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Misclassification of occupational disease in lung transplant recipients

David J. Blackley, DrPH[a], **Cara N. Halldin, PhD**[a], **Robert A. Cohen, MD**[a,b], **Kristin J. Cummings, MD**[a], **Eileen Storey, MD**[a], and **A. Scott Laney, PhD**[a]

[a]Respiratory Health Division, National Institute for Occupational Safety and Health, Centers for Disease Control and Prevention, Morgantown, West Virginia, USA

[b]School of Public Health, University of Illinois at Chicago, Chicago, Illinois, USA

Data from the United States Organ Procurement and Transplantation Network (OPTN) registry have been analyzed in recent years to assess post–lung transplant (LT) survival in occupational lung disease patients.[1–3] Registry data include diagnosis codes with limited specificity; each patient is assigned a diagnosis code at waitlist candidacy, at listing, and at LT, and these codes can differ. The use of both numeric and free-text data can produce incompatible or unlikely diagnosis code pairings (such as a numeric code for idiopathic pulmonary fibrosis with a paired free-text entry of “silicosis”). The resulting misclassification could bias findings related to patient characteristics, post-LT survival comparisons and other measures used to summarize outcomes.

Diagnosis codes from OPTN data could be inadequate for case finding and may result in missed occupational lung disease cases. Our objective was to identify and describe adult LT recipients documented as having conditions known to be entirely attributable to occupational exposure, and to calculate the proportion of those patients who were assigned an occupational lung disease diagnosis code at LT.

We requested OPTN data for thoracic transplants performed in the USA during the period January 1987 to December 2014. We queried all observations with both a numeric and free-text entry for “recipient primary diagnosis” (n = 2,742), the final recorded diagnosis for each patient (Figure 1). Free-text entries are specifically requested when Codes 1610 (occupational lung disease: other), 999 (other), 1600 (congenital: other), 1613 (pulmonary fibrosis other) and 1997 (lung disease: other) are entered, and are optional for other diagnosis codes. Two investigators independently reviewed each free-text diagnosis to identify patients with conditions that arise only from occupational exposures,[4] and compared the 2 resulting case lists to assess agreement. Before the comparison, the proportion of specific positive agreement was high (0.989), and if a case was not an unambiguous

Disclosure statement

The authors have no conflicts of interest to disclose. The content is the responsibility of the authors alone and does not necessarily reflect the views of the Department of Health and Human Services, the Centers for Disease Control and Prevention or the National Institute for Occupational Safety and Health (NIOSH). This article was prepared and written by NIOSH employees as part of their employment. The NIOSH institutional review board (IRB) determined this study did not require IRB review (HSRB 16-RDH-NR01), and activities were covered by a signed data use agreement with the United Network for Organ Sharing.

occupational lung disease, then it was excluded. We assigned cases to 7 categories: silicosis; coal workers' pneumoconiosis (CWP); asbestosis; pneumoconiosis not otherwise specified (PNOS); hard metal pneumoconiosis; berylliosis; and a single category to include hypersensitivity pneumonitis with specified work-related cause and other occupational lung diseases. For each occupational lung disease case, we checked the "recipient primary diagnosis" code and calculated the proportion of cases assigned an occupational lung disease–specific diagnosis code. Industry and occupation information is not collected in the OPTN database, but the numeric diagnosis field contains the non-specific code for occupational lung disease (1610) and a separate code for silicosis (448) that was first used in 2002.

We identified 150 patients with an occupational lung disease diagnosis (Table 1); the first LT for one of these patients occurred in 1991. Nearly all recipients (146, 97.3%) were male. Mean age at listing was 54.4 years, mean time on the waitlist was 210 days, and 78 (52.4%) recipients received a bilateral LT. A total of 129 (86%) recipients had silicosis, asbestosis, CWP or PNOS (research suggests this was probably CWP).[5] Private insurance was the primary payer for 73 (49.7%) LTs, Medicare for 41 (27.9%) and other government programs (including Medicaid, Department of Veterans Affairs and other unspecified government agencies and insurance plans) for 31 (21.1%).

Two of 20 (10%) asbestosis patients were assigned an occupational lung disease diagnosis code at LT (Table 2), with the remainder coded as idiopathic pulmonary fibrosis, chronic obstructive pulmonary disease (COPD)/emphysema, other pulmonary fibrosis and other. Six of 21 (29%) hard metal pneumoconiosis, berylliosis and work-related hypersensitivity pneumonitis/other occupational lung disease patients were assigned an occupational diagnosis code. Approximately two thirds of silicosis, CWP and PNOS patients were assigned an occupational diagnosis code (73%, 69% and 65%, respectively). During the period 1991 to 2004, 42% of cases were assigned an occupational code, but this increased to 66% during the subsequent decade ($p = 0.005$).

Although OPTN contains only 2 occupational lung disease diagnosis codes, a total of 10 codes were assigned for the 150 patients in this study. These included: pulmonary veno-occlusive disease (208); fibrocavitary lung disease (302); other—specify (999); primary pulmonary hypertension (1601); cystic fibrosis (1602); idiopathic pulmonary fibrosis/usual interstitial pneumonitis (1604); COPD/emphysema (1607); and pulmonary fibrosis other (1613).

We identified 150 cases of severe occupational lung disease among adults receiving LT in the USA during 1991 to 2014, and found that, although free-text diagnoses specified occupational disease, nearly half were assigned non-occupational diagnostic codes at LT. Among patients in this study, those with silicosis or CWP were more likely to be assigned a numeric code indicating occupational disease. During the last decade, cases identified in a free-text field as occupational were more likely to be assigned an occupational lung disease code at LT; it is possible that, as LTs for these conditions become more common, the system is doing a better job of identifying them.

A substantial number of occupational lung disease cases will be missed if diagnostic codes are the sole variable used for their identification in studies using registry data. If resulting misclassification was random, this failure to identify cases may not alter conclusions, but it could reduce the power needed to detect differences. If it was not random, it could lead to spurious associations or biases in important measures such as post-LT survival. This study had a relatively small sample size and was focused on respiratory diseases caused solely by occupational exposures, but it is likely we underestimated the total number of LTs performed for patients with a work-related contribution to underlying lung disease. We narrowly defined occupational lung disease and did not include conditions possibly related to work, such as ammonia exposure, chlorine gas exposure and traumatic injury. In addition, we did not include patients with free-text diagnoses of conditions that can sometimes arise from occupational exposures, such as COPD. Although we relied on free-text diagnoses to make determinations, it is possible there was misclassification within these fields, and that some patients had more than 1 condition contributing to their need for LT.

This registry contains a wealth of information, but does not collect standardized data on patient industry and occupation. This information would provide clinicians and researchers with tools to better serve patients and the public through more accurate characterization of the burden of severe occupational lung disease, making it possible to design interventions to prevent these diseases from occurring in the first place.

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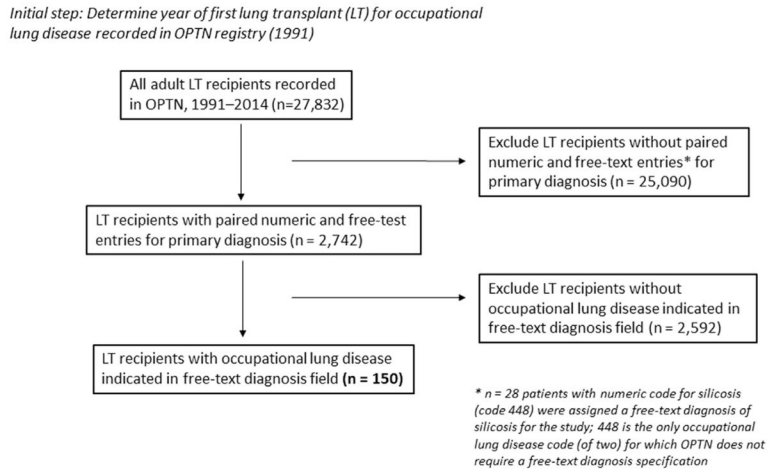

Figure 1.
Flow diagram of exclusion steps for identification of the final sample.

Table 1

Demographics and Clinical Characteristics of Lung Transplant Recipients Determined to Have Occupational Lung Disease (Organ Procurement and Transplantation Network, United States, 1991 to 2014)

Characteristic	Silicosis (*n* = 63)	CWP (*n* = 29)	Asbestosis (*n* = 20)	PNOS (*n* = 17)	Hard metal (*n* = 6)	Berylliosis (*n* = 6)	HP and other (*n* = 9)
Age (years)	51.9 ± 9.6	54.5 ± 5.6	60.0 ± 5.3	57.4 ± 6.2	48.3 ± 8.4	54.8 ± 5.9	57.7 ± 7.1
BMI	24.3 ± 4.3	23.8 ± 4.9	27.3 ± 3.6	27.0 ± 4.7	23.9 ± 4.4	25.7 ± 1.6	26.0 ± 4.3
Creatinine	0.89 ± 0.21	0.91 ± 0.29	0.94 ± 0.18	0.92 ± 0.17	0.84 ± 0.19	0.93 ± 0.22	0.87 ± 0.21
FEV_1 (%)	30.0 ± 12.9	32.5 ± 18.4	47.5 ± 19.7	36.6 ± 20.9	31.3 ± 7.8	51.3 ± 21.6	39.4 ± 16.3
FVC (%)	46.5 ± 18.8	50.2 ± 15.9	49.1 ± 18.5	55.9 ± 19.0	30.7 ± 7.1	54.3 ± 13.9	41.0 ± 14.3
Days on WL	249 ± 266	125 ± 109	201 ± 283	205 ± 212	190 ± 237	132 ± 136	301 ± 283
Ischemic time	5.6 ± 2.2	5.8 ± 2.3	4.2 ± 1.2	6.1 ± 1.7	5.7 ± 0.9	5.6 ± 1.5	4.0 ± 1.1
Bilateral LT	35 (55.6)	15 (51.7)	8 (40.0)	12 (70.6)	2 (33.3)	3 (60.0)	3 (33.3)
Male donor	44 (69.8)	17 (58.6)	13 (65.0)	13 (76.5)	2 (33.3)	5 (83.3)	8 (88.9)
Donor age	33.7 ± 14.3	33.2 ± 13.2	33.1 ± 11.7	32.3 ± 12.0	40.5 ± 11.3	33.3 ± 14.3	31.6 ± 11.6

Data expressed as mean ± standard deviation for continuous variables, or as frequency (%) for counts. BMI, body mass index; CWP, coal workers' pneumoconiosis; FEV_1, forced expiratory volume in 1 second; FVC, forced vital capacity; HP (hypersensitivity pneumonitis) and other include farmer's lung, bagassosis, occupational sulfuric acid inhalation and unspecified occupational lung disease; LT, lung transplant; PNOS, pneumoconiosis not otherwise specified; WL, waitlist.

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Table 2

Free-text Occupational Lung Disease Diagnoses and Assigned Diagnosis Codes at Time of Lung Transplant (Organ Procurement and Transplantation Network, United States, 1991 to 2014)

Free-text diagnosis	Coded as OLD[a]	Not coded as OLD[b]
Silicosis	46 (73.0)	17 (27.0)
CWP	20 (69.0)	9 (31.0)
Asbestosis	2 (10.0)	18 (90.0)
PNOS	11 (64.7)	6 (35.3)
Hard metal	2 (33.3)	4 (66.7)
Berylliosis	2 (33.3)	4 (66.7)
HPs and other	2 (22.2)	7 (77.8)
Column total (%)	85 (56.7)	65 (43.3)

HPs, hypersensitivity; OLD, occupational lung disease; PNOS, pneumoconiosis not otherwise specified.

[a] Includes Code 1610 (occupational lung disease other) and code 448 (silicosis).

[b] Other diagnosis codes include Code 208 (pulmonary veno-occlusive disease), Code 302 (fibrocavitary lung disease), Code 999 (other—specify), Code 1601 (primary pulmonary hypertension), Code 1602 (cystic fibrosis), Code 1604 (idiopathic pulmonary fibrosis/usual interstitial pneumonitis), Code 1607 (chronic obstructive pulmonary disease/emphysema) and Code 1613 (pulmonary fibrosis other specify cause).