Health disparities and associated social determinants of health in interstitial lung disease: a narrative review

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Shareable abstract (@ERSpublications)
People with ILD have disparities in access to antifibrotic medications, clinical trials and lung transplantation, related to individual (age, gender, race) and societal factors. Addressing the root causes are key to reducing the disparities. https://bit.ly/4gK0wgi

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Abstract

Background Health disparities are prevalent across respiratory diseases. Social determinants of health are closely associated with health disparities and account for between 30% and 55% of all health outcomes. In people with interstitial lung disease (ILD), disparities have the potential to significantly impact access to care and health outcomes along many stages of the disease journey.

Aim This review aimed to provide an overview of health disparities in ILD, focusing on the determinants of health and access to care from diagnosis to end of life and to report on some approaches being proposed to address these disparities.

Methods A narrative review of the literature was undertaken using three electronic databases (Ovid Embase, Medline and CINAHL) from inception to May 2024. Disparities and social determinants were mapped to the domains of the Dahlgren–Whitehead model of social determinants of health.

Results A total of 31 studies were eligible for inclusion. Common disparities identified included differences in antifibrotic utilisation, representation in clinical trials, access to ILD care and lung transplantation waiting lists. Associated social determinants included race/ethnicity, gender, geography and socioeconomic status. Paradoxically, telehealth technology and utilisation have the potential to improve access to diagnostic and treatment options for marginalised communities but may exacerbate disparities for those with lower digital literacy and access.

Conclusion Reducing health disparities in ILD will require an awareness and understanding of the root cause of the disparities at both the individual and societal level in order to develop effective interventions that improve access to care for all living with ILD.

Introduction

The World Health Organization (WHO) defines health inequities as "differences in health status or in the distribution of health resources between different population groups, arising from social conditions in which people are born, grow, live, work and age". Such inequities have significant social and economic costs to both individuals and societies. Health disparities are closely correlated with social determinants of health, defined as nonmedical factors that influence disease outcomes and that account for between 30% and 55% of health outcomes [1].

Disparities may arise due to factors including individual characteristics such as gender, race/ethnicity, socioeconomic status (including education, income and insurance status), type of chronic illness, individual choices as well as geographic residence. Disparities can also be related to healthcare systems (*e.g.* healthcare access and quality of healthcare providers) as well as environmental factors (*e.g.* air quality, residential environment and occupational exposures) [2].

Health disparities are prevalent across respiratory diseases and are associated with significant morbidity and mortality, especially among disadvantaged groups [3]. Variations in respiratory health are associated with causal and exacerbation factors such as smoking, air quality, environmental hazard exposure and influenza vaccination coverage [2, 3]. Reviews of health disparities in respiratory health have generally focused on diseases such as COPD and asthma and have reported on the social, behavioural and environmental determinants of respiratory health that include race/ethnicity, socioeconomic status, environmental exposures (*e.g.* smoking, air quality) and access to healthcare and medications [3–5]. However, a multifaceted overview of disparities associated with interstitial lung disease (ILD) has not as yet been conducted.

ILDs comprise over 200 progressive conditions that require multidisciplinary evaluation, expensive therapies and vigilant monitoring. The ILD journey is fraught with various stages where disparities have the potential to impact health outcomes. Diagnosis is often a protracted journey with a timely and accurate diagnosis representing a critically important opportunity to improve patient management, prognosis and outcomes [6]. Lung transplantation is the only "cure", but access and eligibility is limited to a selected minority. Treatment options such as antifibrotics, pulmonary rehabilitation, oxygen therapy and palliative care have the potential to delay progression and provide symptom relief. However, variability in access to such therapies associated with social determinants such as race/ethnicity, gender, geographic location, socioeconomic status and personal preference has led to the development of significant disparities for people with ILD especially in disadvantaged populations [7, 8].

Addressing the disparities in ILD care requires an awareness and understanding of the disparities themselves, the groups most vulnerable to the disparities and the contributing factors that are most amenable to interventions [3]. Raising awareness is a key first step in developing effective translational interventions tailored to address the complex interactions between the multiple drivers of disparity and policies targeted at addressing the barriers to more equitable healthcare. The Dahlgren–Whitehead model of social determinants of health is a socioecological model developed to assist in understanding and conceptualising determinants of health inequities [9]. In this model, the determinants of health and potential policy interventions are organised on five hierarchical levels. These are, in descending order, 1) general socioeconomic, cultural and environmental conditions, 2) living and working conditions, 3) social and community networks, 4) individual lifestyle factors, and 5) age, sex and constitutional factors, with the latter being individual-level stable characteristics. On these levels, so-called "positive health factors", "protective factors" and "risk factors" are assumed to influence health [10].

Thus, this narrative review aimed to provide an overview of health disparities related to ILD based on currently available literature. Specifically, the review focused on identifying the determinants of health associated with ILD care-related disparities, from diagnosis to end-of-life care, and highlights opportunities to address inequity in ILD care and outcomes.

Methods

For this narrative review, we conducted systematic searches of the literature using three electronic databases (Ovid Embase, Medline and CINAHL) from inception to May 2024. Keywords included "interstitial lung disease", "pulmonary fibrosis", "idiopathic pulmonary fibrosis", "progressive fibrotic interstitial lung disease", "healthcare disparities", "geographic disparities", "environmental pollution", "antifibrotics", "clinical trials" and "lung transplantation". In addition, reference lists from eligible studies were also reviewed for any additional relevant publications.

In order to be as far-reaching and comprehensive as possible, our inclusion criteria were kept quite broad to include any study design as well as research papers, conference abstracts and editorials. In addition, we did not limit our search to publications published only in English. However, only studies that focused on disparities (*i.e.* included the terms disparities/equity or associated terms in the title, abstract or other sections of the paper) were selected for final inclusion.

Data extraction items included author list, publication year, country, title, study design, source of population, time frame of data collection, ILD type, description of participants, comparative groups, outcomes, results and conclusions. Social determinants of health that contributed to health disparities were mapped to the domains of the Dahlgren–Whitehead model [11].

Results

A total of 308 studies were identified from the literature review. Following screening and full-text review by one reviewer (G.T.) in consultation with second reviewer (A.E.H.), a total of 31 studies were included (figure 1). Studies were predominantly retrospective cohort studies that utilised data from the USA with

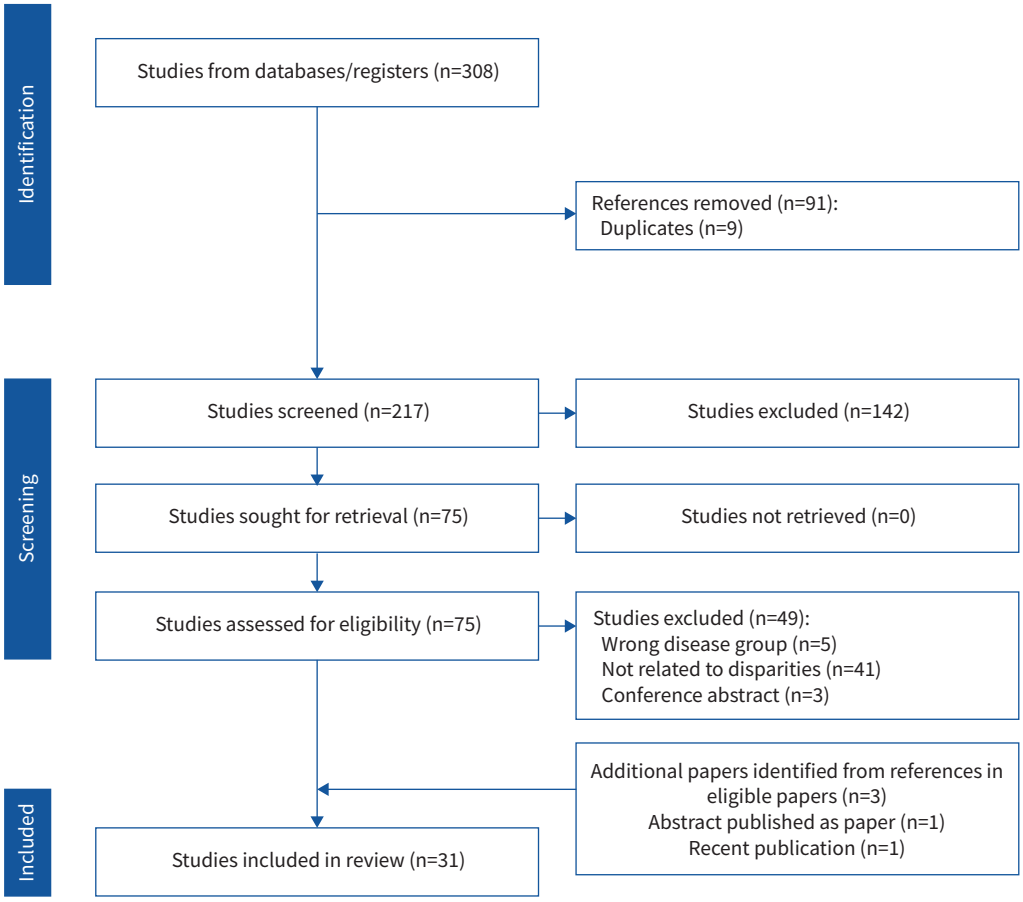

FIGURE 1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.

35% (n=11) reporting on findings using data from a national registry. The review did not identify any interventional studies aimed at reducing disparities. Idiopathic pulmonary fibrosis (IPF) was the sole focus of 42% (n=13) of studies whilst the remaining 58% (n=18) reported on various types of ILDs (including IPF, fibrotic ILD and connective tissue disease-ILD). Year of publication ranged from 2006 to 2024 with the majority (57%) being published in the last 2 years and 48% focusing specifically on assessing disparities (based on title) (table 1 and supplementary file 1).

The review identified a number of health disparities associated with ILD, such as differences in antifibrotic utilisation, representation in clinical trials, access to ILD care and transplantation waiting lists, and survival post-transplant (table 2 and figure 2). These disparities were driven by social determinants of health that included race/ethnicity, gender, geography, socioeconomic status, end-of-life care and utilisation of telemedicine.

In addition, we included studies that comparatively evaluated both ILD and non-ILD entities such as ILD and lung cancer [19] and ILD and stroke [31]. These studies highlight the disparities in care, particularly in palliative care for people with chronic lung diseases such as ILD. This is despite ILD having a longer disease duration and high morbidity and mortality rates that are comparable, if not higher, to those of advanced cancer and stroke patients [19, 31].

Antifibrotic utilisation

Six studies reported on disparities in antifibrotic utilisation (figure 2a), using USA-based data in IPF. Disparities in utilisation of antifibrotics for IPF were based on a number of social determinants of health such as race/ethnicity [14, 30, 43], gender [30], geographic residence (urban *versus* rural) [24, 30] and socioeconomic status [8, 23]. Overall, Black/African American patients were less likely than White and Hispanic patients to be on antifibrotics, but just as likely as Asian patients. However, Hispanic patients were more likely to be on antifibrotics compared to Asian patients. In a study of 14 792 veterans in the USA,

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TABLE 1 Summary of the 31 papers included in the review

First author, publication year	Country	Study design	Source of population	Time	ILD sub-type	Participants	Groups	Reported outcomes
Adegunsoye [12] 2018	USA	Retrospective cohort	Five US hospitals	2000–2016	ILD: IPF, CHP, IPAF, CTD-ILD, unclassifiable	1640 participants: Black patients: 222 White patients: 1251# Hispanic patients: 92# Asian patients: 75#	African American (non-Hispanic black) patients Non-African American patients (non-Hispanic White, non-Hispanic Asian and Hispanic) patients	All-cause mortality All-cause hospitalisation
Adegunsoye [13] 2022	USA	Scientific letter	NA	NA	PF	Black populations	Black patients Other racial and ethnic groups	Access to HRCT Treatment options Lung transplantation
Adegunsoye [14] 2023	USA	Retrospective audit	Pulmonary Fibrosis Foundation Registry External multi-centre validation cohort	2003–2021	PF: IPF, CTD-ILD, fHP, unclassifiable	4792 participants	Hispanic patients Non-Hispanic patients Black patients Non-Hispanic White patients	All-cause mortality Hospitalisation Lung transplant Death
Adegunsoye [15] 2024	USA	Retrospective audit	Pulmonary Fibrosis Foundation Patient Registry	March 2016–December 2019	ILD: IPF, IIP (non-IPF); CTD-ILD; HP, other ILDs	1882 participants	Equations from Hankinson *et al.* [16] for FVC % predicted, Quanjer *et al.* [17] and Bowerman *et al.* [18]	Clinical trial eligibility Antifibrotic eligibility Lung transplant referral eligibility
Ahmadi [19] 2016	Sweden	National registry-based cohort	National registry Swedish Registry of Palliative Care	2011–2013	Patients starting long-term oxygen therapy for physician-diagnosed ILD	285 patients with ILD 10822 patients with lung cancer	Oxygen-dependent ILD Deaths from lung cancer	End-of-life symptom assessments
Assayag [20] 2020	UK	Case review	ILD unit of the Royal Brompton and Harefield NHS Foundation Trust	January 2010–October 2010	IPF, CTD-ILD, HP	60 patients	Diagnosis of IPF based on gender	Diagnosis of IPF based on gender Diagnostic confidence Mortality/prognostic indicator based on gender
Assayag [21] 2021	Canada	National registry	Canadian Registry for Pulmonary Fibrosis	July 2005	ILD of any type	646 ILD 979 CTD-ILD 178 HP 492 unclassifiable ILD 357 other ILDs	ILD subtypes	Medication use: antifibrotics, immunosuppressants Time to treatment initiation

Continued

TABLE 1 Continued

First author, publication year	Country	Study design	Source of population	Time	ILD sub-type	Participants	Groups	Reported outcomes
Assayag [22] 2023	USA/ Canada/ Australasia	Observational study	CARE-PF (November 2020) UChicago (May 2021) AILDR (October 2021)	November 2020–October 2021 for data extraction	IPF, CTD-ILD (including interstitial pneumonia with autoimmune features), HP, unclassifiable ILD	4572 total patients: 3060 from CARE-PF 1046 from UChicago 466 from AILDR	Self-identified CARE-PF: White, Black or African-American, Indigenous Pacific Islander and Alaskan native, Asian patients UChicago: White, Black or African-American, American Indian or Alaska Native, Asian and Native Hawaiian or other pacific islander patients Ethnicity: Hispanic or not Hispanic AILDR: White, Black or African, Indigenous, Asian patients	ILD treatment initiation
Avitzur [23] 2022	USA	Retrospective cohort	ILD programme database at UCSF	2001–2017	IPF	603 total participants	Residential addresses geocoded and linked to CES based on pollution burden, SE indicators, sensitive population indicators (low BW, asthma, CVD)	Higher CES defined as greater disadvantage Baseline lung function Baseline antifibrotic use
DeDent [24] 2022	USA	Research letter	IPF living in California who were seen at the UCSF ILD clinic	2001–2020	IPF	843 total participants	Rural, medium/small metro, large fringe metro (suburban), large central metro (inner cities)	FVC % pred D_{LCO} % pred Mortality
DeDent [25] 2024	USA	Retrospective study	Participants with IPF were identified from the UCSF ILD cohort	2001–2020	IPF	783 total participants	HPI Geocoded home addresses matched to Californian HPI Higher HPI indicates greater advantage	FVC % pred D_{LCO} % pred Mortality
Espinosa [26] 2022	USA	Retrospective cohort Narrative review	Nationwide inpatient database of hospitalisations for IPF	NA	IPF	148 000 total participants	IPF patients with Medicaid, no insurance, SES	Insurance status Lung transplant
Furfaro [27] 2021	USA	Retrospective cohort	Waiting list candidates requiring ECMO support as bridge to lung transplantation in USA	June 2015	Waiting list for lung transplant and receiving ECMO: PAH, IPF, CF, ILD	1064 total participants 74% had ILD	Group A: obstructive diseases, *e.g.* COPD Group B: PAH Group C: CF Group D: IPF and ILD	Transplantation rate Post-transplant survival LAS at time of waitlist removal Risk of death or removal from waitlist due to deterioration

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TABLE 1 Continued

First author, publication year	Country	Study design	Source of population	Time	ILD sub-type	Participants	Groups	Reported outcomes
Gaffney [28] 2018	USA	Retrospective cross-sectional	Adults hospitalised with IPF	1998 and 2011 using ICD-9 codes	IPF	148 877 hospitalisations	Insurance status: 1) Non-Medicaid (private insurance) 2) Medicaid (means-tested for low income) 3) Uninsured (self-pay or no charge) SES: median income of ZIP code	Lung transplantation during hospitalisation Death without transplant among nontransplanted Discharge to rehabilitation facility Thoracic lung biopsy
Gaffney [8] 2022	USA Canada	Editorial on Goobie *et al.* [7]	US (single tertiary referral centre with little racial/ethnic diversity) and Canada (eight registry sites)	NA	Fibrosing ILD	NA	NA	SES (neighbourhood level metric of SE deprivation) Mortality Lung transplant Lung function
Goobie [7] 2022	USA Canada	Retrospective cohort	One US registry site Eight Canadian ILD registry sites	Canadian: 2015–2021 US: 2000–2021	Canadian: fILD (IPF, CHP, CTD-ILD) US: PF	1372 from US site 3357 from Canadian sites	Canadian registry sites US registry site	Survival Lung transplantation Lung function: FVC, D_{LCO}
Johannson [29] 2022	Canada	Retrospective cohort	Canadian registry for PF	2016–2017	Fibrotic ILD: IPF, CTD-ILD, non-IPF IIP, fibrotic HP, unclassifiable ILD	1162 patients 856 lived near to ILD clinic 306 lived far from ILD clinic	Travel distance Six-digit postal codes Geocoding of addresses Near defined as ⩽70 km Far defined as >70 km from clinic	Distance and changes in FVC% over 3 years after initial assessment Distance and time to death or lung transplant Distance and death alone within 5 years
Kaul [30] 2023	USA	Retrospective cohort	VA Healthcare system	2014–2019	IPF	16 034 veterans newly diagnosed with IPF	Veterans with IPF enrolled in VA Healthcare system	Utilisation of pirfenidone, nintedanib Characteristics: age, sex, race, ethnicity, rural *versus* urban, comorbidities, VA medical facility
Khan [31] 2022	USA	Observational study	Johns Hopkins Bayview Medical Center	February–August 2020	ILD	166 patients with prior stroke and cerebrovascular disease 256 patients with ILD	Telemedicine: Virtual video consultations In-person consultations	Reported care quality Reported patient satisfaction

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TABLE 1 Continued

First author, publication year	Country	Study design	Source of population	Time	ILD sub-type	Participants	Groups	Reported outcomes
Kourliouros [32] 2019	UK	Retrospective cohort	UK Transplant Registry held by NHS Blood and Transplant	2004–2014	COPD PF CF Other lung pathologies	2213 patient registrations: 28% COPD 26% PF 25% CF 20% other lung pathologies	Pre-transplant Post-transplant	1-year survival from registration Time to transplant Time to death on transplant list 1-year post-transplant survival 3-year post-registration Blood group Height
Jalbert [33] 2022	North America Europe Asia Australia	Systematic review and meta-analysis Research letter	NA	Searched on 20 April 2021	IPF	37 studies in meta-analysis: 23 RCTs of IPF treatment 14 prospective registry studies	Gender Race/ethnicity	Representation of patient race or gender in clinical studies of IPF
Lederer [34] 2006	USA	Retrospective cohort	Nationwide cohort of wait-listed patients with IPF on the United Network for Organ Sharing	1995–2003	IPF	2635 patients with IPF listed for lung transplantation at 94 transplant centres in US	Black patients Hispanic patients Non-Hispanic patients White patients	Transplantation Survival
Lederer [35] 2006	USA	Retrospective cohort	New York Presbyterian Hospital Lung Transplant Program	2000–2004	IPF	91 IPF patients evaluated for lung transplantation	Black/Hispanic patients White/Asian patients	Survival time following referral for lung transplantation
Mageto [36] 2023	USA	Invited commentary on equity, diversity and inclusion	Paper by Adegunsoye *et al.* [14]	March 2023	PF: CTD-ILD, IPF, fibrotic HP	1904 patients from the Pulmonary Fibrosis Foundation's extensive database of patients with PF from across the US	NA	Disparities based on race, age, ethnicity Antifibrotic utilisation
McVeigh [37] 2018	Ireland	Qualitative study	Two rural and two urban sites in Ireland	2012– 2013	COPD (12) ILD (4) Bronchiectasis (1)	17 bereaved carers 3–18 months since death of patient 18 healthcare professionals	NA	Carers: IPF themes Lack of preparedness for death Lack of consistency in palliative care delivery Role ambiguity
Mooney [38] 2018	USA	Retrospective cohort study	SRTR	On waiting list between May 2005 and March 2015	Group A: COPD Group B: PH Group C: CF Group D: PF	20 684 lung transplant candidates	White Black Asian Hispanic	Waiting list access Waiting list mortality

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TABLE 1 Continued

First author, publication year	Country	Study design	Source of population	Time	ILD sub-type	Participants	Groups	Reported outcomes
Mooney [39] 2019	USA	Discrete event micro-simulation model study	SRTR	On waiting list and all deceased donors between July 2009 and June 2011	Group A: COPD Group B: PH Group C: CF Group D: PF	6538 listed for lung transplant 3502 under 500 miles 3499 under 1000 miles	Historic cohort Donor service area-based model 500-mile lung-sharing model 1000-mile lung-sharing model	Waiting list deaths Mortality rates Transplants
Shankar [40] 2024	England	Retrospective cohort study	British Thoracic Society ILD registry	February 2013–June 2021	IPF	2359	SES (social deprivation measured by index of multiple deprivation) Distance to hospital Time to referral	Overall survival Clinical service-related outcomes: time to diagnosis provision of healthcare resources (oxygen therapy, pulmonary rehabilitation, antifibrotic therapy)
Swaminathan [41] 2022	USA	Retrospective registry cohort	Idiopathic Pulmonary Fibrosis Prospective Outcomes Registry	June 2014–October 2018	IPF	955 patients from 48 centres included: 96 lung transplant and 221 deaths during study period		Lung transplant Death
Swigris [42] 2012	USA	Retrospective cohort	US death certificates compiled by National Center for Health Statistics	Deaths from 1989 to 2007	IPF	38 883 187 US death records 251 058 decedents with IPF whose ethnicity/race was known	White patients Black patients Hispanic patients Others	IPF at time death Age Gender
Zhao [43] 2023	USA	Retrospective cohort	TriNetX Research Network, a global health research network containing millions of patients De-identified data from more than 120 healthcare organisations	June 2023	IPF	47 184 patients with IPF: 74% white 11% Black 13% Hispanic 3% Asian 1% American Indian/ Alaska native 11% unknown	Nintedanib Pirfenidone	Antifibrotic use Lower lung function (FVC <3 L) 3-year mortality <65 years *versus* ⩾65 years

[#]: Comprising non-African American patients. AILDR: Australasian ILD registry; BW: birthweight; CARE-PF: Canadian Registry for Pulmonary Fibrosis; CES: CalEnviroScreen; CHP: chronic hypersensitivity pneumonitis; CF: cystic fibrosis; CTD-ILD connective tissue disease related interstitial lung disease; CVD: cardiovascular disease; D_{LCO}: diffusing capacity of the lungs for carbon monoxide; ECMO: extracorporeal membrane oxygenation; fHP: fibrosing hypersensitivity pneumonitis; FVC: forced vital capacity; HP: hypersensitivity pneumonitis; HPI: Healthy Places Index; HRCT: high-resolution computed tomography; ICD-9: International Classification of Diseases, Ninth Revision; IIP: idiopathic interstitial pneumonia; ILD interstitial lung disease; IPAF interstitial pneumonia with autoimmune features; IPF idiopathic pulmonary fibrosis; fILD: fibrosing interstitial lung disease; NA: not applicable/available; PAH pulmonary arterial hypertension; LAS: lung allocation score; PF pulmonary fibrosis; RCT: randomised controlled trial; SE: socioeconomic; SES: socioeconomic status; SRTR: Scientific Registry of Transplant Recipients; UChicago: University of Chicago ILD registry; UCSF: University of California, San Francisco; VA: Veteran Affairs; ZIP: zone improvement plan.

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TABLE 2 Summary of disparities, social determinants and outcomes associated with interstitial lung disease (ILD)

Disparity	Social determinant	ILD type	Outcome	Reference
Antifibrotic utilisation	Race/ethnicity	IPF (veterans USA)	Black patients/African American patients *versus* White patients less likely to be on antifibrotics 4.6% Black/African American patients *versus* 85.2% White veterans with IPF Black/African American patients *versus* White patients: adjusted[#] OR 0.60 (95% CI 0.49–0.73)	[30]
			The proportion of patients treated with antifibrotic therapy was significantly higher among Hispanic patients (26.6%) and White patients (38.6%), compared to Black patients (8.6%)	[14]
		IPF (veterans USA)	6.2% Black patients *versus* 11.4% White patients (p<0.001) 10.8% Black patients *versus* 20.2% Hispanic patients (p<0.001) 14.7% Black patients *versus* 9.6% Asian patients (p<0.001) 21.1% Hispanic patients *versus* 16.3% Asian patients	[43]
		ILD: IPF, IIP, CTD-ILD, HP	Compared to equations from Bowerman *et al*. [18] and Hankinson *et al.* [16], ILD clinical trial eligibility was misclassified in 22% of Black patients, 14% of Hispanic/Latin American patients and 12% of White patients Antifibrotic eligibility was misclassified in 21% of Black patients, 17% of Hispanic/Latin American patients and 19% of White patients Lung transplant referral eligibility was misclassified in 6% of Black patients, 14% of Hispanic/Latin American patients and 12% of White patients Similar trends observed when comparing equations from Quanjer *et al*. [17] and Hankinson *et al.* [16]	[15]
	Urban/rural	IPF (veterans USA)	Rural *versus* urban residents less likely to utilise antifibrotics	[43]
			Rural (10.0%) *versus* inner city (21.3%) *versus* suburban (25.7%) *versus* small metro (14.3%)	[24]
			Rural OR 0.88 (95% CI 0.80–0.97) compared to urban	[29]
	Gender	IPF (veterans USA)	Females *versus* males less likely to utilise antifibrotics Adjusted[#] OR 0.41 (95% CI 0.27–0.63)	[30]
	Mortality rate	IPF	Lower 3-year mortality rate for White patients with IPF on antifibrotics *versus* White patients not on antifibrotics 26.5% *versus* 29.7%; p<0.001 No mortality differences observed among Hispanic, Asian or Black individuals treated or not treated with antifibrotics	[43]
	SES: geocoded residential addresses linked to CalEnviroScreen	fILD	Greater relative disadvantage, less likely to be on antifibrotics at time referred to ILD centre Highest population vulnerability quartile *versus* lowest quartile OR 0.33; 95% CI 0.18–0.60; p=0.001	[23]
		SES: area deprivation index in USA and Canadian Index of Multiple Deprivation	High out-of-pocket costs for antifibrotics in the USA make them unaffordable for many In the USA, only one in four IPF patients have been prescribed these drugs since they were approved in 2014, possibly due to the high out-of-pocket costs (an average of USD 4700 per year) making them unaffordable for many	[44, 45]

Continued

TABLE 2 Continued

Disparity	Social determinant	ILD type	Outcome	Reference
Representation in clinical studies (RCTs and observational prospective registry studies)	Race/ethnicity	IPF	Non-White subjects under-represented in clinical studies of IPF Proportion of non-White participants: North America 7% (95% CI 5–9%), Europe 17% (95% CI 15–20%), international studies that included Asia or Australia 23% (95% CI 18–29%) Pooled proportion of non-White individuals: 14% (range 3–32%) with no significant difference between RCTs and registry studies Race is frequently under-reported by researchers and unpublished especially in registry studies (83% of RCTs, 29% registry studies)	[33, 36]
Lung transplantation	Race/ethnicity	IPF	Prevalence of lung transplantation lower in Black patients but similar in Hispanic and White patients: 39% of Black patients, 47% of Hispanic patients and 46% of White patients Black and Hispanic patients more likely to undergo double transplant	[34, 41]
			Hispanic and Black minority patients *versus* non-Hispanic White and Asian patients less likely to be listed for lung transplantation	[26]
			Black patients youngest at time of lung transplantation *versus* Hispanic and White patients Mean±SD age: Black patients 58.6±8.6 years; Hispanic patients 60.5±6.1 years and White patients 66.9±6.7 years; p<0.001	[14]
		IPF, CTD-ILD, fHP	Wait list mortality Adjusted mortality rate higher among non-Hispanic Black and Hispanic patients *versus* non-Hispanic White patients with IPF listed for lung transplant Non-Hispanic Black patients: HR 1.24, 95% CI 1.05–1.46, p=0.01 Hispanic patients: HR 1.28, 95% CI 1.08–1.56, p=0.01 Independent of age, gender, BMI, medical comorbidities, insurance and SES Additional adjusted for FVC % pred: no longer significant Black patients: HR 1.16, 95% CI 0.98–1.36, p=0.09 Hispanic patients: HR 1.21, 95% CI 0.99–1.98, p=0.056 Unadjusted model: *versus* non-Hispanic White patients: Non-Hispanic Black patients: HR 1.31, 95% CI 1.17–1.47 Hispanic patients: HR 1.61, 95% CI 1.41–1.83 Asian patients: HR 1.54, 95% CI 1.20–1.98 Fully adjusted model[§]: Non-Hispanic Black patients: HR 1.05, 95% CI 0.93–1.18 Hispanic patients: HR 1.02, 95% CI 0.88–1.18 Asian patients: HR 0.90, 95% CI 0.70–1.16	[35]

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TABLE 2 Continued

Disparity	Social determinant	ILD type	Outcome	Reference
			Illness severity at transplant listing Black patients *versus* White, Asian, Hispanic patients: Younger (52 years *versus* 61, 60, 58 years) Lower FVC % pred in Black patients (43 *versus* 47, but similar to Asian and Hispanic patients 40, 40) 6MWD lower in Black patients *versus* White patients (720 m *versus* 835 m) but higher than Asian and Hispanic patients (690 and 650 m, respectively) Lower LAS than White, Asian and Hispanic patients (39.8 *versus* 41.4, 43.9, 43.3) No difference in risk-adjusted waitlist mortality by race/ethnicity	[38]
			Black and Hispanic patients had greater severity of disease at time of listing	[41]
			Adjusted waitlist access to transplant was lower in non-White patients Non-Hispanic Black patients: HR 0.88, 95% CI 0.83–0.94 Hispanic patients: HR 0.87, 95% CI 0.81–0.94 Asian patients: HR 0.83, 95% CI 0.73–0.96	[38]
			People with PF (49%) had lowest number of transplants and highest waiting list mortality compared to those with COPD (79%), CF (62%) or other lung pathologies (61%)	[32]
			In addition, patients with pulmonary arterial hypertension bridging to transplant on ECMO had lower transplant rates than other lung conditions such as ILD or CF	[27]
			US patients with IPF residing in most deprived quartile of neighbourhoods 64% less likely to have lung transplant *versus* least deprived Such disparity not seen in Canadian cohort	[8, 28]
	SES: neighbourhood-level metric of SE deprivation	COPD, CF, other lung pathologies	Patients with IPF who have access to lung transplant centre and live in more affluent area have higher probability of receiving lung transplant Lung transplant: HR 1.22 (95% CI 1.13–1.31) per USD 10 000 increase Death: HR 0.99 (95% CI 0.94–1.04) per USD 10 000 increase Access to centre with lung transplant programme: HR 4.31 (95% CI 1.76–10.54)	[41]
			Lower SES (median ZIP code income) less likely to undergo transplant OR for lowest *versus* highest income quartile: 0.46, 95% CI 0.32–0.66 Non-White patients had lower probability of lung transplantation in both US and Canadian cohorts based on area deprivation index levels	[28]

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TABLE 2 Continued

Disparity	Social determinant	ILD type	Outcome	Reference
	Insurance status: 1) Non-Medicaid - private insurance 2) Medicaid (means-tested for low-income patients) 3) Uninsured: self pay or no charge	fILD	Medicaid, uninsured and patients of lower SES less likely to receive transplant	[7]
			Adjusted[¶] OR for Medicaid (OR 0.30, 95% CI 0.16–0.57) or no insurance (OR 0.22, 95% CI 0.07–0.72) were less likely to result in a lung transplantation compared to hospitalisations of those with non-Medicaid insurance	[28]
			Medicaid or no insurance patients less likely to be discharged to rehabilitation facility Medicaid: OR 0.46, 95% CI 0.35–0.60 No insurance: OR 0.52, 95% CI 0.35–0.77	[7]
			Longer distance to lung transplant programme associated with decreased likelihood of lung transplant but not death HR 0.96 (95% CI 0.92–0.99) per 10-mile increase for lung transplant HR 1.02 (95% CI 0.97–1.07) per 10-mile increase for death	[41]
			Residing longer distance from ILD clinic associated with greater risk of death or lung transplant compared to those residing closer HR for adjusted models[+] 1.52, 95% CI 1.10–2.11 Finding was predominantly driven by patients with CTD-ILD; HR 2.14 (95% CI 1.16–3.94)	[29]
	Geographic – travel and distance from ILD specialist centre	IPF	Broader geographic sharing of lung donors associated with decreased waitlist mortality in all disease groups Waitlist mortality rate (median deaths (IQR), per 100 waitlist-years): Donor service area: 17.1 (16.8–17.3) 500-mile lung sharing 12.9 (12.7–13.1) 1000- mile lung sharing 11.0 (10.9–11.1) Greatest difference in waitlist mortality was seen in PF candidates Decrease in regional waitlist mortality *versus* donor service area-based allocation policy 0.1–7.1 deaths per 100 waitlist-years with 500-mile lung sharing 3.3–9.2 deaths per 100 waitlist-years with 1000-mile lung sharing	[39]
	Geographic sharing of lung donors		Small magnitude in predicted post-transplant survival	

Continued

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TABLE 2 Continued

Disparity	Social determinant	ILD type	Outcome	Reference
Access to ILD care	Geographic location: rural *versus* suburban	IPF	Rural patients present to specialist care with worse disease severity Higher proportion presenting with dyspnoea Rural 56% *versus* large central metro 87%; p=0.014 Higher frequency of reported oxygen use (rural 34.5% *versus* large central metro 16.1%); p=0.016 Lower pulmonary function: FVC % pred (rural mean 66.6±19.1 *versus* 70.0±18.3); p=0.11 D_{LCO} % pred (rural mean 43.4±15.4 *versus* 18.9±19.1); p<0.001 Highest rate not insured Median (IQR): rural 12.3 (7.5–16.7) *versus* large central metro 5.7 (2.6–10.1); p⩽0.001 Highest level of high school graduates Rural mean±SD: 24.3±7.1 *versus* large central metro 14.4±8.5; p<0.001	[24]
	Travel distance to sub-speciality clinic Near at ⩽70 km Far >70km	IPF, CTD-ILD, non-IPF IIP, fHP, unclassifiable ILD	ILD patients closer to ILD clinic had significantly lower mean 6MWD at presentation compared to those farther away Closer (mean±SD) 386±120 *versus* farther 419±123; p=0.004 More likely to be female 56% farther *versus* 49% closer; ever-smokers 69% farther *versus* 61% closer in overall cohort and in CTD-ILD Patients with ILD travelling longer distance had less severe disease but were at greater risk of death or lung transplant *versus* those living closer to an ILD clinic Adjusted[f] HR 1.52 (95% CI 1.10–2.11)	[29]
	LTOT for ILD *versus* patients on Swedish Registry of Palliative Care and died from lung cancer	ILD *versus* lung cancer	ILD *versus* cancer patients had underutilised palliative care services Survival from start of LTOT for ILD median 8.4 months (IQR 3.4–19.2 months) Deaths in ILD more likely unexpected (15% *versus* 4%; p<0.001) and less likely in palliative care setting (41% *versus* 59%) In ILD patients, there were fewer EOL discussions with patients (41% *versus* 59%; p<0.001) and families (52% *versus* 73%; p<0.001) Fewer consultations with palliative care team (6% *versus* 19%; p>0.05) Lower rates of complete relief from breathlessness (17% *versus* 33%; p<0.001) Less frequently prescribed medications at EOL for death rattle (77% *versus* 88%; p<0.001), pain (83% *versus* 96%; p=0.001), anxiety (79% *versus* 91%; p<0.00)	[19]
	Geographic location	ILD, COPD, bronchiectasis	Provision of palliative care can be influenced by geographic location Rural areas less resourced Lack of availability of generalist and specialist care services in primary care settings	[37]

Continued

TABLE 2 Continued

Disparity	Social determinant	ILD type	Outcome	Reference
	Socioeconomic: geocoded home addresses matched to Healthy Places Index: included eight domains of social determinants of health	IPF	Disadvantaged neighbourhoods associated with worse pulmonary function and increased mortality More disadvantaged neighbourhoods, people presented at ILD care centre with worse disease severity (HR 1.14, adjusted 95% CI 0.55–1.72; p>0.001) This was mainly driven by social factors Living in disadvantage areas increased the risk of death only in those with normal to mildly impaired lung function: FVC % predicted values >70% at presentation, quartile 1 *versus* quartile 4 associated with 82% increase in mortality risk (HR 1.82, 95% CI 1.21–2.74)	[25]
	Race/ethnicity	PF	Black patients are generally less likely to receive diagnostic medical imaging, especially CT scans and experience a delay in diagnosis compared to other racial and ethnic groups	[14, 46]
		IPF, CTD-ILD	Initiation of ILD treatment earlier in White patients compared to non-White patients and men compared to women	[13, 22]
	Virtual *versus* in-person	ILD *versus* stroke	Telemedicine participants more likely to be White, more affluent and a woman regardless of clinical diagnosis Virtual *versus* in-person (overall): Less likely to be Black patients (virtual 20% *versus* 29%; p=0.014) Female (virtual 56% *versus* 63%; p=0.024) Higher median income p=0.009 ILD specific: virtual *versus* in-person Black patients 20% *versus* 31% 57% women *versus* 72% Average age 64 *versus* 59 years Lower education less likely to report satisfaction with telemedicine ILD: 81% very satisfied with telemedicine Older participants more likely to experience technical difficulties and prefer in-person interviews	[31]

[#]: Patient demographic characteristics (age, sex, race/ethnicity), urban *versus* rural residence, Veterans Affairs (VA) or non-VA care, comorbidities, index year of diagnosis, follow-up time, and facility level clustering. [¶]: Age, race, gender, insurance, year, zip income quartile, hospital region, hospital location, hospital teaching status, hospital bed size, and AHRQ Elixhauser Comorbidity index for in-hospital mortality. [+]: Adjusted for age, sex, and baseline forced vital capacity (FVC) percent predicted. [§]: adjusted model includes variables for race/ethnicity, age, gender, diagnosis group, transplant type, United Network for Organ Sharing region, blood type, height, county median household income, antibody crossmatch requirement, mechanical ventilation or extracorporeal membrane oxygenation (ECMO) use and lung allocation score at listing. [ƒ]: age, sex, and baseline FVC percent predicted. 6MWD: 6-min walking distance; BMI: body mass index; CF cystic fibrosis; CT: computed tomography; CTD-ILD: connective tissue disease related interstitial lung disease; D_{LCO}: diffusing capacity of the lung for carbon monoxide; EOL: end of life; fHP: fibrosing hypersensitivity pneumonitis; fILD: fibrosing interstitial lung disease; HP: hypersensitivity pneumonitis; HR: hazard ratio; IIP: idiopathic interstitial pneumonia; IPF: idiopathic pulmonary fibrosis; IQR: interquartile range; LAS: lung allocation score; OR: odds ratio; LTOT: long term oxygen therapy; PF: pulmonary fibrosis; RCT: randomised controlled trial; SES socioeconomic status.

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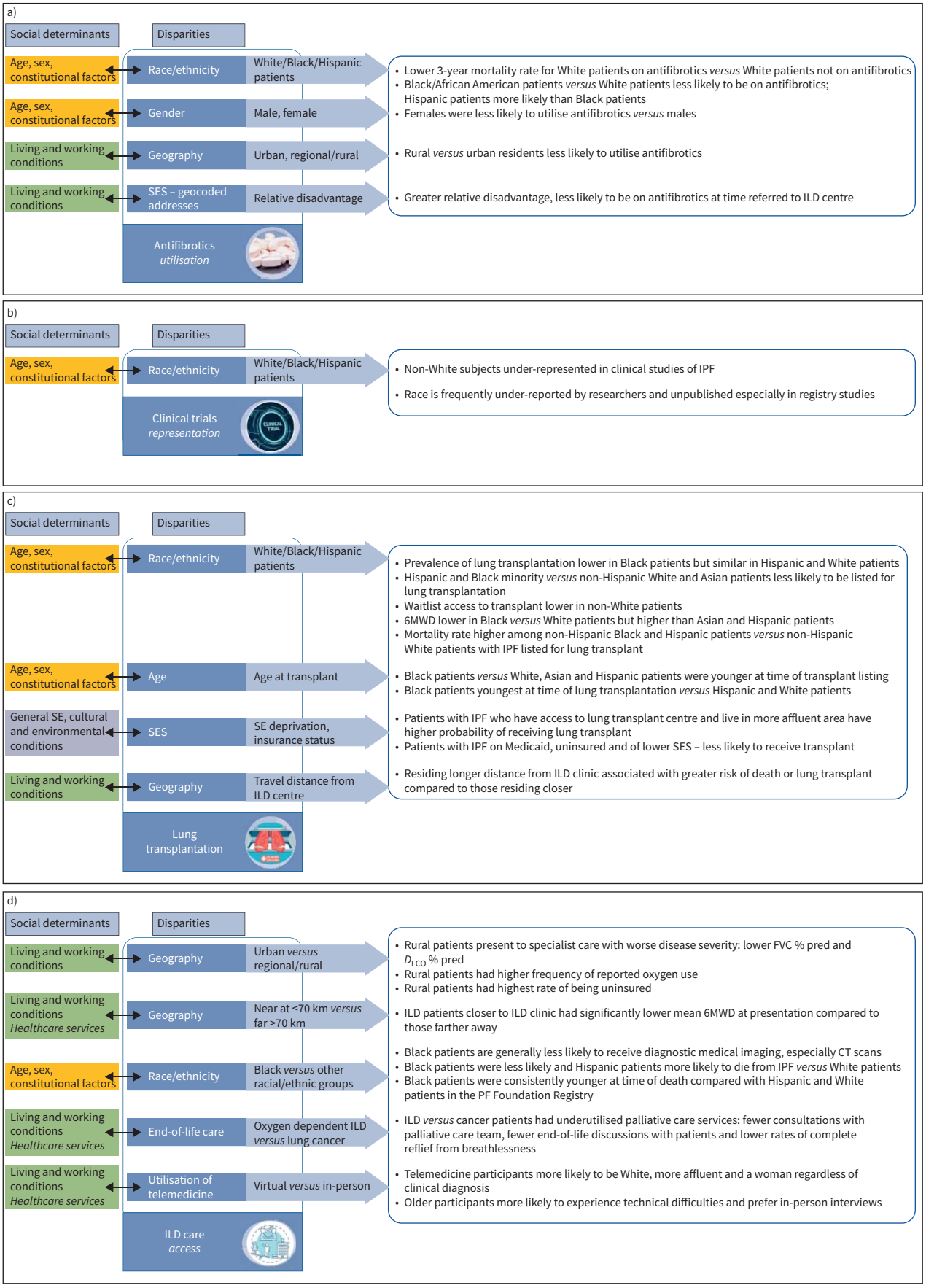
a)
Social determinants
Disparities
Age, sex, constitutional factors
Race/ethnicity
White/Black/Hispanic patients
• Lower 3-year mortality rate for White patients on antifibrotics versus White patients not on antifibrotics
• Black/African American patients versus White patients less likely to be on antifibrotics; Hispanic patients more likely than Black patients
• Females were less likely to utilise antifibrotics versus males
Age, sex, constitutional factors
Gender
Male, female
Living and working conditions
Geography
Urban, regional/rural
• Rural versus urban residents less likely to utilise antifibrotics
Living and working conditions
SES – geocoded addresses
Relative disadvantage
• Greater relative disadvantage, less likely to be on antifibrotics at time referred to ILD centre
Antifibrotics utilisation
b)
Social determinants
Disparities
Age, sex, constitutional factors
Race/ethnicity
White/Black/Hispanic patients
• Non-White subjects under-represented in clinical studies of IPF
• Race is frequently under-reported by researchers and unpublished especially in registry studies
Clinical trials representation
c)
Social determinants
Disparities
Age, sex, constitutional factors
Race/ethnicity
White/Black/Hispanic patients
• Prevalence of lung transplantation lower in Black patients but similar in Hispanic and White patients
• Hispanic and Black minority versus non-Hispanic White and Asian patients less likely to be listed for lung transplantation
• Waitlist access to transplant lower in non-White patients
• 6MWD lower in Black versus White patients but higher than Asian and Hispanic patients
• Mortality rate higher among non-Hispanic Black and Hispanic patients versus non-Hispanic White patients with IPF listed for lung transplant
Age, sex, constitutional factors
Age
Age at transplant
• Black patients versus White, Asian and Hispanic patients were younger at time of transplant listing
• Black patients youngest at time of lung transplantation versus Hispanic and White patients
General SE, cultural and environmental conditions
SES
SE deprivation, insurance status
• Patients with IPF who have access to lung transplant centre and live in more affluent area have higher probability of receiving lung transplant
• Patients with IPF on Medicaid, uninsured and of lower SES – less likely to receive transplant
Living and working conditions
Geography
Travel distance from ILD centre
• Residing longer distance from ILD clinic associated with greater risk of death or lung transplant compared to those residing closer
Lung transplantation
d)
Social determinants
Disparities
Living and working conditions
Geography
Urban versus regional/rural
• Rural patients present to specialist care with worse disease severity: lower FVC % pred and D_{LCO} % pred
• Rural patients had higher frequency of reported oxygen use
• Rural patients had highest rate of being uninsured
Living and working conditions Healthcare services
Geography
Near at ≤70 km versus far >70 km
• ILD patients closer to ILD clinic had significantly lower mean 6MWD at presentation compared to those farther away
Age, sex, constitutional factors
Race/ethnicity
Black versus other racial/ethnic groups
• Black patients are generally less likely to receive diagnostic medical imaging, especially CT scans
• Black patients were less likely and Hispanic patients more likely to die from IPF versus White patients
• Black patients were consistently younger at time of death compared with Hispanic and White patients in the PF Foundation Registry
Living and working conditions Healthcare services
End-of-life care
Oxygen dependent ILD versus lung cancer
• ILD versus cancer patients had underutilised palliative care services: fewer consultations with palliative care team, fewer end-of-life discussions with patients and lower rates of complete reflief from breathlessness
Living and working conditions Healthcare services
Utilisation of telemedicine
Virtual versus in-person
• Telemedicine participants more likely to be White, more affluent and a woman regardless of clinical diagnosis
• Older participants more likely to experience technical difficulties and prefer in-person interviews
ILD care access

FIGURE 2 Key disparities and associated determinants of health associated with interstitial lung disease (ILD). Disparities and social determinants of health associated with a) utilisation of antifibrotics for people with ILD, b) representation of people with ILD in clinical trials, c) lung transplantation for people with ILD and d) access to ILD care. 6MWD: 6-min walk distance; CT: computed tomography; D_{LCO}: diffusing capacity of the lung for carbon monoxide; IPF: idiopathic pulmonary fibrosis: PF: pulmonary fibrosis; SE: socioeconomic; SES: socioeconomic status.

Kaul *et al.* [30] reported that only 4.6% of Black/African American patients with IPF were on antifibrotics compared to 85.2% of White patients. In adjusted regression models (adjusted for age, sex, race/ethnicity, urban *versus* rural residence, Veterans Affairs (VA) or non-VA care, comorbidities, index year of diagnosis, follow-up time and facility-level clustering), Black/African American patients were 40% less likely to be on antifibrotics (OR 0.60, 95% CI 0.49–0.73). The study also found that females were 59% less likely to utilise antifibrotics compared to males (OR 0.41, 95% CI 0.27–0.63) and those residing in rural areas were 12% less likely to utilise antifibrotics compared to those in urban areas (adjusted OR 0.88, 95% CI 0.80–0.97) [30]. Disparities in utilisation were recently reported to be associated with eligibility based on the equation from Hankinson *et al.* [16] for forced vital capacity (FVC) % predicted compared to the updated Global Lung Function Initiative equation [18]. In a retrospective audit of 1882 participants from the Pulmonary Fibrosis Foundation Registry, 20% of patients were misclassified with Black patients being the most (22%) misclassified ethnic group [15].

In terms of mortality rates, Zhao *et al.* [43] reported a significantly lower 3-year mortality rate for White patients on antifibrotics compared to White patients not on antifibrotics (26.5% *versus* 29.7%; p<0.001). No significant differences were observed among Hispanic, Asian or Black individuals with IPF treated or not treated with antifibrotics.

Socioeconomic status based on geocoded residential addresses showed that those with greater relative disadvantage were less likely to be on antifibrotics when referred to an ILD centre compared to those with lowest levels of disadvantage (highest population vulnerability quartile *versus* lowest quartile OR 0.33, 95% CI 0.18–0.60; p=0.001) [23].

In the USA, only one in four IPF patients have been prescribed antifibrotics since 2014 [44]. High out-of-pocket costs (an average of USD 4700 per year) may make them unaffordable for many, as identified by Dempsey *et al.* [44] based on a large US database of deidentified administrative claims data.

Representation in clinical trials

Representation of participants in clinical studies (randomised controlled trials (RCTs) and observational registry studies) (figure 2b) based on race/ethnicity was examined in one study [33] and highlighted in a commentary [36]. Findings indicated that non-White individuals were under-represented in clinical studies of IPF with proportions ranging from 7% in North America to 23% in international studies that included Asia and Australia. How this compares with real-world populations is challenging to determine, given the lack of epidemiological data. In addition, the study found that race was under-reported by researchers, especially in registry studies compared to RCTs (29% *versus* 83%). Women seemed to be more fairly represented in RCTs compared to registry studies; however, there was wide variability across studies [33].

Lung transplantation

Disparities related to lung transplantation were reported in 12 studies (figure 2c), nine of which were based on USA data, one from the USA and Canada, one from Canada, and one from the UK. People with pulmonary fibrosis (PF) had lower number of transplants (49%) and higher waiting list mortality compared to those with COPD (79%) and other lung pathologies (61%) [32]. In addition, patients with pulmonary arterial hypertension bridging to transplant on extracorporeal membrane oxygenation had lower transplant rates than other lung conditions such as ILD or cystic fibrosis [27]. Race/ethnicity were associated with lower prevalence of lung transplantation [34, 35, 41], having access to waiting lists [26], greater severity of illness at time of transplantation [38, 41], younger age at time of transplantation [14] and greater waiting list mortality [35].

Overall, Hispanic and Black minorities with IPF were less likely to be listed for transplantation compared to non-Hispanic White and Asian patients (non-Hispanic Black patients: hazard ratio (HR) 0.88, 95% CI 0.83–0.94; Hispanic patients: HR 0.87, 95% CI 0.81–0.94; Asian patients: HR 0.83, 95% CI 0.73–0.96) [38].

The prevalence of lung transplantation in Black patients with IPF was lower than that for White patients; however, proportions were similar between Hispanic and White patients (39% Black, 47% Hispanic, 46% White) [34, 41].

At time of listing, Black patients were younger compared to White, Asian and Hispanic patients (52 years *versus* 61, 60 and 58 years, respectively); had lower FVC % predicted compared to White patients, but similar values to Asian and Hispanic patients (43% *versus* 47%, 40% and 40% respectively) and had a lower 6-min walking distance (6MWD) compared to White patients (720 feet *versus* 835 feet) but longer distances compared to Asian and Hispanic patients (690 feet and 650 feet, respectively) [38].

Patients with IPF who were enrolled at lung transplant centres and lived in a more affluent area were 22% more likely to receive a lung transplant (HR 1.22, 95% CI 1.13–1.31 per USD 10 000 increase in median ZIP code income) [41]. Uninsured or on Medicaid and patients of lower socioeconomic status were less likely to undergo a lung transplant, compared to those with non-Medicaid insurance (Medicaid adjusted OR 0.30, 95% CI 0.16–0.57; no insurance OR 0.22, 95% CI 0.07–0.72) [28]. Those with Medicaid or no insurance were less likely to be discharged to a rehabilitation facility [26].

Greater geographic distance from a lung transplant programme was associated with decreased likelihood of lung transplant but not death (HR 0.96, 95% CI 0.92–0.99 per 10-mile increase for lung transplant and HR 1.02, 95% CI 0.97–1.07 per 10-mile increase for death) [41]. In a microsimulation modelling of lung allocation based on different geographic lung-sharing policies, broader geographic sharing of donor lungs beyond the designated donor service area was associated with a decreased waitlist mortality in all ILD types with greatest difference observed in people with PF (median deaths (interquartile range (IQR)) per 100 waitlist years: donor service area: 17.1 (16.8–17.3); 500-mile lung sharing 12.9 (12.7–13.1); 1000-mile lung sharing 11.0 (10.9–1.1)) [29, 39].

Access to ILD care

Access to various aspects of ILD care was reported in 10 studies with disparities associated with race/ethnicity, geographic location and travel distance to a speciality ILD centre (figure 2d) [13, 14, 19, 22, 24, 25, 29, 31, 37, 46].

Substantial geographic heterogeneity in initiation of ILD treatment was reported by Assayag *et al.* [22] based on registry data from three countries. Earlier treatment initiation and more frequent treatment was reported in men and White patients in Canada; however, treatment was more common in women and non-White patients in Chicago. The Australasian Registry reported no significant racial differences in treatment.

In general, Black patients attending an emergency department were less likely to receive diagnostic medical imaging, especially computed tomography (CT) scans compared to other racial and ethnic groups (17.8% for White patients compared to 13% for Black patients; OR 0.80, 95% CI 0.77–0.83) [46]. This disparity persisted after controlling for other patient and hospital characteristics [13, 46].

In resource-poor settings and developing countries, limited access to chest CT imaging and spirometry are common impediments to the early diagnosis of PF. In addition, in such environments, there is a higher proportion of uninsured or underinsured individuals and the structural inequalities in the healthcare system have a significant impact on access (or lack of) to high quality primary care and referral to specialised pulmonary care [13].

Geographic residency and distance to speciality clinics were also reported as key barriers to accessing ILD care. Rural (*versus* suburban) patients in general presented to specialist care with worse disease severity [24, 25]. This included a significantly higher proportion presenting with dyspnoea (98% rural *versus* 87% suburban), a higher frequency of reported oxygen use (34.5% rural *versus* 16.1% suburban), lower pulmonary function (FVC% predicted and diffusing capacity of the lung for carbon monoxide % predicted) and higher rate of uninsured individuals (median (IQR): rural 12.3% (7.5–16.7) *versus* large central metro 5.7% (2.6–10.1%); $p \leqslant 0.001$). ILD patients who lived closer to an ILD clinic had significantly lower 6MWD at presentation compared to those living farther away: closer (mean±SD) 386±120 *versus* farther 419±123; p=0.004 [29]. A greater travelling distance was associated with an increased risk of death or lung transplant compared to those living closer to an ILD clinic (adjusted HR 1.52, 95% CI 1.10−2.11) [29].

Patients dying with oxygen-dependent ILD had less palliative care input, received lower quality end-of-life care and experienced more breathlessness compared with patients dying of lung cancer [19]. In ILD, death was more likely to be unexpected (15% *versus* expected 4%), less likely to occur in a palliative care setting (17% *versus* 40%) and there were fewer end-of-life discussions with patients (41% *versus* 59%) and families (52% *versus* 73%). Patients with ILD had lower rates of complete relief from breathlessness (17%

versus 33%, p<0.001) [19]. Provision of palliative care was also influenced by geographic location with rural areas being less resourced [37].

Overall, Black patients were consistently younger at time of death compared with Hispanic and White patients in the Pulmonary Fibrosis Foundation Registry (mean±SD age: Black, 68.7±8.4 years; Hispanic, 72.9±7.6 years; and White, 73.5±8.7 years; p<0.001) [14]. African American race was also associated with younger age at ILD diagnosis, decreased all-cause mortality and decreased risk for all-cause hospitalisation but had similar rates of respiratory hospitalisation in patients with ILD compared to non-African American patients [12].

Utilisation of telemedicine (virtual *versus* in-person) was more likely to be reported in White, more affluent and female patients regardless of clinical diagnosis [31]. Similar findings were reported in people with ILD: virtual *versus* in-person; Black 20% *versus* White 31%; 57% women *versus* 72% men; and average age 64 years *versus* 59 years. In addition, less educated and older participants less likely to report satisfaction with telemedicine.

The drivers of disparities identified in this review were mapped across three of the four domains of the Dahlgren–Whitehead model of social determinants of health. Living and working conditions (*e.g.* geography) were the most common social health determinants associated with various aspects of ILD followed by age/sex/constitutional factors (table 2 and figure 2). Social determinants associated with the domain of social and community networks, which includes social status and general socioeconomic, cultural and environmental conditions (*e.g.* cultural perspectives of a population), were not reported in any of the papers in this review.

Discussion

Our review of published literature has identified disparities in ILD care and outcomes for areas such as antifibrotic utilisation, clinical trial representation, access to ILD care and lung transplantation listing and mortality. Contributing to these disparities were a number of social determinants of health that, when mapped to the domains of the Dahlgren–Whitehead model, were most frequently associated with the domain of living and working conditions (healthcare services and distance from ILD specialist centres) followed by an individual's age/sex/constitutional factors. Our findings suggest that addressing the disparities identified under the domain of living and working conditions has the potential to improve access to care and outcomes for people with ILD. In addition, telehealth technology and utilisation have the potential to improve access to diagnostic imaging, access to clinical trials and treatment options in marginalised communities.

Our understanding of the complex interactions of race/ethnicity, gender, socioeconomic status and environment impact on ILD outcomes remains limited [36]. Whilst this review, based on currently available data, identified the more pervasive disparities and social determinants, it also revealed the critical gaps in our understanding and reporting of disparities and drivers associated with ILD. Of note was the lack of data evaluating social determinants of health associated with social and community networks, such as social exclusion, discrimination and isolation. Such factors have the potential to disadvantage certain groups from accessing adequate healthcare information and services [47]. One approach proposed to strengthen social support networks is the utilisation of digital technology. In more recent times, the term "social networks" has been expanded to refer to digital platforms such as websites designed to help people communicate and share information [10]. This could include the collection and/or dissemination of information or be a conduit for providing emotional support amongst peers with the potential to reach populations that might otherwise be difficult to reach. Conversely, such networks may further contribute to health inequities particularly associated with social differences in health and digital literacy and access. Therefore, the potential for digital technology to reduce disparities is highly dependent on an individual's access to both tangible and intangible resources, which are likely to overlap across the various societal and individual levels [48].

Community-centred drivers associated with disparities in ILD have also not been evaluated to any extent. These include factors within the general socioeconomic, cultural and environmental conditions domain such as health literacy, language, cultural beliefs (including treatment efficacy and mistrust of healthcare workers) and individual choices and factors (*e.g.* medication compliance). For example, a patient's lack of adherence to a recommended treatment is likely related to a cascade of factors that include patient health literacy, medication beliefs, patient–provider communication and healthcare access, as reported in other respiratory diseases such as asthma [49].

The review also revealed a paucity of research undertaken to examine potential disparities associated with key management options for ILD as recommended in international guidelines [50]. In particular, nonpharmacological approaches for management of the high symptom burden such as pulmonary rehabilitation, oxygen therapy, palliative care and psychosocial support, even though barriers such as access, costs and travelling impediments have been documented [51, 52]. As reported in recent reviews, telemedicine effectively addresses various barriers associated with access through remote consultations, monitoring and diagnosis that are facilitated by utilisation of technological advancements. In particular, telemedicine has the potential to impact geographical accessibility by extending reach to remote and underserved areas. Data supporting such claims is somewhat limited but has been demonstrated in areas such as stroke, diabetes and pregnancy management [53, 54]. Future research should consider the potential role of telehealth models of care that may address some of the identified key barriers to care.

In addition, some of the disparities identified may, in part, be attributed to the heterogenous ILD subtypes reported by the included studies given each subtype is characterised by differing clinical manifestations and progression. As a result, recommendations for management and treatment options are often based on the specific subtype and underlying aetiology that may contribute to the disparities in treatment and care across social determinants such as race and gender [55].

The body of literature included in this review identifies key disparities in ILD care and outcomes; however, we did not identify any studies that aimed to reduce these disparities. There was a lack of interventions developed to explicitly target either individual and/or societal drivers of disparity. The world's respiratory societies (the American Thoracic Society and European Respiratory Society) have earmarked the reduction of health disparities in noncommunicable respiratory diseases as a priority [2, 3, 56, 57]. The process invariably begins with a heightened awareness of existing gaps in burden and treatment that guide the development and advocacy of policies addressing the origins of health disparities [58]. Similarly, in 2023, the British Thoracic Society published their position statement on health inequalities that form part of the long-term plan of reducing health inequalities [59]. Other countries have also released action plans aimed at reducing disparities to respiratory health. For example, in 2019, the National Strategic Action Plan for Lung Conditions was published in Australia with equitable access (best care for all) being a top-six priority area [60]. However, the success and impact of such policies and initiatives will require strong international commitments and work with leaders from governments, academia and organisations to address and reduce avoidable health inequalities [61]. In addition, the findings highlight the need for a "call to action" from granting bodies to prioritise funds for research on interventions that aim to reduce disparities in ILD.

Developing and implementing policies that directly address the identified disparities in ILD is an important starting point. Biologic factors such as race/ethnicity may not be modifiable but mandating that clinical trials include and report on a diverse representation can contribute to increasing access to care for under-represented populations. As exemplified by the Food and Drug Administration in the USA, the mandatory introduction of the reporting of race/ethnicity in all clinical trials in 2017 has seen a significant increase in participation and reporting of non-White participants [62].

Greater utilisation of antifibrotics is often hampered by lack of access to specialist centres, primarily due to geographic distances. The advancement of online platforms enabling virtual multidisciplinary meetings have been shown to provide improved service and greater outreach for both clinicians and patients [63]. A reduction in costs associated with such treatments should also be advocated for particularly for those more disadvantaged patients. Telehealth technology has the potential to make a significant impact on reducing disparities in ILD. The development of telerehabilitation programmes [64], teletrials [65], remote monitoring [66] and teleconsultations allows for greater coverage of underserved populations, reduces travel time and costs, and provides greater network for patients and healthcare providers and services. In addition, the role of ILD expert centres in the establishment of "hub and spoke" models of care may also provide an alternative approach to greater access to ILD care. In such models, the ILD speciality centre acts as the "hub" providing support, capacity building and education to other centres ("spokes") facilitating a more patient-centred approach that minimises unnecessary travel and facilitates access to ancillary local services such as pulmonary rehabilitation [67]. Paradoxically, however, the utilisation of telehealth has the potential to exacerbate health inequities in populations with lower levels of digital literacy and access. The establishment of "hub and spoke' models of care may also provide an alternative approach to greater access to ILD care [68].

Addressing disparities associated with lung transplantation is particularly critical given lung transplantation is one of the few treatment options that has the potential to extend and improve quality of life for patients with advanced lung disease [69]. Race/ethnicity and socioeconomic status (in particular insurance status)

have been negatively associated with many aspects along the continuum of lung transplantation. This includes referral process, transplantation process (evaluation, listing and allocation) and post-transplant outcomes [70]. The introduction of the lung allocation score in 2005 in the US, was aimed at improving access to donor lungs by prioritising access to sicker and older patients. Further modification expanded the donor service area with the aim of reducing waitlist mortality [71]. However, these well-intended efforts led to unintended negative consequences such as increasing costs, reduced efficiencies and worsening of access to certain subgroups of patients [72]. From a global perspective, 2021 data suggest an increase in lung transplants in countries such as Austria, Belgium and Canada, although factors driving this increase are still to be elucidated. In developing countries such as Brazil and India, thoracic transplants are growing rapidly. However, African nations are experiencing worse geographic disparities due to a lack of skilled workforce, infrastructure and institutional support [73]. Therefore, although disparities associated with lung transplantation exist globally, the drivers differ both between and within different environments and will require a more concerted and standardised frameworks to allow exchange of best practices and technical expertise, as suggested by the WHO [74].

Disparities associated with access to palliative care for noncancer patients were also identified as key areas where factors such as race/ethnicity, geography and lack of available services acted as key drivers of inequities. The importance of early palliative care for chronic life-limiting conditions such as ILD is often underestimated, although studies have reported an improvement in quality of life and reduction in symptom burden [75]. Barriers to greater and earlier utilisation of palliative care services are multifaceted and include a misunderstanding by patients and providers of its purpose and the ability to integrate it into other modalities of care. However, these barriers may be secondary to the under-recognition of the palliative care needs of people with ILD, the unfamiliarity and discomfort with palliative services in general, and the misconception by patients that it may be a barrier to referral for lung transplant [76, 77]. In addition, infrastructure-based barriers such as lack of resources for outpatient palliative referrals can lead to reliance on community services which at times may be overstretched [77]. In ILD, the provision of palliative care requires an integrated team approach to best address the needs of the individual and their families. In some settings, an ILD nurse specialist plays an important role [78]. However, such expertise and resources are not always available. In such environments, support may be provided by a variety of health professionals that includes physicians, physiotherapists, social workers and, in some cultures, family and community workers [72]. In addition, there may be a hesitancy by some physicians to refer patients too early following diagnosis due to lack of knowledge or confidence to initiate discussions or uncertainty as to whether referral to palliative care is appropriate [79, 80]. Further research is needed to develop optimal palliative care support for patients and their families taking into account both individual needs and capacities of healthcare systems.

Alongside research efforts is the need for supportive government policy frameworks for health service models of care that incorporate more equitable funding and access to treatments are imperative. Most importantly, if we are to reduce the disparities in ILD, we need to ensure a greater consumer engagement in the design and development of new policies, service deliveries and research interventions to explicitly target both individual and societal drivers of disparity [81]. This should include those with a lived experience of the disease as well as members from minority communities and/or disadvantaged groups.

Given that the disparities associated with ILD are complex and multilevel, clinical strategies to address these disparities must therefore be comparably multilevel and target many aspects of ILD care in a similar way as that taken for asthma [49]. Such an approach needs to address social determinants that often transverse the individual and societal levels outlined in the Dahlgren–Whitehead model, which would involve collaborative partnerships between providers, patients and communities. Several strategies that could be applied in clinical settings to reduce disparities include the need for routine assessment of the patient's beliefs, financial barriers to disease management, health literacy and digital literacy. Healthcare providers should undergo training in unconscious bias, cultural competence training and communication skills [49].

The broad search strategy used in this review can be viewed as a strength as it allowed a more comprehensive search of the literature not limited by language or study design. One limitation is its narrative design, which did not include a formal assessment of bias. However, given the objectives of the review, we feel this did not significantly limit our ability to synthesise the findings; rather, it highlighted the somewhat limited reporting of disparities in ILD compared to other lung conditions such as asthma and COPD. Most of the studies we identified addressed disparities in the USA (23/31, 74%), so we could draw few conclusions about disparities in ILD care for other countries.

In conclusion, reducing health disparities in ILD care and outcomes will require change at many levels, from individuals to providers to health policy leaders, in order to create broad societal transformations. Addressing the root causes will require the inclusion of patients in the design, testing and implementation of interventions and must be flexible to address local barriers to care in dissemination of interventions. In addition, all cultures must be engaged in healthcare decisions and education and support for self-management needs to be promoted.

Points for clinical practice

- Healthcare professionals and policy makers should be aware of health disparities affecting ILD care and their potential to impact on patient outcomes.
- Telemedicine technology has the potential to reduce some of the disparities associated with access to care for people with ILD but, paradoxically, may also exacerbate inequities.

Questions for future research

- Research agendas should prioritise interventions aimed at addressing the root causes of disparities and should include patients in the design, development and implementation.

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