

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.

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 and Acronyms	
BTT	= bridge to transplantation
ECMO	= extracorporeal membrane oxygenation
INTERMACS	= 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

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

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

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.



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