

# Inadequate Palliative Care in Chronic Lung Disease

## An Issue of Health Care Inequality

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### Abstract

Patients with chronic lung diseases suffer higher symptom burden, lower quality of life, and greater social isolation compared with patients with other diagnoses, such as cancer. These conditions may be alleviated by palliative care, yet palliative care is used less by patients with chronic lung disease compared with patients with cancer. Underuse is due, in part, to poor implementation of primary palliative care and inadequate referral to specialty palliative care. Lack of primary and specialty palliative care in patients with chronic lung disease falls short of the minimum standard of competent health care, and represents a disparity in health care and a social injustice. We invoke the ethical principles of justice and

sufficiency to highlight the importance of this issue. We identify five barriers to implementing palliative care in patients with chronic lung disease: uncertainty in prognosis; lack of provider skill to engage in discussions about palliative care; fear of using opioids among patients with chronic lung disease; fear of diminishing hope; and perceived and implicit bias against patients with smoking-related lung diseases. We propose mechanisms for improving implementation of palliative care for patients with chronic lung disease with the goal of enhancing justice in health care.

**Keywords:** palliative care; chronic lung disease; justice in healthcare; metastatic cancer; healthcare equality

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Effective palliative care offers patients significant improvements in quality of life, including relief from symptoms and stresses of serious illness and reduced social isolation (1). Palliative treatments can be offered concurrently with restorative or curative therapies and are provided by both clinicians who are not palliative care specialists (“primary palliative care”) and palliative care specialists (“specialty palliative care”) (2, 3). Medical indications for palliative care arise at all stages of serious illness, and merit attention regardless of diagnosis or prognosis (1). Despite advances, research on and implementation of palliative care have largely focused on patients with cancer (4). Patients with other conditions,

including chronic lung disease, are less likely to receive medically indicated palliative care than are patients with cancer. Compared with patients with cancer, patients with chronic lung disease often experience higher symptom burden, worse quality of life, and more social isolation (5–8). The palliative care needs of patients with chronic lung disease frequently go unmet (9).

This Perspective proposes an ethical principle of sufficiency that enjoins the medical community to competently meet all of a patient’s basic health care needs. We invoke a formal principle of justice that requires physicians to treat similar cases similarly. We urge that patients with similar palliative care needs

merit similar treatment, regardless of diagnosis. We review the empirical literature related to provision of palliative care, which demonstrates unequal provision of both primary and specialty palliative care. Two ethical principles, the *formal principle of justice* and the *principle of sufficiency*, establish that omitting to offer palliative care to patients with chronic lung disease who experience symptom burdens as high as or higher than those of patients with other diseases is not ethically justified. We suggest that offering and implementing palliative care treatments for patients with chronic lung disease require more explicit decision-making

by clinicians when clinical options are discussed with patients and their families. Medical need, not diagnosis, should be the guiding principle that determines whether or not to offer palliative care. Finally, we explore practical barriers to palliative care in chronic lung disease and offer suggestions for reducing these barriers. Some of the research presented in this Perspective has been previously reported in the form of an abstract (10).

### Palliative Care in Chronic Lung Disease as an Issue of Justice

Justice concerns the respect due each of us. In health care, justice can be understood in terms of a *principle of sufficiency* (11) that requires meeting patients' basic health care needs and providing competent care. Justice also concerns fairness in allocating health care resources and is often expressed in terms of a *principle of formal justice* (12), which requires treating similar cases similarly. Accordingly, patients who are similar in ethically relevant respects deserve similar treatment.

In applying these twin principles to palliative care, we can say, first, that competent palliative care represents basic health care that should be available to all patients with medical need (3, 13). Second, disparities in care among patients with different medical diagnoses who present with similar palliative care needs fall short of justice standards. Although patients with chronic lung disease may not experience explicit discrimination, the fact that palliative care for this population has not been standardized and is provided unevenly on a provider-by-provider basis signals implicit rationing, contributing to lower levels and inconsistent implementation of care (14, 15). More explicit decision-making and consistent practice standards are a much-needed corrective to the systematic disadvantage that patients with chronic lung disease experience compared with patients with cancer. Although knowledge of palliative care may be uneven among clinicians, the remedy is not to accept this as a given, but rather to improve education and move toward equal and appropriate access to palliative care for all patients (3). In what follows, we focus on these twin principles to identify barriers to palliative care and to

propose how to address them most effectively.

### Palliative Care for Chronic Lung Disease as an Issue of Health Care Disparities

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families...through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” and advocates integrating palliative care early in the trajectory of a patient's illness, regardless of prognosis or potential for cure (16). We regard “palliative care” broadly as encompassing both primary and specialty palliative care (3). Implementing palliative care for patients with chronic illness improves care for both patients and their families and is associated with decreased costs and lower levels of use of nonbeneficial care (17, 18).

Patients with chronic lung disease experience symptom burden that impacts their quality of life and contributes to social isolation (5); however, this burden is often underappreciated by clinicians, especially when compared with patients with cancer (7, 19). Importantly, patients with chronic lung disease may experience symptom burden as high as or higher than that of patients with cancer and for longer periods of time (6–8). In one analysis, we demonstrated that patients dying in the intensive care unit with chronic obstructive pulmonary disease (COPD) and interstitial lung diseases (ILD) receive fewer indicators of palliative care on average than those with metastatic cancer (10). Patients with COPD are more likely to receive cardiopulmonary resuscitation 1 hour before death and patients with ILD were less likely to have assessment of their pain than were patients with cancer. Both patients with COPD and ILD were less likely to have a discussion of prognoses compared with patients with cancer. Further, patients with chronic lung disease had longer lengths of stay in the intensive care unit compared with patients with cancer, suggesting ample opportunities to provide palliative care to these patients.

Our findings are consistent with those of others who have shown that patients with chronic lung disease receive

less primary palliative care and have significantly less access to specialty palliative care compared with patients with cancer (8, 20). Patients with COPD are less likely to be referred to palliative care specialists compared with patients with cancer (21) and are also less likely to receive prescriptions for opioids and benzodiazepines than patients with lung cancer despite a similar symptom burden (22). The prevalence of depression and anxiety, both of which are associated with poor outcomes in patients with chronic lung disease, is as high as or higher than in patients with cancer, yet patients with chronic lung disease frequently are not treated (8).

Increasing attention has been given to implementing support services for family members of patients with cancer (23), whereas family members of patients with chronic lung disease often do not have access to such resources despite evidence of their experiencing high physical and emotional burden (24). Because of extensive research and focus, palliative care has been formally recommended as the standard care for patients with advanced or metastatic cancer (25). Patients with chronic lung disease, however, have not received similar recognition. These results fail to meet the requirement of formal justice, that is, the requirement to treat similar cases similarly, and should be corrected.

### Barriers to Implementing Palliative Care for Patients with Chronic Lung Disease

It is important to understand and address the central barriers to implementing palliative care in patients with chronic lung disease. Barriers include (1) uncertainty in prognosis; (2) lack of knowledge and expertise among providers about how to engage in palliative care discussions; (3) concerns related to using opioids in patients with chronic lung disease; (4) fear of diminishing hope; and (5) perceived and implicit bias against patients with smoking-related or other “self-inflicted” lung diseases.

#### Uncertainty in Prognosis

Prognostication in patients with chronic lung disease is more difficult and less certain

than in patients with cancer (26). Robust data exist for patients with various types of cancer that have contributed to developing prognostic models that accurately predict a survival time of 6 months or less (27). By contrast, accurate prediction is less frequently available for patients with chronic lung disease. An analysis from the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study found that among hospitalized patients with lung cancer who were 2 days from death, the best available predictive model showed that less than 10% of patients would be alive in 6 months; by comparison, for hospitalized patients with COPD who were 2 days from death, the best available models predicted almost 50% 6-month survival (28).

Prognostication for chronic lung diseases remains difficult today (29, 30). Importantly, prognostic uncertainty, more common in patients with chronic lung disease, results in lower rates of implementing palliative care (31). This uncertainty creates barriers to providing palliative care because clinicians inappropriately equate palliative care with end-of-life care (4, 26, 31). In addition, the hospice benefit, as defined by Medicare and Medicaid reimbursement requirements, requires a degree of prognostic certainty of death within 6 months that has meant that patients with chronic lung disease are less likely to receive these services (32). A principle of sufficiency requires that palliative care not be based on prognosis or life expectancy, but on need. Therefore, the common misconception among health care professionals that palliative care should be offered only to patients at the end of life creates a barrier to providing competent care to patients with chronic lung disease (33).

#### **Lack of Knowledge and Expertise**

Clinicians caring for patients with chronic lung disease often lack the knowledge or skill set to offer effective palliative care and may be unsure whether a palliative care referral is appropriate. This is partly the result of medical education, which has focused primarily on restorative or curative care, leaving clinicians unprepared to engage in effective communication to address palliative needs (34). Lack of effective skills coupled with limited time to coordinate extra care

often leaves clinicians with little incentive to engage in effective palliative care discussions with their patients (35). Most patients with advanced chronic lung disease, such as oxygen-dependent COPD, report that their clinicians have not discussed advance care planning or end-of-life care with them (26). Patients with ILD and pulmonary fibrosis report a desire to engage in discussion about end-of-life care, yet this need is generally unmet (36). Medical schools and graduate education programs are increasingly educating students and raising awareness about primary palliative care, palliative care specialists, and differences between palliative care and hospice (37). We are hopeful that future generations of health professionals will demonstrate increased understanding of the benefits of palliative care and possess the skills necessary to provide primary palliative care and appropriately refer patients to palliative care specialists when needed.

#### **Concerns Related to Opiates**

Despite significant symptom burden from pain, dyspnea, cough, and anxiety, clinicians caring for patients with chronic lung disease often worry about providing opioids or benzodiazepines because of fear of respiratory depression or addiction (38). Dyspnea and chronic cough contribute to increasing levels of anxiety, hopelessness, and social isolation (6, 36, 39). Patients with chronic lung disease also experience significant pain (4, 8, 22). Randomized trials suggest that patients with advanced COPD receive significant benefit and improved quality of life from effective opioid treatment for dyspnea and that the doses required are often low and safe (38, 40, 41). Patients with ILD and COPD report improved quality of life after treatment of pain with low doses of opioids (36). Importantly, there was no increase in adverse events, such as respiratory depression or death, in any of the prior studies (40, 41). Despite this evidence, physicians remain hesitant to prescribe opioids for fear that they may contribute to adverse events or addiction (38, 42). As a result, patients with chronic lung disease unjustly experience symptoms of untreated pain, dyspnea, cough, and anxiety.

#### **Fear of Diminishing Hope**

Clinicians often fear that discussing palliative care will destroy hope or

precipitate a sense of abandonment by the patient (43). Maintaining hope despite poor prognoses may pose a barrier to discussing palliative care or advance care planning for clinicians (44). In addition, clinicians may feel more comfortable focusing on restorative or curative therapy because of the pervasive dichotomous “cure versus no cure” medical culture (45). This discomfort does not, however, justify avoiding palliative therapies. It warrants change to better ensure optimal patient care. The biopsychosocial model of patient care offers a vantage point for viewing the prolonged course of declining health that many patients with chronic illness face (1).

Patients with chronic lung disease report feeling frustrated by poor communication and discussion surrounding advance care planning, and often feel that important therapeutic and symptomatic goals are not discussed (5, 26, 36). High-quality communication may offer more, not less, hope to patients by eliciting patient-centered goals and offering palliative therapies that meet those goals while continuing to provide medically appropriate restorative therapies (43, 44, 46). Such discussions may help clinicians better understand symptoms that patients with chronic lung disease may be experiencing and how these symptoms impact quality of life, contribute to social isolation, and affect caregivers and family members (4).

#### **Perceived and Implicit Bias**

Last, implicit bias toward patients with COPD and other smoking-related lung diseases may contribute to decreased implementation of palliative care, especially when patients are unable to quit smoking (47). Although clinicians may not intentionally express explicit biases, clinicians may be unaware of unintentionally expressed implicit biases that patients may perceive (48, 49). Patients often experience smoking-related stigma and feel responsible for their disease (50). Although few data exist in delineating whether clinicians limit palliative care for patients with chronic lung disease, based on a patient's smoking status, treatment resulting from provider bias is inappropriate in patient care, even if unintentional (51). Models of just health care rationing have overwhelmingly concluded that interjecting social values into the delivery of health care unfairly disadvantages vulnerable populations,

including patients from minority racial groups, patients with lower levels of education, and patients from lower levels of socioeconomic status.

For example, a high proportion of patients with COPD, a respiratory disease largely due to smoking, are from lower levels of socioeconomic status (52). Symptom burden in patients with COPD is higher for patients with lower levels of socioeconomic status and lower levels of education, as well as for minority patient populations (53). Differing value systems between patients and clinicians, and among clinicians, lead to inconsistencies in care provided to similar patients who would benefit similarly from a given therapy (54). A clinician may question the benefit of palliative care for patients with chronic lung disease if they continue to smoke. Such inconsistencies may be dangerously construed as discriminatory and prejudiced toward underserved and vulnerable patients. As such, patients with smoking-related lung disease who would benefit from palliative or other therapies should be offered those interventions. Clinicians should refrain from interjecting personal values into care for patients with smoking-related lung disease or those with chronic lung disease who continue to smoke. Clinicians should also understand that patients may experience discrimination or bias based on their smoking history even if such discrimination is not intended or even present.

### Moving Forward: Opportunities to Improve Palliative Care and Reduce Disparities

The ethical principle of sufficiency requires health professionals to reduce barriers to meeting the basic palliative care needs of their patients. Providers caring for many chronically ill patients, such as oncology patients, are increasingly recognizing the importance of care models that integrate palliative care concurrently

with restorative therapies (55). The chronic care model proposed by Wagner suggests that identifying palliative care needs in patients with chronic lung disease may help improve access to palliative interventions for this patient population (56). For example, patient-centered medical homes can provide an opportunity for clinicians to integrate palliative care for patients with chronic lung disease (57). In addition, data suggest that patients with COPD who receive interventions based on the chronic care model have lower levels of use of health care (58).

Studies suggest that patients with chronic illness, including COPD, benefit from dedicated outpatient palliative care teams (59). Studies of clinics that integrate palliative care into the treatment of dyspnea for patients with chronic lung disease show promising results (60). Early integration of palliative services with increased implementation of such care models may help patients with chronic lung disease receive palliative care sooner while allowing patients to concurrently pursue restorative therapies (9). These models may also yield a more sustainable health care system for patients with chronic lung disease as a result of using both primary and specialty palliative care concurrently (3). Automatically integrating palliative care for patients with chronic lung disease would also reduce the influence of bias and prognostic uncertainty. Policy or other system-level changes that include incentives for early integration of palliative care may increase implementation of advance care planning and palliative care services in patients with chronic lung disease. Last, these system-level changes and care models would provide opportunities to measure delivery of palliative care with the goal of reducing disparities in palliative care in patients with chronic lung disease.

Ongoing education of medical and nursing students, postgraduate trainees, and practicing clinicians should encompass primary palliative care and proper timing of

referrals to palliative care specialists for patients with chronic lung disease. Use of simple prompts, such as the surprise question (“Would you be surprised if the patient died within 12 months?”) may serve as effective reminders to clinicians to initiate palliative therapies and begin advance care planning (2). Criteria proposed as guidelines for initiating palliative care in the inpatient setting could similarly serve as guidelines for assessing palliative care needs in the outpatient setting (2). This should include assessing symptoms, social and spiritual needs, patient understanding of illness and treatment options, and patient-centered goals of care. This approach may encourage clinicians to make assessing and treating palliative care a higher priority (2).

### Conclusions

Patients with chronic lung diseases suffer from high symptom burden, low levels of quality of life, and social isolation that may be alleviated by palliative care. Patients with chronic lung disease underuse palliative care, largely because of shortcomings in the implementation of primary palliative care and referrals to specialty palliative care, and fare worse than patients with other diagnoses, such as cancer. This falls short of justice standards by failing to respond competently to patients’ basic health care needs and should be remedied. We have explored practical barriers to implementing palliative care for patients with chronic lung disease and recommended strategies for reducing barriers and improving care. We have also proposed mechanisms to increase implementation of palliative care for patients with chronic lung disease. Taking these important steps is essential to implementing a more just health care system. ■

**Author disclosures** are available with the text of this article at [www.atsjournals.org](http://www.atsjournals.org).

### References

- 1 Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* 2015;373:747–755.
- 2 Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. *J Palliat Med* 2011;14:17–23.
- 3 Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 2013; 368:1173–1175.
- 4 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.

- 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 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.
- 7 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.
- 8 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.
- 9 Schroedel CJ, Yount SE, Szmulowicz E, Hutchison PJ, Rosenberg SR, Kalhan R. A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease: a potential role for specialist palliative care? *Ann Am Thorac Soc* 2014;11:1433–1438.
- 10 Brown CE, Engelberg RA, Nielsen EL, Curtis JR. Palliative care for patients dying in the ICU with chronic lung disease compared to metastatic cancer. *Ann Am Thorac Soc* (In press).
- 11 Powers M, Faden R. Social justice: the moral foundations of public health and health policy. New York: Oxford University Press; 2006.
- 12 Beauchamp TL, Childress JF. Principles of biomedical ethics. New York: Oxford University Press; 2001.
- 13 Jecker NS, Pearlman RA. An ethical framework for rationing health care. *J Med Philos* 1992;17:79–96.
- 14 Scheunemann LP, White DB. The ethics and reality of rationing in medicine. *Chest* 2011;140:1625–1632.
- 15 Ham C, Coulter A. Explicit and implicit rationing: taking responsibility and avoiding blame for health care choices. *J Health Serv Res Policy* 2001;6:163–169.
- 16 World Health Organization. Cancer: WHO definition of palliative care. 2016 [accessed 19 Jan 2016]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
- 17 Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med* 2014;28:130–150.
- 18 Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A, Douglas HR, Normand CE. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25:150–168.
- 19 Janssen DJA, 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.
- 20 Gilbert CR, Smith CM. Advanced lung disease: quality of life and role of palliative care. *Mt Sinai J Med* 2009;76:63–70.
- 21 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.
- 22 Au DH, Udris EM, Fihn SD, McDonnell 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;166:326–331.
- 23 Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009;18:1379–1393.
- 24 Figueiredo D, Gabriel R, Jácome C, Cruz J, Marques A. Caring for relatives with chronic obstructive pulmonary disease: how does the disease severity impact on family carers? *Aging Ment Health* 2014;18:385–393.
- 25 Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, Basch EM, Ferrell BR, Loscalzo M, Meier DE, Paice JA, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol* 2012;30:880–887.
- 26 Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J* 2008;32:796–803.
- 27 Salpeter SR, Malter DS, Luo EJ, Lin AY, Stuart B. Systematic review of cancer presentations with a median survival of six months or less. *J Palliat Med* 2012;15:175–185.
- 28 Claessens MT, Lynn J, Zhong Z, Desbiens NA, Phillips RS, Wu AW, Harrell FE Jr, Connors AF Jr. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT. *J Am Geriatr Soc* 2000;48(5, Suppl):S146–S153.
- 29 Pinto-Plata VM, Cote C, Cabral H, Taylor J, Celli BR. The 6-min walk distance: change over time and value as a predictor of survival in severe COPD. *Eur Respir J* 2004;23:28–33.
- 30 Ley B, Collard HR, King TE Jr. Clinical course and prediction of survival in idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med* 2011;183:431–440.
- 31 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.
- 32 Centers for Medicare & Medicaid Services. Medicare.gov [website]: Hospice & respite care. 2016 [accessed 19 Jan 2016]. Available from: <https://www.medicare.gov/coverage/hospice-and-respite-care.html>
- 33 Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, Abernethy AP, Weinberger M. "Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc* 2014;3:e000544.
- 34 Sullivan AM, Lakoma MD, Block SD. The status of medical education in end-of-life care: a national report. *J Gen Intern Med* 2003;18:685–695.
- 35 Groot MM, Vernooij-Dassen MJ, Verhagen SC, Crul BJ, Grol RP. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliat Med* 2007;21:697–703.
- 36 Bajwah S, Higginson IJ, Ross JR, Wells AU, Birring SS, Patel A, Riley J. Specialist palliative care is more than drugs: a retrospective study of ILD patients. *Lung* 2012;190:215–220.
- 37 Aldridge MD, Hasselaar J, Garralda E, van der Eerden M, Stevenson D, McKendrick K, Centeno C, Meier DE. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. *Palliat Med* 2016;30:224–239.
- 38 Rocker G, Horton R, Currow D, Goodridge D, Young J, Booth S. Palliation of dyspnoea in advanced COPD: revisiting a role for opioids. *Thorax* 2009;64:910–915.
- 39 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.
- 40 Abernethy AP, Currow DC, Frith P, Fazekas BS, McHugh A, Bui C. Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. *BMJ* 2003;327:523–528.
- 41 Jennings A-L, Davies AN, Higgins JP, Gibbs JS, Broadley KE. A systematic review of the use of opioids in the management of dyspnoea. *Thorax* 2002;57:939–944.
- 42 Young J, Donahue M, Farquhar M, Simpson C, Rocker G. Using opioids to treat dyspnea in advanced COPD: attitudes and experiences of family physicians and respiratory therapists. *Can Fam Physician* 2012;58:e401–e407.
- 43 Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Ann Intern Med* 2003;138:439–443.
- 44 Curtis JR, Engelberg R, Young JP, Vig LK, Reinke LF, Wenrich MD, McGrath B, McCown E, Back AL. An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *J Palliat Med* 2008;11:610–620.
- 45 Jecker NS, Self DJ. Separating care and cure: an analysis of historical and contemporary images of nursing and medicine. *J Med Philos* 1991;16:285–306.
- 46 Pantilat SZ. Communicating with seriously ill patients: better words to say. *JAMA* 2009;301:1279–1281.
- 47 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.

- 48 Banaji MR, Greenwald AG. *Blindspot: hidden biases of good people*. New York: Delacorte Press; 2013.
- 49 FitzGerald C. A neglected aspect of conscience: awareness of implicit attitudes. *Bioethics* 2014;28:24–32.
- 50 Berger BE, Kapella MC, Larson JL. The experience of stigma in chronic obstructive pulmonary disease. *West J Nurs Res* 2011;33:916–932.
- 51 Jecker NS. Caring for “socially undesirable” patients. *Camb Q Healthc Ethics* 1996;5:500–510.
- 52 Barbeau EM, Krieger N, Soobader M-J. Working class matters: socioeconomic disadvantage, race/ethnicity, gender, and smoking in NHIS 2000. *Am J Public Health* 2004;94:269–278.
- 53 Eisner MD, Blanc PD, Omachi TA, Yelin EH, Sidney S, Katz PP, Ackerson LM, Sanchez G, Tolstykh I, Iribarren C. Socioeconomic status, race and COPD health outcomes. *J Epidemiol Community Health* 2011;65:26–34.
- 54 van Boekel LC, Brouwers EP, van Weeghel J, Garretsen HF. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. *Drug Alcohol Depend* 2013;131:23–35.
- 55 Partridge AH, Seah DS, King T, Leighl NB, Hauke R, Wollins DS, Von Roenn JH. Developing a service model that integrates palliative care throughout cancer care: the time is now. *J Clin Oncol* 2014;32:3330–3336.
- 56 Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* 1998;1:2–4.
- 57 Fromer L. Implementing chronic care for COPD: planned visits, care coordination, and patient empowerment for improved outcomes. *Int J Chron Obstruct Pulmon Dis* 2011;6:605–614.
- 58 Adams SG, Smith PK, Allan PF, Anzueto A, Pugh JA, Cornell JE. Systematic review of the chronic care model in chronic obstructive pulmonary disease prevention and management. *Arch Intern Med* 2007;167:551–561.
- 59 Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 2004;164:83–91.
- 60 Booth S, Bausewein C, Rocker G. New models of care for advanced lung disease. *Prog Palliat Care* 2011;19:254–263.