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Palliative Care and Location of Death in Decedents With Idiopathic Pulmonary Fibrosis

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BACKGROUND: Palliative care, integrated early, may reduce symptom burden in patients with idiopathic pulmonary fibrosis (IPF). However, limited information exists on timing and clinical practice. The purpose of this study was to describe the time course of events prior to death in patients with IPF managed at a specialty center with a focus on location of death and timing of referral for palliative care.

METHODS: Data were retrospectively extracted from the health system's data repository and obituary listings. The sample included all decedents, excluding lung transplant recipients, who had their first visit to the center between 2000 and 2012.

RESULTS: Median survival for 404 decedents was 3 years from diagnosis and 1 year from first center visit. Of 277 decedents whose location of death could be determined, > 50% died in the hospital (57%). Only 38 (13.7%) had a formal palliative care referral and the majority (71%) was referred within 1 month of their death. Decedents who died in the academic medical center ICU were significantly younger than those who died in a community hospital ward ($P = .04$) or hospice ($P = .001$).

CONCLUSIONS: The majority of patients with IPF died in a hospital setting and only a minority received a formal palliative care referral. Referral to palliative care occurred late in the disease. These findings indicate the need to study adequacy of end-of-life management in IPF and promote earlier discussion and referral to palliative care. CHEST 2015; 147(2):423-429

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ABBREVIATIONS: DLCO = diffusing capacity of the lung for carbon monoxide; IPF = idiopathic pulmonary fibrosis; ILD = interstitial lung disease

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Idiopathic pulmonary fibrosis (IPF) is a fatal, progressive, scarring lung disease with a variable course.[1] Mean survival from diagnosis ranges from 2 to 3 years, with some patients dying within the first year following diagnosis.[2,3] Management of patients with IPF is particularly challenging because there is no medical therapy with proven survival benefit. Lung transplantation remains the only option to improve survival.[4]

IPF is characterized by an unpredictable course with some patients experiencing prolonged periods of slow, progressive decline and others succumbing to acute exacerbations.[5,6] Consequently, clinicians, patients, and caregivers often fail to perceive disease course variability and experience high levels of stress and anxiety as the disease relentlessly progresses.[7-9] For these reasons, patients with IPF represent a distinct minority group eligible for early referral to palliative care. How early and how often such referrals occur is unknown. This information is important because improved understanding of referral patterns may lead to improved patient outcomes.[10]

Regardless of disease course, patients with IPF eventually reach the stage where death is imminent. To have a meaningful effect, palliative care services should be provided early in the course of disease.[11] The goals of palliative care are to provide symptom management, prevent and relieve suffering, and support the best possible quality of life, regardless of stage of the disease or need for other therapies.[12] In patients with newly diagnosed metastatic lung cancer, referral to palliative care within 12 weeks of diagnosis led to improvement in quality of life and mood compared with patients receiving standard care. Those patients receiving palliative care also had less aggressive care at the end of life, but longer survival.[13] For patients with IPF who are not approved for lung transplant, there is an increasing consensus that palliative care should occur early following diagnosis, considering the lack of effective medical interventions.[7,8,14,15] However, we were unable to identify specific recommendations in the literature regarding timing. Our clinical impression was that referral to palliative care more commonly occurred late, a concern given the unpredictable course of this disease.

The purpose of this study was to describe the time course of events prior to death in patients with IPF who did not receive a lung transplant and were managed at a specialized center, with a focus on location of death and timing of referral to palliative care. Lung transplant recipients were excluded because, once transplanted, disease management differs.

Materials and Methods

Setting

Data were extracted retrospectively for decedents with IPF who had their first visit to the University of Pittsburgh Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease (ILD) between 2000 and 2012. The Simmons Center, a large specialty ILD program affiliated with the University of Pittsburgh Medical Center, annually evaluates approximately 200 new patients with IPF referred from national and international locations. The study was approved by the University of Pittsburgh Committee for Oversight of Research and Clinical Training Involving Decedents (CORID No. 411).

Procedure

The Simmons Center maintains a clinical database of all clinic visits and tracks outcomes for each patient during their disease course. During the study interval (2000-2012), 860 patients with a confirmed diagnosis of IPF were seen at the center. Using the center's database, we identified 465 patients with a confirmed diagnosis of IPF who died between 2000 and 2012. To determine location of death, two sources were used: the health system's data repository to capture in-hospital mortality in the 18 hospitals belonging to our health system network[16] and an Internet search for published death notices. Obituary information was cross-checked against the Simmons Center clinical database to confirm patient identity.

Using this search strategy, we were able to identify date of the first center visit and date of death for the 465 decedents. After excluding lung transplant recipients (n = 61), location of death was determined for 277 decedents and could not be identified for 127 decedents (Fig 1). Those under evaluation or listed for lung transplantation were included in this analysis. We identified 41 patients with a palliative care consultation through a search of dictated palliative-care consultation notes in the data repository. Of those patients, 38 had a known location of death and were included in the data analysis.

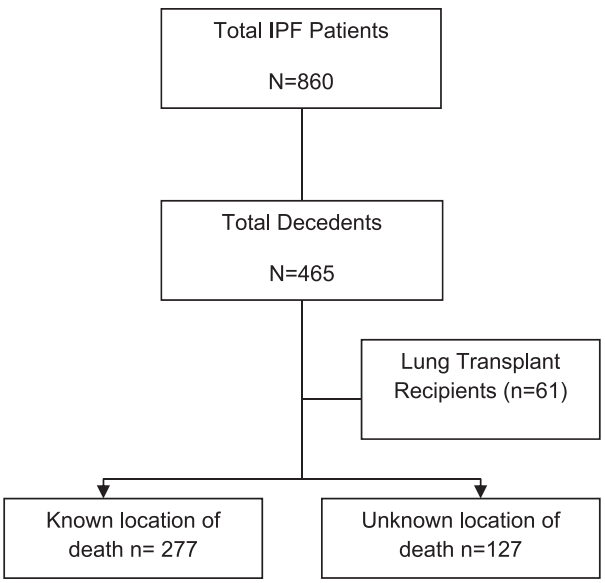

Figure 1 – *A total of 465 decedents were referred for evaluation between 2000 and 2012. After excluding lung transplant recipients and those with an unknown location of death, 277 decedents remained for analysis. IPF = idiopathic pulmonary fibrosis.*