Inequity and the Interstitium: Pushing Back on Disparities in Fibrosing Lung Disease in the United States and Canada

If two patients, one poor and one wealthy, have the same fibrosing interstitial lung disease (fILD), could differential access to quality health care determine which one lives and which one dies? A study published in this issue of the Journal suggests that it may—but also that such inequity is not inevitable.

In a provocative analysis in this issue of the Journal, Goobie and colleagues (pp. 459–467) provide the first transnational comparison of outcomes among individuals with this serious progressive condition, which requires multidisciplinary evaluation, expensive therapies, and vigilant monitoring (1–3). They assessed the effects of patients’ socioeconomic status (which they estimated based on a neighborhood-level metric of socioeconomic deprivation) on their outcomes, including mortality, lung transplantation, and lung function. Among U.S. patients with fILD, they identified a striking mortality gap: death rates were 51% higher for those living in the most deprived quartile of neighborhoods relative to those in the least deprived quartile (95% confidence interval, 1.17–1.95). No such disparity was present among Canadians with fILD. While lung transplant rates for all clinical conditions combined showed no consistent socioeconomic gradient in either nation, U.S. patients with idiopathic pulmonary fibrosis (IPF) residing in the most deprived quartile of neighborhoods were 64% less likely to have a lung transplant relative to those in the least deprived neighborhoods—a disparity that was not apparent among Canadians with IPF.

The study is not without limitations. Deprivation was assessed at the neighborhood (not the individual) level, and the type of deprivation score differed in the two nations. Apart from lung transplantation, no metrics of care utilization or quality were assessed. The U.S. cohort was drawn from a single tertiary referral center, with little racial/ethnic diversity, whereas the Canadian cohort was drawn...
from eight registry sites. Differences in the demographics between the two cohorts preclude direct comparisons of transplant and mortality rates in the two countries. Nevertheless, this well-designed study illuminates stark and potentially preventable inequalities in care and outcomes that should concern pulmonologists and policymakers alike.

The analysis was not designed to identify the mechanisms underlying the disparities. However, health system factors are likely candidates. In the 1960s and 1970s, Canadian provinces implemented comprehensive single-payer insurance systems covering all residents, largely without cost barriers (e.g., copays or deductibles); the system was consolidated at the federal level by the Canada Health Act of 1984. The implementation of Canadian Medicare reduced socioeconomic disparities in the use of health care (4) and narrowed inequality in medically preventable mortality between those residing in rich versus poor neighborhoods (5). In the United States, public coverage expansions (notably Medicare and Medicaid [1965] and the Affordable Care Act [2010]) cut the numbers lacking insurance and improved health, yet left some 44 million uninsured (6) and 30 million completely uninsured. Cost-related barriers to care continue to contribute to disparities in health and death in the United States for the general population (7, 8), and likely for those with fILD.

Unequal access to fILD-specific care could explain at least some of the disparate outcomes documented by Goobie and colleagues. For those with IPF, two antifibrotic agents slow lung function loss and may reduce exacerbations and mortality (3); such agents are also beneficial for some patients with non-IPF fILD (2). However, in the United States, only one in four IPF patients have been prescribed these drugs since they were approved in 2014, possibly because their high out-of-pocket costs (an average of >$4,700/yr) make them unaffordable for many (9). Cost-sharing for physician care could also be a barrier: more than 40% of IPF patients in the United States have not seen a pulmonologist (9). Similarly, expensive immunosuppressive medications frequently used in inflammatory fILDs, such as those associated with connective-tissue disease, may be out of reach for many patients. For instance, one quasi-experimental analysis found that an increase in out-of-pocket drug costs led to a ~70% increase in the proportion of Medicare beneficiaries with rheumatoid arthritis who went more than 30 days without filling a prescription for a disease-modifying immunomodulator (10). Access to high-quality care and management of comorbid conditions associated with fILD, including pulmonary hypertension, heart disease, and chronic obstructive pulmonary disease (COPD), may also play a role. Finally, while pulmonary rehabilitation improves exercise tolerance and quality of life among patients with IPF, access barriers likely generate disparities in uptake for this population, as they do among patients with COPD (11, 12).

The socioeconomic gradient in lung transplantation observed by Goobie and colleagues among U.S. patients with IPF also raises concerns about equity in lung transplant referral and evaluation. Their finding is consistent with those from previous studies, including among hospitalized patients with pulmonary fibrosis (13) and individuals with cystic fibrosis on U.S. registries (14, 15). Poor patients may find themselves caught in a catch-22: inability to afford posttransplant care undermines their eligibility for transplantation eligibility, but without a transplant, escape from a respiratory disability may be impossible. For those unable to afford such drugs (and other posttransplant care), it is admittedly true that transplantation could cause more harm than good. However, this begs the question of whether the imposition of cost barriers on such patients is prudent or morally justifiable.

Medical care, of course, is only one determinant of health and often not the most important. The lungs are an internal organ uniquely exposed to our external environment. Socioeconomic (and racial) disparities in pollution exposure might also contribute to differences in outcomes among those with fILD (16). Other exposures that disproportionately impact lower-income individuals (including cigarette smoke, food deserts, and unhealthy workplaces) may also be relevant factors. Future research should elucidate the mechanisms of the disparities observed by Goobie and colleagues, as well as targets for mitigation.

Ensuring equity in care for all patients with fILD is an urgent priority for the pulmonary community. Policy change is needed and should start with the achievement of universal coverage without onerous financial barriers that disproportionately harm chronically ill patients. Additionally, we need to advocate for more equitable and just care of patients with chronic lung disease within our own institutions. The outcomes of patients diagnosed with fILD must not be determined by their wealth.

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Adam W. Gaffney, M.D., M.P.H.
Harvard Medical School
Boston, Massachusetts
and
Division of Pulmonary and Critical Care Medicine
Cambridge Health Alliance
Cambridge, Massachusetts

Anna J. Podolanczuk, M.D., M.S.
Division of Pulmonary and Critical Care Medicine
Weill Cornell Medical College
New York, New York

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