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Pediatric ventricular assist device use as a bridge to transplantation does not affect long-term quality of life

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Objective: The present study sought to determine the long-term quality of life (QOL) of children who required long-term ventricular assist device (VAD) support as a bridge to transplantation (BTT) compared with children who underwent heart transplantation without VAD support. Currently, 20% of children undergoing heart transplantation have required a VAD as a BTT. Few data have been published assessing how children requiring a VAD as a BTT will fair in terms of their long-term QOL.

Methods: The present study used a cross-sectional design, using the Core and Cardiac modules of the Pediatric Quality of Life Inventory survey. In a secondary analysis, the factors associated with worse QOL outcomes among the VAD patients were also investigated.

Results: At follow-up (median, 4.2 years), between the 21 children who required a VAD as a BTT and 42 who went straight to transplantation, no significant differences were found in the QOL as measured using the Psychosocial Health Summary Score, Physical Health Summary Score, or Total Score in the survey's Core Module, nor were any differences found in the outcomes assessed using the survey's Cardiac Module. Of the patients who required a VAD, only the presence of a neurologic complication was associated with worse QOL, which was demonstrated by decreased Physical Health Summary and Cardiac Communication scores.

Conclusions: Over the long term, surviving children who required a long-term VAD as a BTT experience a similar QOL as those who went straight to transplantation. (J Thorac Cardiovasc Surg 2014;147:1334-43)

In recent years, the number of children supported by a ventricular assist device (VAD) has increased considerably, with up to 20% of children undergoing heart transplantation requiring a bridge with a VAD,¹ a dramatic increase from the early 1990s.² Pediatric VAD use is likely to increase further, given the recent US Food and Drug Administration approval of the Berlin Heart EXCOR Pediatric VAD (Berlin Heart AG, Berlin, Germany).³ VADs have been shown to improve survival to transplantation compared with extracorporeal membrane oxygenation (ECMO).^{4,5} VAD use as a bridge to transplantation (BTT) has had equal or better rates of post-transplantation survival compared to medical therapy alone as a BTT,⁶⁻¹³ although the outcome data have been limited. With the efficacy of adult and pediatric VAD use established, it is appropriate to assess the long-term outcomes beyond survival alone.

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Pediatric VAD use is associated with a high rate of infection, stroke, and bleeding,⁴ all of which can cause significant morbidity with respect to the neurologic and quality of life (QOL) outcomes. Our aim was to assess the QOL of children who required a long-term VAD as a BTT compared with those patients who went straight to transplantation (STT).

METHODS

We used a cross-sectional study design to evaluate QOL outcomes in pediatric survivors after heart transplantation, comparing those patients supported with a VAD as a BTT and patients never supported by a VAD.

The patients selected for inclusion had undergone heart transplantation from January 2005 to August 2011 at our institution, were ≤ 18 years old at transplantation, were ≥ 1 year post-transplantation, and were alive during the study period. Patients were excluded from the study if they had undergone previous transplantation, had previously been weaned from a VAD, or had undergone multiorgan transplantation. The BTT group was composed of those patients who had required long-term VAD support, defined as ≥ 14 days. This minimum duration of support was used because it has been our institution's practice to consider long-term use of VADs for patients expected to require support for ≥ 14 days.

We conducted a secondary analysis limited to those patients supported by a VAD as a BTT to evaluate which patient and device characteristics might be associated with a lower QOL score.

With the approval of our institutional review board, the parents of each patient who had undergone heart transplantation were interviewed by telephone. After obtaining consent, they were asked to complete the Pediatric Quality of Life Inventory (PedsQL) Core Module version 4.0 and the PedsQL Cardiac Module version 3.0 by telephone.

The Core Module of the PedsQL survey consists of 21 to 23 questions that assess the patient's level of physical, emotional, social, and school

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Abbreviations a	nd Acronyms
BTT	= bridge to transplantation
ECMO	= extracorporeal membrane
	oxygenation
INTERMACS	S = Interagency Registry for
	Mechanically Assisted Circulatory
	Support
PedsQL	= Pediatric Quality of Life Inventory
QOL	= quality of life
STT	= straight to transplantation
TPN	= total parenteral nutrition
VAD	= ventricular assist device

functioning. The participants are asked to rate the patient's difficulty with various activities or symptoms using a 5-point Likert scale. The score is then translated to a point system from 0 to 100, where 0 indicates

significant impairment in function and 100 indicates no impairment. The scores are then aggregated into a Psychosocial Health Summary Score, consisting of the weighted average of the emotional, social, and school functioning scores, a Physical Health Summary Score, consisting of the physical functioning score, and a total score. The PedsQL includes 5 different surveys according to the patient's age group: 2 to 4, 5 to 7, 8 to 12, 13 to 18, and 18 to 25 years old. The surveys are similar, with only slight modifications in wording related to patient age (eg, use of the word "teen" instead of "child") and excluding 2 nonapplicable questions for the 2- to 4-year-old group.

The Cardiac Module of the PedsQL survey assesses 6 dimensions of QOL: symptoms related to cardiac disease, problems related to heart medication, problems related to the patient's perceived physical appearance, treatment anxiety, cognitive problems, and communication problems. As with the Core Module, the Cardiac Module has versions for each age group. Because the Cardiac Module does not have a version for patients >18 years old, the survey for patients aged 13 to 18 years was used, substituting the term "young adult" for "teen."

The PedsQL survey was administered over the course of 1 month, and the first available parent or guardian was interviewed. The PedsQL Core and Cardiac Modules have been previously validated for both

TABLE 1. Group characteristics

Characteristic	Total $(n = 63)$	BTT (n = 21)	STT (n = 42)	P value
Gender				
Male	36 (57)	12 (57)	24 (57)	1.00
Female	27 (43)	9 (43)	18 (43)	
Race				
Asian	2 (3)	0 (0)	2 (5)	.11
Black	15 (24)	7 (33)	8 (19)	
Hispanic	22 (35)	10 (48)	12 (29)	
White	24 (38)	4 (19)	20 (48)	
Age at follow-up (y)				
2-4	12 (19)	7 (33)	5 (12)	.54
5-12	28 (44)	5 (24)	23 (55)	
>13	23 (37)	9 (43)	14 (33)	
Highest parent reported education				
Higher than HS degree	44 (70)	12 (57)	32 (76)	.11
HS degree	11 (17)	5 (24)	6 (14)	
Less than HS degree	8 (13)	4 (19)	4 (6)	
Heart failure etiology				
Acquired	45 (71)	18 (86)	27 (64)	.08
Congenital	18 (29)	3 (14)	15 (36)	
Total previous CPB frequency				
0	41 (65)	17 (81)	24 (57)	.03
1-2	16 (25)	4 (19)	12 (29)	
>2	6 (10)	0 (0)	6 (14)	
Intubated	20 (32)	12 (57)	8 (19)	<.01
Hemodialysis use	2 (3)	2 (10)	0 (0)	.11
TPN use	18 (29)	12 (57)	6 (14)	<.01
Parent report of current chronic health condition	12 (19)	4 (19)	8 (19)	1.00
Parent report of overnight hospital visit in previous year	28 (44)	10 (48)	18 (43)	.72
Parent report of ED/urgent care visit in previous year	32 (51)	12 (57)	20 (48)	.48
Age at follow-up (y)	9.04 (5.6-17.3)	7.38 (4.3, 18.0)	9.42 (6.6-15.5)	.37
Age at transplantation (y)	5.13 (1.1-12.6)	4.28 (1.0-13.5)	5.3 (1.22-10.3)	.76
Interval since transplantation (y)	4.21 (2.9-5.8)	3.33 (2.8-3.8)	4.81 (3.4-6.4)	<.01
Ischemic time* (min)	263 (206-313)	264 (211-297)	260 (205-327)	.96
Poverty level by census block	12.8 (5.3-22.4)	12.8 (6.1-29.7)	12.8 (4.7-21.6)	.44

Data presented as n (%) or median (interquartile range [25th-75th]). BTT, Bridge to transplantation; STT, straight to transplantation; HS, high school; CPB, cardiopulmonary bypass; TPN, total parenteral nutrition; ED, emergency department. *Ischemic time available for only 55 patients.

	T	otal	В	TT	S	ТТ	
PedsQL Section	Median	IQR	Median	IQR	Median	IQR	P value
Core Module							
Psychosocial Health Summary	83.3	69.2-90.8	81.7	70.0-90.0	84.2	68.3-91.7	.66
Physical Health Summary	87.5	71.9-100	90.6	75.0-96.9	84.4	68.8-100	.80
Total score	82.6	71.0-91.3	81.94	70.7-92.9	82.6	71.7-91.3	.53
Cardiac Module							
Heart problems and treatment	89.3	85.4-96.4	92.9	85.7-100	89.3	82.1-96.4	.28
Treatment II	100	90.0-100	95.8	83.0-100	100	90-100	.33
Perceived physical appearance	100	83.3-100	100	83.3-100	100	83.3-100	.54
Treatment anxiety	100	75.0-100	87.5	62.5-100	100	81.3-100	.43
Cognitive problems	80.0	50.0-95	80	50.0-95.0	77.5	55.0-95.0	.58
Communication	100	75.0-100	100	66.7-100	100	83.3-100	.28

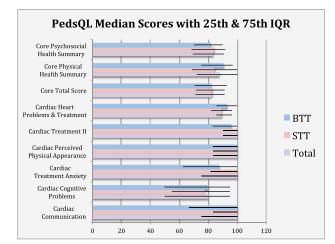
PedsQL, Pediatric Quality of Life Inventory; BTT, bridge to transplantation; STT, straight to transplantation; IQR, interquartile range (25th-75th percentiles).

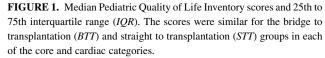
in-person and telephone acquisition.¹⁴⁻¹⁷ Each survey was administered by 1 of 2 trained instructors, who followed the PedsQL script exactly and audited each other's interviews to ensure consistency was maintained. For Spanish-speaking parents, an interviewer fluent in Spanish conducted the interview.

Although the PedsQL survey includes both a parent survey and a self-survey completed by the patient, the present study used only the parent survey to ensure interview feasibility by telephone and to maintain consistency among the patients of each age group. The parent survey has been validated independently of the self-survey.¹⁶

The potential confounders of the relationship between pretransplantation VAD support and QOL were considered a priori and were collected from the electronic medical record systems and available billing data. Data were collected for each patient's demographic information, age at transplantation, age at the PedsQL survey, heart failure etiology, medical history, time since transplantation, and current health condition as perceived by the parents, including recent illnesses, hospital admissions, or presentation to the emergency room.

As a proxy for socioeconomic status, the percentage of persons living in poverty in the patient's census block group, a previously validated measure, was collected from the 2010 United States Census data.^{18,19} For 3 patients,





the residential address was unknown, so the poverty level for the ZIP code of the patient's post office box was used.

For the secondary analysis evaluating the variables associated with lower PedsQL scores within the VAD group, the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) score at VAD implantation, VAD duration, VAD type, and VAD complications were collected. The data collected to assess whether a patient required mechanical ventilation, hemodialysis, or total parenteral nutrition (TPN) at VAD implantation were taken from billing data for the day before VAD implantation because applicable medical records were not available for all patients. For comparison, similar data were collected for STT patients from the day before transplantation. A patient was considered to have had a neurologic complication if either a new neuroradiologic finding appeared while the patient was maintained on the VAD or new neurologic symptoms developed during VAD support (eg, seizure).

Descriptive data were reported using proportions, medians, and 25th to 75th percentile interquartile range. A comparison of the characteristics between the BTT and STT groups was performed using the χ^2 , χ^2 for trend, and Fisher exact tests for categorical variables and the Mann-Whitney U or Kruskal-Wallis test for continuous variables, as appropriate. A comparison of the QOL scores between the BTT and STT groups and among the characteristics within the VAD subanalysis were performed using the Mann-Whitney U test and Spearman's rank correlation. The 5- to 7-year-old group was combined with the 8- to 12-year-old group for the individual analysis by age group, because the latter group contained only 1 BTT patient.

RESULTS

From January 2005 to August 2011, 101 patients underwent heart transplantation at Texas Children's Hospital. Of these, 34 required a VAD before transplantation. Of the 101 patients, 26 were excluded from the study (8 BTT and 18 STT patients) because they did not meet the inclusion criteria, and 12 (5 BTT and 7 STT patients) were excluded because they were deceased at the time of the study. The remaining 63 patients (21 BTT and 42 STT) were included in the study. The parents or guardians of all included patients were successfully contacted. One parent, whose child was in the STT group, declined to complete the survey, yielding a 98% completion rate. Of the surveyed BTT patients, 13 had been supported with a Berlin EXCOR (Berlin Heart AG), 6 with a HeartMate II (Thoratec Corp, Pleasanton, Calif), 1 with a Rotaflow (Maquet Cardiovascular, Wayne, NJ), and 1 with a Micromed VAD (MicroMed Technology, Inc, Houston, Tex). The median duration of VAD support was 80 days (range, 16-262).

Four patients surveyed were supported by ECMO at 1 point in their course, 2 of whom were bridged to transplantation with a VAD. Only 1 patient required ECMO for >5 days, and he was not in the VAD group.

The median age at transplantation was 5.1 years (range, 2 months to 18 years), and the median age at follow-up was 9 years, with no significant differences in age between the BTT and STT groups (Table 1). The BTT patients had undergone heart transplantation more recently, with a median interval since transplantation of 3.3 years (interquartile range, 2.7-3.8) versus 4.8 years (interquartile range, 3.4-6.4, P < .01) for the STT patients. The 2 groups had similar characteristics of gender, race, socioeconomic status, and parent education. The BTT patients were more likely to have been supported with TPN and ventilator support on the day before VAD placement. No significant difference was found in the incidence of recent illness, presentation to the hospital, or perceived chronic health condition, as reported by the parents, factors that might have influenced the parental response to the survey.

The median Psychosocial Health Summary Score, Physical Health Summary Score, and total score for the PedsQL Core Module were similar for the BTT and STT groups (Table 2 and Figure 1). The median total score for the Core Module was 82.6, similar to that of healthy subjects, previously demonstrated to have a mean total score of 82.3.¹⁷ The median scores of the BTT and STT patients were also similar to the mean scores for patients with moderate cardiovascular disease, defined as those patients who had undergone surgically correction or no longer required therapy, who were previously shown to have a mean total score of 84.6.²⁰ Median data from either study were unavailable for comparison. The scores were also compared by each age-stratified subgroup for the 6 dimensions of the PedsQL Cardiac Module. No difference was found in the outcomes for BTT patients compared with the STT patients (Appendix Table 1).

The secondary analysis of scores for patients who required a VAD as a BTT for any VAD specific factors that might have affected the QOL outcome demonstrated significant findings (Appendix Table 2). The QOL scores did not differ by VAD duration, age at transplantation, or INTERMACS score at VAD placement (Table 3). Of the VAD patients, 62% were supported by a pulsatile VAD, and the scores were not different between those with pulsatile versus continuous VAD support. Additional indicators of the patient's degree of illness at VAD placement, including ventilatory support, hemodialysis use, and TPN use, were not associated with a significant difference in outcome. Also, the patients faired similarly regardless of whether the etiology of heart failure was acquired or congenital heart disease and regardless of the number of previous cardiopulmonary bypass runs they had experienced. No differences were found in the QOL scores among the race categories or by socioeconomic status. Complications, including VAD-related infection, reoperation or pump change, and neurologic complications, were also assessed. Only the presence of a neurologic complication (n = 5) was associated with a lower QOL score, with a statistically significant difference in the patient's Physical Health Summary score (50 vs 94) and Cardiac Communication score (67 vs 100).

In the BTT patients, the interval since transplantation had a moderate positive correlation with the QOL score in the Cardiac Communication dimension that was statistically significant (correlation coefficient, 0.52; P = .01). Patient age at follow-up also demonstrated a moderate positive correlation with the Cardiac Communication score in the BTT patients.

DISCUSSION

Recent evidence has shown that a VAD can effectively support a pediatric patient to heart transplantation.²¹ However, pediatric VAD support has had a significant complication rate, especially for younger children requiring extracorporeal devices, with the potential to affect the long-term QOL of patients. These complications have included bleeding (42%-50%), infection (50%-63%), and stroke (29%).⁴ The present study is the largest to date to assess the long-term QOL outcomes of pediatric patients who required VAD support as a BTT compared with patients who went STT.

One recent study used the PedsQL Core Module to determine the OOL outcomes in patients using mechanical circulatory support. However, these had focused mainly on patients bridged with ECMO, with, at most, 11 patients sustained by a VAD. The study found similar QOL outcomes for patients requiring mechanical circulatory support compared to the STT group.²²

In a recent study by Uzark and colleagues²³ of the long-term QOL outcomes of 174 pediatric patients who had undergone heart transplantation, the patients demonstrated significantly lower psychosocial and physical functioning scores compared with the healthy norms and patients who had undergone curative heart surgery. VAD use was not evaluated in their study.²³

Our study did not demonstrate any statistically significant difference between the BTT and STT patients for the Core or Cardiac Module outcomes, either in total or for each age category. Both groups also scored similarly to published normative values for the PedsQL survey. More than 33% of heart transplantation patients in the study by Uzark and colleagues²³ had impaired psychosocial functioning scores,

	Neurolo	ogic complication			VAD type		Gender
PedsQL section	Yes (n = 5)	No (n = 16)	P value	Pulsatile (n = 13)	Continuous (n = 8)	P value	Male (n = 12)
Core							
Psychosocial	61.7 (61.5-84.6)	82.5 (71.7-90.8)	.24	84.6 (65.4-92.3)	76.7 (70-83.3)	.34	74.17 (62.6-86.7)
Physical	50 (34.4-78.1)	93.8 (76.6-100)	.01	90.6 (62.5-100)	89.1 (76.6-95.3)	.86	92.18 (68.7-100)
Total	68.1 (51.2-71.2)	85.32 (79.4-93.2)	.09	85.9 (67.9-93.5)	80.4 (74.5-85.3)	.64	82.61 (66.1-89.7)
Cardiac							
Heart problems and treatment	92.86 (78.6-92.9)	91.1 (85.7-100)	.49	92.9 (89.3-100)	85.7 (82.1-96.4)	.30	98.21 (87.5-100)
Treatment II	91.7 (90.0-100)	100 (80.0-100)	.90	100 (83.3-100)	90 (80-100)	.41	95.83 (81.7-100)
Perceived physical appearance	100 (83.3-100)	100 (87.5-100)	.90	100 (91.7-100)	100 (62.5-100)	.59	100 (91.7-100)
Treatment anxiety	100 (75.0-100)	87.5 (59.4-100)	.72	87.5 (62.5-100)	100 (68.8-100)	.37	100 (71.9-100)
Cognitive problems	50 (30.0-91.7)	80 (50-97.5)	.40	50 (50-83.3)	90 (62.5-100)	.21	55 (42.5-92.5)
Communication	66.67 (0-83.3)	100 (83.3-100)	.02	83.3 (25.0-100)	100 (95.8-100)	.14	100 (66.7-100)

TABLE 3. Factors affecting outcome of patients bridged to transplantation with VAD

Data presented as median (IQR [25th-75th percentile]) or correlation coefficient. VAD, Ventricular assist device; PedsQL, Pediatric Quality of Life Inventory; INTERMACS, Interagency Registry for Mechanically Assisted Circulatory Support.

defined as a score >1 standard deviation below the population mean. Our patients faired much better, with only 14% of STT patients and 19% of BTT patients scoring low.

Our outcomes are more consistent with the results of another study by Uzark and colleagues,²⁰ which demonstrated that nearly 16% of patients with cardiovascular disease of any sort had impaired psychosocial functioning scores. The scores were inversely proportional to the degree of cardiovascular illness. The patients in our study had a median total score similar to the mean total score of the children in the study by Uzark and colleagues²⁰ who had had moderate cardiovascular disease, defined as those who had undergone curative surgery or no longer required medications.

We found few statistically significant risk factors among the patients who required a VAD. Neurologic complications, including radiologically evident stroke and seizures, were associated with poorer Physical Health Summary scores on the Core Module and lower Communication scores on the Cardiac Module. This might reflect the long-term nature of the neurologic injury sustained by the patient and should raise concerns about the patient's future neurodevelopment. Closer long-term follow-up might be indicated for these patients to assess and treat any developmental problems that occur.

Although the recent Berlin Heart study by Fraser and colleagues⁴ reported that the complication rate increased with VAD duration, the present study did not establish any significant correlation between VAD duration and QOL outcome. The difference might have been because the study by Fraser and colleagues⁴ considered all patients with VAD use, including nonsurvivors, and our study the assessed outcomes only for patients well enough to both survive to transplantation and be alive at the time of the present study.

Although the severity of illness at transplantation has been shown to increase the risk of graft rejection in the long term in pediatric patients,²⁴ the INTERMACS score, need for ventilatory support, TPN, or hemodialysis at VAD placement did not correlate with the QOL outcome. Also, the heart failure etiology did not affect the outcome. It might be that maintenance of adequate cardiac output with a VAD while awaiting transplantation is associated with improved post-transplantation QOL in patients who are particularly ill, or it might be a reflection of selection bias.

Among the BTT patients, both age at follow-up and the interval since transplantation had a moderate positive correlation with the Cardiac Communication score. The questions constituting the PedsQL Cardiac Communication assessment have focused on the patients' ability to discuss their medical condition with others, an ability that likely increases with age, explaining why a longer interval since transplantation demonstrated improved outcomes.

Altogether, our results have shown that patients who require a VAD to maintain circulatory support as a BTT are likely to have QOL outcomes, as perceived by their parents, comparable to those who went STT. Furthermore, the indicators of the child's degree of illness at VAD implantation, measures of the child's socioeconomic status, and VAD type does not appear to affect the QOL outcomes. Only the occurrence of neurologic complications was shown to have some potential effect on the long-term outcomes.

One limitation of the present study was its small sample size, which might have limited the power to detect more subtle differences between the 2 groups. Another limitation was the use of only the parent survey. This was done both to maximize the response rate, given the easier access to patients by telephone, and to have comparable results across all age groups. Previous studies have shown the correlation

Gender		VAD duration		Age at transplanta	tion	INTERMACS score at VAD placement				
Female (n = 9)	P value	Correlation coefficient	P value	Correlation coefficient	P value	Correlation coefficient	<i>P</i> value			
84.62 (81.7-92.3)	.07	0.13	.56	-0.11	.62	-0.32	.17			
87.5 (75.0-93.7)	.60	-0.07	.75	0.25	.26	0.05	.83			
81.94 (78.3-92.9)	.38	0.06	.81	0.08	.71	-0.25	.30			
85.71 (85.7-92.9)	.07	-0.02	.93	-0.06	.79	-0.64	.79			
100 (83.3-100)	.86	0.12	.59	0.02	.92	-0.32	.18			
100 (83.33-100)	.46	-0.005	.98	-0.06	.81	0.23	.35			
75 (56.25-100)	.34	0.05	.82	0.41	.06	0.02	.93			
80 (50-95)	.46	0.185	.42	0.32	.16	-0.01	.97			
100 (33.3-100)	.86	-0.351	.12	0.36	.11	-0.18	.46			

TABLE 3. Continued

to be high between the parental and child response, and we believe the inclusion of patient responses would not have resulted in significantly different results.^{17,22,23} Although the results demonstrated similar parental perceived QOL between the BTT and STT groups, only limited conclusions could be drawn about the patient's perceived QOL. Finally, our study was an assessment of the QOL in surviving patients. Thus, the results could reflect survivor bias, because the QOL could not be measured in the most severely ill patients who had died.

CONCLUSIONS

The results of the present study have helped to establish that the QOL is similar between VAD-supported patients and those who went STT. Additional studies are required to assess the long-term QOL of VAD patients as the technology evolves. Incorporating QOL scores and preventative strategies into patient care may be beneficial. The present study provides additional information to clinicians, patients, and their families during the decision-making process for VAD use.

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		T	otal	B	TT	S	TT	
PedsQL section	Age category (y)	Median	IQR	Median	IQR	Median	IQR	P valu
Core								
Psychosocial Health Summary	Total	83.3	69.2-90.8	81.7	70.0-90.0	84.2	68.3-91.7	.66
,	2-4	84.8	69.2-93.3	84.8	64.4-88.6	85	76.9-94.2	
	5-12	81.7	66.7-90	81.7	78.3-90	81.67	66.7-88.3	
	>13	83.3	75-90.8	80	70-83.3	86.67	78.3-91.7	
Physical Health Summary	Total	87.5	71.9-100	90.6	75-96.9	84.38	68.7-100	.80
	2-4	76.6	56.2-92.2	75	56.2-84.4	100	75-100	
	5-12	82.8	56.2-100	100	93.7-100	75	56.2-100	
	>13	90.6	78.1-96.9	90.6	78.1-96.9	92.19	78.1-96.8	
Total score	Total	82.6	71-91.3	81.9	70.6-92.9	82.61	71.7-91.3	.53
	2-4	80.7	66.1-94.6	71.4	66.1-87.4	80.95	80.5-96.4	
	5-12	83.1	62-89.7	88.0	85.9-93.5	80.43	62-87.5	
	>13	84.8	78.3-90.8	80.4	78.3-85.9	88.59	78.3-91.3	
Cardiac								
Heart problems and treatment	Total	89.3	85.4-96.4	92.9	85.7-100	89.28	82.1-96.4	.28
	2-4	92.9	87.5-94.6	92.9	87.5-94.6	92.86	89.3-92.9	
	5-12	89.3	83.9-96.4	96.4	89.3-100	85.71	83.9-92.9	
	>13	89.3	80.4-98.2	85.7	85.7-100	91.07	78.6-96.4	
Treatment II	Total	100	90-100	95.8	83-100	100	90-100	.33
	2-4	95.8	83.3-100	83.3	79.2-100	100	91.7-100	
	5-12	100	91.7-100	100	100-100	100	90.8-100	
	>13	95	87.5-100	90	80-100	95	90-100	
Perceived physical appearance	Total	100	83.3-100	100	83.3-100	100	83.3-100	.54
	2-4	100	100-100	100	95.8-100	100	100-100	
	5-12	100	83.3-100	100	83.3-100	100	87.5-100	
	>13	83.3	66.7-100	100	83.3-100	83.33	66.7-100	
Treatment anxiety	Total	100	75-100	87.5	62.5-100	100	81.2-100	.43
-	2-4	81.2	65.6-100	75	31.2-87	93.75	87.5-100	
	5-12	93.7	78.1-100	87.5	87.5-100	93.75	78.1-100	
	>13	100	84.4-100	100	81.2-100	100	87.5-100	
Cognitive problems	Total	80	50-95	80	50-95	77.5	55-95	.58
	2-4	70.8	50-95.8	50	50-87.5	75	66.7-100	
	5-12	65	50-92.5	50	40-60	75	50-95	
	>13	85	70-97.5	95	80-100	80	100-100	
Communication	Total	100	75-100	100	66.7-100	100	83.3-100	.28
	2-4	45.8	0-100	25	0-91	66.67	0-100	
	5-12	100	66.7-100	100	66.7-100	100	75-100	
	>13	100	100-100	100	100-100	100	100-100	

APPENDIX TABLE 1. PedsQL Cardiac and Core Module scores stratified by age category

PedsQL, Pediatric Quality of Life Inventory; BTT, bridge to transplantation; STT, straight to transplantation; IQR, interquartile range (25th-75th percentiles).

APPENDIX TABLE 2	Clinical factors	affecting outcome of	patients BTT with VAD
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		tor use on day AD implantati		Hemodialysis use on day before VAD implantation				TPN use on day before VAD implantation			Pump change			Race				Parent education level			
PedsQL section	Yes (n = 12)	No (n = 9)	P value	Yes (n = 2)	No (n = 19)	P value	Yes (n = 12)	No (n = 9)	P value	Yes (n = 10)	No (n = 3)	<i>P</i> value	Black (n = 7)	Hispanic (n = 10)	White (n = 4)		HS incomplete or less (n = 4)	•	Some college or more (n = 12)		
Core																					
Psychosocial	84.8 (66.7-92)	78.3 (70-81.7)	.28	82.7 (65.4-100)	81.7 (70-87.5)	.69	84.8 (74.2-92)	73.3 (63.5-81.7)	.08	84.8 (63.5-98.3)	78.3 (71.9-85.3)	.81	73.3 (70-80)	83.3 (63.5-85)	94.2 (77.7-99.2)	.22	82.3 (71.7-84.8)	70 (61.7-83.3)	82.5 (71.7-95.3)		
Physical	90.6 (76.6-98.4)	87.5 (71.9-93.7)) .70	81.2 (62.5-100)	90.6 (75-95.3)	1.00	92.2 (68.7-100)	87.5 (75-93.7)	.55	84.4 (50-100)	93.7 (78.1-96.9)	.69	96.9 (82.8-100)	76.6 (67.9-85.9)	92.2 (78.9-96.6)	.21	76.6 (62.5-85.9)	71.9 (34.4-90.6)	93.7 (82.8-100)		
Total	83.9 (69.7-93.5)	80.4 (70.6-85.9)	.51	82.1 (64.3-100)	81.94 (71.04-90.4)	.86	83.9 (75.9-93.5)	78.3 (68-85.6)	.34	85 (67.9-96.4)	85.9 (75.1-89.4)	.81	80.4 (74.5-87)	81.2 (67.9-85.9)	94.9 (78.9-96)	.36	76.7 (69.6-83.4)	70.6 (51.2-85.9)	87 (79.3-94.5)		
Cardiac																					
Heart problems	91.1 (85.4-100)	92.9 (85.7-96.4)	.81	98.2 (96.4-100)	89.3 (85.7-98.2)	.24	92.9 (85.7-100)	89.3 (85.7-96.4)	.75	92.9 (89.8-100)	96.4 (91.1-98.2)	.81	85.7 (82.1-98.2)	91.1 (85.7-100)	94.6 (91.1-98.2)	.61	91.1 (87.1-92.9)	100 (85.7-100)	91.1 (85.7-98.2)		
and treatment																					
Treatment II	95.8 (81.7-100)	100 (83.3-100)	.86	91.7 (83.3-100)	100 (81.7-100)	1.00	95.8 (83.3-100)	100 (80-100)	.86	100 (91.7-100)	83.3 (79.2-91.7)	.37	100 (85-100)	95.8 (75-100)	91.7 (83.3-100)	.91	87.5 (70.8-100)	100 (91.7-100)	95 (83.3-100)		
Perceived physical	100 (87.5-100)	100 (83.3-100)	.81	100 (100-100)	100 (83.3-100)	.47	100 (95.8-100)	100 (83.3-100)	.34	100 (91.7-100)	100 (83.3-100)	.81	100 (91.7-100)	100 (83.3-100)	100 (91.7-100)	.85	95.8 (68.7-90.6)	100 (100-100)	100 (83.3-100)		
appearance																					
Treatment anxiety	100 (68.7-100)	87.5 (56.2-100)	.55	50 (0-100)	87.5 (68.7-100)	.69	81.2 (40.6-100)	100 (81.2-100)	.34	93.75 (75-100)	0.00 (0-43.7)	.08	100 (87.5-100)	78.1 (50-100)	87.5 (37.5-100)	.48	78.1 (68.7-90.6)	100 (56.2-100)	93.7 (62.5-100)		
Cognitive problems	71.67 (39.2-100)	80 (50-85)	1.00	75 (50-100)	80 (47.5-93.3)	.61	55 (42.5-95.8)	83.33 (50-95)	.46	70 (50-91.7)	40 (36.7-45)	.08	50 (42.5-97.5)	81.7 (50-100)	70 (55-85.8)	.94	84.2 (66.7-92.5)	100 (50-100)	55 (42.5-85.8)		
Communication	95.83 (66.7-100)	100 (33.3-100)	.86	50 (0-100)	100 (66.7-100)	.61	91.7 (45.8-100)	100 (91.7-100)	.51	75 (25-100)	100 (50-100)	.81	100 (79.2-100)	100 (25-100)	91.7 (41.7-100)	.89	62.5 (12.5-100)	100 (66.7-100)	100 (75-100)		

Data reported as median and interquartile range (25th-75th percentile). BTT, Bridge to transplantation; VAD, ventricular assist device; PedsQL, Pediatric Quality of Life Inventory; TPN, total parenteral nutrition; HS, high school; CPB, cardiopulmonary bypass; SES, socioeconomic status; CC, correlation coefficient.

Cardiothoracic Transplantation

APPENDIX TABLE 2. Continued

Parent ducation level	Heart failure etiology			Pr	evious CPB		5	SES	Age at	follow-up		val since lantation	Ische	mic time	Reoperation frequency on VAD		VAD-related infection		Pump change frequency	
P value	Acquired (n = 18)	Congenital (n = 3)	P value	No (n = 17)	Yes (n = 4)	P value	сс	P value	сс	P value	сс	P value	сс	P value	сс	P value	сс	P value	СС	P value
.47	70 (70-91.7)	83.3 (65-75.8)	.15	80 (70-90)	83.1 (70.8-88.5)	1.00	-0.19	.41	-0.03	.89	0.40	.07	-0.12	.64	0.27	.24	-0.18	.44	0.29	.33
.08	78.1 (75-96.9)	90.6 (75-89.1)	1.00	90.6 (75-96.9)	85.9 (64.1-96.9)	1.00	-0.13	.58	0.39	.08	0.38	.87	0.28	.25	0.09	.69	-0.14	.54	0.01	.98
.20	70.6 (71.4-93.5)	83.4 (69.3-79.3)	.53	81.9 (70.6-93.5)	79.7 (69.7-90.4)	.96	-0.19	.40	0.18	.43	0.41	.07	0.1	.69	0.24	.29	-0.2	.38	0.25	.40
.73	85.7 (85.71-69.35)	92.9 (82.1-91.1)	.41	92.9 (85.7-100)	89.3 (82.1-94.6)	.52	0.13	.58	-0.16	.49	-0.03	.89	-0.05	.84	0.05	.82	-0.25	.27	-0.02	.94
.64	90 (83.3-100)	100 (85-95)	.74	100 (83.3-100)	95 (82.5-100)	.96	-0.06	.78	-0.09	.69	0.25	.27	-0.3	.21	0.08	.74	0.09	.68	0.17	.57
.66	100 (91.7-1000)	100 (83.3-100)	.96	100 (91.7-100)	91.7 (75-100)	.57	-0.04	.85	-0.21	.35	-0.23	.31	-0.06	.82	-0.09	.68	-0.29	.19	0.22	.46
.89	87.5 (62.5-100)	93.75 (71.8-93.7)	1.00	87.5 (62.5-100)	93.7 (43.7-100)	1.00	-0.11	.65	0.25	.28	-0.06	.81	0.24	.33	-0.05	.83	0.03	.89	0.31	.31
.36	50 (50-95)	80 (40-75)	.67	80 (50-95)	41.7 (31.7-41.7)	.27	-0.004	.99	0.26	.25	-0.02	.92	-0.02	.93	0.08	.74	0.002	.99	0.49	.09
.77	91.7 (62.5-95.8)	100 (66,7-100)	.74	100 (66.7-100)	62.5 (16.7-95.8)	.27	0.13	.56	0.55	.01	0.52	.01	0.06	.81	-0.03	.9	-0.16	.50	-0.11	.71