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Circumstances Surrounding End-of-Life in Pediatric Patients Pre- and Post-Heart Transplant: A Report from the Pediatric Heart Transplant Society

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Abbreviations: HTx = heart transplant; ICU = intensive care unit; PHTS = Pediatric Heart Transplant Society

Running Head: End-of-Life in Pediatric Heart Transplant

Circumstances Surrounding End-of-Life in Pediatric Patients Pre- and Post-Heart Transplant: A Report from the Pediatric Heart Transplant Society

Abstract

Background: Although mortality has decreased considerably in pediatric heart transplantation, waitlist and post-transplant death rates remain notable. End-of-life focused research in this population, however, is very limited. This Pediatric Heart Transplant Society study aimed to describe the circumstances surrounding death of pediatric heart transplant patients.

Methods: A retrospective analysis of the multi-institutional, international, Pediatric Heart Transplant Society registry was conducted. Descriptive statistics and univariate analyses were performed to 1) describe end-of-life in pediatric pre- and post-heart transplant patients and 2)

examine associations between location of death and technological interventions at end-of-life with demographic and disease factors.

Results: Of 9,217 patients (0-18 years) enrolled in the registry between 1993-2018, 2,804 (30%) deaths occurred; 1,310 while awaiting heart transplant and 1,494 post-heart transplant. The majority of waitlist deaths (89%) occurred in the hospital, primarily in ICU (74%) with most receiving mechanical ventilation (77%). Fewer post-transplant deaths occurred in the hospital (22%). Out of hospital death was associated with older patient age ($p<0.01$).

Conclusions: ICU deaths with high use of technological interventions at end of life were common, particularly in patients awaiting heart transplant. In this high mortality population, findings raise challenging considerations for clinicians, families, and policy makers on how to balance quality of life amidst high risk for hospital-based death.

Introduction

Medical advancements have led to overall longer median survival in pediatric heart transplant recipients. However, mortality rates remain high both pre- and post-heart transplantation. Approximately 25% of infants and 13% of children on the heart transplant waitlist do not survive to transplantation.[1] Among those who go on to receive a donor heart, approximately 1 in 10 pediatric heart transplant recipients die in the first year.[1,2] Beyond the high risk early post-transplant period, approximately 20% experience death 5 years post-transplant.[2,3] While the adult heart failure and transplant communities have provided scoping reviews,[4] practice guidelines,[5-7] and palliative care focused interventions[8,9] to improve care across the course of heart failure, heart transplant and at end-of-life, the pediatric community has given considerably less attention to this important aspect of care.[10]

To date, much of what we know about circumstances surrounding death in pediatric advanced heart disease and heart transplantation is based on single-center experiences, which indicate high rates of hospital-based deaths with intubation frequently performed near end-of-life.[11,12] Building upon these initial studies, increased understanding of circumstances surrounding death, including location of death and interventions performed at end-of-life in a large, multi-site sample, will enable the pediatric transplant community to move forward with guidelines and interventions to improve the quality of care patients and families receive at a

child's end-of-life. Thus, in response to calls for increased research study,[13] this Pediatric Heart Transplant Society (PHTS) registry analysis study aimed to 1) describe the circumstances surrounding death of pediatric heart transplant patients, including transplant status at time of death, primary and contributing causes of death, location of death, and use of technological interventions at end-of-life and 2) examine associations between location of death and technological interventions at end-of-life with demographic, disease, and transplant-related factors.

Patients and Methods

Patients

PHTS maintains an international pediatric heart transplant data registry with 56 contributing centers from four countries providing demographic and clinical data at the time of heart transplant listing and in the years to follow. Inclusion criteria for the current study included: pediatric heart transplant patient aged 0-18 years (waitlist or post-transplant) enrolled in PHTS between 1993 and 2018. Patients were stratified into two cohorts: 1) pre-transplant (waitlist) and 2) post-transplant.

Methods

All data forms collected by PHTS from contributing sites can be found on the PHTS website (https://pediatricheartransplantsociety.org/2015-forms/). To accomplish the aims of this study, data was utilized from the following PHTS forms: Demographics, Listing, Re-Listing, Transplant, and Death. Descriptive statistics were presented as frequency and percentage (%) for categorical variables and median and interquartile range (IQR) for continuous variables. Univariate associations between location of death and technological interventions at end-of-life with demographic, disease, and transplant-related factors were assessed using Chi-square test, Fisher's exact test, or Wilcoxon rank sum test, as appropriate. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA). A statistical significance of 0.05 was used for two-sided tests.

Results

Sample Characteristics

Patient demographics, transplant characteristics, primary causes of death, and contributing causes of death are detailed in Table 1. Of the 9,217 registry entries, 2,804 (30%)

deaths occurred; 1,310 while awaiting heart transplant and 1,494 post-heart transplant (Figure 1). Location of death was recorded for 1,113 patients (40% of total deaths; Figure 1). Sensitivity analyses showed that patients without location of death recorded were more likely to be Caucasian/non-Hispanic (p=0.03) and have private insurance (p=0.001) compared to those with death location. Diagnosis was similar between those with location of death recorded and those without.

Location of Death

Of the 804 waitlist deaths with location of death indicated, 89% occurred in the hospital, primarily in ICU settings (74%). Location of death was captured for proportionately fewer post-heart transplant recipients, with only 309 post-heart transplant patients having death location known or recorded. Fewer than a quarter (22%) died in a hospital, however, hospital deaths were predominately within an ICU setting (74%).

Location of death was unrelated to patient sex, race, ethnicity, or insurance type in waitlist and post-transplant patients (Table 2). Older patients were more likely to die out of the hospital among both waitlist (p=0.01) and post-transplant patients (p=0.001). Waitlist patients with a primary etiology of congenital heart disease were more likely to experience an in-hospital death compared to those with primary cardiac tumor, cardiomyopathy, or myocarditis (p=0.04). Primary etiology was unrelated to location of death in post-transplant patients. Year of transplant was also associated with location of death, with considerably more out of hospital deaths occurring in those transplanted between the years of 2011-2019 (64%; p<.0001) compared to transplanted between 1993-2000 (7%) and 2001-2010 (29%).

Technological Interventions at End-of-Life

Among waitlist deaths, technological interventions at end-of-life were common. The majority (77%) received continuous invasive mechanical ventilation near time of death. A subset (39%) were supported by ECMO/VAD at time of death and 69% were receiving inotrope support. Although a smaller proportion of post-transplant patients died in the hospital when compared to waitlist patients, use of technological interventions at end-of-life were still common in hospital-based deaths. Approximately half (52%) received mechanical ventilation near end-of-life, while 18% and 21% were supported by ECMO/VAD and inotropes, respectively.

Discussion

Despite considerable improvements in both waitlist and post-transplant survival in pediatric heart transplant, death occurred in ~1/3 of patients captured in this international registry over a 25-year period. Of the registry entries with complete death data, ICU-based deaths with high use of technological interventions were common, particularly in waitlisted patients. Although dying at home is the preference of most adolescents with other life-threating conditions,[14] the majority of pediatric heart transplant waitlist patients die in an ICU. This is not particularly surprising since survival on the transplant waitlist is likely to require close medical monitoring and continued advanced therapy interventions, as demonstrated by study findings. However, for some patients, this raises challenging, and potentially conflicting, clinical implications for clinicians, families, and policy makers. To qualify for highest 1A pediatric heart transplant listing status in the United State, a pediatric waitlist patient must be hospitalized or receiving mechanical circulatory support. Across many other pediatric conditions, patients and families can opt to receive concurrent care, which includes access to both life-prolonging treatments and hospice care. Within pediatric heart transplant, however, those at highest risk of death on the waitlist must choose between greatest likelihood for donor offer by being hospitalized, even if care could be provided via outpatient home-based services, and a potential end-of-life care aligned with one's wishes, such as a home-based death.

Consistent with previous work,[11,12,15] findings also demonstrated high use of technological interventions at end-of-life. Use of these potentially life-saving technological interventions near end-of-life may indeed be the preference of some patients and families. However, unlike adult heart failure and other serious pediatric conditions, little is known about pediatric heart transplant patients' desires for their end-of-life care, despite their high mortality risks. Emerging research suggests that the end-of-life care needs of pediatric heart transplant patients are unmet. For example, in a pilot study of adolescents and young adults pre-heart transplant, the majority stated a desire to discuss their prognosis and end-of-life preferences, but fewer than half had.[16]

Both findings and limitations of the current study highlight important future directions for research and practice. First, missing death data was notable. This was an unexpected, yet important limitation to highlight. For 60% of deaths in the most robust pediatric transplant database available, location of death was unknown or unreported. The development of interventions specific to end-of-life hinges on a foundational understanding of what occurs.

Through PHTS and other cardiac registries, we may enhance understanding of patients' end-of-life with improved data collection methods and the inclusion of other important variables. For example, data specific to palliative care team involvement, advance care planning documentation (i.e., do not resuscitate orders), or patient/family preferred location of death were not available for this study, but would have improved our understanding of the end-of-life care experience for patients and families. The use of patient- and caregiver-proxy reported outcome (PRO) measures may be an additional route for improving data collection specific to end-of-life. For example, a multisite electronic PRO-based study in pediatric advanced cancer, the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) Study, yielded important insights about both physical and psychological symptoms in young oncologic patients in the 12 weeks prior to their death.[17] Recognizing the hesitation of clinicians and researchers to conduct end-of-life focused research due to concerns of inducing unnecessary burden on patients and families, a recent systematic review of the pediatric literature suggests that patients and parents perceive more benefits from participating in palliative and end-of-life care focused research than burdens.[18]

Second, given the high rate of mortality with invasive interventions near end-of-life observed in the current study, we must broaden our understanding of transplant patients and families' wants for end-of-life discussions and intervention. Pediatric transplant clinicians have spoken to the challenges of balancing the hopefulness of transplant with the risks of morbidity and mortality on the waitlist and post-transplant. Among multi-organ transplant clinicians, only ~20% reported that they often or very often discuss dying or advance care planning with adolescent solid organ transplant patients.[19] However, given findings from the current study, as well as a single-center experience underscoring the unexpectedness of death in pediatric post-transplant recipients,[12] clinicians are encouraged to systematically assess both patient and family preferences specific to end-of-life communication and preferences as part of routine pre- and post-transplant care. Research from pediatric oncology has demonstrated that more prognostic disclosure from clinicians, even when likelihood of cure from cancer was low, resulted in greater communication-based hope in parents.[20] The most common barriers to optimal end-of-life care for pediatric oncology patients per bereaved caregivers have been identified as 1) delayed or no communication about prognosis, limiting care specific to comfort and quality of life, 2) limited emotional support for both patients and caregivers, and 3) lack of home-based, concurrent care

models, where both life-prolonging and palliative care interventions are provided.[21,22] Delayed or no discussion of prognosis with medical team or child has contributed to regret in bereaved caregivers of pediatric patients.[21,23] Parents of children who die of advanced heart disease recognized no chance for survival only an average of two days prior to death.[15] Thus, taken together with current study findings and what has been demonstrated across other pediatric critical illness populations, the field of pediatric heart failure/transplant must begin to engage patients and parents in stakeholder-led research and intervention specific to prognostic and end-of-life care focused communication.

Lastly, primary palliative care training for heart transplant multidisciplinary providers is imperative.[10] Primary palliative care is the practice of providing palliative care services, including symptom management and goals of care discussions, within the regular care of the patient and family. Research has demonstrated that pediatric cardiologists who have received some didactic training in palliative care feel more competent in integrating palliative care based practices.[24] A pilot study demonstrated that an intervention focused on advance care planning documentation for young adults seen in a pediatric heart failure/transplant clinic was well received and effective,[25] pointing to the value of wider-spread integration of this practice in pediatric heart transplant. Further, continuing to describe how pediatric heart transplant and pediatric palliative care teams can best work together to serve our patients and families who often have concurrent care goals will be important.[26]

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Data Statement

The data that support the findings of this study are available from the Pediatric Heart Transplant Society. Restrictions may apply to the availability of these data, which were used with approval from the Pediatric Heart Transplant Society.

Disclosures

The authors have no financial or industry relationships specific to this research to disclose.

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Table 1. Demographics, Transplant characteristics, and Primary/contributing causes of death (N=9,217)

Patient demographics	N=9,217
Male sex	5,146 (55.8)
Race (not mutually exclusive)	
Caucasian/White	6,446 (69.9)
African American/Black	1,652 (17.9)
American Indian or Alaskan Native	88 (1.0)
Asian	298 (3.2)
Hawaiian or other Pacific islander	47 (0.5)
Other	581 (6.3)
Unknown/Undisclosed	280 (3.0)
Ethnicity	
Hispanic	1,623 (17.6)
Non-Hispanic	6,386 (69.3)
Unknown	1,208 (13.1)
Primary Insurance	
Charitable Donation	9 (0.1)
Free	222 (2.4)
Government	4,394 (47.7)
Private	3,484 (37.8)
Self Pay	79 (0.9)
Other	193 (2.1)
Unknown/Not reported	836 (9.1)
Primary Etiology	
Cardiac Tumor	32 (0.3)
Cardiomyopathy	4,026 (43.7)
Congenital Heart Disease	4,840 (52.5)
Myocarditis	313 (3.4)
Other	6 (0.1)

Transplant/Post-transplant characteristics	N=6,793
Age at Transplant, years	4.1 (0.6-12.7)
Year of Transplant	
1993-2000	1,140 (16.8)
2001-2010	2,296 (33.8)
2011-2019	3,357 (49.4)
Time since transplant, years	4.1 (1.4-8.3)
Patient seen for follow-up (anytime during post-transplant)	5,644 (96.6)
Death	N=2,804
Primary cause of death	
Cardiac	1,300 (46.4)
GI/Intestinal Complications	24 (0.9)
Hepatic Failure	7 (0.2)
Infection	227 (8.1)
Major bleeding (non-neurological)	82 (2.9)
Malignancy/Cancer	53 (1.9)
Neurologic	169 (6.0)
Pulmonary embolism	9 (0.3)
Pulmonary hypertension/RV failure	40 (1.4)
Rejection	222 (7.9)
Renal Failure	31 (1.1)
Respiratory failure	170 (6.1)
Suicide	1 (0.0)
Trauma/Accidental	105 (3.7)
Other	248 (9.8)
Unknown	114 (4.1)
Not reported	2 (0.1)
Contributing cause of death	
Cardiac	430 (15.3)
Family decision to withdraw of support	124 (4.4)
Hepatic Failure	34 (1.2)
Infection	252 (9.0)
Major bleeding (non-neurological)	81 (2.9)
Malignancy/Cancer	31 (1.1)
Neurologic	156 (5.6)

	Non-compliance	96 (3.4)
	Poor donor preservation	4 (0.1)
	Primary graft failure (onset < 24 hours post-transplant)	11 (0.4)
	Pulmonary embolism	18 (0.6)
	Pulmonary hypertension/RV failure	85 (3.0)
	Rejection	187 (6.7)
	Renal Failure	337 (12.0)
	Respiratory failure	94 (3.4)
	Suicide	0 (0.0)
	Trauma/Accidental	57 (2.0)
	Other	754 (26.9)
	Unknown	67 (2.4)

* Data are presented as N (%) for categorical variables and Median (interquartile range) for continuous variables.

Table 2. Associations of Demographics and Transplant and Post-transplant characteristics by Location of Death (N=1,113)

Characteristics	While awaiting heart transplant				Post-heart transplant			
		In-hospital at time of death				In-hospital at time of death		
	All (N=804)	Yes (N=718)	No (N=86)	P-value[¥]	All (N=309)	Yes (N=69)	No (N=240)	P-value[¥]
Patient demographics								
Male sex	453 (56.3)	407 (56.7)	46 (53.5)	0.57	177 (57.3)	33 (47.8)	144 (60.0)	0.07
Age at death, years	0.8 (0.2-3.1)	0.7 (0.2-2.9)	1.2 (0.5-5.5)	0.01	11.1 (3.1-17.1)	6.9 (1.3-13.8)	12.3 (3.8-17.8)	0.001
Race (not mutually exclusive)				0.23[†]				0.98[†]
Caucasian/White	527 (65.5)	478 (66.6)	49 (57.0)		191 (61.8)	43 (62.3)	148 (61.7)	
African American/Black	169 (21.0)	154 (21.4)	15 (17.4)		77 (24.9)	18 (26.1)	59 (24.6)	
American Indian or Alaskan Native	9 (1.1)	7 (1.0)	2 (2.3)		3 (1.0)	1 (1.4)	2 (0.8)	
Asian	24 (3.0)	19 (2.6)	5 (5.8)		10 (3.2)	2 (2.9)	8 (3.3)	
Hawaiian or other Pacific islander	6 (0.7)	5 (0.7)	1 (1.2)		1 (0.3)	0 (0.0)	1 (0.4)	
Other	56 (7.0)	44 (6.1)	12 (14.0)		21 (6.8)	5 (7.2)	16 (6.7)	
Unknown/Undisclosed	29 (3.6)	22 (3.1)	7 (8.1)		12 (3.9)	2 (2.9)	10 (4.2)	
Ethnicity				0.53				0.55
Hispanic	159 (19.8)	139 (19.4)	20 (23.3)		68 (22.0)	15 (21.7)	53 (22.1)	
Non-Hispanic	537 (66.8)	479 (66.7)	58 (67.4)		213 (68.9)	40 (58.0)	173 (72.1)	
Unknown/Not reported	108 (13.4)	100 (13.9)	8 (9.3)		28 (9.1)	14 (20.3)	14 (5.8)	

Primary Insurance				0.89[α]				0.81[α]
	Charitable Donation	0 (0.0)	0 (0.0)	0 (0.0)		0 (0.0)	0 (0.0)	0 (0.0)	
	Free	19 (2.4)	17 (2.4)	2 (2.3)		9 (2.9)	2 (2.9)	7 (2.9)	
	Government	426 (53.0)	374 (52.1)	52 (60.5)		163 (52.8)	33 (47.8)	130 (54.2)	
	Private	253 (31.5)	223 (31.1)	30 (34.9)		105 (34.0)	20 (29.0)	85 (35.4)	
	Self Pay	5 (0.6)	5 (0.7)	0 (0.0)		1 (0.3)	1 (1.4)	0 (0.0)	
	Other	11 (1.4)	9 (1.3)	2 (2.3)		11 (3.6)	1 (1.4)	10 (4.2)	
	Unknown/Not reported	90 (11.2)	90 (12.5)	0 (0.0)		20 (6.5)	12 (17.4)	8 (3.3)	
Primary Etiology				0.04[‡]				0.23[‡]
	Cardiac Tumor	4 (0.5)	3 (0.4)	1 (1.2)		0 (0.0)	0 (0.0)	0 (0.0)	
	Cardiomyopathy	221 (27.5)	189 (26.3)	32 (37.2)		117 (37.9)	30 (43.5)	87 (36.3)	
	Congenital Heart Disease	553 (68.7)	502 (69.9)	51 (59.3)		185 (59.9)	37 (53.6)	148 (61.7)	
	Myocarditis	26 (3.2)	24 (3.3)	2 (2.3)		7 (2.3)	2 (2.9)	5 (2.1)	
Transplant/Post-transplant characteristics									
Age at Transplant, years						4.1 (0.7-11.5)	1.7 (0.5-7.4)	5.2 (0.7-12.4)	0.02
Year of Transplant									<.0001
	1993-2000					36 (11.7)	20 (29.0)	16 (6.7)	
	2001-2010					104 (33.7)	34 (49.3)	70 (29.2)	
	2011-2019					169 (54.7)	15 (21.7)	154 (64.2)	
Time since transplant, years						2.0 (0.3-6.9)	1.5 (0.1-6.0)	2.6 (0.4-7.0)	0.02
Patient seen for follow-up (anytime during post-transplant)						200 (64.7)	36 (52.2)	164 (68.3)	0.01

[*] Data are presented as N (%) for categorical variables and Median (interquartile range) for continuous variables.

[¥] P-value from Chi-square test for categorical variables and Wilcoxon rank sum test for continuous variables.

[†] Comparison was made as Caucasian/White vs. all others (except Unknown/Undisclosed) and p-value came from Chi-square test.

[α] Comparison was made as Government vs. Private and p-value came from Chi-square test.

[‡] Comparison was made as Congenital Heart Disease vs. all others and p-value came from Chi-square test.