Demographics and Baseline Characteristics of Patients with Idiopathic Pulmonary Fibrosis (IPF) in a Real-World Setting: Results of 847 Patients Enrolled in the Radico-ILD Cohort in France

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Rationale: Idiopathic pulmonary fibrosis (IPF) is a rare condition and few epidemiological data are available in France. This specific research project aims to describe characteristics of treated IPF patients and the impact of antifibrotic treatments in terms of morbidity and mortality in the French real-life setting. Methods: The French RaDiCo (Rare Disease Cohort)-ILD (idiopathic Interstitial Lung Diseases) registry is an ongoing observational study initiated in June 2017, with a sub-analysis of IPF patients. This longitudinal long-term cohort includes pediatric and adult patients with ILD and is supported by the national network of reference and competence centers for rare pulmonary diseases. IPF was diagnosed using international ATS/ERS 2011 criteria with a diagnosis of IPF or working diagnosis of IPF by multidisciplinary discussion. Here, we present the baseline data of IPF patients. Results: Between June 15th 2017 and September 4th 2019, 1246 ILD patients were enrolled in the RaDiCo-ILD registry from 18 centers, including 847 with IPF (68%). IPF patients were mostly male (82.7%), with a mean age of 72.5 ± 9 years at inclusion and a mean BMI of 26.8 ± 4.3; 44.6 % of IPF patients included were incident cases, with a median length between diagnosis and inclusion of 8.9 months (Q1=0.9 and Q3=26.4); 25.3% had a biopsy. The mean FVC at IPF diagnosis was 73.4 ± 25.0 % of predicted value (n=561), and the mean DLCO at IPF diagnosis was 39.6 ± 18.2 % predicted value (n=498). Among patients with available information on anti-fibrotic treatment, 347 had been treated (at least one dose) with nintedanib, and 312 with pirfenidone; among patients treated with antifibrotics, 113 were treated with both treatments sequentially. Conclusions: The RaDiCo-ILD registry provides accurate real-world data on the demographics of patients with IPF in France. It will generate a long-term follow-up and will be an invaluable tool to describe the natural history and progression of patients with IPF in real-life conditions.

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