CHEST

Differences in Health Care and Palliative Care Use at the End of Life

A Comparison Study Among Lung Cancer, COPD, and Idiopathic Pulmonary Fibrosis

Angela O. Suen, MD; Kara Bischoff, MD; Anand S. Iyer, MD, MSPH; Keerthana Radhakrishnan, MS; Cynthia Fenton, MD; Jonathan P. Singer, MD; Rebecca L. Sudore, MD; Ashwin Kotwal, MD; and Erica Farrand, MD

BACKGROUND: Patients with lung cancer, idiopathic pulmonary fibrosis (IPF), and COPD have high symptom burden, poor quality of life, and high health care use at the end of life. Although proactive integration of palliative care in lung cancer can improve outcomes, it is unclear whether similar practices have been adopted in COPD and IPF care.

RESEARCH QUESTION: Do patients with COPD and IPF have different patterns of health care and palliative care use at the end of life compared with patients with lung cancer?

STUDY DESIGN AND METHODS: We retrospectively identified deceased patients with lung cancer, COPD, or IPF with ≥ 1 outpatient visit at the University of California, San Francisco, in the last 6 months of life. We compared outpatient palliative care and opioid prescriptions, inpatient palliative care, hospitalizations, intensive care use, and in-hospital death in the last 6 months of life between each group. We used multivariable logistic regression to calculate adjusted ORs (aORs) of each outcome, with lung cancer as the reference group.

RESULTS: Among 1,819 patients, patients with COPD and IPF were more likely to be male and older at the time of death compared with patients with lung cancer. Compared with patients with lung cancer, patients with COPD and IPF showed a lower adjusted odds ($P <$ .001) of receiving outpatient palliative care (COPD: aOR, 0.26 [95% CI, 0.19-0.36]; IPF: aOR, 0.48 [95% CI, 0.32-0.70]), outpatient opioid prescription (COPD: aOR, 0.50 [95% CI, 0.40-0.63]; IPF: aOR, 0.40 [95% CI, 0.29-0.54]), and a higher odds of end-of-life ICU use (COPD: aOR, 2.88 [95% CI, 2.11-3.93]; IPF: aOR, 4.15 [95% CI, 2.66-6.49]). Patients with IPF showed higher odds of receiving inpatient palliative care (aOR: 2.02 [95% CI, 1.30-3.13]; $P = .002$).

INTERPRETATION: This study showed that patients with COPD and IPF are less likely to receive outpatient palliative care and opioid prescriptions and are more likely to use end-of-life intensive care than patients with lung cancer. Further research should explore health system barriers contributing to differences in care patterns to optimize quality of life and to align with patient goals of care.

CHEST 2024; 166(6):1487-1496

KEY WORDS: advanced lung disease; COPD; end of life; idiopathic pulmonary fibrosis; palliative care

FOR EDITORIAL COMMENT, SEE PAGE 1277

ABBREVIATIONS: aOR = adjusted OR; IPF = idiopathic pulmonary fibrosis; UCSF = University of California, San Francisco

AFFILIATIONS: From the Division of Pulmonary, Allergy, and Critical Care Medicine, Department of Medicine (A. O. S., J. P. S., and E. F.), the Division of Palliative Medicine, Department of Medicine (K. B.), the Division of Hospital Medicine, Department of Medicine (K. R. and C. F.), the Division of Geriatrics, Department of Medicine (R. L. S. and A. K.), University of California San Francisco; the Department of Medicine, San Francisco VA Medical Center (R. L. S. and A. K.), San Francisco, CA; the Division of Pulmonary, Allergy, and Critical Care Medicine, Division of Gerontology, Geriatrics, and Palliative Care, and School of Nursing (A. S. I.), University of Alabama at Birmingham; and the, Birmingham Veterans Affairs Medical Center (A. S. I.), Geriatrics Research Education and Clinical Center, Birmingham, AL.

CORRESPONDENCE TO: Angela O. Suen, MD; email: angela.suen@ucsf.edu

DOI: https://doi.org/10.1016/j.chest.2024.08.018

Take-home Points

Study Question: Do patients with COPD and idiopathic pulmonary fibrosis (IPF) have different patterns of health care and palliative care use at the end of life compared with patients with lung cancer?

Results: In a single-center study, patients with COPD and IPF were less likely to receive outpatient palliative care and symptom-focused care and were more likely to use intensive care at the end of life than patients with lung cancer.

Interpretation: Interventions are needed to guide earlier palliative care integration and to identify when and how best to integrate palliative care for those living with advanced COPD and IPF.

COPD and idiopathic pulmonary fibrosis (IPF) are serious respiratory illnesses marked by recalcitrant symptoms, significant functional decline over time, and high health care use near the end of life.[1-6] Disease-modifying treatments may help to avoid exacerbations and may slow disease progression, but may not alleviate symptoms fully and do little to alter the disease trajectory, particularly in later stages of the disease.[7,8] People with advanced COPD or IPF often experience refractory dyspnea and cough for longer periods than those with lung cancer, indicating a high need for symptom support.[9,10] Furthermore, these symptoms have significant impacts on emotional well-being, health-related quality of life, and ability to carry out activities of daily living.[11] If left unaddressed, these factors can contribute to high end-of-life health care use, which is costly and is not aligned with patient preferences.[12,13]

Palliative care is a medical specialty focused on alleviating symptoms and supporting patients and their families at any stage of a serious illness.[14] Importantly, palliative care can be provided concurrently with disease-modifying treatment.[14] Integration of palliative care into chronic disease care models was pioneered in oncology. Multiple studies have demonstrated that proactive palliative care integration in the management of patients with lung cancer improves overall survival, reduces symptom burden, eases the suffering of patients and their families, and is associated with reduced health care use at the end of life.[15-18] Given these multiple demonstrated benefits, early palliative care now is part of the gold standard of management for patients with lung cancer.[19] Multiple thoracic societies now call for more proactive palliative care integration into the ambulatory setting for people with serious respiratory illness.[20-22]

Studies suggest that palliative care use in COPD and interstitial lung disease at the end of life is low.[4,9,23-26] When it is used, palliative care often is introduced late, when opportunities for benefit may be reduced.[3,27] However, these studies use older data in a time when palliative care may not be available widely. Palliative care has expanded by over 200% since the early 2000s,[28] and studies using recent data are needed to provide insights on the current landscape. Furthermore, a comparison of COPD and IPF with lung cancer as the reference reveal ongoing differences in health care and palliative care use that can inform future efforts to increase integrated palliative care in COPD and IPF. To our knowledge, one study previously examined this, but was limited to ICU decedents.[23]

To begin to address this knowledge gap, we performed a single-center cohort study of palliative care and health care use in COPD and IPF compared with lung cancer. We performed this study in an academic institution with a well-established palliative care practice serving patients with cancer and noncancer serious illness.[29,30] We sought to identify use differences that could represent potential gaps in care models between these serious respiratory illnesses. We hypothesized that adults with COPD and IPF would have lower palliative care use and higher end-of-life inpatient care, including intensive care, than those with lung cancer.

Study Design and Methods

Study Setting and Design

This cohort study leveraged both inpatient and outpatient electronic health record data from a quaternary-level hospital system (University of California, San Francisco [UCSF]). UCSF has two outpatient palliative care services for people with cancer and noncancer serious illnesses. Both services use interdisciplinary teams consisting of a physician or a nurse practitioner, as well as social work, nursing, and pharmacy support to provide high-quality palliative care, including symptom management, advance care planning, and patient and caregiver support. Patients are referred to outpatient palliative care services per referring provider discretion; no referrals are triggered, nor are referral criteria universally agreed on. Neither outpatient palliative care team is physically embedded in the same

space as referring providers (eg, thoracic oncologists or pulmonologists), although the palliative care and referring teams do collaborate in the care of patients. The Consolidated Standards of Reporting Trials diagram summarizing our study sample appears in Figure 1.

Patient Population

We identified 2,918 patients who died between January 1, 2015, and December 31, 2022, and met criteria for at least one of three diagnoses: lung cancer, COPD, and IPF. We used validated diagnostic criteria and registry data to identify: (1) 1,493 patients with biopsy-proven lung cancer from the cancer registry of the UCSF Hellen Diller Family Comprehensive Cancer Center, (2) 1,052 patients aged 35 years or older with COPD and at least one outpatient and one inpatient encounter for COPD using International Classification of Diseases, Ninth Revision, Clinical Modification codes (discharge diagnosis codes J41-J44 and outpatient diagnosis codes 491, 492, 493.2, and 496) within 5 years before death,[31] and (3) 530 patients with IPF who either met validated diagnostic criteria[32] or were identified from the UCSF Interstitial Lung Disease longitudinal database. We used the California Death Registry to verify date of death. We excluded 153 patients who had > 1 diagnosis and 946 patients who had no outpatient visits in the 6 months before death, yielding a final sample of 1,819 patients with lung cancer, COPD, or IPF who received care at UCSF in the last 6 months of life. This study was approved by the institutional review board (No. 19-29222) at UCSF.

Palliative Care and Health Care Use

Inpatient and outpatient palliative care services at UCSF for oncologic and nononcologic disease were available during the study period.[29,30] Outcomes studied were palliative care and health care use in the 6 months before death. Palliative care use included outpatient palliative care visits, opioid prescriptions, and inpatient palliative care consultations. We measured opioid prescriptions as a limited proxy for symptom-focused care provided

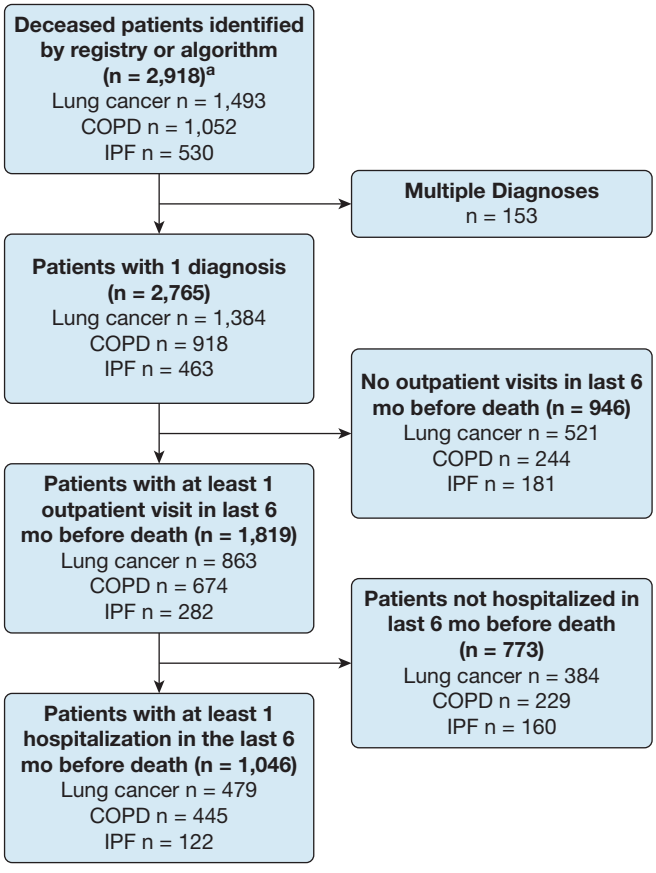

Figure 1 – *Consolidated Standards of Reporting Trials diagram.* [a]*Numbers represent the total number of patients and not the total number of diagnoses, because patients may have > 1 diagnosis. IPF = idiopathic pulmonary fibrosis.*

by any member of the health care team. Opioid use was extracted from the medication list in the electronic health record, which then was verified by medical staff and may include self-reported opioids if prescribed outside of the UCSF system. Health care use outcomes included hospitalizations, use of high-flow nasal cannula (which can be provided on the medical wards and in the ICU), ICU admissions, use of mechanical ventilation, and in-hospital deaths.

Participant Characteristics and Covariates

Sociodemographic and clinical information included age, sex, race and ethnicity, and comorbidities using the validated, weighted Charlson Comorbidity Index, where an increasing score is associated with a higher risk of death at 10 years.[33]

Statistical Analysis

We first examined differences in baseline demographics and health care use among the three groups using Rao-Scott χ^2 tests. We then used multivariable logistic regression to determine the adjusted ORs (aORs) of end-of-life palliative care and health care use in COPD and IPF using lung cancer as the reference group. We adjusted for the following covariates, selected a priori because of their known impact on end-of-life health care and palliative care use: age, sex, race and ethnicity, and Charlson Comorbidity Index. To study inpatient health care use, we limited the sample to those who had at least one hospitalization in the last 6 months of life. We then performed a sensitivity analysis adjusting the thresholds of outpatient visits ($\geq$ 2, 3, and 5 outpatient visits). These sensitivity analyses ensured that the study population was representative of patients who regularly receive care at UCSF and that the results were reproducible in those with multiple diagnoses, which likely represents a sicker cohort. We performed statistical analysis using STATA version 18 software (StataCorp).

Results

Of the 1,819 patients, 863 patients (47.4%) had lung cancer, 674 patients (37.0%) had COPD, and 282 patients (15.5%) had IPF. Demographic data of patients with lung cancer, COPD, and IPF are summarized in Table 1. Overall, patients with COPD and IPF were older at time of death and were more likely to be male ($P < .001$) than patients with lung cancer. Patients with

TABLE 1] Demographic Table Stratified by Diagnosis (N = 1,819)

Variable	Lung Cancer	COPD	IPF	Total	*P* Value
No. of patients	863 (47.4%)	674 (37.0%)	282 (15.5%)	1,819	NA
Age at time of death, y					< .001
30-50	45 (5.2%)	8 (1.2%)	0	53 (2.9%)	
51-70	406 (47.1%)	178 (26.4%)	105 (37.2%)	689 (37.9%)	
71-90	391 (45.3%)	373 (55.3%)	166 (58.9%)	930 (51.1%)	
91-110	21 (2.4%)	115 (17.1%)	11 (3.9%)	147 (8.1%)	
Mean age, y	69.6 (11.5)	78.0 (12.2)	74.0 (10.2)	73.4 (12.2)	< .001
Sex					< .001
Female	441 (51.1%)	303 (45.0%)	104 (36.9%)	848 (46.6%)	
Male	422 (48.9%)	371 (55.0%)	178 (63.1%)	971 (53.4%)	
Race or ethnicity					< .001
White	459 (53.2%)	346 (51.3%)	163 (57.8%)	968 (53.2%)	
Black	62 (7.2%)	95 (14.1%)	8 (2.8%)	165 (9.1%)	
Latinx	50 (5.8%)	47 (7.0%)	41 (14.5%)	138 (7.6%)	
Asian	232 (26.9%)	146 (21.7%)	42 (14.9%)	420 (23.1%)	
Native American	2 (0.2%)	1 (0.2%)	3 (1.1%)	6 (0.3%)	
Native Hawaiian	9 (1.0%)	2 (0.3%)	2 (0.7%)	13 (0.7%)	
Charlson Comorbidity Index	10.2 (2.7)	8.8 (4.3)	6.1 (4.5)	9.0 (3.9)	< .001
Home oxygen use	148 (17.2%)	172 (25.5%)	45 (16.0%)	365 (20.1%)	< .001

Data are presented as No. (%) or mean (SD). IPF = idiopathic pulmonary fibrosis; NA = not applicable.

TABLE 2] Proportion of Patients With Lung Cancer, COPD, and IPF Using Palliative Care and Health Care in the Last 6 Months of Life (N = 1,819)

Variable	Lung Cancer	COPD	IPF	Total	*P* Value
No. of patients	863 (47.4)	674 (37.0)	282 (15.5)	1,819	NA
Palliative care use					
Palliative care visit(s)	294 (34.1)	62 (9.2)	42 (14.9)	398 (21.9)	< .001
Outpatient opioid prescription	626 (72.5)	344 (51.0)	119 (42.2)	1,089 (59.9)	< .001
Inpatient palliative care consultation[a]	165 (34.5)	108 (24.3)	52 (42.6)	325 (31.1)	< .001
Health care use					
Hospitalization(s)	479 (55.5)	445 (66.0)	122 (43.3)	1,046 (57.5)	< .001
High-flow nasal cannula use[a]	70 (14.6)	65 (14.6)	33 (27.1)	168 (16.1)	.002
ICU admission[a]	139 (29.0)	195 (43.8)	68 (55.7)	402 (38.4)	< .001
Ventilator use[a]	62 (12.9)	91 (20.5)	38 (31.2)	191 (18.3)	< .001
In-hospital death[a]	146 (30.5)	172 (38.7)	58 (47.5)	376 (36.0)	.001

Data are presented as No. (%) unless otherwise indicated. IPF = idiopathic pulmonary fibrosis; NA = not applicable.
[a]Outcomes in inpatient health care use have a different denominator to include only those who were hospitalized (n = 1,046).

IPF had fewer comorbidities than those with lung cancer or COPD (6.1 vs 10.2 vs 8.8, respectively; $P < .001$). More patients with COPD used supplemental oxygen than those with lung cancer or IPF (25.5% vs 17.2% vs 16%, respectively; $P < .001$).

Unadjusted palliative care and health care use in the last 6 months of life are described in Table 2. Overall, patients with lung cancer were more likely to receive outpatient palliative care compared with patients with COPD or IPF (34% vs 9% vs 15%, respectively; $P < .001$). More patients with lung cancer received an opioid prescription than either patients with COPD or those with IPF (73% vs 51% vs 42%, respectively; $P < .001$). Compared with patients with lung cancer, fewer patients with COPD and more patients with IPF received inpatient palliative care consultations (35% vs 24% vs 43%, respectively; $P < .001$). Fewer patients with IPF were hospitalized at the end of life than either patients with COPD or those with lung cancer (lung cancer, 56%; COPD, 66%; IPF, 43%; $P < .001$). Compared with patients with lung cancer, patients with COPD and those with IPF showed higher intensive care use at the end of life, including ICU admission (29% vs 44% vs 56%, respectively; $P < .001$) and mechanical ventilation (13% vs 21% vs 31%, respectively; $P < .001$). More patients with IPF used high-flow nasal cannula than either patients with lung cancer or those with COPD (lung cancer, 15%; COPD, 15%; IPF, 27%; $P = .002$). Finally, a higher proportion of patients with COPD and IPF died during hospitalization than patients with lung cancer (31% vs 39% vs 48%; $P = .001$).

A forest plot of aORs of end-of-life palliative care and other health care use in COPD vs lung cancer is depicted in Figure 2. Compared with lung cancer, patients with COPD showed lower odds of outpatient palliative care visits (aOR, 0.26; 95% CI, 0.19-0.36; $P < .001$), lower odds of receiving an outpatient opioid prescription (aOR, 0.50; 95% CI, 0.40-0.63; $P < .001$), and similar odds of receiving an inpatient palliative care consultation (aOR, 0.91, 95% CI, 0.66-1.25; $P = .545$). Patients with COPD showed higher odds of inpatient health care use in the last 6 months of life, including hospitalization (aOR, 2.23; 95% CI, 1.75-2.84; $P < .001$), ICU admission (aOR, 2.88; 95% CI, 2.11-3.93; $P < .001$), and mechanical ventilator use (aOR, 2.48; 95% CI, 1.68-3.66; $P < .001$). A trend toward higher odds of high-flow nasal cannula use (aOR, 1.38; 95% CI, 0.92-2.06; $P = .12$) in patients with COPD was found; however, this finding was not statistically significant. Patients with COPD showed a higher odds of dying in the hospital compared with patients with lung cancer (aOR, 1.73; 95% CI, 1.27-2.35; $P < .001$).

A forest plot of aORs of end-of-life palliative care and other health care use in IPF vs lung cancer is depicted in Figure 3. Compared with patients with lung cancer, patients with IPF showed lower odds of outpatient palliative care visits (aOR, 0.48; 95% CI, 0.32-0.70; $P < .001$), lower odds of outpatient opioid prescription (aOR, 0.40; 95% CI, 0.29-0.54; $P < .001$), and higher odds of receiving an inpatient palliative care consultation (aOR, 2.02; 95% CI, 1.30-3.13; $P = .002$). Patients with IPF showed similar odds of inpatient

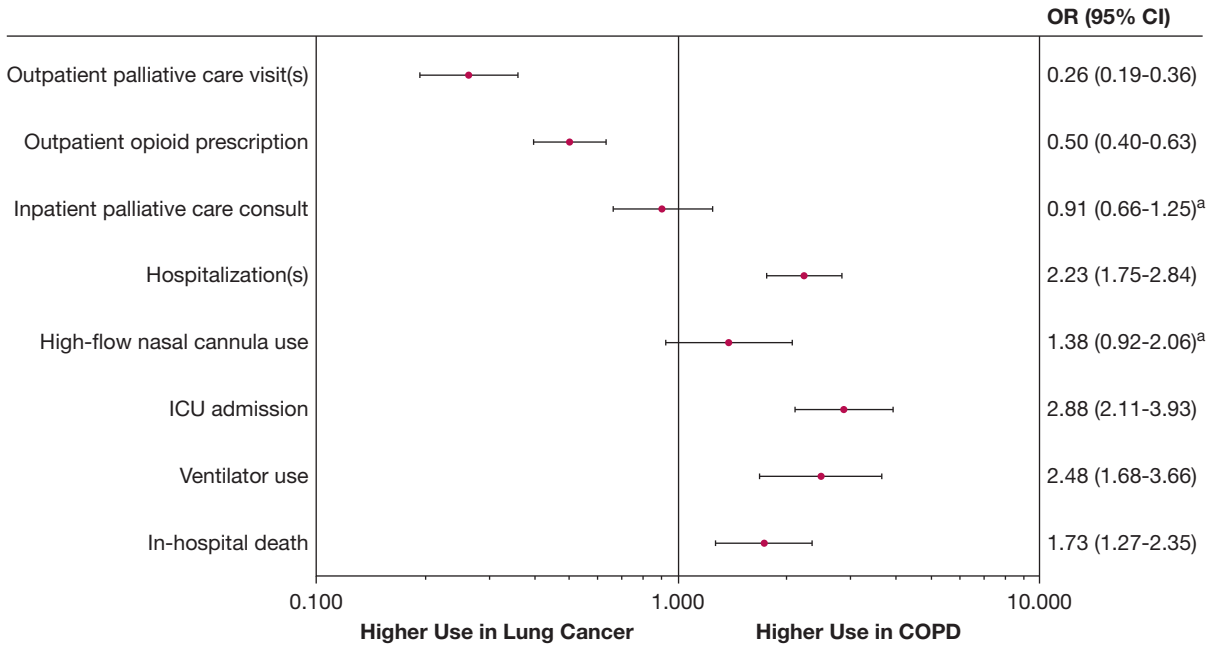

Figure 2 – *Forest plot showing adjusted ORs for end-of-life health care and palliative care use in COPD compared with lung cancer in the last 6 months of life. Models are adjusted for age, sex, race and ethnicity, and Charlson Comorbidity Index.* [a]P *value* $> .05$*, not statistically significant; all other ORs have* P *value of* $< .001$.

hospitalization (aOR, 1.14; 95% CI, 0.83-1.57; $P = .411$); however, after being hospitalized, patients with IPF showed higher intensive care use, including high-flow nasal cannula use (aOR, 2.88; 95% CI, 1.73-4.82; $P < .001$), ICU admission (aOR, 4.15; 95% CI, 2.66-6.49; $P < .001$), and mechanical ventilator use (aOR, 3.69; 95% CI, 2.22-6.13; $P < .001$). Finally, patients with IPF showed higher odds of dying in the hospital compared with patients with lung cancer (aOR, 2.24; 95% CI, 1.46-3.46; $P < .001$). Our sensitivity analysis using different thresholds of outpatient care use yielded similar results for both the COPD and IPF cohorts.

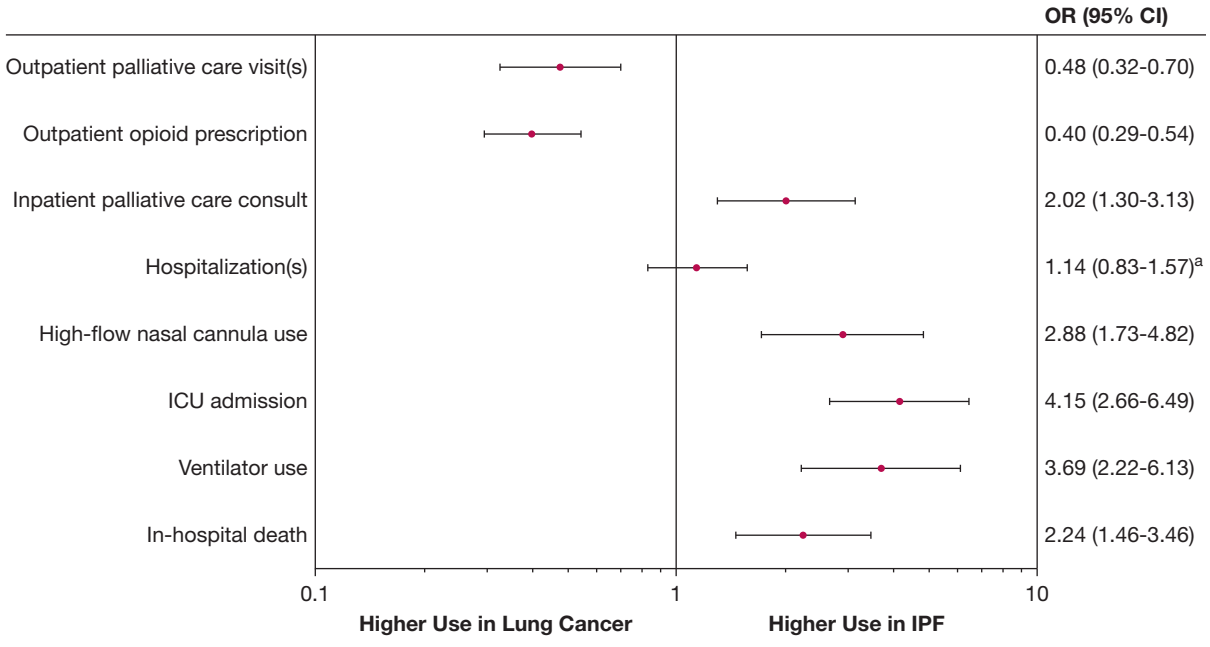

Figure 3 – *Forest plot showing adjusted ORs for end-of-life health care and palliative care use in idiopathic pulmonary fibrosis compared with lung cancer in the last 6 months of life. Models are adjusted for age, sex, race and ethnicity, and Charlson Comorbidity Index.* [a]P $< .05$*; otherwise,* P $< .001$.

Discussion

In this single-center cohort study in a quaternary academic medical center with robust outpatient and inpatient palliative care services, we found that patients with COPD and IPF showed marked differences in end-of-life health care use. In particular, these patients showed lower use of outpatient palliative care, higher intensive care use including ventilator use, and higher rates of in-hospital death in the last 6 months of life when compared with those with lung cancer. Patients with COPD were more likely to be hospitalized than either patients with lung cancer or IPF. Patients with COPD and IPF have been found to have similar end-of-life care preferences as patients with lung cancer: to avoid the hospital and maximize time at home.[34,35] Therefore, the high intensity of inpatient end-of-life care and lower outpatient palliative care may reflect goal-discordant care and an opportunity to improve the alignment of patient preferences with care received.[24] Overall, our findings suggest a need for palliative care integration in the care of patients with COPD and IPF.

Our side-by-side comparison reveals unique differences in which palliative care is used across two chronic lung diseases. Despite the availability of a robust integrated palliative care team in oncology and chronic lung disease at this quaternary medical center, patients with COPD and IPF showed lower outpatient palliative care use and opioid use compared with patients with lung cancer. Furthermore, patients with COPD at the end of life showed lower outpatient and inpatient palliative care use compared with patients with IPF, suggesting that an even larger palliative care gap exists for patients with COPD than those with IPF. These differences may be the result of several potential health system and patient-level barriers. Given the slowly progressive nature of COPD, it may be challenging for clinicians to identify the final stages of COPD and to determine the optimal timing and suitability of a palliative care referral.[22] People with COPD can be overly optimistic about prognosis and can normalize their symptoms, leading to patient preferences to avoid involvement of an additional medical specialty.[36] Both clinicians and patients may have misconceptions about palliative care as being purely end-of-life care or hospice care.[22] Consequently, clinicians might address potential misconceptions early in the disease course and normalize palliative care engagement.

Although patients with IPF and those with lung cancer showed similar hospital use at the end of life, patients with IPF were much more likely to use intensive care and inpatient palliative care consultations. We hypothesize that this observation is in part the result of the natural course of IPF, in which a minority of patients with IPF go on to experience an acute exacerbation.[37] However, those who do demonstrate an acute exacerbation of IPF have high rates of intensive care use for hypoxemic respiratory failure and mortality rates of $\geq$ 50%.[37] Our study found that more than one-half of all patients with IPF who were hospitalized required high-flow nasal cannula or mechanical ventilation. Other than supportive therapy (perhaps a limited trial of steroids and lung transplantation, where available), no definitive treatments exist for an IPF exacerbation.[37-39] In the absence of prior advance care planning to guide treatment decisions, patients and families would have substantial inpatient palliative care needs with complex decision-making, symptom management, and increased patient and family support in the setting of critical illness. More work is needed to understand the circumstances with which an inpatient palliative care consultation is ordered, because it will yield insights into whether and how outpatient palliative care support can improve serious illness communication, advance care planning, and the delivery of goal-concordant care.[40]

Looking to the future for COPD and IPF, we need to consider when palliative care should be involved, who should receive specialty palliative care services, and how pulmonary and palliative care teams should best collaborate. Consensus exists for early introduction of palliative care as part of primary palliative care provided by clinicians.[41,42] Primary palliative care can be provided by primary care and pulmonologists and is directed at advance care planning and basic management of physical symptoms and psychosocial needs.[43] It should be provided early in the disease course and alongside disease-modifying treatment with planned transition to specialty palliative care with disease progression and increasing needs.[21,22,43] Primary palliative care frameworks in pulmonary medicine only recently have been generated and have not been adopted broadly into clinical practice, but are showing early promise.[21,22] For example, patients with IPF and their families reported that early advance care planning discussions were valuable and helped them to prepare for the future and to preserve patient agency.[40,44] Although many pulmonary and critical care physicians may have received some serious illness communication training in the ICU, those strategies may not prepare them adequately to provide the care that is needed in the outpatient setting.[45] Future

work should include training for pulmonary clinicians to provide primary palliative care.

Second, research is needed to identify the optimal model and timing for when specialty palliative care is indicated. Specialty palliative care is provided by clinicians who completed specialty training in palliative care and who care for those with complex needs.[41,43] The outpatient palliative care team in our health system, like many others, is highly interdisciplinary, consisting of nurses, social workers, spiritual care providers, and physicians who work together to provide comprehensive support for both patients and their families throughout a serious illness.[29] It is an intensive resource, and optimal timing is important to ensure that those who benefit the most receive the extra support. Kalluri et al[46] demonstrated efficacy using a palliative care model in which palliative care was integrated into a multidisciplinary interstitial lung disease clinic and showed that this model reduced symptom burden as well as end-of-life acute and intensive care use.[47] In contrast, qualitative work by Iyer et al[48] showed that patients preferred specialty palliative care introduction at moderate stages of COPD. Palliative care guidelines in COPD proposed by Iyer et al[22] recommend a "levers" approach in which specialty palliative care is triggered based on symptoms, worsening lung function, or frequent severe exacerbations. Finally, it is unknown how both teams should collaborate. Work to develop integrated palliative care approaches in COPD and IPF is ongoing, and early results suggest that outpatient palliative care can improve patient-oriented outcomes and goal-concordant care at the end of life.[21,30,46-49] Certainly, integration should be specific to the disease and local health care environment. Whether palliative care is integrated into primary care, general pulmonology and subspecialty pulmonary clinics will depend on where patients with COPD and IPF are accessing care and the availability of local resources.

Our study outcomes of specialty palliative care use and opioid prescriptions do not provide a comprehensive overview of high-quality palliative care or primary palliative care use.[50] We used opioid prescriptions as a limited proxy for receipt of symptom-focused care at the end of life. Detailed information (such as indication, dosing, frequency of medication, fill history, and symptom relief) is needed to determine if these treatments are actually used or effective. Future work should include other domains of high-quality palliative care such as advance care planning, attending to psychological or social support needs, spiritual or religious aspects of care, or hospice use. Furthermore, studies of effective palliative care should take into consideration symptom burden. We are not able to stratify patients by symptom burden or exacerbation frequency, and this limits our ability to understand differences in potential unmet palliative care needs of patients with COPD, IPF, or lung cancer.

Our study has several limitations. First, although our health system is a large-volume center for lung cancer, COPD, and IPF, this is a single-centered study, and findings may not be generalizable. On average, the availability of specialty palliative care for noncancer illness tends to be lower in other health systems compared with our center,[51] and so we speculate that on average other health systems may have more pronounced differences in care patterns. Second, our results may underestimate actual health care use because our health system serves as a referral center and patients have received care outside of UCSF. To circumvent this, we performed a series of sensitivity analyses using different thresholds of outpatient visits to identify those who use our health care system consistently. Finally, we were unable to qualify severity of disease or to use death data to clarify cause of death, and so we cannot determine if patients died directly of their lung disease.

Interpretation

Our results indicate that patients with COPD and IPF are less likely to receive outpatient palliative care and are more likely to use intensive care at the end of life than patients with lung cancer. Interventions are needed to guide earlier palliative care integration and to identify when and how best to integrate palliative care for those living with advanced COPD and IPF.

Funding/Support

This study was supported by the National Institutes of Health [Grants T32AG000212 (A. O. S.), K76AG064327 (A. S. I.), U01HL145435 (J. P. S.), K24AG054415 (R. L. S.), and K23AG065438 (A. K.)]. E. F. is supported by the Doris Duke Foundation [Grant 2022049].

Financial/Nonfinancial Disclosures

The authors have reported to *CHEST* the following: A. S. I. reports consulting fees from AstraZeneca, Verona, and Medscape outside the scope of this study. A. K. reports a grant from Humana Inc and research consulting fees from Papa Health outside the submitted work. None declared (A. O. S., K. B., K. R., C. F., J. P. S., R. L. S., E. F.).

Acknowledgments

Author contributions: A. O. S., K. B., and E. F. had full access to all study data and take responsibility for data integrity and accuracy. Concept and design: A. O. S. and E. F. Acquisition, analysis, or data interpretation: A. O. S., K. B., A. S. I., J. P. S., C. F., K. R., and E. F. Manuscript writing and revision: A. O. S., K. B., A. S. I., J. P. S., R. L. S., A. K., and E. F. Administrative, technical, or material support: C. F. and K. B. Supervision: K. B. and E.F.

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

References

1. Habraken JM, ter Riet G, Gore JM, et al. Health-related quality of life in end-stage COPD and lung cancer patients. *J Pain Symptom Manage*. 2009;37(6):973-981.
2. Cox IA, Arriagada NB, De Graaff B, et al. Health-related quality of life of patients with idiopathic pulmonary fibrosis: a systematic review and meta-analysis. *Eur Respir Rev*. 2020;29(158):1-22.
3. Iyer AS, Goodrich CA, Dransfield MT, et al. End-of-life spending and healthcare utilization among older adults with chronic obstructive pulmonary disease. *Am J Med*. 2020;133(7):817-824.e1.
4. Au DH, Udris EM, Fihn SD, McDonell MB, Curtis JR. Differences in health care utilization at the end of life among patients with chronic obstructive pulmonary disease and patients with lung cancer. *Arch Intern Med*. 2006;166(3):326.
5. Farrand E, Iribarren C, Vittinghoff E, et al. Impact of idiopathic pulmonary fibrosis on longitudinal health-care utilization in a community-based cohort of patients. *Chest*. 2021;159(1):219-227.
6. Farrand E, Collard HR, Guarnieri M, et al. Extracting patient-level data from the electronic health record: expanding opportunities for health system research. *PLoS One*. 2023;18(3):e0280342.
7. Maher TM, Strek ME. Antifibrotic therapy for idiopathic pulmonary fibrosis: time to treat. *Respir Res*. 2019;20(1):205.
8. Carette H, Zysman M, Morelot-Panzini C, et al. Prevalence and management of chronic breathlessness in COPD in a tertiary care center. *BMC Pulm Med*. 2019;19(1):95.
9. Ahmadi Z, Lundström S, Janson C, et al. End-of-life care in oxygen-dependent COPD and cancer: a national population-based study. *Eur Respir J*. 2015;46(4):1190-1193.
10. Luckett T, San Martin A, Currow DC, Johnson MJ, Barnes-Harris MM, Phillips JL. A systematic review and meta-analysis of studies comparing burden from lung cancer and chronic obstructive pulmonary disease. *Palliat Med*. 2020;34(10):1291-1304.
11. Yohannes AM, Murri MB, Hanania NA, et al. Depressive and anxiety symptoms in patients with COPD: a network analysis. *Respir Med*. 2022;198:106865.
12. Iyer AS, Bhatt SP, Garner JJ, et al. Depression is associated with readmission for acute exacerbation of chronic obstructive pulmonary disease. *Ann Am Thorac Soc*. 2016;13(2):197-203.
13. Iyer A, Wells JM, Bhatt SP, et al. Life-space mobility and clinical outcomes in COPD. *Int J COPD*. 2018;13:2731-2738.
14. Center to Advance Palliative Care. About palliative care. Center to Advance Palliative Care website. Accessed March 12, 2024. https://www.capc.org/about/palliative-care/
15. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363:733-775.
16. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *JCO*. 2015;33(13):1438-1445.
17. Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med*. 2014;2(12):979-987.
18. Ferrell B, Sun V, Hurria A, et al. Interdisciplinary palliative care for patients with lung cancer. *J Pain Symptom Manage*. 2015;50(6):758-767.
19. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *JCO*. 2017;35(1):96-112.
20. Janssen DJA, Bajwah S, Boon MH, et al. European Respiratory Society clinical practice guideline: palliative care for people with COPD or interstitial lung disease. *Eur Respir J*. 2023;62(2):2202014.
21. Sullivan DR, Iyer AS, Enguidanos S, et al. Palliative care early in the care continuum among patients with serious respiratory illness: an official ATS/AAHPM/HPNA/SWHPN policy statement. *Am J Respir Crit Care Med*. 2022;206(6):E44-E69.
22. Iyer AS, Sullivan DR, Lindell KO, Reinke LF. The role of palliative care in COPD. *Chest*. 2022;161(5):1250-1262.
23. Brown CE, Engelberg RA, Nielsen EL, Curtis JR. Palliative care for patients dying in the intensive care unit with chronic lung disease compared with metastatic cancer. *Annals ATS*. 2016;13(5):684-689.
24. Lindell KO, Liang Z, Hoffman LA, et al. Palliative care and location of death in decedents with idiopathic pulmonary fibrosis. *Chest*. 2015;147(2):423-429.
25. Rush B, Hertz P, Bond A, McDermid RC, Celi LA. Use of palliative care in patients with end-stage COPD and receiving home oxygen: national trends and barriers to care in the United States. *Chest*. 2017;151(1):41-46.
26. Koyauchi T, Suzuki Y, Sato K, et al. Quality of dying and death in patients with interstitial lung disease compared with lung cancer: an observational study. *Thorax*. 2021;76(3):248-255.
27. Liang Z, Hoffman LA, Nouraie M, et al. Referral to palliative care infrequent in patients with idiopathic pulmonary fibrosis admitted to an intensive care unit. *J Palliat Med*. 2017;20(2):134-140.
28. Growth of Palliative Care in U.S. Hospitals: 2018 Snapshot (2000–2016): Center to Advance Palliative Care. 2018. Accessed September 19, 2024. https://media.capc.org/filer_public/27/2c/272c55c1-b69d-4eec-a932-562c2d2a4633/capc_2018_growth_snapshot_022118.pdf
29. Bischoff KE, Lin J, Cohen E, et al. Outpatient palliative care for noncancer illnesses: one program's experience with implementation, impact, and lessons learned. *J Palliat Med*. 2022;25(10):1468-1475.
30. Bischoff KE, Choi S, Su A, et al. Better together: a mixed-methods study of palliative care co-management for patients with interstitial lung disease. *J Palliat Med*. 2021;24(12):1823-1832.
31. Gershon AS, Wang C, Guan J, Vasilevska-Ristovska J, Cicutto L, To T. Identifying individuals with physician diagnosed COPD in health administrative databases. *COPD*. 2009;6(5):388-394.
32. Ley B, Urbania T, Husson G, et al. Code-based diagnostic algorithms for idiopathic pulmonary fibrosis case validation and improvement. *Ann Am Thorac Soc*. 2017;14(6):880-887.
33. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis*. 1987;40(5):373-383.
34. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J*. 2008;32(3):796-803.
35. Kalluri M, Claveria F, Ainsley E, Haggag M, Armijo-Olivo S, Richman-Eisenstat J. Beyond idiopathic pulmonary fibrosis diagnosis: multidisciplinary care with an early integrated palliative approach is associated with a decrease in acute care utilization and hospital deaths. *J Pain Symptom Manage*. 2018;55(2):420-426.
36. Hart JL, Summer AE, Ogunduyile L, et al. Accuracy of expected symptoms and subsequent quality of life measures among adults with COPD. *JAMA Netw Open*. 2023;6(11):e2344030.
37. Collard HR, Ryerson CJ, Corte TJ, et al. Acute exacerbation of idiopathic pulmonary fibrosis. An international working group report. *Am J Respir Crit Care Med*. 2016;194(3):265-275.
38. Farrand E, Vittinghoff E, Ley B, Butte AJ, Collard HR. Corticosteroid use is not associated with improved outcomes in acute exacerbation of IPF. *Respirology*. 2020;25(6):629-635.

39. Raghu G, Remy-Jardin M, Richeldi L, et al. Idiopathic pulmonary fibrosis (an update) and progressive pulmonary fibrosis in adults: an official ATS/ERS/JRS/ALAT clinical practice guideline. *Am J Respir Crit Care Med*. 2022;205(9):E18-E47.

40. Kalluri M, Orenstein S, Archibald N, Pooler C. Advance care planning needs in idiopathic pulmonary fibrosis: a qualitative study. *Am J Hosp Palliat Med*. 2022;39(6):641-651.

41. Schenker Y, Arnold R. The next era of palliative care. *JAMA*. 2015;314(15):1565.

42. Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med*. 2013;368(13):1173-1175.

43. Von Gunten CF. Secondary and tertiary palliative care in US hospitals. *JAMA*. 2002;287(7):875.

44. Pooler C, Richman-Eisenstat J, Kalluri M. Early integrated palliative approach for idiopathic pulmonary fibrosis: a narrative study of bereaved caregivers' experiences. *Palliat Med*. 2018;32(9):1455-1464.

45. Paulsen K, Wu DS, Mehta AK. Primary palliative care education for trainees in U. S. medical residencies and fellowships: a scoping review. *J Palliat Med*. 2021;24(3):354-375.

46. Kalluri M, Lu-Song J, Younus S, et al. Health care costs at the end of life for patients with idiopathic pulmonary fibrosis evaluation of a pilot multidisciplinary collaborative interstitial lung disease clinic. *Ann Am Thorac Soc*. 2020;17(6):706-713.

47. Lu-Song J, Bakal JA, Younus S, et al. The impact of integrated palliative care on survival in idiopathic pulmonary fibrosis: a retrospective multicenter comparison. *Am J Hosp Palliat Med*. 2024;41(6):610-618.

48. Iyer AS, Nicholas Dionne-Odom J, Ford SM, et al. A formative evaluation of patient and family caregiver perspectives on early palliative care in chronic obstructive pulmonary disease across disease severity. *Ann Am Thorac Soc*. 2019;16(8):1024-1033.

49. Kalluri M, Luppi F, Ferrara G. What patients with idiopathic pulmonary fibrosis and caregivers want: filling the gaps with patient reported outcomes and experience measures. *Am J Med*. 2020;133(3):281-289.

50. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th edition. *J Palliat Med*. 2018;21(12):1684-1689.

51. Quinn KL, Wegier P, Stukel TA, Huang A, Bell CM, Tanuseputro P. Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA Netw Open*. 2021;4(3):e210677.