Exploring relationships between resources and practices of ILD centers and outcomes in patients with idiopathic pulmonary fibrosis: data from the IPF-PRO Registry

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IPF-PRO™ ILD-PRO™

INTRODUCTION

- Although international guidelines for the diagnosis and management of IPF have been published,[1,2] performance benchmarks have not been established.
- There are few data on how site-specific management practices relate to patient outcomes.
- The Idiopathic Pulmonary Fibrosis Prospective Outcomes (IPF-PRO) Registry (NCT01915511) is a prospective observational US registry that enrolled patients with IPF that was diagnosed or confirmed at the enrolling center in the previous 6 months.[3]

AIM

- To assess associations between the resources and practices of the enrolling centers in the IPF-PRO Registry and patient outcomes.

METHODS

- Sites that had enrolled ≥10 patients into the IPF-PRO Registry were sent an online survey about their resources, operations, and self-assessment practices prior to the COVID-19 pandemic. Sites completed the survey between 5 February and 1 June 2020.
- For every site, we estimated the 1-year event rate of clinically relevant outcomes.
- We assessed whether site-level heterogeneity existed for each patient-level outcome, and if so, we investigated potential site-level drivers of the heterogeneity. Models were adjusted for differences in patient case mix among sites by adjusting for factors known to be associated with the outcomes. These comprised demographic characteristics, measures of disease severity, and comorbidities.

CONCLUSIONS

- Substantial heterogeneity was observed in the event rates of clinically relevant outcomes across sites in the IPF-PRO Registry. However, after controlling for differences in patient case mix, there was no site-level heterogeneity in patient outcomes.
- Further studies are needed on resources, systems and management practices that may improve outcomes in patients with IPF.

RESULTS

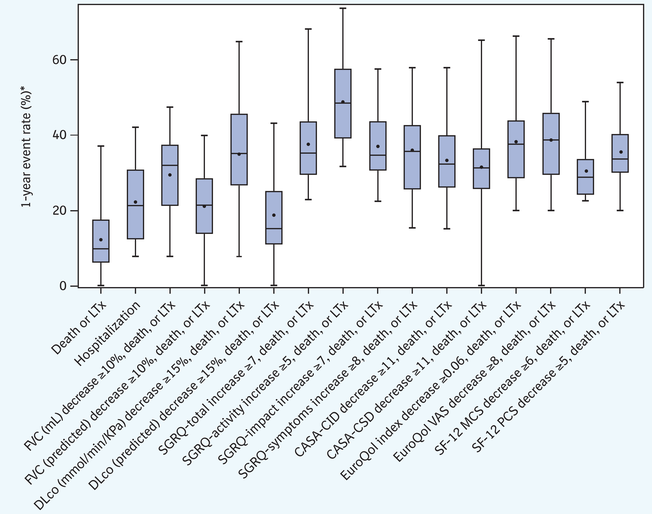
- All 27 sites that were sent the questionnaire completed it. These sites had enrolled 920 of the 1002 patients in the registry. The median (Q1, Q3) number of enrolled patients at these sites was 26 (19, 45).

Characteristics of the sites

Median (Q1, Q3) number of ILD physician specialists
6 (3, 8)

- Actively following >100 patients with IPF: **70.4%**
- Nurse leader to co-ordinate clinical activities: **77.8%**
- Weekly multi-disciplinary conferences: **48.1%**
- Access to chest radiologist: **96.3%**
- Access to lung pathologist: **100%**
- Lung transplant program at site: **66.7%**
- Started or completed an ILD-related quality improvement program in last 2 years: **40.7%**
- Patients routinely participate in remote monitoring: **22.2%**
- Site has support group or refers patients to support group: **92.6%**

Site-specific event rates of outcomes at 1 year



*Cumulative incidence rate for hospitalization; Kaplan-Meier rates for all other outcomes.

The crosses denote the mean values, the mid-line of the boxes the median values, the boundaries of the boxes the 25th and 75th percentiles, the whiskers the minimum and maximum values.

CASA-Q, Cough and Sputum Assessment Questionnaire; CID, cough impact domain; CSD, cough symptoms domain; LTx, lung transplant; MCS, mental component summary; PCS, physical component summary; SF-12, 12-Item short form survey; SGRQ, St. George's Respiratory Questionnaire; VAS, visual analog scale.

Associations between site practices and patient outcomes

- After adjusting for differences in patient case mix among sites, there was no significant site-level heterogeneity for any of the outcomes studied (p>0.05 for all). Median site-level hazard estimates for the outcomes ranged from 0.97 to 1.06.
- The p-value for site-level heterogeneity in hospitalization was 0.052. When the relationships between site practices and risk of hospitalization were assessed, after adjusting for patient case mix, "starting/completing an ILD-related quality improvement project in the previous 2 years" was associated with a lower risk of hospitalization (HR 0.60 [95% CI: 0.44, 0.82]) and "patients routinely participate in some form of remote monitoring" was associated with a higher risk of hospitalization (HR 1.46 [95% CI: 1.04, 2.05]). After controlling for patient case mix and these site practices, there was no significant site-level heterogeneity for hospitalization.

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IPF-PRO™ Registry enrolling centers: Albany Medical Center, Albany, NY; Baylor College of Medicine, Houston, TX; Baylor University Medical Center at Dallas, Dallas, TX; Cleveland Clinic, Cleveland, OH; Columbia University Medical Center/New York Presbyterian Hospital, New York, NY; Duke University Medical Center, Durham, NC; Froedtert & The Medical College of Wisconsin Community Physicians, Milwaukee, WI; Houston Methodist Lung Center, Houston, TX; Lahey Clinic, Burlington, MA; Loyola University Health System, Maywood, IL; Lynchburg Pulmonary Associates, Lynchburg, VA; Medical University of South Carolina, Charleston, SC; National Jewish Health, Denver, CO; NYU Medical Center, New York, NY; Piedmont Healthcare, Austell, GA; Pulmonary Associates of Stamford, Stamford, CT; PulmonIx LLC, Greensboro, NC; Renovatio Clinical, The Woodlands, TX; Salem Chest and Southeastern Clinical Research Center, Winston Salem, NC; South Miami Hospital, South Miami, FL; St. Joseph's Hospital, Phoenix, AZ; Stanford University, Stanford, CA; Temple University, Philadelphia, PA; The Oregon Clinic, Portland, OR; Tulane University, New Orleans, LA; UNC Chapel Hill, Chapel Hill, NC; University of Alabama at Birmingham, Birmingham, AL; University of California, Davis, Sacramento, CA; University of California Los Angeles, Los Angeles, CA; University of Chicago, Chicago, IL; University of Cincinnati Medical Center, Cincinnati, OH; University of Louisville, Louisville, KY; University of Miami, Miami, FL; University of Michigan, Ann Arbor, MI; University of Minnesota, Minneapolis, MN; University of Pennsylvania, Philadelphia, PA; University of Pittsburgh, Pittsburgh, PA; University of Virginia, Charlottesville, VA; UT Southwestern Medical Center, Dallas, TX; Vanderbilt University Medical Center, Nashville, TN; Vermont Lung Center, Colchester, VT; Wake Forest University, Winston Salem, NC; Washington University, St. Louis, MO; Weill Cornell Medical College, New York, NY; Wilmington Health and PMG Research, Wilmington, NC; Yale School of Medicine, New Haven, CT.

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