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Employment after heart transplantation among adults with congenital heart disease

Dmitry Tumin PhD[1,2] | Helen Chou BS[1] | Don Hayes Jr. MD, MS[1,3,4] | Joseph D. Tobias MD[1,2,5] | Mark Galantowicz MD[6,7] | Patrick I. McConnell MD[6,7]

[1]Department of Pediatrics, The Ohio State University College of Medicine, Columbus, Ohio, USA

[2]Department of Anesthesiology & Pain Medicine, Nationwide Children's Hospital, Columbus, Ohio, USA

[3]Department of Internal Medicine, The Ohio State University College of Medicine, Columbus, Ohio, USA

[4]Section of Pulmonary Medicine, Nationwide Children's Hospital, Columbus, Ohio, USA

[5]Department of Anesthesiology, The Ohio State University College of Medicine, Columbus, Ohio, USA

[6]Department of Surgery, The Ohio State University College of Medicine, Columbus, Ohio, USA

[7]Department of Cardiothoracic Surgery, Nationwide Children's Hospital, Columbus, Ohio, USA

Correspondence
Dmitry Tumin, Department of Anesthesiology & Pain Medicine, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205, USA.
Email: tumin.1@osu.edu

Abstract

Objective: Adults with congenital heart disease may require heart transplantation for end-stage heart failure. Whereas heart transplantation potentially allows adults with congenital heart disease to resume their usual activities, employment outcomes in this population are unknown. Therefore, we investigated the prevalence and predictors of work participation after heart transplantation for congenital heart disease.

Design: Retrospective review of a prospective registry.

Setting: United Network for Organ Sharing registry of transplant recipients in the United States.

Patients: Adult recipients of first-time heart transplantation with a primary diagnosis of congenital heart disease, performed between 2004 and 2015.

Interventions: None.

Outcome measures: Employment status reported by transplant centers at required follow-up intervals up to 5 y posttransplant.

Results: Among 470 patients included in the analysis (mean follow-up: 5 ± 3 y), 127 (27%) worked after transplant, 69 (15%) died before beginning or returning to work, and 274 (58%) survived until censoring, but did not participate in paid work. Multivariable competing-risks regression analysis examined characteristics associated with posttransplant employment, accounting for mortality as a competing outcome. In descriptive and multivariable analysis, pretransplant work participation was associated with a greater likelihood of posttransplant employment, while the use of Medicaid insurance at the time of transplant was associated with a significantly lower likelihood of working after transplant (subhazard ratio compared to private insurance: 0.55; 95% confidence interval: 0.32, 0.95; $P = .032$).

Conclusions: Employment was rare after heart transplantation for congenital heart disease, and was significantly less common than in the broader population of adults with congenital heart disease. Differences in return to work were primarily related to pretransplant employment and the use of public insurance, rather than clinical characteristics.

KEYWORDS
employment, health insurance, heart transplantation

1 | INTRODUCTION

Clinical outcomes of congenital heart disease (CHD) have improved markedly in recent decades due to advances in surgical and medical management.[1] Nevertheless, CHD is implicated in developmental delay, deficits in educational attainment, and nonparticipation in the labor force.[2–5] Among adults with CHD, heart transplantation (HTx) is a treatment option for end-stage heart failure after previous surgical intervention, or for CHD manifesting in later life.[6,7] HTx potentially allows transplant recipients to return to their usual activities, but the costs of transplantation and lifelong follow-up in the United States (US) create the risk of a "transplant trap," such that transplant recipients may forego paid work to retain eligibility for public health insurance.[8,9] Prior studies of adults with CHD have demonstrated low rates of work participation relative to the general population, particularly among adults with severe disease[10–12]; yet it remains unknown to what extent adults with CHD successfully pursue paid work if they undergo HTx. To characterize the prevalence of paid work after HTx performed for CHD in adulthood, we examined data from a US registry of transplant recipients. Our secondary aim was to examine clinical and socioeconomic characteristics of HTx recipients with CHD that were associated with employment after transplantation.

2 | METHODS

The study was deemed exempt from review by the Institutional Review Board at Nationwide Children's Hospital. The United Network for Organ Sharing (UNOS) registry was queried for recipients of first-time HTx, age 18 y and older, with a primary diagnosis of CHD, with or without prior surgical repair.[13] Data were included if the HTx was performed in June 2004 or later, as posttransplant employment status was not tracked prior to this date. With the available data including follow-up through December 2016, HTx performed up to December 2015 were selected for analysis, to allow at least 1 y of follow-up for recipients. Patients receiving multiorgan transplants and patients with no follow-up data on employment status were excluded. Transplant centers were required to report recipients' employment status (i.e., whether or not patients were working for income) at each transplant anniversary, up to 5 y posttransplant, as previously described.[9,14,15] The primary outcome in the study was working for income at any point during post-HTx follow-up. Mortality before return to work was considered as a competing risk.

Patient characteristics were tabulated according to posttransplant employment status, and compared using unpaired *t*-tests for continuous data and chi-square tests for categorical data. Multivariable Fine-Gray competing-risks regression was used to model the likelihood of working after HTx, while accounting for mortality as a competing risk.[16,17] Covariates in this analysis included patient age, gender, and race; educational attainment; insurance status at the time of HTx (private, Medicaid, Medicare, or others); history of pretransplant employment (i.e., "working for income" recorded at the time of wait listing or transplantation); prior cardiac surgery (including prior surgical repair of CHD, if indicated in the primary indication for HTx field); body mass index (BMI); pretransplant serum creatinine; pulmonary vascular resistance (PVR); left ventricular assist device (LVAD) bridge to transplant; intraaortic balloon pump (IABP); pretransplant mechanical ventilation; and year of transplant.

To complete missing data on covariates for the multivariable analysis, we used multiple imputation by chained regression.[18] The number of imputations was selected according to the fraction of missing information, and 20 imputed data sets were created for analysis.[19] The imputation models included all covariates listed above, in addition to the outcome of HTx (posttransplant employment, mortality before return to work, or censoring) and duration of follow-up until employment, mortality prior to employment, or censoring. The multivariable model was estimated separately for each imputed data set, and estimates were combined across imputations as previously described.[18,20] Data analysis was performed in Stata/IC 13.1 (College Station, TX), with $P < .05$ considered statistically significant.

3 | RESULTS

The UNOS registry included 654 adults undergoing first-time HTx for CHD between June 2004 and December 2015. After excluding 46 patients who received multiorgan transplants and 138 patients with no follow-up data on employment status, there remained 470 patients in the final analytic sample, with an average duration of follow-up of 5 ± 3 y. The characteristics of patients included in the study are summarized in Table 1 according to whether each patient was employed after HTx. Of the study cohort, 127 (27%) patients were reported to be employed after HTx, 69 (15%) patients died before beginning or returning to work, and 274 (58%) patients survived but did not participate in paid work according to the reporting transplant center. When considering only patients with at least 1 y of follow-up (n = 437), 119 (27%) returned to work after HTx.

In the overall study cohort, mean time until employment was first reported among the 127 patients who worked after HTx was 13 ± 6 mo, and all patients in this group were employed within 30 mo of HTx. Patients who were employed posttransplant were significantly more likely to have private health insurance and to have worked prior to HTx, and tended to have lower BMI, compared to patients who never worked posttransplant (Table 1). When considering health insurance coverage among patients who did not return to work, public insurance coverage (Medicaid or Medicare) was slightly more common among those who died after transplant (34 of 69, 49%) than among patients who survived but did not return to work (116 of 274, 42%), although this difference was not statistically significant (chi-square $P = .299$).

There were 191 patients missing data on one or more covariates, specifically PVR (149 cases missing data), educational attainment (44 cases), pretransplant employment (35 cases), and serum creatinine (4 cases). After multiple imputation to complete missing data on covariates, a multivariable model of posttransplant employment was fitted as shown in Table 2, accounting for mortality prior to return to work as a

TABLE 1 Characteristics of adults undergoing heart transplantation for congenital heart disease (N = 470)

Variable	Cases missing data	Not working after transplant (N = 343) mean (SD) or N (%)	Working after transplant (N = 127) mean (SD) or N (%)	*P*
Age at transplant (y)	0	35 (14)	36 (13)	.881
Female	0	150 (44%)	41 (32%)	.025
Race	0			.493
White		285 (83%)	111 (87%)	
Black		21 (6%)	5 (4%)	
Others		37 (11%)	11 (9%)	
Educational attainment	44			.084
High school or less		159 (51%)	50 (43%)	
Some college		82 (26%)	27 (23%)	
College graduate		70 (23%)	38 (33%)	
Health insurance	0			.002
Private		189 (55%)	95 (75%)	
Medicaid		75 (22%)	17 (13%)	
Medicare		75 (22%)	14 (11%)	
Others		4 (1%)	1 (1%)	
Pretransplant employment	35	29 (9%)	37 (31%)	<.001
Prior cardiac surgery	0	308 (90%)	114 (90%)	.992
BMI (kg/m^2)	0	25 (5)	23 (5)	.002
Serum creatinine (mg/dL)	4	1.1 (0.4)	1.1 (0.5)	.612
PVR (Wood units)	149	2.4 (2.6)	2.0 (1.3)	.158
LVAD	0	30 (9%)	10 (8%)	.763
IABP	0	8 (2%)	7 (6%)	.082
Mechanical ventilation	0	10 (3%)	3 (2%)	.745
Year of transplant	0	2010 (3)	2010 (3)	.757

BMI, body mass index; IABP, intraaortic balloon pump; LVAD, left ventricular assist device; PVR, pulmonary vascular resistance; SD, standard deviation.

competing risk. Among covariates in the analysis, only pretransplant employment was associated with increased likelihood of posttransplant employment (subhazard ratio [SHR] = 2.95, 95% CI: 1.80, 4.83; $P < .001$). Medicaid public insurance (SHR = 0.55, 95% CI: 0.32, 0.95; $P = .032$) and greater BMI at the time of transplant (SHR for 5 kg/m^2 increase = 0.69; 95% CI: 0.56, 0.85; $P < .001$) predicted lower likelihood of posttransplant employment. Other demographic characteristics, history of cardiac surgery, and measures of disease severity prior to transplant were not significantly associated with adults' work participation after HTx for CHD.

4 | DISCUSSION

Among patients surviving to adulthood, long-term outcomes of CHD often include low levels of educational and career attainment.[5,21,22] CHD-associated neurocognitive deficits, including problems with language, memory, attention, and planning, have been attributed to prolonged cyanosis, neurological deficits after cardiopulmonary bypass surgery, and interrupted education due to prolonged hospitalization.[5] Some adults with CHD undergo HTx for symptomatic ventricular or biventricular dysfunction that cannot be controlled by maximal medical treatment.[23] The implications of HTx for social participation, particularly employment, are mixed. Whereas HTx enables recovery of physical functioning and eventual return to work, transplant recipients may face employer discrimination, a need to take significant time off work or retrain for a different occupation, and a reluctance to find work if it would end the patients' eligibility for public health insurance.[24–27] Adults with CHD undergoing HTx may also experience further disruptions in employment due to renal, pulmonary, and hepatic dysfunction associated with CHD.[7,28] Consistent with obstacles to posttransplant employment described in prior studies, our analysis of long-term employment outcomes after HTx among adults with CHD demonstrates that few patients find work after transplantation and that a lack of prior work experience and reliance on means tested public health insurance are strongly associated with remaining unemployed after HTx.

In the present study, 27% of adults with CHD undergoing HTx were employed at some point after transplant, with a mean follow-up duration of 5 y. This proportion is similar to data recently reported for US adults of working age receiving HTx for any indication in 2010–2014[9] but is lower than the 3-y post-HTx employment rate

TABLE 2 Multivariable competing-risks regression of employment after heart transplantation, accounting for competing outcome of mortality prior to beginning or returning to work (N = 470)

Variable[a]	SHR	95% CI	*P*
Age at transplant (y)	1.00	(0.99, 1.02)	.811
Female	0.67	(0.45, 1.01)	.057
Race			
White	ref.		
Black	0.70	(0.22, 2.23)	.543
Others	0.91	(0.50, 1.64)	.749
Educational attainment			
High school or less	ref.		
Some college	1.20	(0.70, 2.07)	.505
College graduate	0.97	(0.58, 1.61)	.892
Health insurance			
Private	ref.		
Medicaid	0.55	(0.32, 0.95)	.032
Medicare	0.64	(0.37, 1.10)	.102
Others	1.60	(0.11, 23.02)	.729
Pretransplant employment	2.95	(1.80, 4.83)	<.001
Prior cardiac surgery	0.76	(0.40, 1.44)	.401
BMI ([kg/m^2]/5)	0.69	(0.56, 0.85)	<.001
Serum creatinine (mg/dL)	0.86	(0.53, 1.39)	.542
PVR (Wood units)	0.88	(0.77, 1.01)	.061
LVAD	0.90	(0.49, 1.67)	.092
IABP	1.90	(0.90, 3.99)	.092
Mechanical ventilation	0.87	(0.33, 2.30)	.783
Year of transplant	1.02	(0.96, 1.08)	.460

[a]Missing data on covariates completed using multiple imputation. Model estimates were combined across 20 imputed data sets.
BMI, body mass index; CI, confidence interval; IABP, intraaortic balloon pump; LVAD, left ventricular assist device; PVR, pulmonary vascular resistance; SHR, subhazard ratio.

(46%) for adults ages 25–60 reported in the International Society for Heart and Lung Transplantation Registry.[29] In single-center studies conducted in countries with single-payer health insurance, rates of employment after HTx have ranged from 25% to 69%, although these estimates are limited by small samples and inconsistent durations of follow-up.[30–32] Most importantly, our results suggest significantly lower employment participation after HTx for CHD, compared to the overall population of US adults with CHD (64%).[25] In part, lower employment among adults with CHD who receive HTx may be attributed to the severity of CHD and probable presence of comorbidities that limit work ability even after patients recover from the transplant. These pretransplant differences in health status may explain some of the association between pretransplant work history and posttransplant employment in our analysis. Yet, the multivariable analysis suggested that clinical status at the time of transplantation had little association with eventual employment outcomes. Therefore, it is likely that some adults who had received HTx for CHD would be able to participate in paid work, but may be deterred from this by the difficulty of finding appropriate employment, or by the trade-offs between work participation and eligibility for public health insurance.[8]

Opportunities to support employment after successful HTx for CHD cut across multiple domains of health policy and posttransplant care. First, in light of recent healthcare reforms creating insurance marketplace exchanges and requiring commercial policies to cover preexisting conditions,[33] social work services may help HTx recipients find affordable health insurance coverage compatible with work participation, if they cannot obtain employer-sponsored health insurance. Second, interventions providing medically appropriate career counseling may help adults with CHD find suitable work after HTx.[34,35] Third, initiatives to educate employers about the abilities and limitations of patients with CHD may improving hiring outcomes.[34] Lastly, encouraging patients to complete higher education or job training may increase employment rates posttransplant.[4] Tempering these possibilities; however, the deficit in post-HTx employment in the US compared to data from the ISHLT suggests that some aspects the US labor market and health coverage regime may fundamentally limit incentives to work after HTx among patients medically cleared to do so.

The findings of the present study share the strengths and limitations of prior analyses addressing employment status in the UNOS transplant registry.[9,14,26] Most importantly, employment data in this registry lack detail on occupation, employment start and end dates, reasons for not working, and other types of social participation (e.g., volunteering, pursuing further education) that may substitute for paid work. Therefore, while we demonstrate a high rate of unemployment among adults with CHD who had received HTx, the participation of this cohort in other social roles remains to be explored in future research. The influence of socioeconomic status, broadly defined, is also difficult to determine from these data. However, the available measure of educational attainment was not associated with return to work in our study. Additionally, UNOS data include a limited range of covariates describing comorbidities in transplant recipients, so it is possible that some complications of CHD (e.g., CHD-associated neurological deficits) ultimately influenced posttransplant work participation but could not be captured in the present analysis. Lastly, UNOS follow-up data may vary in accuracy and timeliness due to differences in data reporting across centers and over time.

Notwithstanding these limitations, we report employment outcomes of a large cohort of adults with CHD undergoing HTx. Similar to other populations of transplant recipients, unemployment in this cohort is high; and is significantly higher than the unemployment rate previously reported in the broader population of adults with CHD. Notably, likelihood of posttransplant employment was primarily associated with type of health insurance coverage and pretransplant work participation, but was generally not associated with clinical characteristics or measures of disease severity. In addition to individual-level interventions supporting patients' return to work after recovering from HTx, our results suggest considering how use of means-tested public health insurance may disincentivize employment in this population with lifelong special healthcare needs.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design, interpretation of data, statistical analysis, and drafting of the manuscript: Tumin

Interpretation of data and drafting of the manuscript: Chou

Acquisition of data, interpretation of data, and revision of the manuscript: Hayes

Interpretation of data and revision of the manuscript: Tobias

Interpretation of data and revision of the manuscript: Galantowicz

Interpretation of data and revision of the manuscript: McConnell

ORCID

Dmitry Tumin PhD http://orcid.org/0000-0002-9180-7656

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