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Official publication of the American College of Chest Physicians



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Chest 2010;137:674-691
DOI 10.1378/chest.09-1543

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ISSN:0012-3692

A M E R I C A N C O L L E G E O F



P H Y S I C I A N S[®]



American College of Chest Physicians Consensus Statement on the Management of Dyspnea in Patients With Advanced Lung or Heart Disease

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Background: This consensus statement was developed based on the understanding that patients with advanced lung or heart disease are not being treated consistently and effectively for relief of dyspnea.

Methods: A panel of experts was convened. After a literature review, the panel developed 23 statements covering five domains that were considered relevant to the topic condition. Endorsement of these statements was assessed by levels of agreement or disagreement on a five-point Likert scale using two rounds of the Delphi method.

Results: The panel defined the topic condition as “dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart disease.” The five domains were: measurement of patient-reported dyspnea, oxygen therapy, other therapies, opioid medications, and ethical issues. In the second round of the Delphi method, 34 of 56 individuals (61%) responded, and agreement of at least 70% was achieved for 20 of the 23 statements.

Conclusions: For patients with advanced lung or heart disease, we suggest that: health-care professionals are ethically obligated to treat dyspnea, patients should be asked to rate the intensity of their breathlessness as part of a comprehensive care plan, opioids should be dosed and titrated for relief of dyspnea in the individual patient, both the patient and clinician should reassess whether specific treatments are serving the goal of palliating dyspnea without causing adverse effects, and it is important for clinicians to communicate about palliative and end-of-life care with their patients.

CHEST 2010; 137(3):674–691

Abbreviations: ACCP = American College of Chest Physicians; NPPV = noninvasive positive pressure ventilation; PLB = pursed-lip breathing; RCTs = randomized controlled trials

EXECUTIVE SUMMARY

This consensus statement was initiated based on the understanding that patients with advanced lung or heart disease are not currently being treated consistently and effectively for relief of dyspnea. The purpose is to summarize available evidence in order to improve the care and treatment of dyspnea in this population. An expert panel of specialists in pulmonary medicine, cardiology, nursing, and palliative care developed our findings. Selection of the expert

panel and the development of the consensus statement followed policy established by the American College of Chest Physicians (ACCP). After extensive discussion and consideration, the panel defined the topic condition as “dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart disease.”

Endorsement of suggestions for the care and management of the subject patient population was accomplished using the Delphi method. Based on results of a literature review from 1966

to 2008, the expert panel developed an online survey consisting of 23 statements covering five domains (measurement of patient-reported dyspnea, oxygen therapy, other nonpharmacologic therapies, opioid medications, and ethical issues) that were identified as being relevant to the management of dyspnea in patients with advanced lung or heart disease. Levels of agreement or disagreement were assessed for each statement on a five-point Likert scale. For the first round, members of the expert panel independently rated agreement or disagreement for each statement. Based on these responses, all statements were reviewed and modified, if appropriate, to enhance clarity. For the second round, the 23 statements were sent to 56 clinicians from five relevant ACCP specialty NetWork steering committees. A total of 34 individuals (61% response rate) independently completed the questionnaire. An acceptable level of agreement ($\geq 70\%$) was achieved for 20 of 23 statements. Based on the results of the survey, the following suggestions were derived for the management of patients with advanced lung or heart disease who experience dyspnea at rest or with minimal physical activity and are distressed despite optimal therapy.

Measurement of Patient-Reported Dyspnea

1. Patients should be asked to routinely and regularly rate the intensity of their

Manuscript received June 30, 2009; revision accepted September 24, 2009.

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Funding/Support: This project was commissioned by the American College of Chest Physicians (ACCP) and is considered an official project of this organization.

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DOI: 10.1378/chest.09-1543

breathlessness as part of a comprehensive care plan.

2. The patient-reported rating of breathlessness should be routinely documented in the medical record to guide management and interdisciplinary care.
3. The assessment of dyspnea should include inquiry into the distress, meaning, and unmet needs that accompany breathlessness.
4. The use of any particular instrument over another for the measurement of dyspnea is not suggested at the present time.
5. Health-care professionals are ethically obligated to treat dyspnea, and patients and their families should be reassured that they will be provided the means to effectively treat this symptom.
6. Therapies should generally be started with the understanding that the patient and clinician will reassess whether specific treatments are serving the goal of palliating dyspnea without causing adverse effects.

Oxygen Therapy for Relief of Dyspnea

7. Supplemental oxygen can provide relief of dyspnea for patients who are hypoxic at rest.
8. Supplemental oxygen can provide relief of dyspnea for patients who are hypoxic during minimal activity.

Other Nonpharmacologic Therapies for Relief of Dyspnea

9. Pursed-lip breathing can be an effective strategy for relief of dyspnea.
10. Relaxation can be an effective strategy for relief of dyspnea.
11. Noninvasive positive pressure ventilation can provide relief of dyspnea.

Opioid Medications for Relief of Dyspnea

12. Oral and/or parenteral opioids can provide relief of dyspnea.
13. Opioids should be dosed and titrated for the individual patient with consideration of multiple factors (eg, renal, hepatic, pulmonary function, and current and past opioid use) for relief of dyspnea.
14. Respiratory depression is a widely held concern with the use of opioids for the relief of dyspnea.

Ethical Issues for Relief of Dyspnea at End of Life

15. **Concerns about contributing to addiction and/or physical dependence should never limit effective treatment or palliation of dyspnea.**
16. **The “principle of double effect” provides a rationale for using opioids or sedatives that might hasten death, provided that the purpose of increasing doses is to relieve dyspnea.**
17. **Anxiety and depression frequently accompany dyspnea and require evaluation.**
18. **Clinicians should understand that family members from some cultures may have different perspectives on the role of the family and who should be involved in decisions about treating dyspnea at the end of life.**
19. **The clinician should anticipate differences in family perspectives and/or spiritual beliefs on the value of maintaining consciousness at the end of life and the value of suffering, and be prepared to apply principles of culturally effective end-of-life care to these situations.**
20. **It is important for clinicians to communicate about palliative and end-of-life care with their patients.**

Dyspnea is a prominent symptom among patients with advanced lung or heart disease.¹ In a systematic review, the reported prevalence of breathlessness was >90% in patients with advanced COPD and >60% in those with advanced heart disease.² About 94% of patients with chronic lung disease experience dyspnea in the last year of life.³ A retrospective analysis of a prospective cohort from the Study to Understand Patient Preferences and Outcomes of Treatment found that dyspnea was the overriding complaint of patients who died of COPD and that “serious dyspnea” was far more common (66%) than “serious pain” (25%).⁴ The investigators reported that patients with COPD were more likely to die with poor control of dyspnea than patients who had lung cancer.⁵

The perception of dyspnea is considered analogous to the perception of pain and consists of sensory (intensity) and affective (unpleasantness) dimensions.⁶ Similar cortical processes appear to underlie the experience of dyspnea and pain. Clearly, both symptoms can result in human suffering. Anxiety, depression, and other psychologic factors occur frequently in patients with advanced disease and influence breathlessness.⁷ Although uncertainties and

questions remain about the exact mechanisms that cause dyspnea, it is a distressing symptom that requires attention, consideration, and treatment by health-care providers.

The purpose of this consensus statement is to influence clinical practice and to provide suggestions for the management of dyspnea in patients with advanced lung or heart disease. This topic was proposed based on the understanding that patients are not being treated consistently and effectively for the relief of dyspnea under these conditions.⁸⁻¹¹

The panel agreed that this consensus statement was intended for care of the patient in whom medical therapy has been optimized, and the focus of treatment is on symptom management, relief of suffering, and maintenance of quality of life. After extensive discussion and consideration, the panel defined the target patient population as those with “dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart disease.” “Advanced” stage refers to progressive disease with a limited prognosis.

METHODS

Literature Search

The ACCP research methodologist performed a MEDLINE literature search of English language articles on human subjects for the period of 1966 to 2008. The purpose of the literature search was to evaluate published studies on this topic condition and to identify topic domains that would form the basis of the consensus survey. The following search strategy and key terms were used to capture studies relevant to the topic:

- Patient population: advanced, severe, end-stage, end-of-life lung or heart disease
- Condition: dyspnea, breathlessness
- Intervention: treatment, therapy, palliation or palliative care, pharmacologic, drug, opioids, nonpharmacologic
- Other: measurement, ethics.

Patients with cancer were not included in this review because high-quality evidence is available on end-of-life care in this population. However, there are gaps in our knowledge about the management/palliation of breathlessness as experienced daily by patients with advanced lung or heart disease.

The literature search was initially limited to randomized controlled trials (RCTs). However, because of the paucity of data, the literature search was expanded to include prospective studies, case series, and systematic reviews. After the initial literature review was completed, each primary author of the different domains reviewed the articles and critically added or removed references or review articles that he/she considered relevant. These additional materials were then reviewed for inclusion/exclusion by the secondary author of the domain and the first three authors of the consensus statement. The materials were then provided to the expert panel for consideration.

Five domains were derived from the results of the literature search and included: measurement of patient-reported dyspnea, oxygen therapy, other nonpharmacologic treatment, opioid medications, and ethical issues. A primary and a secondary author

were identified among members of the expert panel to review the results of the literature search and to generate statements for consideration for each of the five domains. Each statement was then reviewed and, if deemed appropriate, revised by the panel members.

Expert Panel Members

The consensus development process was organized following ACCP policy. Participation was obtained by open nomination from the ACCP membership through the ACCP NetWork system. NetWork committees consist of members of the ACCP who are physicians, nurses, or other health-care professionals with a specific interest in a particular topic. The expert panel members consisted of cardiopulmonary physicians and nurses who were selected based on their clinical and/or research expertise in evaluating and/or providing care to the patient population. Panel members served as content experts on specific domains (key topics) addressed in the consensus statement. Panel members also participated in the development and initial round of the Delphi survey.

Delphi Method

Endorsement of consensus statements on the management of dyspnea in patients with advanced lung or heart disease was accomplished using a modified Delphi method.¹² The Delphi approach was chosen because it represents an established method of obtaining expert opinion, determining levels of agreement, and evaluating the degree of consensus on a given topic. It has been used widely in various areas of health-care research, including the development of guidelines for best practice, content of curricula, and the definition of professional roles and clinical protocols.^{13,14} Anonymity was derived from the absence of face-to-face interaction. The survey was distributed online, and participants responded independently to the questionnaire. Levels of agreement or disagreement were assessed for each statement on a five-point Likert scale (Table 1). Responses were accessed by the ACCP research methodologist for statistical analysis and determination of the level of expert consensus and appropriateness of management suggestions.

For the first round, the survey was sent to the 15 expert panel members, who independently rated agreement or disagreement for each of the 23 statements. Based on these responses, each statement was reviewed and modified, if deemed appropriate, to enhance clarity. For the second round, the 23 statements were sent to 56 clinicians from five relevant ACCP specialty NetWork steering committees: Clinical Pulmonary Medicine, Respiratory Care, Airways, Palliative and End-of-Life Care, and Cardiovascular Medicine and Surgery.

Statistical Analysis

Levels of agreement for the Delphi method are presented as percent agreement (rated as 4 or 5 on the Likert scale) as well as the range, mean, and median values.¹⁵⁻²⁰ Consensus on a topic can

be determined if a certain percentage of the votes falls within a prescribed range.²¹ The results of the data analysis derived from the survey are expressed as the percentage of respondents scoring an item either 4 ("somewhat agree") or 5 ("agree"). For the purposes of the consensus statement, agreement among the respondents of $\geq 70\%$ for each statement was considered *a priori* to represent consensus.^{21,22}

RESULTS

The results of the literature review are presented in tables located in the Appendices. The results of the Delphi survey are presented in Tables 2 to 7.

Literature Search

The literature search retrieved a total of 13 RCTs, 10 systematic reviews, 10 prospective studies, seven retrospective studies, seven case studies, and two topic reviews that were relevant to the management of dyspnea in patients with advanced lung or heart disease. A summary of these reports is presented in Appendices 1 to 5. Studies that measured the effectiveness of an intervention for the relief of dyspnea during exercise were excluded from review because the expert panel believed the target patient population would have difficulty performing exercise testing because of dyspnea at rest or during minimum activity.

Measurement of Patient-Reported Dyspnea

Asking patients to report the severity and/or distress of their breathlessness has been suggested in order to assess its impact on an individual's overall health status and to provide a baseline value to evaluate the response to specific therapies.²³⁻³⁰ This approach is analogous to the assessment of pain that is mandated in health-care encounters to guide pain awareness and management.

Although dyspnea is multidimensional and includes an affective component, an initial strategy is to ask the patient to report the intensity or severity of breathlessness.²³⁻³¹ Three instruments—the 0 to 10 scale developed by Borg,³² the visual analog scale,^{33,34} and the numerical rating scale^{35,36}—have demonstrated usefulness in assessing breathlessness in patients with advanced disease. In comparative trials, superior performance has not been demonstrated with any of these instruments in patients with advanced lung or heart disease (Appendix 1).^{2,35,37,38} Interventions might decrease the unpleasantness or distress associated with dyspnea without decreasing its intensity (as similar to pain).

Oxygen Therapy

Patients With Hypoxemia: Oxygen therapy is the standard of care for the treatment of patients with

Table 1—Likert Scale Used by Respondents to Report the Level of Agreement or Disagreement for Each Statement

Level	Response
1	Disagree
2	Somewhat disagree
3	Neither agree nor disagree
4	Somewhat agree
5	Agree

Table 2—Statements on the Measurement of Patient-Reported Dyspnea

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
1	Patients with advanced lung or heart disease should be asked to routinely and regularly rate the intensity of their breathlessness as part of a comprehensive care plan.	94	2-5	4.8 (5)
2	For patients with advanced lung or heart disease, the patient-reported rating of breathlessness should be routinely documented in the medical record to guide management and interdisciplinary care.	91	2-5	4.6 (5)
3	For patients with advanced lung or heart disease, the assessment of dyspnea should include inquiry into the distress, meaning, and unmet needs that accompany breathlessness.	100	4-5	4.7 (5)
4	For patients with advanced lung or heart disease, the use of any particular instrument over another for the measurement of dyspnea is not suggested at the present time.	74	1-5	4.1 (4)
5	For patients with advanced lung or heart disease, health-care professionals are ethically obligated to treat dyspnea and to reassure patients and their families that they will provide the means to effectively treat this symptom.	97	3-5	4.7 (5)
6	For patients with advanced lung or heart disease, therapies should generally be started with the understanding that the patient and clinician will reassess whether specific treatments are serving the goal of palliating dyspnea without causing adverse effects.	100	4-5	4.9 (5)

hypoxemia.^{39,40} However, only a limited number of studies have evaluated the short-term effects of supplemental oxygen therapy on breathlessness at rest in patients with advanced lung disease (Appendix 2).⁴¹⁻⁴⁵ Two studies reported significant improvement in dyspnea with oxygen therapy,^{42,45} whereas the other two studies found no benefit.^{41,43} There are no RCTs evaluating the effects of oxygen in reducing breathlessness in patients with advanced heart disease.

Patients Without Hypoxemia: The literature search strategy used for this consensus statement did not identify any studies evaluating the effects of supplemental oxygen for the relief of dyspnea in patients with advanced lung or heart disease who were not hypoxemic at rest.

Other Nonpharmacologic Approaches

The expert panel chose to focus on several nonpharmacologic approaches that are more commonly used in clinical practice to relieve dyspnea. These include pursed-lip breathing (PLB), cool air move-

ment on the face with a fan, relaxation therapy, and noninvasive positive pressure ventilation (NPPV). A summary of studies on the effectiveness of these treatments in patients with advanced lung or heart disease is presented in Appendix 3.⁴⁶⁻⁵⁷ A Cochrane review has summarized the nonpharmacologic interventions for treatment of breathlessness in advanced stages of malignant and nonmalignant diseases.⁵⁷

The literature review also considered studies of anxiolytic medications, antidepressants, phenothiazines, inhaled furosemide, inhaled lidocaine, music therapy, and acupuncture for relief of dyspnea. As there are only a few reports on these interventions in the target patient population, the information was considered insufficient to be included in this consensus statement.

PLB: PLB is a breathing strategy often used spontaneously by patients with airway obstruction, particularly those with COPD, to relieve breathlessness. PLB performed during rest improves oxygen saturation and reduces carbon dioxide levels by promoting a slower and deeper breathing pattern.⁵⁸⁻⁶⁰ Bianchi

Table 3—Statements on Oxygen Therapy for Relief of Dyspnea

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
7	For patients with advanced lung or heart disease who are hypoxemic at rest, supplemental oxygen can provide relief of dyspnea.	76	1-5	3.9 (4)
8	For patients with advanced lung or heart disease who are hypoxemic during minimal activity, supplemental oxygen can provide relief of dyspnea.	74	1-5	3.8 (4)

Table 4—Statements on Other Nonpharmacologic Therapies for Relief of Dyspnea

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
9	For patients with advanced lung or heart disease, pursed-lip breathing can be an effective strategy for relief of dyspnea.	76	2-5	4.0 (4)
10	For patients with advanced lung or heart disease, relaxation can be an effective strategy for relief of dyspnea.	85	3-5	4.2 (4)
11	For patients with advanced lung or heart disease, noninvasive positive pressure ventilation can provide relief of dyspnea.	82	1-5	4.1 (4)

et al⁴⁶ found that 22 patients with COPD reported a modest but significant decrease in breathlessness (Δ 0.3 units on the Borg scale; $P < .04$) and a corresponding reduction in end-expiratory volume with PLB compared with spontaneous breathing.

Fan: Patients with respiratory disease often describe that movement of cool air with a fan or fresh air reduces breathlessness.⁶¹ Laboratory studies have shown that cold air directed on the cheek decreases dyspnea induced in healthy individuals.⁶² However, to our knowledge, there are no studies published in peer-review journals that have examined the use of a fan and/or cool air for the relief of dyspnea in patients with advanced lung or heart disease.

Relaxation Therapy: Two studies measured the effects of relaxation on perceived dyspnea in patients with COPD at rest.^{47,48} Gift et al⁴⁷ found that patients reported less dyspnea after listening to a recorded-relaxation message compared with sitting quietly. Renfro⁴⁸ reported that progressive muscle relaxation was effective in reducing dyspnea in 20 patients with COPD after each of four weekly sessions ($P = .04$) but not at the end of the 4-week period.

NPPV: The rationale for NPPV is that by unloading the respiratory muscles, the decreased work of breathing might provide relief of dyspnea. In three systematic reviews, authors concluded that use of NPPV improved patients' perception of dyspnea in those with advanced COPD or acute respiratory failure.⁵³⁻⁵⁵

In four RCTs, there was a modest-to-significant improvement in patient-reported dyspnea with NPPV.⁴⁹⁻⁵² As relief of dyspnea with NPPV may not

relate to changes in arterial blood gases, it is appropriate to reassess the breathlessness experienced by patients receiving such ventilatory support at frequent intervals.

Opioid Medications

Opioids are naturally occurring, semisynthetic, and synthetic drugs that bind to opioid receptors to produce relief of dyspnea. Opioids may have multiple mechanisms of action for symptom relief, including reductions in ventilation, oxygen consumption, sensitivity to hypercapnia, the central perception of dyspnea (similar to the reduction in the central perception of pain), and anxiety associated with dyspnea.⁶³ Opioids are administered in oral, parenteral, and nebulized forms. Although oral morphine is the most commonly prescribed opioid for the relief of dyspnea, other medications include diamorphine, dihydrocodeine, fentanyl, hydromorphone, and oxycodone.⁶⁴ Specific concerns about the study designs of various RCTs are that the opioid dose was relatively small, doses were not titrated to achieve a threshold dose for symptom relief, and the dosing intervals may have been too long.

Oral and Parenteral Opioids: The effects of oral and/or parenteral opioids for relief of dyspnea at rest are variable (Appendix 4).⁶⁵⁻⁷⁷ In one review of 13 studies involving patients with a variety of advanced chronic diseases, Jennings and colleagues⁶³ concluded that morphine was effective in relieving dyspnea (standard mean difference, -0.31 ; CI -0.51 to -0.31). In two reviews of palliative care, the authors concluded

Table 5—Statements on Opioid Medications for Relief of Dyspnea

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
12	For patients with advanced lung or heart disease, oral and/or parenteral opioids can provide relief of dyspnea.	78	1-5	4.1 (4)
13	For patients with advanced lung or heart disease, opioids should be dosed and titrated for the individual patient with consideration of multiple factors (eg, renal, hepatic, and pulmonary function, and current and past opioid use) for relief of dyspnea.	94	3-5	4.8 (5)
14	For patients with advanced lung or heart disease, respiratory depression is a widely held concern with the use of opioids for the relief of dyspnea.	100	4-5	4.7 (5)

Table 6—Statements on Ethical Issues for Relief of Dyspnea at End of Life

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
15	For patients with advanced lung or heart disease, concerns about contributing to addiction and/or physical dependence should never limit effective treatment or palliation of dyspnea.	81	2-5	4.4 (4)
16	For patients with advanced lung or heart disease, the "principle of double effect" provides a rationale for using opioids or sedatives that might hasten death, provided that the purpose of increasing doses is to relieve dyspnea.	72	1-5	4.0 (4)
17	For patients with advanced lung or heart disease, anxiety and depression frequently accompany dyspnea and require evaluation.	97	3-5	4.9 (5)
18	For patients with advanced lung or heart disease, clinicians should understand that family members from some cultures may have different perspectives on the role of the family and who should be involved in decisions about treating dyspnea at the end of life.	97	3-5	4.8 (5)
19	For patients with advanced lung or heart disease, the clinician should anticipate differences in family perspectives and/or spiritual beliefs on the value of maintaining consciousness at the end of life and the value of suffering, and be prepared to apply principles of culturally effective end-of-life care to these situations.	97	3-5	4.9 (5)
20	For patients with advanced lung or heart disease, it is important for clinicians to communicate about palliative and end-of-life care with their patients.	100	4-5	4.9 (5)

that short-term opioids are effective in improving dyspnea in patients at the end of life.^{27,76}

Nebulized Opioids: Opioid receptors are located throughout the respiratory tract.⁷⁵ The rationale for the nebulized route of administration is that these medications bind to these opioid receptors and might relieve dyspnea without causing systemic side effects. Although there is anecdotal support for the use of nebulized opioids, data from two RCTs found that nebulized morphine was no better than nebulized saline for relieving dyspnea.^{69,70} Jennings and colleagues⁶³ concluded that nebulized opioids did not relieve breathlessness.

Adverse Effects With Opioids: Fear of overdosing and the development of respiratory depression are common concerns in caring for patients with advanced lung or heart disease who experience severe dyspnea. Chan et al⁷⁹ reported that higher doses of opioids and

benzodiazepines used in the withdrawal of life-sustaining treatment were not associated with a decreased time from withdrawal of life support to death. Other studies found that survival time was unrelated to morphine dosage.⁸⁰⁻⁸²

Of 11 studies that provided information on arterial blood gases or oxygen saturation, only one study reported any significant changes in oxygenation after opioid administration.⁸³ Although the arterial carbon dioxide partial pressure increased with opioid use, the value did not exceed 40 mm Hg.⁸⁴ Other adverse effects that may occur with opioids include constipation, confusion, drowsiness, hallucinations, nausea/vomiting, and psychosis.

Ethical Issues

The major ethical issues identified in this review include the obligation to treat or palliate dyspnea, appropriate opioid dosing and associated concerns of

Table 7—Statements That Did Not Achieve Consensus for Relief of Dyspnea

No.	Statement	Agreement, %	Range	Rating, Mean (Median)
21	For patients with advanced lung or heart disease who are nonhypoxemic at rest or with minimal activity, supplemental oxygen can provide relief of dyspnea and improve exercise endurance.	47	1-5	3.2 (3)
22	For patients with advanced lung or heart disease, nebulized opioids do not provide equivocal or additional relief of dyspnea beyond that achieved with parenteral or oral opioids.	59	1-5	3.8 (4)
23	For patients with advanced lung or heart disease, fresh air or cool air movement with a fan directed toward the face can be an effective strategy for relief of dyspnea.	61	1-5	3.7 (4)

addiction, cultural sensitivity, and effective communication (Appendix 5).⁸⁵⁻⁹² Many patients with advanced lung or heart disease have a tremendous concern about the experience of dying, and a large component of this anxiety is focused on their breathing difficulty and "suffocating."^{85,86,93} Recent statements and guidelines emphasize the obligation of physicians and nurses to use available treatments to relieve dyspnea in this patient population.^{1,30,57} The principle of double effect provides a justification for using opioids or sedatives that might hasten death, as long as the purpose of titrating doses is to control or relieve symptoms.⁹⁴

Conflict among clinicians, patients, and family members about treating symptoms may arise when clinicians and family members have different cultural perspectives on end-of-life care. Blackhall et al^{87,88} proposed that clinicians should understand that family members from some cultures may have very different perspectives on the role of the family and who should be involved in decisions about treating symptoms at the end of life. Patients and families may also vary in their perspectives on the value of maintaining consciousness at the end of life and the value of suffering. It is important to anticipate differences in perspectives and be prepared to apply principles of culturally effective end-of-life care to these situations.

There is evidence that patients with advanced lung or heart disease receive poor-quality palliative and end-of-life care compared with patients who have cancer.^{5,95-97} One reason these patients may receive poor-quality palliative care is that patient-physician communication about end-of-life care is unlikely to occur.^{89,90,98} Understanding the barriers to this communication may be an important step to improving communication about end-of-life care.⁹¹ Although most patients with advanced disease would like to discuss end-of-life care with their physicians, few physicians discuss such issues with their patients.^{89,90,98}

Delphi Method

For the first round of evaluation for consensus, 12 of the 15 panel members (80%) completed the survey. For the second round of evaluation for consensus, 34 of 56 individuals (61%) completed the survey. Acceptable levels of agreement were obtained for 20 of 23 statements during the second round of the survey (Tables 2-6). Three statements did not achieve agreement (Table 7).

DISCUSSION

Despite the high prevalence of dyspnea in patients with advanced lung or heart disease, the current literature review and previous reviews demonstrate the paucity of scientific data on the management of this

symptom.^{1,27,76,99,100} The majority of RCTs on this topic have focused on patients with advanced COPD, whereas information addressing dyspnea management in patients with advanced heart disease is quite limited.

With the Delphi method, consensus was achieved on 20 of 23 statements. However, a high level of agreement among experienced clinicians does not necessarily reflect clinical practice. With the Delphi method, statements can be revised followed by additional rounds of asking respondents to rate agreement or disagreement. However, panel members believed that this process was unlikely to achieve consensus for three statements (Table 7). Management suggestions derived from the Delphi method should not be used for performance measurement or for competency purposes, because they are not evidence-based as defined by the ACCP Health and Science Policy Committee.

There was consensus that patients with advanced lung or heart disease should be asked to routinely and regularly rate the intensity of breathlessness and that these ratings should be documented in the medical record. Similarly, the American Thoracic Society has stated that symptom management for patients with advanced respiratory disease should rely on a dyspnea scale as reported by the patient to assess its severity and the effects of therapy.¹ Although assessment of a patient's intensity of pain is a requirement, it is not standard practice for health-care providers to ask patients to provide a rating of dyspnea.

There was clear consensus on the use of oxygen to relieve dyspnea in patients with hypoxemia even though the results of four RCTs do not demonstrate a consistent benefit. The American College of Physicians has recommended that oxygen be used for short-term relief of hypoxemia as part of the management of dyspnea in patients at the end of life.⁷⁶ Only 47% of respondents believed that supplemental oxygen would relieve dyspnea that occurs at rest or with minimal activity in patients without hypoxemia. The literature search did not identify any studies that evaluated oxygen therapy in a population of patients without hypoxemia.

Our survey demonstrated consensus for using oral or parenteral opioids to relieve dyspnea, for titrating doses of opioids in individual patients, and for concern about respiratory depression. Previous reviews and statements support these findings.^{27,43,101-103} However, there was uncertainty among respondents whether nebulized opioids provide equivocal or additional relief of dyspnea compared with systemic delivery. Two systematic reviews concluded that nebulized opioids are no more effective than nebulized placebo for relieving dyspnea.^{63,76}

There was strong consensus relating to various ethical issues for palliating dyspnea, particularly at the end of life. For example, agreement was high that health-care professionals are ethically obligated to treat dyspnea, and that the effectiveness of specific treatments and possible side effects should be reassessed by both patients/families and the clinician. Seventy-two percent of respondents agreed with the statement that the principle of double effect provides justification for using opioids or sedatives to relieve dyspnea even though this might hasten death. This principle, along with other ethical issues, emphasizes the importance of communication with the patient and family members and creates an awareness that different perspectives may exist among families and cultures.

This consensus statement was initiated based on the understanding that patients with advanced lung or heart disease are not currently being treated consistently and effectively for relief of dyspnea. The purpose was to provide suggestions to improve the treatment of dyspnea in this patient population. The results of the literature review demonstrated a paucity of scientific information on this topic. Using the Delphi method to develop consensus, acceptable agreement was achieved for 20 of 23 statements that covered the domains of measurement of patient-reported dyspnea, oxygen therapy, other nonpharmacologic therapies, opioid medications, and ethical issues. There is a need and opportunity to enhance our knowledge with additional research to improve the management of dyspnea in patients with advanced lung or heart disease.

Appendix 1—Comparison of Instruments to Measure Dyspnea in Advanced Lung or Heart Disease

Study/Year	Study Design	Instrument/Assessment	Outcomes/Results
Gift and Narsavage ³⁵ /1998	PS; COPD; N = 188	Patients rated their present dyspnea by using the VAS and the NRS. They also rated their usual dyspnea (dyspnea during the past week).	Concurrent validity of the NRS was supported by the high correlation of its scores with scores from the VAS. Conversion of the NRS to a 0-to-100 scale and comparison with the VAS (by using a paired <i>t</i> test to determine if the correlated scores were similar for clinical decision making) showed that scores were not significantly different. A paired <i>t</i> test showed a difference in scores on the NRS obtained before and after ambulation, supporting the construct validity of the NRS. Scores on the NRS for present dyspnea were poorly correlated with ratings of usual dyspnea, indicating that present dyspnea and usual dyspnea are different constructs.
Powers and Bennet ³⁷ /1999	PS; Patients on mechanical ventilation; N = 28	VAS, Vertical VAS, Borg, NRS, Faces scale	The five rating scales had acceptable test-retest reliabilities, with intraclass correlation coefficients ranging from 0.81 to 0.97. Criterion validity of the four scales also was acceptable, with Spearman rank-order correlation coefficients from 0.76 to 0.96. The rating scales were not correlated with most of the physiologic variables. At least half of the patients reported moderate-to-severe dyspnea.
Bausewein et al ² /2007	SR; Patients with advanced cardiorespiratory disease	33 tools for assessment of breathlessness	No one tool assessed all the dimensions of this complex symptom, which affects the psychology and social functioning of the affected individual and their family; most focused on physical activity. As yet there is no one scale that can accurately reflect the far-reaching effects of breathlessness on the patient with advanced disease and on the family.
Mahler and Jones ³⁹ /1997	SR; Patients with advanced lung disease	Multidimensional and disease-specific instruments	Although multidimensional instruments provide an “indirect” measure of dyspnea, those scales have been tested extensively and have demonstrated significant improvements with a variety of treatments for patients with advanced lung diseases. For clinical trials evaluating a new therapy or procedure, disease-specific measures are more appropriate because patients and clinicians find the items more relevant. Furthermore, there is greater potential for demonstrating a significant change with a disease-specific instrument.

NRS = numerical rating scale; PS = prospective study; SR = systematic review; VAS = visual analog scale.

Appendix 2—Oxygen Therapy for the Palliation of Dyspnea in Advanced Lung or Heart Disease

Study/Year	Study Design	Intervention	Outcomes/Results
Liss and Grant ⁴¹ /1988	RCT; COPD with breathlessness at rest; N = 8	0, 2, or 4 L/min of air or oxygen through nasal cannula for 5 min at each level	No significant effect of inspired oxygen concentration, gas flow, arterial oxygen tension, or arterial carbon dioxide tension on breathlessness was found. There was, however, a significant increase in breathlessness after nasal anesthesia ($P < .005$).
Swinburn et al ⁴² /1991	RCT; Severely disabled hypoxemic patients with COPD; n = 12; ILD patients; n = 10	28% oxygen and air by Venturi face mask, each gas on two occasions	The patients with COPD stated that air helped their breathing on 15 of 24 occasions and that oxygen helped on 22 of 24 occasions ($P < .05$). In the patients with ILD, the values were 6 of 20 and 13 of 20 occasions, respectively ($P < .05$).
O'Donnell et al ⁴³ /2001	RCT; Advanced COPD; N = 11	60% oxygen or room air during rest	No significant difference in Borg rating was reported for room air or oxygen at rest.
Booth et al ⁴⁴ /2004	SR; COPD and chronic heart failure	Oxygen therapy	There was no evidence for the use of oxygen therapy for the relief of dyspnea in chronic heart failure and limited evidence for its use in COPD.
Alvisi et al ⁴⁵ /2003	PS; Severe chronic airway obstruction; N = 10	Supplemental oxygen at rest before and after 5, 15, and 25 min of oxygen administration	During 30% oxygen breathing, the VAS score significantly decreased.

ILD = interstitial lung disease; RCT = randomized controlled trial. See Appendix 1 for expansion of other abbreviations.

Appendix 3—Other Nonpharmacologic Treatment of Dyspnea in Advanced Lung or Heart Disease

Study/Year	Study Design	Intervention	Outcomes/Results
PLB			
Bianchi et al ⁴⁶ /2004	PS; Mild to severe COPD; N = 22	PLB or spontaneous breathing	Borg score decreased with PLB ($P < .04$).
Relaxation			
Gift et al ⁴⁷ /1992	RCT; COPD with dyspnea at rest; N = 26	Relaxation via prerecorded tape	Dyspnea was reduced in the relaxation group; control group remained the same or became worse.
Renfro ⁴⁸ /1988	PS; COPD with dyspnea at rest; N = 20	PMR for four weekly sessions plus daily home practice with taped instructions	PMR was shown by t tests to be more effective than the control in reducing dyspnea ($P = .04$). Dyspnea and respiratory rate were correlated positively during each session ($r = 0.21$). Dyspnea and state anxiety were correlated positively at the end of 4 wk with respiratory rate ($r = 0.62$) and heart rate ($r = 0.50$).
NPPV			
Casanova et al ⁴⁹ /2000	RCT; Stable, severe COPD; N = 52	NPPV plus "standard care" or standard care alone for 1 yr	Borg dyspnea rating dropped from 6 to 5 ($P < .039$) in the NPPV group.
Lien et al ⁵⁰ /2000	RCT; Stable, severe COPD; N = 12	Bilevel positive airway pressure for pressure preset ventilation or PLV-100 as a home-care volume preset ventilator was used via a nasal or facial mask. The four types (two ventilators and two masks) of NPPV were used for 20 min each, with a randomized sequence.	Short-term use of bilevel positive airway pressure via either a nasal or facial mask reduces the sense of dyspnea compared with the use of PLV-100, which worsens the sense of dyspnea.

(Continued)

Appendix 3—continued

Study/Year	Study Design	Intervention	Outcomes/Results
Jolliet et al ⁵¹ /1999	RCT; Severe COPD; N = 20	NPPV was administered in the following randomized crossover design: (a) 45 min with air:oxygen or helium:oxygen; (b) no ventilation for 45 min; and (c) 45 min with air:oxygen or helium:oxygen.	Dyspnea score decreased more with helium:oxygen than with air:oxygen ($P < .05$).
Clini et al ⁵² /2002	RCT; COPD with CVF; N = 90	NPPV + LTOT or LTOT alone for 2 y	Resting dyspnea changed differently over time in the two groups in favor of NPPV + LTOT. Compared with LTOT alone, the addition of NPPV to LTOT in stable COPD patients with CVF improved dyspnea.
Ries et al ⁵³ /2007	SR; Advanced COPD and/or severe hypoxemia at rest or during exercise	Pulmonary rehabilitation including supplemental oxygen therapy and NPPV	Noninvasive ventilation may be helpful for selected patients with advanced COPD.
Kolodziej et al ⁵⁴ /2007	SR; Severe, stable COPD	NPPV	Health-related quality of life and dyspnea, the least studied outcomes, showed improvement with bilevel NPPV.
Curtis et al ⁵⁵ /2007	SR; ARF, patients and families who chose to forego all life support, receiving comfort measures only (category 3).	NPPV	To date, no studies have fully assessed the effectiveness and safety of NPPV specifically in patients who are in category 3, even though NPPV may reduce symptoms of dyspnea in a broader group of patients with ARF from COPD, in patients with respiratory failure, and in selected patients with stable chronic respiratory failure from COPD.
Leung and Bradley ⁵⁶ /1999	CS; Progressive CHF with dyspnea at rest	Nocturnal CPAP	Following application of CPAP, a remarkable improvement in the patient's condition was observed, with alleviation of dyspnea.
General			
Bausewein et al ⁵⁷ /2008	SR; Advanced malignant and nonmalignant diseases	Miscellaneous nonpharmacologic interventions	Vibration of patient's chest wall, electrical stimulation of leg muscles, walking aids, and breathing training can help to relieve shortness of breath. There were mixed results for the use of acupuncture/acupressure. Further interventions identified were counseling and support, either alone or in combination with relaxation-breathing training, music, relaxation, a hand-held fan directed at a patient's face, case management, and psychotherapy. There are several nondrug methods available to relieve shortness of breath in incurable stages of cancer and other illnesses. There are currently not enough data to judge the evidence for these interventions.

ARF = acute respiratory failure; CHF = congestive heart failure; CPAP = continuous positive airway pressure; CS = case study; CVF = chronic ventilatory failure; LTOT = long-term oxygen therapy; NPPV = noninvasive positive pressure ventilation; PLB = pursed-lip breathing; PMR = progressive muscle relaxation. See Appendices 1 and 2 for expansion of other abbreviations.

Appendix 4—Opioid Medications for Relief of Dyspnea in Advanced Lung or Heart Disease

Study/Year	Study Design	Intervention	Outcomes/Results
Oral/Parental			
Poole et al ⁶⁵ /1998	RCT; Advanced COPD; N = 16	Orally administered, sustained-release morphine was compared with placebo in two 6-wk treatment periods separated by a 2-wk washout period.	There were no differences between treatments in breathlessness scored on daily diary cards or on the Dyspnea subscale of the Chronic Respiratory Questionnaire. Almost all subjects experienced adverse effects related to morphine.
Munck et al ⁶⁶ /1990	RCT; Normocapnic patients with severe COPD; N = 19	Open single-dose safety study (part one) followed by an RCT comparing two 7-d treatment periods of 1 g of paracetamol tid with 60 mg of codeine plus 1 g of paracetamol tid, respectively (part two).	FVC, FEV ₁ , and dyspnea at rest were unchanged. Gastrointestinal side effects were reported significantly ($P < .02$) more often during treatment with codeine plus paracetamol.
Abermethyl et al ⁶⁷ /2003	RCT; Refractory COPD; N = 42/48	4 d of 20 mg oral morphine with sustained release followed by 4 d of identically formulated placebo, or <i>vice versa</i> .	Participants reported significantly different dyspnea scores when treated with morphine in the morning ($P = .011$) or in the evening ($P = .006$). Sustained-release, oral morphine at low dosage provides significant symptomatic improvement in refractory dyspnea in the community setting.
Allen et al ⁶⁸ /2005	CS; Terminal stage of idiopathic pulmonary fibrosis; N = 11	Diamorphine by injection followed by oral morphine	Subjective breathlessness decreased in the first 15 min ($P < .0001$). Follow-up treatment with oral morphine remained effective in reducing the symptom of breathlessness, and no patient showed signs of respiratory depression.
Nebulized			
Nosedal et al ⁶⁹ /1997	RCT; Advanced lung; N = 17; one patient with heart disease	Saline + O ₂ , or 10 mg morphine + O ₂ , or 20 mg morphine + O ₂ , or 10 mg morphine + O ₂ , at 2 L/min for 10 min over 4 consecutive days	No difference in mean VAS after 10 min of nebulization was observed over the 4 study days. Respiratory frequency significantly decreased on the 4 d, with a trend to correlation between VAS rating and parallel change in respiratory frequency (Spearman rank correlation coefficient = 0.46; $P = .09$)
Eaton and MacDonald ⁷⁰ /1999	RCT; End-stage disease (N = 17), including lung (n = 13) and heart (n = 1)	Each patient was given all four treatments, one treatment/d. The four treatments were saline + O ₂ (5 L/min), 10 mg morphine + O ₂ (5 L/min), 20 mg morphine + O ₂ (5 L/min), and 10 mg of morphine + forced air.	Patients' perception of their shortness of breath improved after each of the four treatments, but no significant differences were detected between any of the treatments. Nebulized morphine was no better than nebulized saline for relieving patients' perception of breathlessness.
Graff et al ⁷¹ /2004	CS; Terminal cystic fibrosis	Nebulized fentanyl for 3 d	Treatment reduced the modified Borg score.
Janahi et al ⁷² /2000	CS; End-stage cystic fibrosis	Inhaled morphine sulfate for 10 d	Therapy was effective in improving patients' Borg score.
Farncombe and Chater ⁷³ /1993	CS; End-stage chronic lung disease (n = 2); end-stage heart failure (n = 2)	Nebulized morphine	Nebulized morphine provided relief of breathlessness.
Cohen and Dawson ⁷⁴ /2002	CS; End-stage cystic fibrosis	Nebulized morphine	The nebulized morphine was found to have a modest effect on the patient's dyspnea, with no significant differences found between the varying doses.
Lanuke et al ⁷⁵ /2003	CS; Idiopathic pulmonary fibrosis	Nebulized morphine	Morphine provided some relief from the patient's cough and dyspnea, permitting the patient to feel comfortable at rest.
Reviews			
Lorenz et al ²⁷ /2004	SR; End-of-life patients with various conditions	Palliative care	Strong evidence supports treating dyspnea from chronic lung disease with short-term opioids.

(Continued)

Appendix 4—continued

Study/Year	Study Design	Intervention	Outcomes/Results
Qaseem et al ⁷⁶ /2008	SR; End-of-life patients	Evidence-based interventions including use of morphine for the relief of dyspnea	Evidence from 13 studies shows a valuable effect of morphine for dyspnea in advanced lung disease. However, using nebulized opioids compared with oral opioids showed no additional benefit.
Jennings et al ⁶³ /2002	SR; Advanced lung disease	Opioid therapy for relief of breathlessness	Eighteen studies were identified of which nine involved the non-nebulized route of administration and nine the nebulized route. A small but statistically significant positive effect of opioids was seen on breathlessness in the analysis of studies using non-nebulized opioids. There was no statistically significant positive effect seen for exercise tolerance in either group of studies or for breathlessness in the studies using nebulized opioids.
Thomas and von Gunten ⁷⁷ /2002	R; Patients with dyspnea	Clinical management of dyspnea	Measurements of respiratory rate, oxygen saturation, and arterial blood gases do not measure dyspnea. Medical management can be directed at the underlying cause when the potential benefits outweigh the burdens of such treatment. In rare cases for which symptomatic treatment does not control dyspnea to the patient's satisfaction, sedation is an effective, ethical option.
LeGrand et al ⁶⁴ /2003	R; Patients with dyspnea	Opioids	Clinicians caring for patients with advanced disease should not hesitate to use opioids for the management of dyspnea, provided doses are titrated carefully to effect and toxicity is monitored carefully, as in pain control.

CS = case study; R = review. See Appendix 1 for expansion of other abbreviations.

Appendix 5—Ethical Issues for the Relief of Dyspnea in Advanced Lung or Heart Disease

Study/Year	Study Design	Ethical Issue	Outcomes/Results
Elkington et al ⁸⁵ /2005	RS; End-of-life COPD; N = 209	Obligation to treat	Patients who died of COPD lacked surveillance and received inadequate services from primary and secondary care in the year before they died. The absence of palliative care services highlights the need for research into appropriate models of care to address uncontrolled symptoms, information provision, and end-of-life planning.
Elkington et al ⁸⁶ /2004	RS; End-of-life COPD; N = 25	Obligation to treat	Some patients' only health-care contact was through repeat prescriptions from their general practitioner, whereas three had regular follow-up by a respiratory nurse specialist who linked community and secondary care. Overall, follow-up, systematic review, or structured care were uncommon.
Chan et al ⁷⁹ /2004	RS; Critically ill patients on life support; N = 75	Opioid dosing and addiction	There was no statistically significant relationship between the average hourly narcotic and benzodiazepine use during the 1-h period prior to ventilator withdrawal until death, and the time from ventilator withdrawal to death. The restriction of medication assessment in the last 2 h of life showed an inverse association between the use of benzodiazepines and time to death. For every 1 mg/h increase in benzodiazepine use, time to death was increased by 13 min ($P = .015$). There was no relationship between narcotic dose and time to death during the last 2 h of life ($P = .11$).

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Appendix 5—continued

Study/Year	Study Design	Ethical Issue	Outcomes/Results
Daly et al ⁸⁰ /1996	RS; Critically ill patients on life support; N = 42	Opioid dosing and addiction	Morphine was administered to 88% of the patients during withdrawal of mechanical ventilation. Survival duration was unrelated to morphine dosage, but did correlate with ventilatory status at the time of withdrawal.
Stone et al ⁸¹ /1997	RS; Critically ill patients	Opioid dosing and addiction	Sedated patients survived for a mean of 1.3 d after the start of sedation, and there was no detectable difference in survival from the date of admission between sedated and nonsedated patients.
Thorns and Sykes ⁸² /2000	RS; Critically ill patients during last week of life; N = 238	Opioid dosing and addiction	Median doses of opioid were low (26.4 mg) in the last 24 h of life, and patients who received opioid increases at the end of life did not show shorter survival than those who received no increases. The doctrine of double effect therefore need not be invoked to provide symptom control at the end of life.
Blackhall et al ⁸⁷ /1995	PS; Subjects ≥ 65 y of age from one of four different cultures; N = 800	Cultural sensitivity	Korean-American and Mexican-American subjects were more likely to hold a family-centered model of medical decision making rather than the patient autonomy model favored by most of the African-American and European-American subjects. This finding suggests that physicians should ask their patients if they wish to receive information and make decisions or if they prefer that their families handle such matters.
Blackhall et al ⁸⁸ /1999	PS; Subjects ≥ 65 y of age from one of four different cultures; N = 800	Cultural sensitivity	European-Americans were the least likely to both accept and want life support ($P < .001$). Mexican-Americans were generally more positive about the use of life support and were more likely to personally want such treatments ($P < .001$). Ethnographic interviews revealed that this was due to their belief that life support would not be suggested if a case was truly hopeless. Compared with European-Americans, Korean-Americans were very positive regarding life support (RR = 6.7, $P < .0001$); however, they did not want such technology personally (RR = 1.2, $P = .45$). Ethnographic interviews revealed that the decision of life support would be made by their family. Compared with European-Americans, African-Americans felt that it was generally acceptable to withhold or withdraw life support (RR = 1.6, $P = .06$), but were the most likely to want to be kept alive on life support (RR = 2.1, $P = .002$).
Curtis et al ⁸⁹ /2004	PS; Patients with oxygen-dependent COPD; N = 115	Effective communication	The patients reported that most physicians do not discuss how long the patients have to live, what dying might be like, or patients' spirituality. Patients rated physicians highly at listening and answering questions. Areas patients rated relatively low included discussing prognosis, what dying might be like, and spirituality/religion. Patients' assessments of physicians' overall communication and communication about treatment correlated well with the quality of care.

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Appendix 5—continued

Study/Year	Study Design	Ethical Issue	Outcomes/Results
Heffner et al ⁹⁰ /1996	PS; End-of-life COPD; N = 105	Effective communication	Ninety-nine of the 105 subjects (94.3%) had health worries, the most common of which was fear of increasing dyspnea (33.3%). Although 93.8% had opinions about intubation, less than 42% had completed an AD. Most subjects wanted information about ADs (88.6%) and life support (68.6%); pulmonary rehabilitation programs, lawyers, and physicians were preferred sources for AD information. Although 98.9% of the patients wanted patient-physician AD discussions, only 19.0% had such discussions, only 15.2% had discussed life support, and only 14.3% thought that their physicians understood their end-of-life wishes.
Knauft et al ⁹¹ /2005	PS; Patients with oxygen-dependent COPD; N = 115	Effective communication	Only 32% of patients reported having a discussion about end-of-life care with their physician. Two of 15 barriers and eight of 11 facilitators were endorsed by >50% of patients. The most commonly endorsed barriers were “I’d rather concentrate on staying alive,” and “I’m not sure which doctor will be taking care of me.” Two barriers were significantly associated with lack of communication, as follows: “I don’t know what kind of care I want,” and “I’m not sure which doctor will be taking care of me.” The greater the number of barriers endorsed by patients, the less likely they were to have discussed end-of-life care with physicians ($P < .01$), suggesting the validity of these barriers. Conversely, the more facilitators, the more likely patients were to report having had end-of-life discussions with their physicians ($P < .001$).
Curtis et al ⁹² /2002	RS; Family members of deceased patients; N = 252	Effective communication	Higher QODD questionnaire scores were significantly associated with death at home ($P < .01$), death in the location the patient desired ($P < .01$), lower symptom burden ($P < .001$), and better ratings of symptom treatment ($P < .01$). Although the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences ($P < .01$), compliance with treatment preferences ($P < .001$), and family satisfaction regarding communication with the health-care team ($P < .01$). Availability of a health-care team member at night or on weekends was also associated with a higher QODD score ($P < .001$).

AD = advanced directive; QODD = Quality of Dying and Death; RS = retrospective study; RR = relative risk. See Appendix 1 for expansion of other abbreviations.

ACKNOWLEDGMENTS

Financial/nonfinancial disclosures: The authors have reported to *CHEST* the following conflicts of interest: Dr Carrieri-Kohlman has received grant money covering a small portion of her salary from an NIH RO1 grant entitled "Dyspnea Self-Management: Internet or Face-to-Face." The overall aim of this proposal is to compare the impact of a new Internet-based dyspnea self-management program (I-DSMP) with a face-to-face program (f-DSMP) and an Attention Control (AC) that has been shown to be effective in patients with COPD. Dr Mularski has received grant monies from the US Department of Veterans Affairs; the Centers for Disease Control and Prevention; the National Heart, Lung, and Blood Institute; the Robert Wood Johnson Foundation; the National Cancer Institute; the National Quality Forum; Novartis; and Spiration for COPD research. He serves or has served on the Agency for Healthcare Research and Quality COPD Comparative Effectiveness and the Centers for Medicare & Medicaid Services COPD T&P advisory committees. He serves or has served as an American Thoracic Society voting representative on the American Medical Association's Physician Consortium for Performance Improvement without compensation except for travel expenses. Dr Campbell has received consulting fees from the Center to Advance Palliative Care. She serves as President of the Hospice & Palliative Nurses Association, and is Senior Associate Editor of the *Journal of Palliative Medicine*. Dr Ely receives grant monies and consulting fees from Eli Lilly, Pfizer, Hospira, Aspect, Glaxo Smith-Kline, and serves on speakers' bureaus for these organizations. Drs Mahler, Selecky, Benditt, Curtis, Manning, Varkey, Carter, Chiong, Hansen-Flaschen, O'Donnell, Waller, and Mr Harrod have reported to *CHEST* that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

Other contributions: This work was performed at the American College of Chest Physicians in Northbrook, Illinois.

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Chest 2010;137; 674-691
DOI 10.1378/chest.09-1543

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