# Palliative Care for Patients Dying in the Intensive Care Unit with Chronic Lung Disease Compared with Metastatic Cancer

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## Abstract

**Rationale:** Palliative care has been focused largely on patients with cancer, and yet patients with chronic lung diseases also have high morbidity and mortality. The majority of deaths in intensive care units (ICUs) follow decisions to withhold or withdraw life-sustaining treatments, suggesting that palliative care is critically important in this setting.

**Objectives:** We explored differences in receipt of elements of palliative care among patients with interstitial lung disease (ILD) and chronic obstructive pulmonary disease (COPD) who die in ICUs compared with patients with cancer.

**Methods:** We identified patients with COPD, ILD, or metastatic cancer who died in the ICUs of 15 Seattle-area hospitals between 2003 and 2008. We used robust multivariable logistic and linear regression to compare differences in receipt of elements of palliative care and length of stay.

**Measurements and Main Results:** Compared with patients with cancer, patients with COPD were more likely to receive cardiopulmonary resuscitation before death and patients with ILD were less likely to have documentation of pain assessment in the last day of life. Patients with ILD and COPD were less likely to have a do-not-resuscitate order in place at the time of death and less likely to have documentation of discussions about prognosis than patients with cancer. Patients with COPD had longer hospital lengths of stay, and patients with COPD and ILD had longer ICU lengths of stay.

**Conclusions:** Among patients who die in the ICU, patients with ILD and COPD receive fewer elements of palliative care and have longer lengths of stay than patients with cancer. These findings identify areas for improvement in caring for patients with chronic lung diseases.

Clinical trial registered with www.clinicaltrials.gov (NCT00685893).

**Keywords:** chronic lung disease; chronic obstructive pulmonary disease; interstitial lung disease; metastatic cancer; palliative care

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Palliative care is recognized as an important component of care for all patients with life-limiting illness (1, 2); however, historically, palliative care has been focused on patients with malignant diseases (1, 3, 4) and has been underused in patients with chronic lung disease (1). Recently, interest has grown in providing palliative care for patients with chronic lung disease, including chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD) (1, 5, 6). The goals of palliative care for these patients include improving quality of life, symptom management, and advance care planning (5, 7).

In the United States, approximately 20% of deaths occur in or shortly after a stay in the intensive care unit (ICU), and the proportion of deaths that involve an ICU stay has been increasing over the past decade (8–11). Of the deaths that occur in the ICU, the majority involve decisions to withhold or withdraw life-sustaining treatments, suggesting that the quality of palliative and end-of-life care is critically important in the ICU setting (12–14). To study the degree of implementation of elements of palliative care for patients with chronic lung disease who died in the ICU, we compared elements of palliative care received by patients with ILD or COPD with patients with metastatic cancer. The research reported in this publication was performed at Harborview Medical Center and the University of Washington, Seattle, Washington.

## Methods

### Setting and Data Collection

We performed a secondary analysis of the Integrating Palliative and Critical Care study, an unblended, cluster randomized trial that has previously been described (15, 16). In brief, the Integrating Palliative and Critical Care study investigators examined whether an interdisciplinary, multifaceted quality improvement intervention improved ICU clinicians' ability to provide end-of-life care to critically ill patients and their families. Fifteen of the sixteen eligible Seattle- and Tacoma-area hospitals enrolled, including one university hospital, one university-affiliated county hospital, four non–university-affiliated teaching hospitals, and nine nonteaching hospitals. The intervention targeted clinicians and hospitals, not individual patients or family members, and promoted clinician behavior change. To identify eligible patients, we used daily hospital admission, discharge, and transfer records from the participating hospitals. Patients were eligible if they died in the ICU or within 30 hours following transfer to another hospital location between 2002 and 2008. We excluded patients with ICU stays shorter than 6 hours on the ground that clinicians had insufficient time with these patients to affect their end-of-life care. All procedures were approved by the institutional review boards at all institutions.

Trained chart abstractors reviewed patient medical records using a standardized protocol and training regimen including 80 hours of formal training with instruction on the protocol, guided practice charts, and independent chart review followed by reconciliation with an abstraction trainer. Five percent of charts were coreviewed to ensure greater than 95% agreement on all abstracted data elements.

### Sample

Patients who were eligible for this secondary analysis included those diagnosed with COPD, ILD, or metastatic cancer. Patients with more than one of these diagnoses were excluded. Diagnoses were determined using International Classification of Diseases, Ninth Revision, codes.

### Outcome Variables

For the outcome variables in our analyses, we used medical record documentation of evidence for eight unique elements of palliative care: (*1*) avoidance of cardiopulmonary resuscitation (CPR) in the hour before death, (*2*) pain assessment in the last 24 hours before death, (*3*) presence of a do-not-resuscitate (DNR) order at time of death, (*4*) discussion of prognosis within the first 72 hours of ICU admission, (*5*) consultation with palliative care experts, (*6*) involvement of a spiritual care provider, (*7*) withdrawal of life-sustaining measures before death, and (*8*) presence of an advance directive.

All palliative care outcomes were dichotomously categorized as present or absent. Although these elements are not necessarily associated with better quality of care in all patients, at a group level they are indicators of implementation of elements of palliative care (17, 18). Medical records also provided information regarding the number of days in the ICU and overall hospital length of stay. Patients' demographic information was obtained from their medical records (age, sex, hospital, and whether care was received before or after the hospital received the quality improvement intervention) and Washington State death certificate data (racial and/or ethnic minority status, marital status, and education).

### Analyses

To test for differences in patient demographics between the three diagnostic groups, we used Pearson's $\chi^2$ for dichotomous items (sex, racial and/or ethnic minority status, and marital status) and one-way analysis of variance for continuous items (age, hospital length of stay, and ICU length of stay). We tested the association of disease with all outcomes using robust regression models, associating the two chronic lung diseases of interest (with cancer being the reference group) with the outcome: logistic regression models for the dichotomous palliative care outcome variables and linear regression models for length-of-stay outcomes.

All regression models were adjusted for confounders of the association between patient diagnosis and palliative care outcomes. Potential confounders were patient age, sex, minority status, education level, hospital, and the hospital's intervention status at the time the patient received care. For a variable to qualify as a confounder, we required that its addition to the unadjusted model between diagnosis and outcome change the estimated coefficient for at least one of the diagnoses by at least 10%. If the unadjusted coefficients for both diagnoses of interest had $P$ values greater than 0.50, we omitted the test for confounding and used the unadjusted model as the final result. Statistical significance for all tests of association between diagnosis and outcome was set at $P < 0.05$.

## Results

We identified a total of 122 patients with ILD, 677 patients with COPD, and 210 patients with metastatic cancer. After eliminating patients with two or more of these diagnoses to ensure that we would be able to assess the association of each unique disease with the receipt of elements of palliative care in the ICU, our analytic sample included 79 patients with ILD, 592 patients with COPD, and 158 patients with metastatic cancer (Table 1). On average, patients with cancer were younger than patients in the other two groups. A higher proportion of patients with metastatic cancer were from racial and/or ethnic minority groups. Patients with COPD were less likely to be married. The proportion of women by patient groups did not vary significantly.

Table 2 shows the unadjusted proportion of elements of palliative care, with a high proportion of patients having their pain assessed, avoiding CPR in the last hour of life, and having life support withheld or withdrawn before death. Approximately 60% of patients had documentation of an advance directive in their medical records. By contrast, only a

**Table 1.** Characteristics of patients with interstitial lung disease, chronic obstructive pulmonary disease, or cancer dying in the intensive care unit

| Characteristic | ILD (*n* = 79) | COPD (*n* = 592) | Cancer (*n* = 158) | *P* Value* |
|---|---|---|---|---|
| Age, yr, mean (SD) | 72.3 (13.4) | 73.6 (11.0) | 64.0 (12.7) | **<0.001** |
| Female sex, n (%) | 39.2 (31) | 40.7 (241) | 47.5 (75) | 0.274 |
| Nonwhite, n (%) | 21.5 (17) | 14.0 (83) | 31.6 (50) | **<0.001** |
| Married, n (%) | 54.4 (43) | 40.9 (240) | 55.1 (87) | **0.001** |

*Definition of abbreviations*: COPD = chronic obstructive pulmonary disease; ILD = interstitial lung disease.

Bold values indicate significance set at $P \leqslant 0.05$.

**P* values for associations with categorical predictors were assessed using Pearson's $\chi^2$ tests. *P* values for variables scored continuously were assessed using one-way analysis of variance. Significance was set at $P = 0.05$.

minority of patients had documentation of a discussion of prognosis or provision of palliative care consultations or spiritual care consultations.

Adjusted models (Table 3) indicated that patients with COPD were less likely to avoid CPR in the hour before death than patients with metastatic cancer (odds ratio [OR], 0.43; 95% confidence interval [CI], 0.20–0.90). Patients with ILD were less likely to have documentation of an assessment of their pain in the last 24 hours of life (OR, 0.43; 95% CI, 0.19–0.97). Compared with patients with metastatic cancer, patients with ILD or COPD were less likely to have a DNR order in place at the time of death (OR, 0.40; 95% CI, 0.19–0.86; and OR, 0.49; 95% CI, 0.27–0.86, respectively). Last, patients with either ILD or COPD were less likely to have documentation of a discussion of their prognoses than patients with metastatic cancer (OR, 0.36; 95% CI, 0.19–0.66; OR, 0.62; 95% CI, 0.43–0.90, respectively). There were no significant differences among the remaining four elements of palliative care: palliative care consultation, spiritual care involvement, life support withheld or withdrawn, and presence of advance directives.

Hospital lengths of stay were longer in patients with COPD than among those with metastatic cancer (2.55 d; 95% CI, 0.19–4.92) (Table 4). The ICU lengths of stay for patients with ILD or COPD were also longer than for those with metastatic cancer (2.75 d; 95% CI, 0.52–4.98; and 2.93 d; 95 CI, 0.77–5.09, respectively).

## Discussion

Our findings suggest that patients with COPD or ILD and their surrogate decision makers may receive less preparation for end-of-life decisions in the ICU than patients with metastatic cancer do. Despite longer ICU and hospital lengths of stay that suggest more time to implement advance care planning and end-of-life discussions for both of these patient populations, these patients are more likely to receive CPR shortly before death, less likely to have a DNR order in place at the time of death, and less likely to have documentation of prognostic discussions. In addition, longer ICU lengths of stay for patients who die in the ICU have been used as a marker of poor-quality palliative care in the ICU and may suggest a prolongation of dying associated with inadequate preparation of patients and surrogate decision makers for decisions regarding end-of-life care (19, 20).

In the area of symptom assessment, patients with ILD were less likely to have medical record documentation of pain assessment in the last hour of life than patients with metastatic cancer. While dyspnea and other respiratory symptoms are the most common complaints in patients with chronic lung disease, pain is often underappreciated (1, 21, 22). Importantly, there are many differences between patients with chronic lung disease and patients with cancer, including their trajectory of illness and the palliative care and advance care planning they receive before admission to the ICU. The goal of our study was not to try to adjust for these differences in pre-ICU illness or care, but rather to examine the differences in elements of palliative care received once these patients were admitted to the ICU. These differences highlight opportunities to improve palliative care for patients with chronic lung disease, both before and in the ICU.

**Table 2.** Palliative care processes and lengths of stay for patients dying in the intensive care unit

| | ILD | COPD | Metastatic Cancer |
|---|---|---|---|
| Processes of care, n (%n) | | | |
| No CPR 1 h before death | 94.9 (75) | 89.0 (527) | 93.0 (147) |
| Pain assessed in day before death | 75.9 (60) | 81.6 (483) | 91.1 (144) |
| DNR at time of death | 78.5 (62) | 81.8 (482) | 87.3 (137) |
| Prognosis discussed | 21.5 (17) | 31.4 (186) | 44.3 (70) |
| Palliative care consultation | 12.7 (10) | 8.8 (52) | 10.8 (17) |
| Spiritual care involvement | 50.6 (40) | 44.2 (261) | 44.3 (70) |
| Life support withheld/withdrawn | 75.9 (60) | 75.0 (442) | 76.3 (119) |
| Presence of advance directive | 63.3 (31) | 62.2 (253) | 58.9 (63) |
| Length of stay, median (IQR) | | | |
| Hospital LOS, d | 7.0 (4.0–12.0) | 6.0 (3.0–12.0) | 6.0 (3.0–12.0) |
| ICU LOS, d | 4.2 (1.6–8.6) | 2.9 (1.1–7.4) | 2.3 (0.9–5.3) |

*Definition of abbreviations*: COPD = chronic obstructive pulmonary disease; CPR = cardiopulmonary resuscitation; DNR = do-not-resuscitate order; ICU = intensive care unit; ILD = interstitial lung disease; IQR = interquartile range; LOS = length of stay.

Our findings are particularly important in the context of recent increased recognition of the importance of palliative care for patients with nonmalignant chronic illnesses such as chronic lung disease (4). This recognition demonstrates a shift in focus from the “cure versus no cure” mind-set toward acknowledging the importance of assessing and addressing symptom burden, diminished quality of life, and social isolation that patients with chronic lung disease experience (3, 23–28). Studies outside the ICU setting demonstrate that patients with chronic lung disease experience a high burden of diverse symptoms that impact their quality

**Table 3.** Results of regression analyses of palliative care processes received by patients with interstitial lung disease or chronic obstructive pulmonary disease, compared with patients with cancer (reference group)

| | ILD | | | COPD | | |
|---|---|---|---|---|---|---|
| | OR | 95% CI | *P* Value* | OR | 95% CI | *P* Value* |
| No CPR 1 h before death[†] | 1.11 | 0.33–3.68 | 0.871 | **0.43** | **0.20–0.90** | **0.026** |
| Pain assessed in day before death[‡] | **0.43** | **0.19–0.97** | **0.042** | 0.60 | 0.32–1.13 | 0.114 |
| DNR at time of death[‡] | **0.40** | **0.19–0.86** | **0.019** | **0.49** | **0.27–0.86** | **0.013** |
| Prognosis discussed[§] | **0.36** | **0.19–0.66** | **0.001** | **0.62** | **0.43–0.90** | **0.012** |
| Palliative care consultation[‖] | 0.87 | 0.33–2.28 | 0.771 | 0.52 | 0.26–1.02 | 0.055 |
| Spiritual care involvement[‡] | 1.56 | 0.84–2.90 | 0.157 | 0.97 | 0.63–1.48 | 0.886 |
| Life support withheld/withdrawn[¶] | 0.98 | 0.52–1.85 | 0.955 | 0.93 | 0.62–1.41 | 0.750 |
| Presence of advance directive[¶] | 1.20 | 0.60–2.42 | 0.604 | 1.15 | 0.74–1.77 | 0.535 |

*Definition of abbreviations*: CI = confidence interval; COPD = chronic obstructive pulmonary disease; CPR = cardiopulmonary resuscitation; DNR = do-not-resuscitate order; ILD = interstitial lung disease; OR = odds ratio.

In regression analyses, the association of each palliative care outcome with the two chronic lung diseases of interest was tested using robust logistic regression models with cancer as the reference group. All regression models were adjusted for confounders of the association between patient diagnosis and palliative care outcomes. To qualify as a confounder, the estimated coefficient for diagnosis was found to have changed by at least 10% from the base model containing only the diagnosis, with the addition of one of the following confounders: patient age, sex, minority status, education level, hospital, and the hospital's intervention status at the time the patient received care.

*Bold values indicate significance at $P = 0.05$.

Symbols in left column indicate final models adjusted for [†]age and minority status; [‡]age and hospital; [§]minority status; [‖]age, minority status, and hospital; and [¶]unadjusted.

of life, including shortness of breath, cough, and insomnia (5). Patients with ILD report dyspnea, chest pain, anxiety, and diminished quality of life (1, 3).

Although these patients seem to understand that their lung disease will progress and is likely to be a terminal condition, implementation of palliative care remains limited. Patients with COPD often do not achieve adequate relief of dyspnea and live in fear of suffocation in the last 6 months of life (1). In fact, patients with COPD may experience more severe dyspnea and poorer functional status during a longer and more protracted course of illness than patients with lung cancer (29). Although patients with chronic lung disease face as much, or in some cases more, symptom burden, longer hospital stays, and lower levels of satisfaction of care than patients with cancer (29–32), few discuss their treatment preferences with their physicians or implement advance care planning (7, 33, 34). These studies document inadequate palliative care before ICU admission for patients with ILD or COPD, and our study documents that these shortcomings continue in the ICU setting.

**Table 4.** Results of regression analyses of intensive care unit and hospital lengths of stay for patients with interstitial lung disease or chronic obstructive pulmonary disease, compared with patients with cancer (reference group)

| | ILD | | | COPD | | *P* Value* |
|---|---|---|---|---|---|---|
| | β Value | 95% CI | *P* Value* | β Value | 95% CI | |
| ICU days[†] | **2.75** | **0.52–4.98** | **0.016** | **2.93** | **0.77–5.09** | **0.008** |
| Hospital days[‡] | 2.40 | −0.32 to 5.11 | 0.084 | **2.55** | **0.19–4.92** | **0.034** |

*Definition of abbreviations*: CI = confidence interval; COPD = chronic obstructive pulmonary disease; ILD = interstitial lung disease; ICU = intensive care unit.

Lengths of stay for the two chronic lung diseases were tested using robust linear regression models with cancer as the reference group. All models were adjusted for potential confounders of the association between diagnosis and outcome. To qualify as a confounder, the estimated coefficient for diagnosis was found to have changed by at least 10% from the base model containing only the diagnosis, with the addition of one of the following confounders: patient age, sex, minority status, marital status, education level, hospital, and the hospital's intervention status at the time the patient received care.

*Bold values indicate significance at $P = 0.05$.

Symbols in left column indicate final models adjusted for [†]age, minority status, and hospital and [‡]age, sex, minority status, hospital, and marital status.

There are several important limitations to our study. First, our sample of patients with ILD was smaller than those with COPD and metastatic cancer, reflecting the fact that ILD is relatively rare but suggesting caution in interpreting our findings. Along similar lines, our sample sizes made it difficult to control for type of ICU, which may have played a role in the differences we report here. Second, palliative care elements were obtained by chart abstraction and may have been poorly documented (e.g., dyspnea, discussions of prognosis), thereby resulting in misclassification. For example, lack of documentation of assessment of pain does not necessarily mean that pain assessment did not occur. However, although the medical record may not reflect all care provided, documentation is an important component of medical care that facilitates communication among clinicians and documents quality of care. Third, patients with these three diseases undoubtedly exhibited differences before ICU admission. For example, they may have been admitted for different reasons (e.g., respiratory failure, metabolic derangements, single organ failure, or septic shock), and these different reasons may have influenced the likelihood of participating in end-of-life planning or receiving palliative care. The trajectories of illness these patients experienced may have been quite different and may have influenced initiation of end-of-life discussions or palliative measures before hospitalization. Importantly, prior studies have shown that implementation of palliative care in the outpatient setting is higher in patients with metastatic cancer than among patients with chronic lung disease, and this difference may have affected our findings (24, 35). These differences before the patient's ICU stay may account for some of the differences we identified in palliative care in the ICU and may be targets for improving palliative care for patients with chronic lung disease. Finally, patient deaths occurred between 2003 and 2008, and it is possible that palliative care has improved since that time. However, a prior analysis within this study suggests that completion of these ICU-based palliative care elements had not improved during the 5 years of the study (36). Notably, the provider-directed intervention did not result in increased implementation in palliative care and likely did not affect our findings (15).

In conclusion, patients with ILD or COPD are less likely to receive elements of palliative care in the ICU than patients with metastatic cancer, but they have longer lengths of stay in both the hospital and ICU that may provide opportunities for implementation of palliative care. In future studies, researchers should explore ways to improve implementation of palliative care for patients with chronic lung diseases, both before and during critical illness. ■

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## References

1 Boland J, Martin J, Wells AU, Ross JR. Palliative care for people with non-malignant lung disease: summary of current evidence and future direction. *Palliat Med* 2013;27:811–816.
2 Morrison RS, Meier DE. Palliative care. *N Engl J Med* 2004;350: 2582–2590.
3 Gilbert CR, Smith CM. Advanced lung disease: quality of life and role of palliative care. *Mt Sinai J Med* 2009;76:63–70.
4 Oishi A, Murtagh FE. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals. *Palliat Med* 2014;28: 1081–1098.
5 Bajwah S, Higginson IJ, Ross JR, Wells AU, Birring SS, Riley J, Koffman J. The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals. *Palliat Med* 2013;27:869–876.
6 Rocker GM, Simpson AC, Horton R. Palliative care in advanced lung disease: the challenge of integrating palliation into everyday care. *Chest* 2015;148:801–809.
7 Bajwah S, Koffman J, Higginson IJ, Ross JR, Wells AU, Birring SS, Riley J. 'I wish I knew more ...' the end-of-life planning and information needs for end-stage fibrotic interstitial lung disease: views of patients, carers and health professionals. *BMJ Support Palliat Care* 2013;3:84–90.
8 Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T, Rubenfeld GD; Robert Wood Johnson Foundation ICU End-Of-Life Peer Group. Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med* 2004;32: 638–643.
9 Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309:470–477.
10 Fulton AT, Gozalo P, Mitchell SL, Mor V, Teno JM. Intensive care utilization among nursing home residents with advanced cognitive and severe functional impairment. *J Palliat Med* 2014;17:313–317.
11 Cooke CR, Feemster LC, Wiener RS, O'Neil ME, Slatore CG. Aggressiveness of intensive care use among patients with lung cancer in the Surveillance, Epidemiology, and End Results-Medicare registry. *Chest* 2014;146:916–923.
12 Quill CM, Ratcliffe SJ, Harhay MO, Halpern SD. Variation in decisions to forgo life-sustaining therapies in US ICUs. *Chest* 2014;146:573–582.
13 Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, Ledoux D, Lippert A, Maia P, Phelan D, *et al*.; Ethicus Study Group. End-of-life practices in European intensive care units: the Ethicus Study. *JAMA* 2003;290:790–797.
14 Lindell KO, Liang Z, Hoffman LA, Rosenzweig MQ, Saul MI, Pilewski JM, Gibson KF, Kaminski N. Palliative care and location of death in decedents with idiopathic pulmonary fibrosis. *Chest* 2015;147: 423–429.
15 Curtis JR, Treece PD, Nielsen EL, Downey L, Shannon SE, Braungardt T, Owens D, Steinberg KP, Engelberg RA. Integrating palliative and critical care: evaluation of a quality-improvement intervention. *Am J Respir Crit Care Med* 2008;178:269–275.
16 Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE, Back AL, Rubenfeld GD, Engelberg RA. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: a randomized trial. *Am J Respir Crit Care Med* 2011;183: 348–355.
17 Mularski RA, Curtis JR, Billings JA, Burt R, Byock I, Fuhrman C, Mosenthal AC, Medina J, Ray DE, Rubenfeld GD, *et al*. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. *Crit Care Med* 2006;34(11 Suppl):S404–S411.
18 Glavan BJ, Engelberg RA, Downey L, Curtis JR. Using the medical record to evaluate the quality of end-of-life care in the intensive care unit. *Crit Care Med* 2008;36:1138–1146.
19 Schneiderman LJ, Gilmer T, Teetzel HD, Dugan DO, Blustein J, Cranford R, Briggs KB, Komatsu GI, Goodman-Crews P, Cohn F, *et al*. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003;290:1166–1172.
20 Norton SA, Hogan LA, Holloway RG, Temkin-Greener H, Buckley MJ, Quill TE. Proactive palliative care in the medical intensive care unit: effects on length of stay for selected high-risk patients. *Crit Care Med* 2007;35:1530–1535.
21 Borge CR, Wahl AK, Moum T. Association of breathlessness with multiple symptoms in chronic obstructive pulmonary disease. *J Adv Nurs* 2010;66:2688–2700.
22 Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliat Med* 2005;19:485–491.
23 Johnson JL, Campbell AC, Bowers M, Nichol AM. Understanding the social consequences of chronic obstructive pulmonary disease: the effects of stigma and gender. *Proc Am Thorac Soc* 2007;4:680–682.
24 Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000;55:1000–1006.
25 Rocker GM, Sinuff T, Horton R, Hernandez P. Advanced chronic obstructive pulmonary disease: innovative approaches to palliation. *J Palliat Med* 2007;10:783–797.
26 Pinnock H, Kendall M, Murray SA, Worth A, Levack P, Porter M, MacNee W, Sheikh A. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ* 2011;342:d142.
27 Swigris JJ, Stewart AL, Gould MK, Wilson SR. Patients' perspectives on how idiopathic pulmonary fibrosis affects the quality of their lives. *Health Qual Life Outcomes* 2005;3:61.
28 De Vries J, Seebregts A, Drent M. Assessing health status and quality of life in idiopathic pulmonary fibrosis: which measure should be used? *Respir Med* 2000;94:273–278.

29 Weingaertner V, Scheve C, Gerdes V, Schwarz-Eywill M, Prenzel R, Bausewein C, Higginson IJ, Voltz R, Herich L, Simon ST; PAALiativ Project. Breathlessness, functional status, distress, and palliative care needs over time in patients with advanced chronic obstructive pulmonary disease or lung cancer: a cohort study. *J Pain Symptom Manage* 2014;48:569–81.e1.

30 Rocker GM, Dodek PM, Heyland DK; Canadian Researchers at the End of Life Network. Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: insights from a multicentre study. *Can Respir J* 2008;15:249–254.

31 Bausewein C, Booth S, Gysels M, Kühnbach R, Haberland B, Higginson IJ. Understanding breathlessness: cross-sectional comparison of symptom burden and palliative care needs in chronic obstructive pulmonary disease and cancer. *J Palliat Med* 2010;13: 1109–1118.

32 Edmonds P, Karlsen S, Khan S, Addington-Hall J. A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliat Med* 2001;15:287–295.

33 Sawicki GS, Dill EJ, Asher D, Sellers DE, Robinson WM. Advance care planning in adults with cystic fibrosis. *J Palliat Med* 2008;11:1135–1141.

34 Heffner JE, Fahy B, Hilling L, Barbieri C. Outcomes of advance directive education of pulmonary rehabilitation patients. *Am J Respir Crit Care Med* 1997;155:1055–1059.

35 Gott M, Gardiner C, Small N, Payne S, Seamark D, Barnes S, Halpin D, Ruse C. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliat Med* 2009;23:642–648.

36 DeCato TW, Engelberg RA, Downey L, Nielsen EL, Treece PD, Back AL, Shannon SE, Kross EK, Curtis JR. Hospital variation and temporal trends in palliative and end-of-life care in the ICU. *Crit Care Med* 2013;41:1405–1411.