

Health Insurance Coverage among Young Adult Survivors of Pediatric Heart Transplantation

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Objective To describe the change in health insurance after heart transplantation among adolescents, and characterize the implications of this change for long-term transplant outcomes.

Study design Patients age 15-18 years receiving first-time heart transplantation between 1999 and 2011 were identified in the United Network for Organ Sharing registry and included in the analysis if they survived at least 5 years. The primary exposure was change or continuity of health insurance coverage between the time of transplant and the 5-year follow-up. Cox proportional hazards models were used to determine the association between insurance status change and long-term (>5 years) patient and graft survival.

Results The analysis included 366 patients (age 16 ± 1 years at transplant), of whom 205 (56%) had continuous private insurance; 96 (26%) had continuous public insurance; and 65 (18%) had a change in insurance status. In stepwise multivariable Cox regression, change in insurance status was associated with greater mortality hazard, compared with continuous private insurance (hazard ratio = 1.9; 95% CI: 1.1, 3.2; $P = .016$), whereas long-term patient and graft survival did not differ between patients with continuous public and continuous private insurance.

Conclusions Continuity of insurance coverage is associated with improved long-term clinical outcomes among adolescent heart transplant recipients who survive into adulthood. (*J Pediatr* 2017;■■■■-■■■).

Pediatric heart transplantation is a treatment of last resort for end-stage heart failure and a primary therapy for certain manifestations of congenital heart disease.¹ Continued improvements in the outcomes of pediatric heart transplantation have led to a growing population of pediatric heart transplant recipients surviving to adulthood.² Yet, improved survival poses several challenges for recipients of pediatric heart transplantation. First, late adolescence is associated with poor treatment adherence, particularly with maintenance immunosuppression.^{3,4} Second, transition to adult care can be a time of anxiety and conflict, as patients, parents, and physicians negotiate the transfer of care from one institution to another.⁵ Third, change in insurance status in young adulthood may complicate patients' access to care, and increase the risk of subsequent morbidity and mortality.⁵ In the US, patients undergoing heart transplantation funded by public insurance encounter more restrictive Medicaid eligibility thresholds when they age out of public children's health insurance,⁶ while patients who had private insurance at the time of heart transplantation may age out of dependent coverage by a parent's policy.⁷

Disruption of health insurance coverage makes transition from pediatric to adult cardiology services more challenging⁸ and impacts adult long-term survival after heart transplantation.⁹ To describe health insurance coverage among adult survivors of pediatric heart transplantation, single-center studies have collected data on insurance status at 10-15 years post-transplant.^{10,11} However, among pediatric heart transplant recipients, the frequency of changes between insurance types as patients transition from childhood to adulthood is unclear. Changes or gaps in insurance coverage during this vulnerable time may influence long-term transplant outcomes.^{8,9} We used available national registry data to determine the frequency of private insurance gain (transition from public to private insurance) and private insurance loss (transition from private to public insurance) among young adult survivors of pediatric heart transplantation. Our secondary aim was to examine the effect that changes in health insurance would have for long-term patient and graft survival.

The study was exempted from review by the Institutional Review Board at Nationwide Children's Hospital. Deidentified data were obtained from the United Network for Organ Sharing (UNOS) registry, which tracks solid organ transplant candidates and recipients in the US.¹² As data on insurance coverage were available up to 5 years post-transplant, patients were included in the study if they

ACA	Patient Protection and Affordable Care Act
BTT	Bridge to transplant
HR	Hazard ratio
LVAD	Left ventricular assist device
OPTN	Organ Procurement and Transplantation Network
UNOS	United Network for Organ Sharing

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received first-time heart transplantation at age 15-18 years old, such that all patients were at least 20 years old at their fifth transplant anniversary (ie, older than the Medicaid cut-off for children's coverage eligibility, at age 19 years). Patients were excluded from the analysis if their fifth transplant anniversary was earlier than June 2004 (when the UNOS registry began tracking post-transplant insurance status), or if they experienced graft loss, died, or were lost to follow-up before the fifth transplant anniversary. With available follow-up data ending in December 2016, patients were excluded if they had undergone heart transplantation later than December 2011. Patients were excluded if their payment type at the 5-year follow-up was self-payment, free care, or payment by a foreign government, because of very few patients reporting these payment sources.

Transplant centers reported patients' primary payment type (insurance status) at annual follow-ups as previously described.^{13,14} Reporting of insurance status was discontinued 5 years after transplant. Current Organ Procurement and Transplantation Network (OPTN) policy requires follow-up data to be submitted within 30 days of a transplant anniversary¹⁴; to account for late submission of data to OPTN, we included the most recent available data on insurance status submitted within 1 year of the fifth transplant anniversary when determining patients' post-transplant insurance status.¹⁵ Post-transplant insurance status was compared with patients' insurance status at the time of transplant to determine the following categories of change or continuity of insurance status: (1) continuous private insurance (private insurance both at transplant and at 5-year follow-up); (2) continuous public insurance (Medicaid at transplant and any type of government health coverage at follow-up); and (3) change between private and public insurance from the time of transplant to the 5-year follow-up. The secondary outcomes were patient and graft survival, conditional on survival to 5 years post-transplant.

Patient characteristics were compared according to the type of insurance trajectory (categories 1-3 listed above) using χ^2 tests for categorical data and ANOVA for continuous data. The insurance trajectory was then entered in Cox proportional hazards regression of mortality after the fifth transplant anniversary. A similar analysis was performed for mortality-censored graft survival >5 years post-transplant. Covariates included patient age at transplant, sex, race, body mass index for age percentile (underweight, <5%; normal weight, 5%-84%, overweight, $\geq 85\%$), left ventricular assist device (LVAD) bridge to transplant (BTT), medical condition at transplant (in intensive care unit vs not), indication for heart transplantation (congenital heart disease, dilated cardiomyopathy, or other), and year of transplant. Multivariable Cox models were constructed using forward selection with *P* value of < .2 as the threshold for variable inclusion. Cases with missing data on covariates were excluded from multivariable analysis. All analyses were performed in Stata/IC 13.1 (StataCorp, LP, College Station, Texas), and *P* value of < .05 was considered statistically significant.

Results

The UNOS registry included 692 patients age 15-18 years who received first-time heart transplantation between June 1999 and December 2011. We excluded 180 patients who died before the fifth transplant anniversary, and an additional 138 patients who were retransplanted or were lost to follow-up during this time. We then excluded 5 patients reporting self-pay, 2 patients reporting free care, and 1 patient reporting foreign government payment at the 5-year follow-up. The final study cohort included 366 patients (234/132 male/female, mean age at transplant 16 ± 1 years), of whom 363 had complete data on covariates. Patient characteristics and missing data are summarized in **Table I**. In the study cohort, 205 (56%) patients

Table I. Characteristics of patients surviving more than 5 years after heart transplantation at ages 15-18 years, by health insurance coverage at the time of transplant and at the 5-year follow-up (N = 366)

Variables	Continuous private insurance (N = 205)	Continuous public insurance (N = 96)	Change in insurance status (N = 65)	P
	Mean (SD) or N (%)	Mean (SD) or N (%)	Mean (SD) or N (%)	
Age at transplant (y)	16 (1)	16 (1)	17 (1)	.156
Female	68 (33%)	40 (42%)	24 (37%)	.355
Race				<.001
White	158 (77%)	40 (42%)	38 (58%)	
Black	26 (13%)	36 (38%)	16 (25%)	
Other	21 (10%)	20 (21%)	11 (17%)	
BMI-for-age percentile*				.007
Underweight (<5%)	32 (16%)	7 (7%)	7 (11%)	
Normal weight (5%-84%)	123 (61%)	51 (53%)	30 (47%)	
Overweight ($\geq 85\%$)	48 (24%)	38 (40%)	27 (42%)	
LVAD BTT	43 (21%)	15 (16%)	12 (18%)	.540
In ICU at time of transplant	92 (45%)	42 (44%)	29 (45%)	.983
Indication for transplant				.210
Congenital heart disease	46 (22%)	16 (17%)	12 (18%)	
Dilated cardiomyopathy	117 (57%)	64 (67%)	46 (71%)	
Other	42 (20%)	16 (17%)	7 (11%)	
Year of transplant	2005 (3)	2005 (3)	2005 (4)	.754

BMI, body mass index; ICU, intensive care unit.

*Three cases missing data.

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