A Qualitative Study of Unmet Healthcare Needs in Chronic Obstructive Pulmonary Disease

A Potential Role for Specialist Palliative Care?

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Abstract

Rationale: Patients with chronic obstructive pulmonary disease (COPD) have high symptom burdens and poor health-related quality of life. The American Thoracic Society issued a consensus statement outlining the need for palliative care for patients with chronic respiratory diseases. A better understanding of the unmet healthcare needs among patients with COPD may help determine which aspects of palliative care are most beneficial.

Objectives: To identify the unmet healthcare needs of patients with COPD hospitalized for exacerbation using qualitative methods.

Methods: We conducted 20 semistructured interviews of patients admitted for acute exacerbations of COPD focused on patient understanding of diagnosis and prognosis, effect of COPD on daily life and social relationships, symptoms, healthcare needs, and preparation for the end of life. Transcribed interviews were evaluated using thematic analysis.

Measurements and Main Results: Six themes were identified. (*1*) Understanding of disease: Most participants correctly identified their diagnosis and recognized their symptoms worsening over time. Only half understood their disease severity and prognosis. (*2*) Symptoms: Breathlessness was universal and severe. (*3*) Physical limitations: COPD prevented participation in activities. (*4*) Emotional distress: Depressive symptoms and/or anxiety were present in most participants. (*5*) Social isolation: Most participants identified social limitations and felt confined to their homes. (*6*) Concerns about the future: Half of participants expressed fear about their future.

Conclusions: There are many unmet healthcare needs among patients hospitalized for COPD exacerbation. Relief of symptoms, physical limitations, emotional distress, social isolation, and concerns about the future may be better managed by integrating specialist palliative care into our current care model.

Keywords: chronic obstructive pulmonary disease; dyspnea; symptoms; quality of life; end of life

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Chronic obstructive pulmonary disease (COPD) causes significant morbidity and mortality and has replaced stroke as the third leading cause of death in the United States (1). Patients are usually chronically ill for many years, with intermittent exacerbations (2). The terminal phase of COPD is difficult to predict, and the timing of when to implement supportive care services that meet patients' and caregivers' needs is uncertain. Despite a call for the provision of palliative care for patients with chronic respiratory disease and critical illness by the American Thoracic Society (3) and the 2013 Global Initiative on Chronic Obstructive Lung Disease guidelines (4), specifics on how to deliver this care are lacking.

COPD is associated with a high symptom burden, impaired functional status, and poor health-related quality of life (HRQOL) (5–8). In the last year of life, the majority of patients with COPD are breathless, fatigued, in pain, with depressed mood, home-bound, and frequently hospitalized (9). The high symptom burden and poor HRQOL documented in COPD is comparable to patients with advanced lung cancer (10–13)

It is well established that patients with advanced cancer benefit from palliative medicine. A review of the qualitative literature on patients' perspectives of living and dying with COPD demonstrated the unpredictable nature of the disease, fluctuating needs, and increasing demands over time (14). Physicians caring for patients with COPD should identify patients who could benefit from palliative medicine, as it may improve their physical, psychosocial, and spiritual well-being (15). Several small qualitative studies from Europe have demonstrated a role for palliative care for breathless patients with severe COPD defined by severe airflow limitation (7, 16–21). Whether other patients may benefit, such as those with less severe airflow obstruction, frequent exacerbations, or multiple medical comorbidities, is unknown. A broader understanding of the impact of symptoms on day-to-day life, effect on social relationships, and patient perceptions about end-of-life care among a diverse sociodemographic population, not predicated on severity of disease or breathlessness, is important if results are to be generalizable. We sought to qualitatively evaluate the unmet needs among a well-characterized population of patients hospitalized for COPD exacerbation to determine which needs could be met by additional expertise in palliative care. Some of the results of this study have been previously reported in the form of an abstract (22).

Methods

Design

We performed qualitative analysis of in-depth, semistructured, one-on-one interviews with 20 patients admitted for an acute exacerbation of COPD.

Setting and Participants

This study was conducted at a large, urban, academic medical center in Chicago from 2012 to 2013. Eligible participants included English-speaking patients with a history of COPD admitted for an acute exacerbation of COPD. The first 20 patients meeting eligibility criteria who gave consent were selected for qualitative interviews. We used purposive sampling to include patients who varied in terms of age, race, and sex. Interviews continued until thematic saturation was achieved. Written informed consent was obtained. The study protocol was approved by the Institutional Review Board (STU00059310).

Interviews and Data Collection

Interviews were conducted by one researcher (C.J.S.) during the patient's inpatient admission. The aim of the interview was to provide a description of patient understanding of diagnosis and prognosis, effect of COPD on daily life and social relationships, symptoms, healthcare needs, and preparation for end of life. The interview guide was developed in an iterative fashion in collaboration with two pulmonologists (C.J.S. and R.K.) and one clinical health psychologist with expertise in qualitative research methods (S.E.Y.). Interview domains and sample questions are provided in Table 1. Sociodemographic and clinical data, including disease severity, comorbidities, and therapies, were collected from the patient and the medical record.

Data Analysis

All interviews were audio recorded, transcribed, and thematically analyzed. A progressive coding technique was used to organize data. Two investigators (C.J.S. and P.J.H.) performed open coding on three interviews to generate a code book, which was subsequently modified iteratively. Five additional interviews were coded independently by two investigators (C.J.S. and P.J.H.), and discrepancies were resolved through consensus. The remaining 12 interviews were coded by a single investigator (C.J.S.). Identified themes were compiled and summarized in frequency tables. Data saturation was achieved after 15 interviews, and an additional 5 interviews were completed to purposefully sample underrepresented sociodemographic groups (white men). Based on themes identified during the coding process, a thematic framework was generated.

Results

Sample Characteristics

Of the 20 patients interviewed, the median age was 69 years, 11 (55%) were women, and 12 (60%) were black. Participant characteristics were notable for multiple comorbid conditions and severe airflow obstruction (Table 2).

Findings

Six themes were identified from this qualitative analysis: (*1*) understanding of disease (diagnosis, severity, and prognosis), (*2*) uncontrolled symptoms, (*3*) physical limitations, (*4*) emotional distress, (*5*) social isolation, and (*6*) concerns about the future.

Understanding of Disease (Diagnosis, Severity, and Prognosis)

Most participants could correctly identify their diagnosis as COPD and perceived that it was worsening over time. Although many accepted smoking as the cause for COPD, there was surprise and frustration that their lung disease continued to worsen despite quitting smoking:

> I mean, I had not smoked for 20 some years. It didn't make any sense to me. (76 M)

Most identified other problems that they believed were making their lungs worse, such as age, asthma, diet, dust, pollen, heat,

Table 1. Interview domains and sample questions

Interview Domains	Sample Questions
Experience living with lung disease	Can you tell me what is wrong with your lungs? Can you tell me what a typical day is like for you living with your lung disease?
Symptoms	What kind of symptoms are the most bothersome to you? How do you make yourself feel better?
Social life and relationships	Does your lung disease prevent you from doing the things you enjoy? In what way?
End of life	Do you feel like your doctors have provided you with all the information you need to understand your disease?

Table 2. Participant characteristics (N = 20)

Age, median (range), yr	69 (52–83)
Men, n (%)	9 (45)
Women, n (%)	11 (55)
Race/ethnicity, n (%)	
White	6 (30)
Black	12 (60)
Asian	2 (10)
Marital status, n (%)	
Married	5 (25)
Single (never married, divorced, widowed)	15 (75)
Smoking status, n (%)	
Never	1 (5)
Former	11 (55)
Current	8 (40)
Pack-years, median (range)	10 (1.2–108)
Educational level, n (%)	
Some high school	1 (5)
High school degree/GED	7 (35)
Some college or technical school	8 (40)
College degree	3 (15)
Advanced degree	1 (5)
Comorbid conditions, n (%)	
Hypertension	11 (55)
Heart disease	10 (50)
Hyperlipidemia	9 (45)
DVT/PE	8 (40)
Arrhythmia	5 (25)
Diabetes	4 (20)
Alcohol or illicit drug abuse	4 (20)
Stroke	4 (20)
Depression/anxiety	3 (15)
Chronic kidney disease	3 (15)
Asthma	3 (15)
FEV_1, median (range) (N = 14)	0.88 (0.59–2.77)
FEV_1% predicted, median (range) (N = 15)	39 (22–69)
BMI on hospital admission, median (range)	23.2 (16.2–40.7)
Therapies at the time hospital admission, n (%)	
Inhaled corticosteroid	18 (90)
Long-acting β-agonist	16 (80)
Long-acting anticholinergic	11 (55)
Short-acting bronchodilator	19 (95)
Theophylline	0 (0)
Chronic oral steroids	1 (10)
Roflumilast	3 (15)
Oxygen	10 (50)
Benzodiazepine	3 (15)
Opioid	2 (10)
Antidepressants	0 (0)
Antipsychotics/neuroleptics	1 (5)
Antiepileptics	0 (0)
Hospital admission code status, n (%)	
Full code	20 (100)

Definition of abbreviations: DVT = deep vein thrombosis; GED = General Educational Development; PE = pulmonary embolism.

or the use of supplemental oxygen. Approximately half could identify exactly when their COPD was diagnosed, often after an acute illness. Those remaining described a vague onset of symptoms:

> You know until recently, say within the last couple of years, I never really had problems that I related to a lung disease. It was just I didn't feel well. (78 F)

Half of the participants believed that they had received adequate information to understand their disease severity and prognosis. Of those who did not understand, most wanted more information:

> What can I expect? (76 F)

> I can't feel they've given me that information when I don't know what's going to happen eventually to my lungs. Will they get better? Or will they just progressively get worse? (62 F)

Uncontrolled Symptoms

Breathlessness was universal. Cough, pain, and fatigue were present in greater than half of participants:

> I feel like that commercial with the fish out of the water—you can't catch your breath. That is how it is. It is hard because it's like that is going to be your last breath. (52 F)

For some, symptoms could be unpredictable:

> There is no such thing as a typical day because you never know how you're going to feel. (69 F)

Inhaled medications and rest could provide short-term relief; however, six patients did not find medications to be effective:

> I take everything you can think of to take and it's still not doing any good for me. (56 F)

Although only completed by a few participants, pulmonary rehabilitation was very beneficial.

> I've learned quite a bit from the pulmonary class. Yeah, I learned more from that than I think I have from my doctors. (62 F)

Physical Limitations

Physical activities were identified as challenging by all 20 participants. Every action must be planned, and everyday activities were difficult:

> Everything is very deliberate. I plan every move before I make it because I don't want to go back and do it again. (76 M)

Fifteen of the participants believed that their lungs prevent them from doing the things they enjoy. These activities included travel, driving, playing with grandchildren, working, dining out, and golfing.

Emotional Distress

Feelings of depression and anxiety were described by 14 of the participants. These manifested as annoyance, irritability, disappointment, worry, fear, and frustration:

> I am always depressed because of all the things I cannot do. (78 F)

Feeling breathless made one patient feel

> like you might die before morning comes. (78 F)

However, some participants did not endorse feeling of depression, or had found ways to adapt:

> I refuse to allow that [depression] to linger too long. I focus on changing whatever's going on. (76 F)

Social Isolation

Most participants identified social limitation due to their lung disease, often being confined to their homes and lonely:

> You don't have a social life. (78 F)

> You shun away from your friends because it's hard to keep up and do all those active things that everyone else is doing. (56 M)

Most patients felt well supported by their families. However, patients do not like asking for help:

> I find myself apologizing a lot. I am sorry I cannot do this or that… (76 M)

Concerns for the Future

Half of the participants were fearful about their future, suffering, loss of independence, missing family milestones, and death:

> I've got a grandson that wants to become an NBA star. And I told him I'll live to see him play one game. (56 F)

> I want to breathe as long as possible and I want to have some quality of life. (76 F)

They found comfort in many different things, including good doctors, belief in God, medical advancements, having made plans for death, and family. Many were looking for ways to improve their situation:

> How can I help myself? (76 F)

> Tell me something that's new on the market. (53 F)

Discussion

The results of this qualitative analysis identified several themes outlining the breadth of unmet needs among patients hospitalized for acute COPD exacerbation. Previous work describing the symptom burden (11, 16), breathlessness (17–21), social isolation (7), and issues of death and dying (23) support a role for palliative care among patients with COPD. Identifying key disease milestones or meaningful events have been suggested as potential triggers for the introduction of palliative care (6, 24). Our results suggest that there were significant palliative care needs among a group of sociodemographically diverse patients admitted for an acute exacerbation of COPD. Although all unmet needs deserve further attention and study, we have identified three overlapping areas that could benefit greatly from palliative care intervention: uncontrolled symptoms, social isolation, and future concerns. These themes were selected because they are highly prevalent among this cohort of patients, and management of these problems is fundamental to palliative care.

Uncontrolled Symptoms

Uncontrolled breathlessness, often severe, was universal in this cohort of patients. Patients with COPD with more symptoms have significantly increased mortality independent of their lung function (25). The majority of this cohort was receiving standard medical therapy for their COPD, but very few were receiving opioids or anxiolytics. Opioids are recommended by multiple evidence-based guidelines for the relief of dyspnea (26–28). This finding may suggest that primary care doctors or pulmonologists lack the training and expertise for identifying who would benefit from opioids and anxiolytics and how to appropriately prescribe and monitor their effects (29, 30). A palliative care physician may be less reluctant to initiate these medications and be better equipped for monitoring effectiveness and side effects.

Emotional Distress, Fear, and Social Isolation

Review of the medical record revealed that only three patients had been diagnosed with depression or anxiety, and none were being treated with antidepressants. Despite this, most participants expressed symptoms of depression and anxiety during their interview. The estimated prevalence of depression and anxiety among patients with COPD varies widely (20–80%) (31). For some, breathlessness results in extreme anxiety and fear. Symptoms and resulting physical limitations are likely contributing to the social isolation described by these patients. The social isolation and resulting loneliness likely contribute to their emotional distress and impaired HRQOL. Little is known about what interventions may help relieve the emotional distress and isolation experienced by these patients. Among patients with metastatic lung cancer, early palliative medicine intervention significantly improves depression (32). It is unknown if palliative care for patients with COPD can have similar effects. It is also unknown if treatment of depression and anxiety may reduce social isolation.

Concerns about the Future

About half of the participants expressed concerns about their future for various reasons (e.g., fear of suffering, loss of independence, death). A sense of control was identified as important, and many believed they had not received adequate information to understand their disease severity and prognosis and wanted additional information. Estimating survival among patients with nonmalignant disease is difficult (33), and pulmonologists may not have the comfort or the time to explore goals of care when prognosis is uncertain. Although understanding of prognosis and preparation for end of life were not explored in depth during this interview, they are important areas where a palliative care intervention could play a role (34–42). A palliative care physician may have the objectivity and expertise required to convey this information in a way that the patient can begin to make meaningful decisions about advanced care planning.

Limitations and Future Direction

We interviewed patients during an admission for an acute exacerbation, and therefore the issues expressed as being important may not accurately reflect those issues affecting the patient in day-to-day life. Although we interviewed to the point of data saturation, the themes identified in this study may underestimate the healthcare needs of a larger population. In addition, our interview guide was not comprehensive and did not address all potential areas in which palliative care may be beneficial, such as spiritual concerns or caregiver support.

Conclusions

This qualitative study identified many unmet healthcare needs among patients hospitalized for COPD exacerbation. Integrating specialist palliative care into our current care model for inpatient COPD exacerbation may be one way to address these needs. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

References

1 Miniño AM. Death in the United States, 2009. NCHS data brief, no 64. Hyattsville, MD: National Center for Health Statistics; 2011. pp 1–8.
2 Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330:1007–1011.
3 Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, Levy M, Mularski RA, Osborne ML, Prendergast TJ, *et al.*; ATS End-of-Life Care Task Force. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med* 2008;177:912–927.
4 Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global Strategy for the Diagnosis Management and Prevention of COPD. 2014 [accessed 2014 Mar 1]. Available from: http://www.goldcopd.org/.
5 Barnett M. Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. *J Clin Nurs* 2005;14:805–812.
6 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.
7 Seamark DA, Blake SD, Seamark CJ, Halpin DM. Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliat Med* 2004;18:619–625.
8 Janssen DJ, Spruit MA, Uszko-Lencer NH, Schols JM, Wouters EF. Symptoms, comorbidities, and health care in advanced chronic obstructive pulmonary disease or chronic heart failure. *J Palliat Med* 2011;14:735–743.
9 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.
10 Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage* 2006;31:58–69.
11 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.
12 Habraken JM, ter Riet G, Gore JM, Greenstone MA, Weersink EJ, Bindels PJ, Willems DL. Health-related quality of life in end-stage COPD and lung cancer patients. *J Pain Symptom Manage* 2009;37:973–981.
13 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.
14 Giacomini M, DeJean D, Simeonov D, Smith A. Experiences of living and dying with COPD: a systematic review and synthesis of the qualitative empirical literature. *Ont Health Technol Assess Ser* 2012;12:1–47.
15 Hayle C, Coventry PA, Gomm S, Caress AL. Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: a qualitative study. *Palliat Med* 2013;27:861–868.
16 Elkington H, White P, Addington-Hall J, Higgs R, Pettinari C. The last year of life of COPD: a qualitative study of symptoms and services. *Respir Med* 2004;98:439–445.
17 Gysels M, Bausewein C, Higginson IJ. Experiences of breathlessness: a systematic review of the qualitative literature. *Palliat Support Care* 2007;5:281–302.
18 Gysels M, Higginson IJ. The experience of breathlessness: the social course of chronic obstructive pulmonary disease. *J Pain Symptom Manage* 2010;39:555–563.
19 Gysels M, Higginson IJ. Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *J Pain Symptom Manage* 2008;36:451–460.
20 Gysels MH, Higginson IJ. The lived experience of breathlessness and its implications for care: a qualitative comparison in cancer, COPD, heart failure and MND. *BMC Palliat Care* 2011;10:15.
21 Gysels MH, Higginson IJ. Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliat Support Care* 2009;7:153–162.
22 Schroedl C, Szmuilowicz E, Yount S, Rosenberg S, Kalhan R. Unmet healthcare needs among patients with chronic obstructive pulmonary disease: a qualitative study [abstract]. *Am J Respir Crit Care Med* 2013;137:A1450.
23 Gardiner C, Gott M, Small N, Payne S, Seamark D, Barnes S, Halpin D, Ruse C. Living with advanced chronic obstructive pulmonary disease: patients concerns regarding death and dying. *Palliat Med* 2009;23:691–697.
24 Cawley D, Billings J, Oliver D, Kendall M, Pinnock H. Potential triggers for the holistic assessment of people with severe chronic obstructive pulmonary disease: analysis of multiperspective, serial qualitative interviews. *BMJ Support Palliat Care* 2014;4:152–160.
25 Lange P, Marott JL, Vestbo J, Olsen KR, Ingebrigtsen TS, Dahl M, Nordestgaard BG. Prediction of the clinical course of chronic obstructive pulmonary disease, using the new GOLD classification: a study of the general population. *Am J Respir Crit Care Med* 2012;186:975–981.
26 Marciniuk DD, Goodridge D, Hernandez P, Rocker G, Balter M, Bailey P, Ford G, Bourbeau J, O'Donnell DE, Maltais F, *et al.*; Canadian Thoracic Society COPD Committee Dyspnea Expert Working Group. Managing dyspnea in patients with advanced chronic obstructive pulmonary disease: a Canadian Thoracic Society clinical practice guideline. *Can Respir J* 2011;18:69–78.
27 Qaseem A, Snow V, Shekelle P, Casey DE Jr, Cross JT Jr, Owens DK, Dallas P, Dolan NC, Forciea MA, Halasyamani L, *et al.*; Clinical Efficacy Assessment Subcommittee of the American College of Physicians. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med* 2008;148:141–146.
28 Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, Calverley PM, Gift AG, Harver A, Lareau SC, *et al.*; American Thoracic Society Committee on Dyspnea. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med* 2012;185:435–452.
29 Gaspar C, Alfarroba S, Telo L, Gomes C, Bárbara C. End-of-life care in COPD: a survey carried out with Portuguese pulmonologists. *Rev Port Pneumol* 2014;20:123–130.
30 Hadjiphilippou S, Odogwu SE, Dand P. Doctors' attitudes towards prescribing opioids for refractory dyspnoea: a single-centred study. *BMJ Support Palliat Care* 2014;4:190–192.
31 Maurer J, Rebbapragada V, Borson S, Goldstein R, Kunik ME, Yohannes AM, Hanania NA; ACCP Workshop Panel on Anxiety and Depression in COPD. Anxiety and depression in COPD: current understanding, unanswered questions, and research needs. *Chest* 2008;134:43S–56S.

32 Pirl WF, Greer JA, Traeger L, Jackson V, Lennes IT, Gallagher ER, Perez-Cruz P, Heist RS, Temel JS. Depression and survival in metastatic non-small-cell lung cancer: effects of early palliative care. *J Clin Oncol* 2012;30:1310–1315.

33 Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age Ageing* 2005;34:218–227.

34 Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J* 2008;32:796–803.

35 Curtis JR, Engelberg RA, Wenrich MD, Au DH. Communication about palliative care for patients with chronic obstructive pulmonary disease. *J Palliat Care* 2005;21:157–164.

36 Reinke LF, Slatore CG, Uman J, Udris EM, Moss BR, Engelberg RA, Au DH. Patient-clinician communication about end-of-life care topics: is anyone talking to patients with chronic obstructive pulmonary disease? *J Palliat Med* 2011;14:923–928.

37 Heffner JE. Advance care planning in chronic obstructive pulmonary disease: barriers and opportunities. *Curr Opin Pulm Med* 2011;17:103–109.

38 Janssen DJ, Spruit MA, Schols JM, Wouters EF. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. *Chest* 2011;139:1081–1088.

39 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.

40 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.

41 Reinke LF, Engelberg RA, Shannon SE, Wenrich MD, Vig EK, Back AL, Curtis JR. Transitions regarding palliative and end-of-life care in severe chronic obstructive pulmonary disease or advanced cancer: themes identified by patients, families, and clinicians. *J Palliat Med* 2008;11:601–609.

42 Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest* 2005;127:2188–2196.