

Short Communication

Long-term work participation among cystic fibrosis patients undergoing lung transplantation☆



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Abstract

Background: Patients with cystic fibrosis (CF) experience obstacles to employment, regardless of whether they have undergone lung transplantation (LTx). We investigated socioeconomic and clinical factors predicting long-term employment outcomes in CF patients receiving LTx.

Methods: Data from the United Network for Organ Sharing registry were used to identify CF patients 18–59 years-old who received LTx between 2000 and 2010 and survived greater than 5 years. Long-term employment status was determined by center-reported follow-up data on patients working for income, collected at the 5th transplant anniversary. After multiple imputation to complete missing data on covariates, multivariable logistic regression was used to identify associations between characteristics at or after LTx and long-term work participation.

Results: There were 745 patients who met inclusion criteria and contributed employment data within 365 days of their 5th LTx anniversary. In this cohort, 48% (358/745) were working for income 5 years after LTx. Younger age, male gender, better pulmonary function attained post-transplant, pre-transplant work participation, and private health insurance (compared to government Medicaid or Medicare insurance) at the time of transplant predicted greater odds of post-transplant employment.

Conclusions: Lack of work experience and reliance on government health insurance at the time of transplant predict lower long-term work participation among LTx recipients with CF. By contrast, long-term employment outcomes were not negatively affected by comorbidities at or after transplantation in this cohort. Despite resolving some physiological obstacles to employment in patients with CF, LTx may introduce new socioeconomic barriers to employment.

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1. Introduction

Increasing life expectancy of patients with cystic fibrosis (CF) has allowed for greater labor force participation in this population. Employment among patients with CF is associated with improved physical and social functioning [1], but is limited by severe lung disease, lower body mass index (BMI), and lower educational attainment [2–4].

Lung transplantation (LTx) can alleviate some physiological barriers to employment [5,6]. However, employment among LTx recipients is lower than among recipients of other solid organs [7]. Undergoing LTx may strengthen socioeconomic barriers to employment due to reliance on public insurance programs and disruption of work history [8]. We used a United States (US) transplant registry to describe post-LTx employment in CF patients and identify clinical or socioeconomic factors limiting employment.

2. Methods

Following Institutional Review Board approval and waiver of individual consent, de-identified data up to September 2015 were obtained from the United Network for Organ Sharing (UNOS) [9]. CF patients receiving first-time LTx in 2000–2010 were included if they were 18–59 years old at transplantation, survived at least 5 years, and had known employment status at 5 years post-transplant. Transplant centers reported employment status at annual follow-ups, as previously described [8], with data available until the 5th transplant anniversary. Due to inconsistent timing of reports [10], the most recent employment status reported within 365 days of the 5th transplant anniversary determined if patients were employed (“working for income”) or unemployed.

Multivariable logistic regression was used to examine associations of post-transplant employment with the following variables at transplantation: patient age, gender, pre-transplant employment, educational attainment, payment for LTx (private insurance/self-pay, Medicaid, Medicare, or other), history of diabetes, BMI, forced expiratory volume in 1 s (FEV₁), forced vital capacity (FVC), supplemental oxygen requirement, and median household income (MHI) quartile of patients’ US ZIP codes of residence, using the 2000 Decennial Census data [11]. Post-transplant covariates were assessed up to the 5th transplant anniversary, and included maximal attained FEV₁, diagnoses of bronchiolitis obliterans syndrome (BOS) or malignancy, and renal failure requiring hemodialysis. Multiple imputation by chained equations was used to complete missing data on covariates in 20 imputed data sets [12]. Imputation models included post-transplant employment and all covariates. The **Online Supplement** describes how regression results from each imputed data set were combined.

3. Results

There were 864 patients surviving 5 years after LTx, of whom 745 contributed employment data within 365 days of the 5th transplant anniversary (Fig. 1). Patients missing employment data ($n = 119$) were more likely to be female (57% vs 46%, $p = 0.028$) and to have diabetes (50% vs 35%, $p = 0.002$) than patients with known employment status; but did not differ on other characteristics examined. In the analytic sample, 48% (358/745) were working 5 years after LTx. Table 1 compares study characteristics by employment status 5 years post-transplant. Employed LTx recipients were more likely to have private insurance and to have worked before LTx. Following multiple imputation, multivariable logistic regression models were fitted to

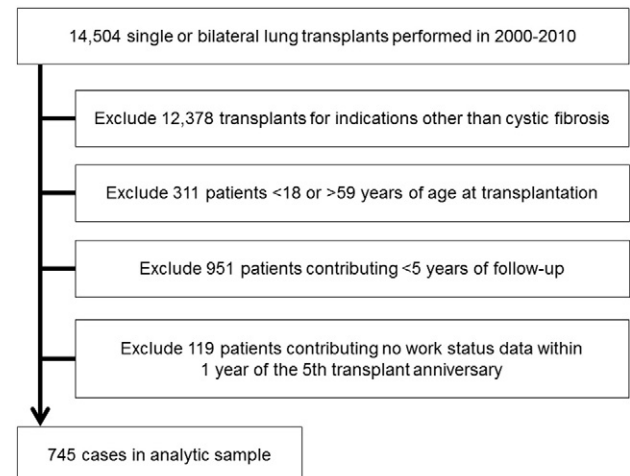


Fig. 1. Seven hundred forty five patients remain for analysis after excluding non-CF transplants, patients <18 or >59 years of age, patients surviving <5 years after transplant, and patients without employment data at 5 years.

each imputed data set (**Online Supplement**) and combined to produce Table 2. Younger age, male gender, private insurance (vs. Medicaid or Medicare), pre-LTx employment, and greater post-LTx FEV₁ were associated with higher odds of post-LTx employment. Other clinical factors assessed at or after LTx were not associated with this outcome.

4. Discussion

Employment is associated with improved clinical outcomes and quality of life among patients with CF [1,2,13] and LTx recipients [14,15]. Yet patients with CF encounter clinical and socioeconomic obstacles to employment. While LTx alleviates some physiologic limitations on work participation, it reinforces socioeconomic barriers to employment. This study demonstrates that unemployment before LTx and reliance on public insurance, rather than morbidity at or after transplantation, predicted lower employment 5 years post-LTx in patients with CF.

By the time of LTx, CF patients have had a lifetime of medical treatments to delay disease progression. In the general CF population, patients with more severe lung disease have higher unemployment rates [1,2,4,5]. Prior studies included too few LTx recipients for a sub-analysis of this group. Using a national transplant registry, we found that higher FEV₁ after LTx reduced unemployment in CF LTx recipients, consistent with data on the broader LTx population [5]. Yet the post-LTx employment rate 48% was comparable to employment rates in the general CF population [1,3,16]. Therefore, LTx may remove the pulmonary burden of disease, but other barriers to work participation remain for CF patients. Particularly, LTx may obviate the need for chest physiotherapies, inhaled medications, and hospitalizations for acute pulmonary exacerbations, but requires costly immunosuppressant medications, surveillance bronchoscopies, and management of any transplant-related complications [17]; other systemic manifestations of CF such as CF-related diabetes and pancreatic insufficiency remain.

Table 1
Characteristics of patients with cystic fibrosis, by work participation at 5 years after lung transplantation (N = 745).

Variable ^a	Not working (N = 387)		Working (N = 358)		P ^b
	Missing data (N)	Mean (SD) or N (%)	Missing data (N)	Mean (SD) or N (%)	
Age	0	32.6 (9.5)	0	31.2 (8.0)	0.031
Female	0	205 (53%)	0	140 (39%)	<0.001
Recent employment	0	39 (10%)	0	68 (19%)	0.001
Educational attainment	39		27		<0.001
High school or less		117 (34%)		92 (28%)	
Some college		109 (31%)		102 (31%)	
College degree		122 (35%)		137 (41%)	
Primary payment	0		0		<0.001
Private insurance or self-pay		238 (62%)		269 (75%)	
Medicaid		47 (12%)		29 (8%)	
Medicare		87 (22%)		41 (11%)	
Other		15 (4%)		19 (5%)	
MHI quartile of ZIP code	11		10		0.272
1 (lowest)		37 (10%)		30 (9%)	
2		64 (17%)		52 (15%)	
3		107 (28%)		85 (24%)	
4 (highest)		168 (45%)		181 (52%)	
Diabetes history	5	127 (33%)	2	128 (36%)	0.439
BMI (kg/m ²)	5	19.6 (2.6)	2	19.7 (2.7)	0.461
FEV ₁ (% predicted)	22	27.6 (15.3)	9	25.4 (12.2)	0.031
FVC (% predicted)	17	41.0 (14.4)	8	40.0 (12.5)	0.340
O ₂ requirement (L/min)	38	3.3 (3.3)	30	3.3 (3.2)	0.786
<i>Post-transplant covariates</i>					
Maximal FEV ₁ (% predicted)	0	90.3 (20.1)	0	92.7 (18.8)	0.094
BOS	0	22 (6%)	1	17 (5%)	0.573
Dialysis	0	4 (1%)	1	1 (0.3%)	0.208
Malignancy	1	10 (3%)	1	7 (2%)	0.566

SD, standard deviation, MHI, median household income (2000 Census Bureau data), BMI, body mass index, FEV₁, forced expiratory volume in 1 s, FVC, forced vital capacity, BOS, bronchiolitis obliterans syndrome.

^a All variables assessed at the time of transplantation, except recent employment (employed at transplantation or at listing), diabetes history (assessed at listing), educational attainment (assessed at listing), and post-transplant covariates (assessed at annual follow-ups up to the fifth anniversary of the transplant).

^b Chi-square test for categorical variables and unpaired t-test for continuous variables.

CF LTx recipients require reliable healthcare coverage to manage these issues. In the US, health insurance may be obtained from public programs (including Medicaid, for low-income families and pregnant women; or Medicare, for elderly or disabled adults), or from commercial insurers (usually provided through employers). In this study, patients with public insurance at LTx were less likely to work 5 years later, as did patients who were unemployed before transplant. These findings are consistent with results from the general LTx population [8], and suggest that post-LTx employment is constrained by reliance on public insurance and lack of recent work history. In 2014, most US CF patients had some health coverage through government programs (53% of patients 18–25y and 55% of patients 26 and older) [18]. Employed LTx recipients may exceed income limits for government assistance, without earning enough to afford high insurance premiums or medication co-pays. This “transplant trap” previously described by Raiz [19] was corroborated by studies reporting a fear of losing social support benefits as a reason to not seek work after transplantation [6,14,15]. Furthermore, we note that employment in the study cohort was less likely among older and female patients. The gender difference mirrors the lower

employment rate among women in the general CF population [2,3,16].

Our analysis of factors limiting employment in CF patients receiving LTx is constrained by some aspects of the data and methods. Center reports of patients’ employment status were potentially inaccurate and included variation in the timing of follow-ups. While multiple imputation was used to complete missing covariate data, some factors relevant in CF (e.g. bacterial cultures) could not be assessed in this registry. The recently enacted Affordable Care Act (ACA) has expanded the availability of both private and public health insurance in the US [20], which may have reduced reliance on public insurance in more recently transplant cohorts, compared to this group of patients transplanted before ACA enactment. Finally, analysis of long-term employment outcomes after LTx introduces survivorship bias. Freedom from post-transplant complications and morbidity is important for long-term post-transplant survival, although specific indicators of post-transplant morbidity were not associated with employment in this study.

Despite these limitations, our study identifies public insurance use and lack of recent work history at the time of transplantation

Table 2

Multivariable logistic regression model of work participation 5 years after lung transplantation among patients with cystic fibrosis (N = 745).

Variable ^a	OR	95% CI	P
Age	0.96	(0.94, 0.98)	<0.001
Female	0.51	(0.37, 0.70)	<0.001
Recent employment	1.94	(1.23, 3.07)	0.004
Educational attainment			
High school or less	ref.		
Some college	1.08	(0.72, 1.62)	0.713
College degree	1.43	(0.94, 2.18)	0.092
Primary payment			
Private insurance or self-pay	ref.		
Medicaid	0.50	(0.29, 0.86)	0.011
Medicare	0.44	(0.28, 0.68)	<0.001
Other	1.14	(0.55, 2.38)	0.727
MHI quartile of ZIP code			
1 (lowest)	ref.		
2	1.19	(0.63, 2.28)	0.592
3	0.91	(0.50, 1.64)	0.745
4 (highest)	1.26	(0.71, 2.21)	0.428
Diabetes history	1.13	(0.81, 1.56)	0.467
BMI (kg/m ²)	1.04	(0.97, 1.10)	0.285
FEV ₁ (% predicted) ^b	0.84	(0.71, 1.00)	0.051
FVC (% predicted) ^b	1.05	(0.88, 1.25)	0.601
O ₂ requirement (L/min)	0.98	(0.93, 1.03)	0.462
Post-transplant covariates			
Maximal FEV ₁ (% predicted) ^b	1.09	(1.00, 1.19) ^c	0.039
BOS	0.89	(0.44, 1.79)	0.747
Dialysis	0.28	(0.03, 2.72)	0.275
Malignancy	0.70	(0.24, 2.00)	0.507

OR, odds ratio; MHI, median household income (2000 Census Bureau data); BMI, body mass index; FEV₁, forced expiratory volume in 1 s; FVC, forced vital capacity; BOS, bronchiolitis obliterans syndrome.

^a All variables assessed at the time of transplantation, except recent employment (employed at transplantation or at listing), diabetes history (assessed at listing), educational attainment (assessed at listing), and post-transplant covariates (assessed at annual follow-ups up to the fifth anniversary of the transplant). Multiple imputation was used to complete missing data on covariates.

^b Value (% predicted) divided by 10.

^c The 95% CI includes 1.00 when rounded to 2 decimal places. Rounding to 3 decimal places, the OR and 95% CI are 1.092 (1.004, 1.187).

as barriers to post-transplant employment in CF patients. Efforts to improve labor force participation post-LTx should center on protecting continuity of insurance coverage and healthcare access among patients returning to work. Education and social support from integrated healthcare teams will continue to play a vital role in CF patients' care post-LTx.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jcf.2016.07.007>.

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