IPF/PPF: Patient and Pulmonologist Perspectives Highlight Care Gaps

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Idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis (PPF) are chronic, progressive lung diseases with significant morbidity and mortality, yet the lived experience of patients often diverges from clinical perspectives. Data presented at ATS 2026 underscored this disparity, revealing critical gaps in communication and understanding that impact patient care and disease management.

KEY TAKEAWAYS

- The Pivot: A formal exploration of patient and pulmonologist perspectives in IPF and PPF reveals significant discordance in perceived disease burden and treatment goals.
- The Data: Patients report higher symptom burden and greater impact on daily life than clinicians perceive, particularly regarding fatigue and mental health.
- The Action: Clinicians should actively solicit patient perspectives on symptom severity and quality of life to align treatment strategies more effectively with patient priorities.

Idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis (PPF) are characterized by irreversible lung scarring, leading to progressive dyspnea, cough, and functional decline.1 These conditions fall under the umbrella of interstitial lung diseases (ILDs), a heterogeneous group of disorders affecting the lung parenchyma. IPF is the most common and severe form of idiopathic interstitial pneumonia, with an estimated prevalence ranging from 10 to 60 cases per 100,000 people globally. PPF, a more recently recognized phenotype, describes a progressive fibrosing course in various ILDs beyond IPF, including chronic hypersensitivity pneumonitis, connective tissue disease-associated ILD, and unclassifiable ILD. Despite advancements in antifibrotic therapies, the management of these conditions remains complex, often focusing on slowing disease progression and managing symptoms.2 Nintedanib and pirfenidone, the two approved antifibrotic agents, have demonstrated efficacy in reducing the rate of FVC decline in IPF and, for nintedanib, in a broader population of progressive fibrosing ILDs.2,3,4 However, the subjective experience of living with IPF and PPF, encompassing physical, psychological, and social dimensions, is not always fully captured or addressed within standard clinical encounters.3 This discrepancy can lead to care pathways that, while medically sound, may not optimally address patient-reported outcomes or quality of life.4

Bridging Perspectives in IPF and PPF

A qualitative study presented at ATS 2026 aimed to delineate the perspectives of both patients with IPF/PPF and their treating pulmonologists regarding disease impact, treatment goals, and communication.5 The study utilized semi-structured interviews with 25 patients diagnosed with IPF or PPF and 15 pulmonologists specializing in interstitial

lung diseases.5 Patient participants included individuals across a spectrum of disease severity and duration, with varying treatment regimens, including those on antifibrotic therapy and those receiving supportive care only. Pulmonologist participants represented a range of clinical experience and practice settings, from large academic centers to smaller community hospitals, ensuring a broad perspective on current clinical practice. Participants were recruited from multiple academic and community pulmonary clinics across North America to ensure a diverse representation of experiences.5 Interviews explored themes such as symptom burden, impact on daily activities, emotional well-being, treatment expectations, and the patient-clinician relationship.5 All interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analysis to identify recurring patterns and divergent viewpoints.5 This rigorous qualitative approach allowed for an in-depth exploration of complex subjective experiences, providing rich contextual data that quantitative methods might not capture.

Key findings revealed notable differences in how patients and pulmonologists perceive the disease. Patients consistently reported a higher burden of symptoms, particularly fatigue and exertional dyspnea, which significantly impacted their daily activities and overall quality of life.6 Many patients also articulated substantial psychological distress, including anxiety and depression, directly related to their diagnosis and prognosis.6 The unpredictable nature of the disease and the progressive decline in lung function often contributed to a pervasive sense of uncertainty and fear. In contrast, pulmonologists tended to focus more on objective measures of disease progression, such as forced vital capacity (FVC) decline and oxygen saturation, and the efficacy of antifibrotic agents in slowing this decline.7 While pulmonologists acknowledged the symptomatic burden, their perception of its severity and impact on patient daily life was often lower than patient self-reports.7

Communication emerged as a critical area of divergence. Patients expressed a desire for more comprehensive discussions about symptom management, psychological support, and the long-term implications of their disease beyond pharmacological interventions.8 Some patients felt that their concerns regarding fatigue, mental health, and social isolation were not fully addressed during clinic visits, which often prioritized discussions about lung function tests and medication adherence.8 Pulmonologists, while recognizing the importance of holistic care, often cited time constraints and a primary focus on disease modification as barriers to more extensive discussions on these topics.9 There was also a perceived difference in treatment goals; patients often prioritized maintaining functional independence and quality of life, whereas pulmonologists frequently emphasized slowing disease progression and preventing acute exacerbations.9

The study's limitations include its qualitative nature and relatively small sample size, which may limit generalizability.10 The findings are based on self-reported experiences and perceptions, which can be subjective.10 While the study aimed for diversity in recruitment, the specific demographic characteristics of the patient and pulmonologist cohorts (e.g., age, gender, socioeconomic status, years of practice) were not detailed, which could influence the generalizability of the findings. The cross-sectional design also provides a snapshot in time, and perspectives may evolve over the course of the disease. Future research could incorporate quantitative measures of patient-reported outcomes alongside clinical assessments to provide a more comprehensive understanding of these disparities.10 Additionally, interventions designed to improve patient-clinician communication and integrate patient-centered care models in IPF/PPF management warrant investigation.10 This could include developing standardized tools for assessing patient-reported outcomes and implementing shared decision-making frameworks in routine clinical practice.

CLINICAL IMPLICATIONS

The data from ATS 2026 serves as a stark reminder that clinical practice, even when evidence-based, can inadvertently overlook the lived reality of patients. Pulmonologists, armed with spirometry results and antifibrotic guidelines, may be missing the profound impact of fatigue and psychological distress that patients with IPF and PPF endure daily. It is not enough to prescribe pirfenidone or nintedanib; clinicians must actively listen to and validate patient experiences, integrating these subjective reports into a more holistic treatment plan. The current model, often driven by objective metrics, risks alienating patients whose primary concerns revolve around maintaining a semblance of normal life.

This disconnect has tangible consequences for patient adherence and overall well-being. If patients feel their most pressing concerns are not being addressed, their engagement with the healthcare system may diminish. Pharmaceutical companies developing new therapies for IPF and PPF should take note; while efficacy in slowing FVC decline is paramount for regulatory approval, real-world adoption and patient satisfaction will increasingly hinge on improvements in patient-reported outcomes. Investing in research that quantifies the impact of therapies on fatigue, dyspnea, and mental health, rather than solely on lung function, is not merely altruistic; it is a strategic imperative for market differentiation and patient-centric care.

Ultimately, bridging this gap requires a systemic shift. Guideline bodies like the American Thoracic Society and European Respiratory Society should consider strengthening recommendations for routine screening of patient-reported outcomes, including fatigue and mental health, in IPF and PPF management. Furthermore, medical education and continuing professional development must emphasize communication skills and empathy, equipping pulmonologists to navigate these complex patient narratives within the constraints of a busy clinic. The goal is not to abandon objective measures, but to integrate them seamlessly with the invaluable subjective data provided by the patient, fostering a truly collaborative approach to chronic disease management.

EDITORIAL & AI STANDARDS

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