Cultural Differences in Palliative Care in Patients With Idiopathic Pulmonary Fibrosis

To the Editor:

We congratulate Lindell and colleagues on their recent article in CHEST (February 2015) on palliative care and location of death in idiopathic pulmonary fibrosis (IPF). Despite advances in treatments that slow disease progression, IPF remains a fatal disease. Radical treatment (ie, to alter the natural history) and palliative therapies often coincide, creating uncertainties as to the timing of palliative care referral, to best meet the needs of the patient, family, and care providers. Lindell and colleagues show that referral to palliative care occurred in a minority of patients and only late in the disease. They also showed that the majority of patients with IPF died in the hospital (57%), with 33% dying in the ICU. The remaining 43% of patients died in a hospice. These findings are discordant with our combined experience, causing us to speculate that cultural factors might be a highly influential determinant of communication about palliation and place of dying.

To explore wider European experience, we asked 51 European IPF experts at the Advancing IPF Research 2014 meeting in Copenhagen, using an interactive voting system, the following question: “Where do the majority of your patients with IPF die?” The possible responses were identical to the terms used by Lindell and colleagues, with the additional option of “at home.” Thirty-nine experts from 15 different countries chose to participate; 70% answered that the majority of their patients died in the hospital, with 8% dying in the ICU and the remaining experts choosing “at home.” We acknowledge that it is not possible to compare the findings of Lindell and colleagues directly with this poll as respondents were asked only to state the place of death in the majority of their patients with IPF.

To explore this further, we looked retrospectively at the location of death in patients with IPF in our centers. In two centers combined, in the past year 29 patients with IPF died: 59% died in the hospital (with 7% dying in the ICU), 38% died at home, and it was unknown where the remaining 3% died. In the third center, implementation of a palliative program resulted in 28% of patients with IPF dying in the hospital, a major reduction. We realize the limitations caused by differences in methodology of collection and time studied compared with the original study. However, both findings are consistent with a wider European experience that patients with IPF seldom die in an ICU or a hospice. Cultural differences may play an important role and should be investigated and taken into consideration when striving to optimize palliative care in patients with IPF.

Marlies Wijsenbeek, MD, PhD
Rotterdam, The Netherlands
Elisabeth Bendstrup, MD, PhD
Aarhus, Denmark
Joy Ross, MD, PhD
Athol Wells, MD
London, England

AFFILIATIONS: From the Department of Pulmonary Medicine (Dr Wijsenbeek), Erasmus MC, University Medical Center Rotterdam; Department of Respiratory Diseases and Allergy (Dr Bendstrup), Aarhus University Hospital; The Royal Marsden & Royal Brompton Palliative Care Service (Dr Ross), The Royal Marsden NHS Foundation Trust; and Interstitial Lung Disease Unit (Dr Wells), Royal Brompton Hospital, Royal Brompton & Harefield NHS Foundation Trust.

FINANCIAL/NONFINANCIAL DISCLOSURES: The authors have reported to CHEST that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

CORRESPONDENCE TO: Marlies Wijsenbeek, MD, PhD, Department of Pulmonary Medicine, Erasmus MC, University Medical Center Rotterdam, Gravendijkwal 230, 3015 CE Rotterdam, The Netherlands; e-mail: m.wijsenbeek-lourens@erasmusmc.nl

© 2015 AMERICAN COLLEGE OF CHEST PHYSICIANS. Reproduction of this article is prohibited without written permission from the American College of Chest Physicians. See online for more details.

DOI: 10.1378/chest.15-0705

References

Response

To the Editor:

We thank Dr Wijsenbeek and colleagues for the information they provided regarding the European experience of location of death for patients with idiopathic pulmonary fibrosis (IPF). One of the aims of our recent article in CHEST\(^1\) was to draw attention to this relatively neglected aspect in the care of patients with IPF: the need for palliative care. The data Dr Wijsenbeek and colleagues provide complement our study, add a global perspective, and, most importantly, support our notion that more research and clear guidelines need to be provided regarding palliative care for patients with IPF.

Overall, the numbers by Dr Wijsenbeek and colleagues are concurrent with our observation. The majority of their patients (59%) died in the hospital, as did the majority of the patients in our study (57%). The general value of this observation is highlighted by the fact that, in response to a question, 70% of European experts on IPF from 15 countries responded that the majority of their patients die in the hospital. Considering the progressive nature of IPF and the limited value of hospitalization in the absence of a transplant option during the final stages of the disease, it is obvious that this number is too high, and other options should be considered and actively advocated.

An interesting difference between our results and those of Dr Wijsenbeek and colleagues has to do with location of death in the hospital. Although in our study, of those who died in our hospital, 33% died in the ICU, in the report by Dr Wijsenbeek and colleagues only 7% died in the ICU. It is hard to assess the reason for this large difference, but it is not surprising considering the difference in ICU bed numbers and their use between different countries.\(^2\) As an example, the United States has seven times more ICU beds per capita compared with the United Kingdom. A large study that assessed the impact of these numbers found significant differences in patterns of admissions of medical patients to the ICU between the United States and the United Kingdom and suggested that the threshold for admission of a medical patient to the ICU in the United States is substantially lower than in the United Kingdom.\(^3\) Generally, patients in the United States had a significantly lower severity of illness, were significantly more likely to be admitted directly from the ED, and included a much larger proportion of the very elderly. Thus, the location of death within the hospital is probably reflective of local practice patterns and availability of ICU beds.

In this context, it is worth mentioning that the Simmons Center is affiliated with a very active, high-volume (>100 per year in the last decade) lung transplant program. Patients with IPF who are pursuing transplant may, in some instances, receive a transplant during or following their ICU admission, and, thus, it is likely that critical care measures would be appropriate and more frequently offered to this population.

A very impressive aspect of the correspondence by Dr Wijsenbeek and colleagues is the implementation of a palliative program that reduced the rate of patients with IPF dying in the hospital by close to 50% to 28%. This is an important finding, because it suggests that active implementation of palliative care may reduce deaths in the hospital, improve the management of the symptoms of patients with IPF in the final stages of their disease, and eventually address the preferences of the patients and their families in the best possible way.

In summary, the correspondence by Dr Wijsenbeek and colleagues reinforces our notion that palliative care has been underused in patients with IPF. We believe that active implementation of palliative care for patients with IPF and discussion of palliative care with patients as soon as the diagnosis is made is critically important. Studies that assess the best ways to educate patients about the disease course and assess patient and family preferences regarding symptom management and palliative care are needed. Perhaps most importantly, a paradigm shift from an afterthought to a foundation of care is required in our approach to palliative care for patients with IPF.

Kathleen O. Lindell, PhD, RN
Margaret Q. Rosenzweig, PhD, ACNP
Joseph Pilewski, MD
Leslie A. Hoffman, PhD, RN
Kevin Gibson, MD
Pittsburgh, PA
Naftali Kaminski, MD
New Haven, CT

AFFILIATIONS: From the University of Pittsburgh Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease at UPMC (Drs Lindell and Gibson), the Division of Pulmonary, Allergy, and Critical Care Medicine (Drs Lindell, Pilewski, and Gibson), and School of Nursing (Drs Rosenzweig and Hoffman), University of Pittsburgh; and Pulmonary, Critical Care, and Sleep Medicine (Dr Kaminski), Yale School of Medicine. Drs Gibson and Kaminski are senior authors.

FINANCIAL/NONFINANCIAL DISCLOSURES: The authors have reported to CHEST the following conflicts of interest: Dr Pilewski has contracts with Vertex Pharmaceuticals Inc, N30 Pharmaceuticals LLC, Constellation Pharmaceuticals, and, previously, with KalaBios Pharmaceuticals Inc. Dr Gibson is a consultant for Gilead Sciences Inc. Dr Kaminski is a consultant to InterMune Inc, Sanofi-Aventis LLC, Biogen Idec Inc, Vertex Pharmaceuticals Inc, Takeda Pharmaceutical Co Ltd, Promedior Inc, Moere Matrix Inc, and Boehringer Ingelheim GmbH;
a past recipient of grants from Gilead Sciences Inc and Celgene Corp; and inventor on patent applications on the use of microRNAs in IPF and on peripheral blood biomarkers in IPF. Drs Lindell, Rosenzweig, and Hoffman have reported that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

**FUNDING/SUPPORT:** This study was supported by the Dorothy P. and Richard P. Simmons endowed chair for Interstitial Lung Disease and the National Institutes of Health [Grant UL1TR000005].

**CORRESPONDENCE TO:** Kathleen O. Lindell, PhD, RN, University of Pittsburgh, Dorothy P. & Richard P. Simmons Center for Interstitial Lung Disease, UPMC, 3459 Fifth Ave, Pittsburgh, PA 15213; e-mail: lindellko@upmc.edu

© 2015 AMERICAN COLLEGE OF CHEST PHYSICIANS. Reproduction of this article is prohibited without written permission from the American College of Chest Physicians. See online for more details.

**DOI:** 10.1378/chest.15-0772

**Acknowledgments**

**Role of sponsors:** The sponsors had no role in the design of the study, the collection and analysis of the data, or the preparation of the manuscript.

**References**

