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ORIGINAL ARTICLE

Trends in place of death in patients with idiopathic pulmonary fibrosis: a ten-year analysis of the United States National Center for Health Statistics WONDER database

Yousaf Hadi[1], Amir Humza Sohail[2], Emily Schiller[3]*, Meher Oberoi[2], Syeda Naqvi[1], Muhammad Aziz[4] Hira Rohail[5], Ali Khan[6]; Muhammad Salman Khan[7], Collin E.M. Brathwaite[2], Micheal Khalife[2], Sarah Hadique[1]

1. Department of Medicine, West Virginia University, Morgantown, West Virginia, United States of America
2. Department of Surgery, NYU Langone Long Island Hospital, Mineola, New York, United States of America
3. NYU Long Island School of Medicine, Mineola, New York, United States of America
4. Department of Medicine, University of Toledo, Toledo, Ohio, United States of America
5. St. George's University School of Medicine, St. George's, Grenada
6. Department of Medicine, Trinity Health Oakland Hospital, Pontiac, Michigan, United States of America
7. Department of Radiology, University of Houston, Houston, Texas, United States of America

*Corresponding author
Emily Schiller
NYU Long Island School of Medicine, Mineola, New York, United States of America
Email: Emily.Schiller@nyulangone.org

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Abstract

Background. Idiopathic pulmonary fibrosis (IPF) has a poor prognosis and carries a high mortality rate. For patients with advanced IPF, death at home or in hospice may be associated with improved quality of life, but data regarding place of death in IPF is lacking.

Aim. To study temporal trends in the place of death for patients dying with IPF.

Methods. We utilized a publicly reported platform to study the place of death in patients with IPF. The United States National Center for Health Statistics (NCHS) WONDER platform was used to access mortality data based on death certificates of all mortalities in the United States for the years 2008-2017. All patients with IPF as the underlying cause of death were included. Mann-Kendall trend test was applied to identify temporal trends.

Results. There were a total of 133200 deaths with IPF as the underlying diagnosis during the study period, with a crude rate of 4.2 per 100,000 deaths. 41%, 21%, 7.5% and 12.5% of deaths occurred in inpatient facilities, at home, in hospice, and in nursing homes/long term care facilities, respectively.
The percentage of deaths in hospice facilities significantly increased during the study period (4.3% in 2008 to 9.6% in 2017; p value < 0.001). This was accompanied by an increase in deaths at home from 26.8% in 2008 to 35.5% in 2017 (p value <0.01) and a decrease in inpatient deaths from 46.9% in 2008 to 36.4% in 2017 (p value <0.01).
A greater proportion of females died in hospice compared to males (7.81% vs 7.27%, p value < 0.0001). Compared to all other race groups, white patients more frequently died in hospice (7.77% vs 4.67%, p value <0.001).

Conclusions. Hospice is underutilized in IPF patients. There is disparity in the use of hospice both in gender and ethnicity, although the disparity in gender may not be clinically relevant.

Relevance for patients. Given the high morbidity and mortality of IPF, early involvement of supportive care and palliation is essential to maximizing the quality of the end-of-life in this patient population.

Keywords: idiopathic pulmonary fibrosis; palliative care; hospice

1. Introduction

Idiopathic pulmonary fibrosis (IPF) is a debilitating disease of unknown cause, which primarily afflicts older adults [1]. It continues to carry a high morbidity and mortality, [2] and is the most common interstitial pulmonary disease worldwide [3]. Lung transplant, available to a small minority of IPF patients, and anti-fibrotic therapy have shown a survival benefit in patients diagnosed with IPF [4]. However, the mean survival of patients from diagnosis is 3-5 years, which is comparable to many malignancies [5, 6]. Patients with IPF, especially in advanced stages, suffer from a large symptom burden including severe shortness of breath, pain, anxiety and depression; these are symptoms that can benefit from hospice and supportive care [7, 8]. Due to the nature of the disease course and poor prognosis, major clinical practice guidelines recommend an integrated approach with early referral to palliative and supportive care, particularly for symptom management [9, 10].

Evidence suggests that a major proportion of IPF patients in the United States die in the inpatient setting and there is low utilization of palliative care in this condition [11]. Further, low hospice utilization in IPF is a phenomenon not unique to the United States [12]. However, high-quality data on end-of-life care, hospice and palliative care utilization and place of death in this cohort are lacking.

We utilized the Center for Disease Control and Prevention (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) platform to study temporal trends in place of death for patients dying with IPF [13].

2. Materials and Methods

2.1. Study Design

This is a retrospective cohort study.

2.2. Data Collection

All patients with IPF as the underlying cause of death in the United States between Jan 1, 2008 and Dec 31, 2017 were included in the study. IPF was defined with the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD 10) code J84.1. Since United States National

Center for Health Statistics (NCHS) WONDER reports all data in ICD-10 code, for deaths before 2009 conversion from ICD-9 to ICD-10 was not required. No patients were excluded from analyses.

The NCHS WONDER platform was used to access mortality data based on death certificates of all mortalities in the United States from Jan 1, 2008 to Dec 31, 2017 [13]. This platform is publicly available and contains data on all deaths in the United States during the reported years. We investigated the place of death and hospice facility utilization rates in patients with IPF. Place of death was categorized as into 7 categories (inpatient, decedent's home, hospice facility, nursing home/long-term care facility, outpatient or emergency room, dead on arrival, and other). Further, the platform was queried to obtain aggregated data on sex (male, female), race (white, non-white) and year of death.

2.3. Statistical Analysis

Mann Kendall trend test was used to obtain the Kendall's Tau coefficient with a 2-sided p value to identify temporal trends in place of death by measuring the rank correlation of nonparametric ordinal variables. The Kendall's Tau coefficient is a test statistic to establish whether two variables (i.e. proportion of deaths in a location and year) may be regarded as statistically dependent. Chi-square test was used to investigate associations between categorical variables and location of death. Race was categorized as white vs non-white to ensure a greater number of patients within each subgroup (and thus a higher statistical power) to detect any difference in place of death between the two categories. All analyses were completed using Stata software (StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC). A p value less than 0.05 was taken as significant.

2.4. Ethics Approval

Given the public availability of data, no approval from the institutional review board was required.

3. Results

There were a total of 133200 deaths with IPF as the underlying diagnosis during the study period, with a crude rate of 4.2 per 100,000 deaths. Crude death rate segregated for males was higher compared to

females (4.7/100,000 versus 3.8/100,000). Crude death rate remained stable, and largely unchanged, during the study period (Range 4.1-4.3/ 100,000).

During the total study period, 41.2% of deaths were reported to have occurred in inpatient facilities. 31.2% of patients died at home. 7.5% of participants died in a hospice facility. 12.5% of deaths were reported in nursing homes/ long term care facilities.

Table 1. Place of death for patients with IPF during the study period (2008-2017)

Place of death	Number	Percentage
Medical Facility – Inpatient	54,817	41.2%
Medical Facility – Outpatient or ER	4,296	3.2%
Medical Facility – Dead on Arrival	277	0.2%
Decedent's home	41,623	31.2%
Hospice facility	10,012	7.5%
Nursing home/long term care facility	16,590	12.5%
Other	4,963	3.7%
Place of death unknown	622	0.5%

Among patients with IPF as the underlying cause of death, inpatient deaths were the most common place of death for all the years included in the study period. The percentage of deaths in hospice facilities significantly increased during the study period of 2008 to 2017 (Mann Kendall trend test tau coefficient: 0.867, 2-sided p value < 0.001), with an absolute change in proportion from 4.3% in 2008 to 9.6% in 2017.

This was accompanied by an increase in deaths at home from 26.8% in 2008 to 35.5% in 2017 (p value <0.01) and a decrease in inpatient deaths from 46.9% in 2008 to 36.4% in 2017 (p value <0.01). These temporal trends are summarized in Table 1 and Figure 1.

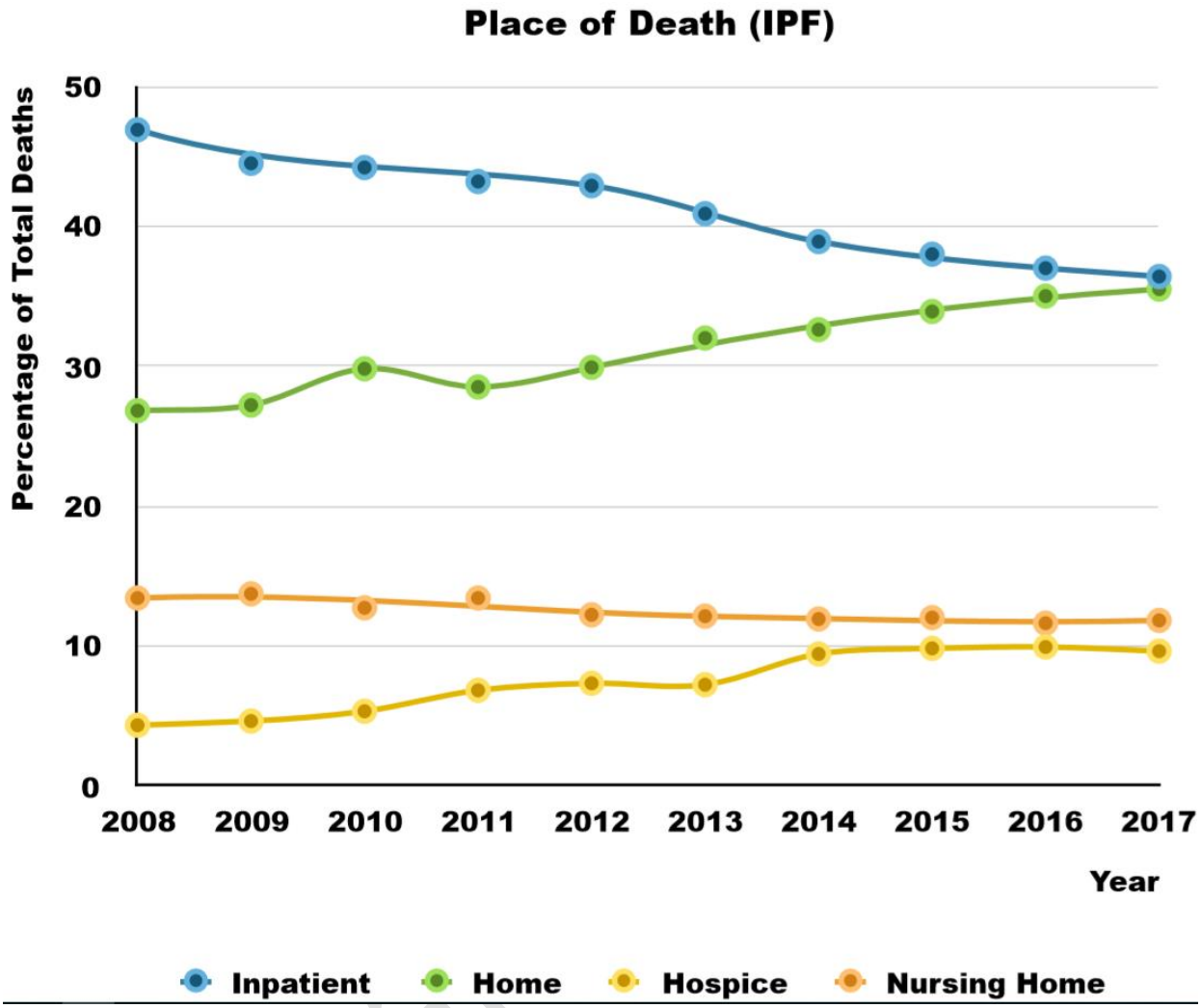

Figure 1. Temporal trends of the place of death in patients with IPF.

A greater proportion of females with IPF died in a hospice facility compared to males during the study period (7.81% vs 7.27%, chi square p value < 0.0001). Compared to all other race groups, white patients more frequently died in a hospice facility during the study period (7.77% vs 4.67%, p value <0.001). The percentage of deaths in hospice for lung neoplasms, chronic obstructive pulmonary disease (COPD), and IPF are juxtaposed in Figure 2.

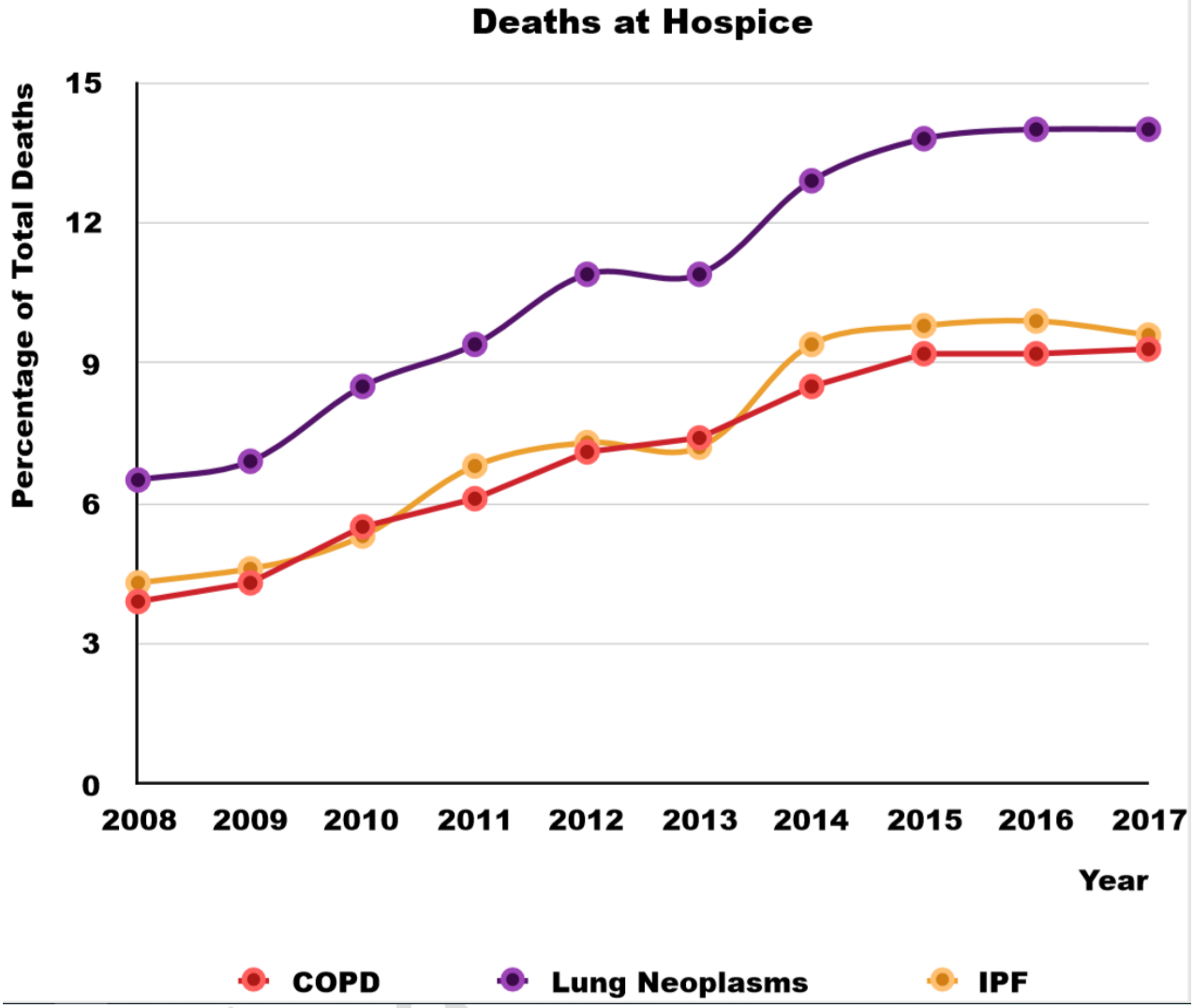

Figure 2. The percentage of deaths in hospice for lung neoplasms, COPD, and IPF.

4. Discussion

Our study captures a cross sectional 'snapshot' of the state of the place of death and end of life care in IPF patients in the United States. It reaffirms and cements the concerns related to end-of-life care in these patients and the significant need for improvement in this realm. This data shows that while the proportion of patients with IPF dying in hospice facilities has considerably increased in the past 10 years (percentage of deaths in hospice facilities increased from 4.3% to 9.6% in the period 2008-2017), inpatient facilities

are still the most common place of death for these patients. Ethnic and gender disparities also exist in hospice utilization in IPF patients.

Previous studies have shown that patients with non-malignancy related terminal illnesses are less likely to receive palliative care referrals compared to patients with a diagnosed malignancy [14]. Rajala et al reported that patients with IPF spent 15% of their last 6 months of life in the hospital and a vast majority died there [11]. Another study conducted in the United States on the registry of a specialized IPF center noted that the majority of their patients died in a hospital [15]. It is noteworthy that only one national database study is available, and in that Scandinavian study by Ahmadi et al., low end of life care utilization rates were found in an IPF sample with a mean survival rate of only 8.4 months [12]. Thus, it can be inferred that a healthcare system bias and deficiency exists in referring non-cancer patients, who may have a prognosis just as poor, to palliative and supportive care.

Interestingly, we found that hospice death rates are significantly lower for non-white populations (4.67%) versus white patients (7.77%). Previous studies have highlighted racial disparity in the uptake of end-of-life care in other disease populations [16]. This disparity may be related to both social and cultural reasons, but physician biases and perceptions may also be contributory. It is unknown if this is related to low acceptability of palliative and supportive care in the non-white population or if a healthcare system deficiency exists in offering such care to these patients. More data is needed to explore the perceptions of minority patients and the healthcare system practice in this regard.

Our study also showed a significantly higher hospice facility utilization among females (7.81%) as compared to males (7.27%). While statistically significant, the small difference may not be of clinical importance. Further, it is difficult to comment whether there are any associated factors underlying this disparity.

There are, however, some limitations in our study. Owing to the design of the study, definitive conclusions cannot be drawn regarding palliative and supportive care referrals that these patients receive. We have relied on the documented ‘underlying cause of death’ on death certificates to identify our population, and thus misclassifications of the underlying reported cause of death may also be a concern;

however, owing to the large, captured sample, any such 'pollution' in this data likely represents a minor challenge with negligible effect on the conclusions drawn from it.

Given the clinical course of disease and high morbidity and mortality, more emphasis needs to be placed on early involvement of supportive care and palliation in end stage IPF to improve end of life care in these patients. Thus, healthcare providers dealing with patients with non-cancer conditions with severe symptoms and poor long-term prognosis and survival, particularly IPF, must be cognizant of this; this can be achieved through a greater emphasis during medical education and training.

From a research standpoint, our study highlights several gaps in literature on place of death, and utilization of end-of-life care in IPF patients. Data on acceptability of supportive care from an IPF patient standpoint, factors underlying the ethnic disparities observed in the study, factors hindering further utilization of hospice are lacking and this should be investigated in future research.

Inpatient facilities constitute the most common place of death for IPF patients, with only 7.5% of IPF patients dying in hospice facilities. However, there was a significant uptrend in proportion of deaths in hospice facilities in IPF patients between 2008 and 2017. There is disparity in place of death in gender and ethnicity. Compared to all other race groups, white patients more frequently died in a hospice facility. Similarly, a greater proportion of females died in hospice compared to males, although the difference may not be clinically significant.

Conflict of interest

The authors declare no conflict of interest.

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