD.

Table 2. Baseline Patient Characteristics Reported in Averages, Percent of Total or Absolute Numbers Comparing Patients with and Without Palliative Care Consultation

Characteristics	PPC Involved (N = 23)	PPC Not Involved (N = 32)
Age at implant (years)	10.0	9.1
Weight at implant (kg)	38.6	35.7
Male sex	50%	61%
Underlying diagnosis		
Dilated cardiomyopathy	61%	50%
Congenital heart disease	30%	25%
Death after VAD implant	33%	15%

No statistically significant differences were identified between the two groups (data not shown).

PPC, pediatric palliative care; VAD, ventricular assist device.

patients undergoing VAD placement at our institution in recent years, describe the timing and extent of PPC involvement and to analyze its impact on patients documented end-of-life directives and clinical outcomes.

Materials and Methods

This was a retrospective observational single-center study of patients receiving a VAD at our institution between January 1, 2014, and December 31, 2017, and included all infants, children, and adolescent patients undergoing device implantation. Patients undergoing temporary extracorporeal membrane oxygenation (ECMO) without conversion to VAD were excluded. Patient data were analyzed through the time of death, VAD explant, or time of heart transplantation.

Pediatric palliative care involvement was identified via chart review by the presence of a) an official PPC consult note charted, b) a PPC intake form with documented subsequent involvement of PPC staff in patient care, or c) repeat PPC staff involvement in patient care or family care conferences as documented in the medical record. The relationship between the presence, extent, and timing of PPC in relation to VAD implant and end-of-life and advance care directives, patient wishes on resuscitation restrictions, and end-of-life experience were also analyzed descriptively.

Statistical Analysis was performed using JMP Pro, version 14.1.0 (SAS Institute Inc., Cary, NC). Circumstances, patient wishes, and advanced directives surrounding patient deaths were compared between cohorts with and without PPC involvement using Fisher's exact testing. *p* values <0.05 were considered statistically significant.

The Stanford University Human Subject Institutional Review Board approved all study activities.

Results

Patient Characteristics

Between January 2014 and December 2017, 55 patients with ADHF underwent VAD implantation at our institution. Baseline demographics and patient characteristics are reported in **Table 1**. Thirty patients (55%) had an underlying dilated cardiomyopathy, 14 (25%) had CHD, and all fell into INTERMACS profiles 1 or 2 at the time of implant. Thirty-seven (67%) were placed on left ventricular device, nine (16%) were on biventricular support, and nine (16%) had single ventricle physiology. Fifteen (27%) required ECMO support at some point during their implant hospitalization. Thirteen (24%) died during their implant hospitalization or while discharged home with their device. Baseline characteristics of patients who received PPC services are compared with those who did not in **Table 2**.

Trends in Pediatric Palliative Care Involvement

Palliative care utilization steadily increased in consecutive years with less than 10% of patients receiving PPC services in 2014, increasing to 65% in 2017, with an overall incidence rate of 42% (n = 23) (**Table 3**).

Fifty-seven percent (n = 13) of first PPC consultations occurred before VAD placement, while 43% (n = 10) occurred after device implantation. Of those patients receiving PPC services, 61% (n = 14) had ongoing support documented throughout their hospitalization, while 39% (n = 9) had a single consultation. Patients who died during their implant hospitalization were more likely to receive PPC services (62%) than those who survived to discharge or underwent heart transplant (38%). Three families (5%) refused PPC consultation when offered by the primary team. The reasons for their refusal were not documented.

End-of-Life Decision-Making and Outcomes

Among the total patient cohort, 7 of 55 (13%) patients documented wishes for limited resuscitation, including the *a priori* refusal of chest compressions or endotracheal intubation in the event of clinical decompensation. Of these, six (85%) had received consultation from the PPC staff during their hospitalization, showing a statistically significant increase in documented resuscitation plans over those without PPC involvement (*p* = 0.017). Advanced directives (end-of-life wishes, Physician Orders for Life-Sustaining Treatment forms, goals-of-care documentation) beyond those pertaining to resuscitation events were documented in four patients (7%), three of whom had palliative care consultations before VAD implant (**Table 4**).

Table 3. Number of Implants, In-Hospital Mortality, Incidence, and Timing of PPC Involvement by Consecutive Years of Study Analysis

Year of Implant	2014	2015	2016	2017
Number of VAD implants	n = 11	n = 10	n = 14	n = 20
In-hospital mortality	18% (n = 2)	30% (n = 3)	<10% (n = 1)	35% (n = 7)
% PPC involvement	<10% (n = 1)	20% (n = 2)	50% (n = 7)	65% (n = 13)
% PPC involvement before VAD implant	None	100% (n = 2)	57% (n = 4)	54% (n = 7)

PPC, pediatric palliative care; VAD, ventricular assist device.

Table 4. Comparing Resuscitation Restrictions and Advanced Directives Among Patients with and Without PPC Involvement

	Full Code	+DNR/DNI	+AD/POLST/ MOLST
+PPC (n = 23)	74% (n = 17)	26% (n = 6)*	13% (n = 3)
-PPC (n = 32)	97% (n = 31)	3% (n = 1)	3% (n = 1)
Total (n = 55)	87% (n = 48)	13% (n = 7)	7% (n = 4)

*Statistical significance with $p < 0.05$.

+PPC, patients with palliative care involvement; -PPC, cohort without consultation; AD, advanced directives; DNR/DNI, do not resuscitate/do not intubate orders; POLST/MOLST, physician/medical orders for life-sustaining treatment.

Of the patients who died after VAD implant, 12 of 13 (92%) died in the hospital setting, while one (8%) died at home in hospice care with device in place. Of the 5 of 13 (38%) patients who died without PPC involvement, two (40%) died from stroke at a hospital other than the implanting hospital, two (40%) died on rescue ECMO, and one (20%) died after extensive resuscitative efforts in the setting of multiorgan failure. Of the 8 of 13 (62%) patients who died having received PPC services, six (75%) had ongoing support by the PPC team during their terminal hospitalization. Five (63%) of these patients died after compassionate withdrawal of mechanical support due to medical futility, one died while receiving home hospice care, and two died acutely in the setting of multiorgan failure and neurologic compromise with attempted resuscitation (**Figure 1**). Patients undergoing compassionate withdrawal all died within 10 minutes of VAD deactivation, with concurrent sedative and pain management for comfort, deactivation of any respiratory support and VAD alarms, in the presence of family and any requested support services such as chaplaincy or music therapy. Patients receiving PPC services were thus more likely to die with goals-of-care being palliative rather than curative ($p = 0.04$).

Discussion

We found that engagement in PPC services in VAD patients increased over time at our institution. Patients and families receiving PPC services were significantly more likely to limit resuscitation efforts in the event of clinical decompensation and experience compassionate withdrawal of mechanical support at the time of death. There was also an increasing trend in these patients to have documented advanced directives that did not

reach statistical significance. Refusal of PPC services occurred rarely.

Although data in the pediatric cardiac population are limited, the benefits of palliative care consultation are well documented in children and adults with other life-limiting conditions. Pediatric palliative care involvement has been shown to improve quality of life, decrease depressive and anxiety symptoms, and increase the frequency of end-of-life care conversations in pediatric patients with cancer.^{6,13} In children with CHD, both Mazwi *et al.*⁹ and May and Thompson⁸ report similar benefits of early PPC involvement. Studies in adults with HF, including VAD patients, show promising trends on the impact of PPC consultations on the patient experience while highlighting the difficulty in assessing the appropriate timing and extent of involvement of these services.^{12,14,15}

Although the current study is the first to document the end-of-life experience in pediatric VAD patients, previous analyses in adults on VADs by Dunlay *et al.*¹⁶ and pediatric heart transplant patients by Hollander *et al.*¹⁷ have shown high rates of in-hospital death, frequent invasive interventions, and use of life-sustaining support in these populations. While our cohort showed similar rates of in-hospital death, those receiving PPC services were more likely to have expressed their end of life wishes to the care team, and to experience controlled withdrawal of life-sustaining care. These findings underscore the benefits of early and sustained PPC involvement in pediatric VAD patients.

Early referral patterns for PPC services at our institution were largely influenced by attending physician preference and considered on a case-by-case basis. The upward trend in PPC involvement over the study period reflects an effort to standardize PPC referral at our center for any patient being considered for VAD placement.

As attempts to use VADs to support an increasing array of medically fragile children, including those with single ventricle CHD or multiple medical comorbidities,^{18–20} the decision to proceed with VAD implant becomes increasingly complex. In the setting of prognostic uncertainties, the potential for suffering without survival,^{21–23} palliative care services can serve patients, families, and treatment teams trying to navigate important decisions. The recognition of the need for a holistic approach to VAD implant decision-making is evident in cardiac providers' positive attitude toward palliative care²⁴ as well as the marked increase in PPC involvement demonstrated at our institution.

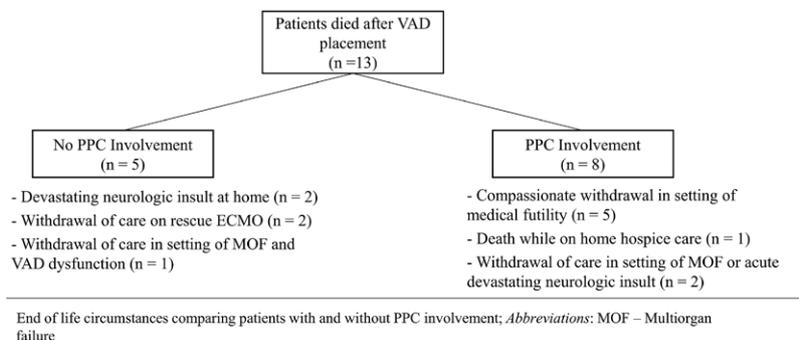


Figure 1. End-of-life circumstances comparing patients with and without PPC involvement. ECMO, extracorporeal membrane oxygenation; MOF, multiorgan failure; PPC, pediatric palliative care; VAD, ventricular assist device.

Our single-center analysis is limited by its retrospective nature and small sample size. Nevertheless, our study demonstrates the increasing involvement of PPC services for VAD patients at our institution, as well as the benefits of PPC consultation to facilitate end-of-life care conversations and earlier documentation of goals-of-care. Further study on the impact of PPC involvement in the pediatric VAD population is needed.

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