

## An Official American Thoracic Society Workshop Report: Assessment and Palliative Management of Dyspnea Crisis

Richard A. Mularski, Lynn F. Reinke, Virginia Carrieri-Kohlman, Mark D. Fischer, Margaret L. Campbell, Graeme Rocker, Ann Schneiderman, Susan S. Jacobs, Robert Arnold, Joshua O. Benditt, Sara Booth, Ira Byock, Garrett K. Chan, J. Randall Curtis, DorAnne Donesky, John Hansen-Flaschen, John Heffner, Russell Klein, Trina M. Limberg, Harold L. Manning, R. Sean Morrison, Andrew L. Ries, Gregory A. Schmidt, Paul A. Selecky, Robert D. Truog, Angela C. C. Wang, and Douglas B. White; on behalf of the ATS Ad Hoc Committee on Palliative Management of Dyspnea Crisis

THIS OFFICIAL WORKSHOP REPORT OF THE AMERICAN THORACIC SOCIETY (ATS) WAS APPROVED BY THE ATS BOARD OF DIRECTORS, JUNE 2013

### Abstract

In 2009, the American Thoracic Society (ATS) funded an assembly project, *Palliative Management of Dyspnea Crisis*, to focus on identification, management, and optimal resource utilization for effective palliation of acute episodes of dyspnea. We conducted a comprehensive search of the medical literature and evaluated available evidence from systematic evidence-based reviews (SEBRs) using a modified AMSTAR approach and then summarized the palliative management knowledge base for participants to use in discourse at a 2009 ATS workshop. We used an informal consensus process to develop a working definition of this novel entity and established an Ad Hoc Committee on Palliative Management of Dyspnea Crisis to further develop an official ATS document on the topic.

The Ad Hoc Committee members defined *dyspnea crisis* as “sustained and severe resting breathing discomfort that occurs in

patients with advanced, often life-limiting illness and overwhelms the patient and caregivers’ ability to achieve symptom relief.”

Dyspnea crisis can occur suddenly and is characteristically without a reversible etiology. The workshop participants focused on dyspnea crisis management for patients in whom the goals of care are focused on palliation and for whom endotracheal intubation and mechanical ventilation are not consistent with articulated preferences. However, approaches to dyspnea crisis may also be appropriate for patients electing life-sustaining treatment.

The Ad Hoc Committee developed a Workshop Report concerning assessment of dyspnea crisis; ethical and professional considerations; efficient utilization, communication, and care coordination; clinical management of dyspnea crisis; development of patient education and provider aid products; and enhancing implementation with audit and quality improvement.

This document has an online supplement, which is accessible from this issue’s table of contents at [www.atsjournals.org](http://www.atsjournals.org)

Ann Am Thorac Soc Vol 10, No 5, pp S98–S106, Oct 2013

Copyright © 2013 by the American Thoracic Society

DOI: 10.1513/AnnalsATS.201306-169ST

Internet address: [www.atsjournals.org](http://www.atsjournals.org)

### Executive Summary

Illustrative Case Presentation

Definition of Dyspnea Crisis

Key Conclusions

### Introduction

### Methods

Consensus Definition of Dyspnea Crisis

Assessment of Dyspnea Crisis

Ethical and Professional

Considerations

Principle of Double Effect

Aid in Dying

Efficient Utilization, Communication, and  
Care Coordination

Clinical Management of Dyspnea Crisis

Development of Patient Education and  
Provider Aid Products

Patients, Caregivers, and Families

Education for Healthcare Professionals

Methods and Modes for Delivery

Enhancing Implementation with Audit  
and Quality Improvement

Directions for Future Research

Conclusions

### Executive Summary

### Illustrative Case Presentation

R.H. was a 64-year-old male with severe cardiopulmonary disease. Pulmonary emphysema was diagnosed 12 years ago, and 6 years ago he had an acute myocardial infarction. At that time, his ejection fraction was 30%. Five years ago he had an FEV<sub>1</sub> of 0.9 liters, and 2 years ago his FEV<sub>1</sub> was 0.5 liters. He received long-term, comprehensive treatment for his chronic

obstructive pulmonary disease (COPD) and cardiomyopathy. This man had severe, slowly progressive chronic dyspnea. The patient and his physician ultimately agreed that cardiopulmonary resuscitation and mechanical ventilation would not be in accord with his goals of care. Nevertheless, episodes of dyspnea crisis prompted numerous urgent trips to the community hospital emergency department, usually by ambulance. Therapies directed at anxiety and panic failed to control his symptoms, and he experienced substantial suffering up until the time of his death.

### Definition of Dyspnea Crisis

The Ad Hoc Committee members offer the following definition of a novel clinical entity of *dyspnea crisis* as “sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers’ ability to achieve symptom relief.”

### Key Conclusions

- Dyspnea crisis most commonly occurs when the following factors interact: acute worsening of dyspnea experience, a heightened psycho-social-spiritual patient response, and a setting by unprepared caregivers who are too overwhelmed to respond in the optimal manner.
- Identification of dyspnea crisis should begin with first responders who may be lay or minimally trained.
- Since dyspnea crisis often occurs in the home or in a care facility away from more advanced medical resources, preparation and practice of simple, effective, and stepwise interventions that are individualized for patients are needed.
- Responding to dyspnea across the disease experience requires comprehensive patient-centered assessment and treatment using coordinated, interdisciplinary care teams.
- Guideline recommended care includes measurement using a dyspnea intensity scale augmented by assessment of a patient’s subjective experience, optimization of disease-modifying treatment strategies, use of palliative medical and nonmedical approaches

effective for dyspnea, and reassessment and adjustment of interventions.

- System-based approaches directed toward prevention and early management of dyspnea crisis are important elements of a comprehensive response, and include care coordination strategies, checklists, and practiced interventions.
- Early involvement of palliative care specialists and use of individualized care plans along with time-limited trials of therapies may increase palliation of dyspnea.
- Advance directives and articulations of preferences, such as by Physicians Orders for Life-Sustaining Treatment (POLST) forms, may increase adherence to stated care and treatment goals.

### Introduction

Dyspnea is a common and often progressively debilitating symptom in advanced chronic disease that is associated with fear, anxiety, activity limitations, and profound suffering (1–6). Recently, there has been national recognition of dyspnea as a priority topic for assessment, management, and care improvement (2, 3, 5, 7–11). Quality measurement bodies such as the National Quality Forum have emphasized the need for patient-centered quality of care evaluation and innovation in advanced lung disease, including a focus on palliation and end-of-life care (7, 12, 13). However, the evidence summarized in these statements and reviews suggest that across diseases and settings, dyspnea palliative care management is inadequate (1, 3–7, 12, 14, 15).

Although existing American Thoracic Society (ATS) Dyspnea Position Statements summarize the evaluation and clinical approaches to dyspnea, they do not address acute crises of dyspnea that can occur suddenly, that may be unresponsive to immediate symptom relief, and that may result in intensive medical utilization, especially at the end of life (1, 6). We conducted an ATS-funded project, *Palliative Management of Dyspnea Crisis*, to focus on identification, management, and resource optimization for patients who experience acute episodes of dyspnea. The early proceedings of the Committee and the Consensus Definition have been previously reported in the form of an abstract (16).

### Methods

An Ad Hoc Committee was commissioned by the ATS to organize a workshop with the goal of summarizing clinical approaches to a novel construct of acute dyspnea episodes termed a “dyspnea crisis.” Four co-chairs were selected by the project organizers, and then participants were chosen by solicitation from the Behavioral Science, Clinical Problems, and Nursing assemblies. All participants were vetted for potential conflicts of interest according to the policies and procedures of the ATS.

In preparation for the workshop, we conducted a comprehensive search (see expanded METHODS in the online supplement) of the medical literature for existing data on the management or palliation of dyspnea from 1990 through 2009. Four reviewers evaluated systematic evidence-based reviews (SEBRs) using a modified tool for the assessment of multiple systematic reviews (AMSTAR) that was adapted to grade the quality of reviews and evidence as: high, moderate, low, or very low and summarized findings for Workshop participants (17–21).

The workshop was conducted on May 15, 2009. During the workshop, members used the systematic evidence review (see EVIDENCE SUMMARY in the online supplement) to develop a consensus definition for the novel clinical entity of dyspnea crisis. They also discussed key areas for future study and clinical refinement along six domains: assessment of dyspnea crisis; ethical and professional considerations; efficient utilization, communication, and care coordination; clinical management of dyspnea crisis; development of patient education and provider aid products; and enhancing implementation with audit and quality improvement. Following the workshop, conclusions and recommendations were refined via e-mail and teleconferences. The literature was searched annually for new evidence that may affect our conclusions and recommendations. Finally, this report was developed to convey our key conclusions, recommendations for future research, and suggestions for educational endeavors that might aid assessment and management of this clinical entity.

## Consensus Definition of Dyspnea Crisis

The Ad Hoc Committee defined dyspnea crisis as “sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers’ ability to achieve symptom relief.” The workshop members focused on dyspnea crisis management for patients receiving palliative care and for whom endotracheal intubation and mechanical ventilation are not consistent with the patient and family’s articulated preferences for healthcare. However, the deliberations of the Ad Hoc Committee also extend to other patients with chronic conditions associated with dyspnea who express a desire for life-prolonging treatment. Similar to the formulation of pain crisis, a dyspnea crisis differs from day-to-day fluctuations in underlying dyspnea by the severity of its magnitude, the overwhelmed caregiver/environment, and one’s biopsychosocial/stress response (Figure 1).

We suggest that a dyspnea crisis most commonly occurs when the following factors interact: acute worsening of dyspnea experience, a heightened psycho-social-spiritual patient response, and a chaotic setting characterized by unprepared caregivers who are too overwhelmed to respond optimally (*see* Figure 1). Dyspnea crisis can occur suddenly and is

characteristically without a readily reversible cause. The role of the living environment and stressed caregiver is emphasized as a principle component of the crisis and as such is a key target for potential interventions. We explored management strategies for dyspnea crisis that are intended to be used with disease-specific interventions and therapies that have already been optimally employed (5).

We also recognized that identification of dyspnea crisis should begin with first responders who may be lay or minimally trained. Since dyspnea crisis often occurs in the home or in a care facility away from more advanced medical resources, we emphasized the importance of preparation and practice of simple and stepwise interventions that are individualized for patients. In responding to dyspnea across the disease experience, committee members stress comprehensive and patient-centered assessment and treatment (22).

## Assessment of Dyspnea Crisis

Dyspnea is a symptom that reflects a multidimensional subjective experience and changes in the biopsychosocial functioning, sensations, and/or cognition of an individual (1, 6). During dyspnea crisis, the patient is likely to experience increasing dyspnea intensity, distress, and fear. At baseline, dyspnea is often

a component of a symptom cluster that includes depression and anxiety. Dyspnea can only be rated by the individual experiencing it. Symptom self-report is acknowledged to be the most valid and reliable means for evaluating the patient’s experience, symptom progression, and response to management. The simplest self-report is a dichotomous “yes” or “no” response to the query “Are you short of breath?” However, such yes-or-no statements are unlikely to aid in palliation, and hence some rating of the intensity of dyspnea is warranted; recent reports suggest using at a minimum some standardized measure such as the 0–10 Numeric Rating Scale augmented by assessment of a patient’s subjective distress and discomfort experience related to the intensity rating of dyspnea (1, 3, 9, 14, 23, 24).

As patients reach the end of life or when their ability to communicate and process information is compromised, such as during ICU admissions, they may be unable to rate their shortness of breath, particularly during a crisis (25–27). For such patients, behavioral evaluation using observed signs associated with respiratory distress is an option (3, 14, 28). Family caregivers are also deeply affected by dyspnea crises—they experience a sense of anxiety, uncertainty, helplessness, and inadequacy (29, 30). An assessment of family-caregiver coping, information needs, desired level of participation in care, and home resources will support caregivers and incorporate them into the healthcare team (30, 31).

## Ethical and Professional Considerations

Central to the clinical management of dyspnea crisis is concomitant comprehensive palliative care early in chronic disease. Palliative care targets the relief of patients’ suffering from multiple sources related to chronic progressive disease. Such suffering may be caused by the disease itself or by side effects from treatment. Palliative care should be viewed as complementary to life-prolonging therapy when both are consistent with patient preferences.

Although the combination of mechanical ventilation and aggressive use of opioids/sedatives can achieve rapid

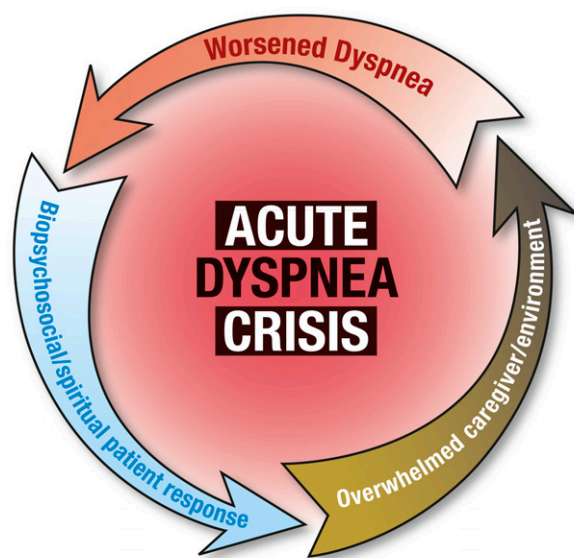


Figure 1. Dyspnea crisis theoretical model.

control of acute dyspnea, this approach carries substantial burdens that may not be consistent with patients' treatment preferences and goals. Other patients may have poorly formulated preferences about mechanical ventilation; for these patients, it is important to clarify goals of care before intubation, whenever possible. One approach that may be particularly beneficial for patients who are unclear about their goals of care is the notion of a time-limited trial—use of a treatment, such as mechanical ventilation or non-invasive ventilation, with frequent time-delimited assessments of whether interventions are meeting agreed upon therapeutic goals.

### Principle of Double Effect

When a dyspnea crisis occurs, some patients' symptoms may not be readily controlled with nonpharmacologic interventions or initial doses of opioids. In these circumstances, symptom control may require escalating doses of opioids and anxiolytic drugs that carry the potential to impair respiratory drive and could possibly hasten the patient's death. Therapy should be guided by and tailored to patients' individual preferences. The principle of double effect is relevant in the management of these situations, and the correct balance between symptom control and risk of hastened death will vary from patient to patient (2–4). The principle suggests that it is morally permissible to accept the possibility of impaired ventilation if the clinical intention is a response to the patient's desire for relief of distressing symptoms such as overwhelming dyspnea (32).

### Aid in Dying

Circumstances may arise in which patients in the midst of a dyspnea crisis request a prescription for medications intended to actively bring about their death. Although physician-assisted suicide is legal in Oregon and Washington, its legal implementation requires a number of procedural steps that cannot be achieved in response to a new request during a dyspnea crisis. We therefore suggest that assisted suicide not be viewed as an option for patients in acute dyspnea crisis who have not previously considered this option. Rather, we recommend aggressive symptom control measures, including expert consultation if needed. If, despite maximal efforts at symptom control, intractable dyspnea

cannot be controlled, palliative sedation is an option (2–4). Palliative sedation offers medical management targeting relief of otherwise intractable pain, dyspnea, or other distressing symptoms that intentionally causes sedation in a patient who is otherwise close to death.

### Efficient Utilization, Communication, and Care Coordination

Workshop participants recognized that successful approaches to the management of dyspnea crisis will require coordinated efforts across care settings, especially within the home or community where expert care providers may not be readily available. When clinicians are only available remotely, such as through telephone or other electronic mechanisms, and are unable to personally examine the patient, they may be reluctant to manage any necessary dose escalation of opioids. Family members play a vital role in caring for patients with chronic, terminal illness. Dyspnea crisis is frightening and anxiety provoking to the patient, family, and caregivers. Therefore it is critical to anticipate, educate, and plan for these events by creating an action plan that is agreed on and periodically reviewed by healthcare providers, the patient, and caregivers.

As a patient's disease worsens, the dyspnea management plan will likely require revision and distribution to potential providers, especially with transfers between different levels of care. The use of electronic records may facilitate caregivers' access to the plan of care updates, though such systems are still not widely used. In addition, having the family embrace a single spokesperson to communicate with healthcare providers may empower their role in care coordination and mitigate deviation from established care plans. Palliative care consultation is a resource that should be considered early in the care of patients with worsening dyspnea to assist in symptom management, end-of-life planning, and care coordination (2–4, 33).

Care plans should be interdisciplinary and revised frequently to include appropriately increasing or decreasing use of acute care resources depending on the patient's disease trajectory and/or changing goals of care. Assessment of the plan will have the goals of maximizing appropriate use of

strategies with proven efficacy (oxygen, mechanical ventilation, opioids, etc.) and avoiding unwanted or ineffective therapies (2, 3, 5, 7–11, 34). Proficiency or expert consultation in current opioid preparations and delivery methods is essential. Integral to coordination are communication skills in anticipatory planning that includes: (1) assessing whether the patient wishes to be involved in decision making and identifying surrogate decision makers; (2) assessing patient/family's goals and concerns about progressive disease and likely outcomes (rather than merely asking about their desire for specific therapies); (3) describing and recommending therapy aligned with the patient's goals and concerns; and (4) discussing uncertainty inherent in medical therapy and negotiating how to proceed within such uncertainty.

Vital to an action plan is identification of who to call for help and when to modify efforts to achieve symptom management or consider transfer to a higher-level care facility. Although care plans and prepared responses may mitigate emergency or tertiary care needs, coordination should expand to involve emergency providers and systems. Among topics, workshop participants emphasized expert application of disease-modifying therapies and aggressive symptom management with transfer to more advanced care settings that should include continued conversations with the patient and/or family regarding their understanding of the disease progression, prognosis, goals of care, and expectations. The patient's care should then be informed by expected responses to therapy aligned with expressed preferences, and may include readdressing the plan of care or initiating a time-limited trial of certain aggressive interventions (2–4, 34). Successful coordination with emergency response may be improved with the use and portability of preference articulations, such as by Physicians Orders for Life-Sustaining Treatment (POLST) forms or registries. Finally, at the time of discharge or transfer from one level of care to another, a written management plan should be used to coordinate treatment and ensure alignment of preferences and strategies for future episodes of dyspnea crisis. Individualized plans should include a checklist of specific written instructions for symptom-controlling medications, nonpharmacologic interventions, and



instructions for when to contact alternate caregivers such as a particular family member, hospice, a triage nurse, or other professionals.

## Clinical Management of Dyspnea Crisis

Dyspnea crisis is a medical emergency, and thus the evaluation and management of dyspnea crisis may best be presented in an algorithmic format to ensure a specific sequence of evidence-based therapies (see the online supplement for evidence tables from systematic reviews as general guidance in dyspnea management). Guidelines in general advocate assessment with a dyspnea intensity scale augmented by assessment of a patient's subjective experience, optimization of disease-modifying treatment strategies, use of palliative medical and nonmedical approaches effective for dyspnea management, and reassessment and adjustment of interventions (1–11, 14, 23, 24, 35).

System-based approaches to prevention and early management of dyspnea crisis are important elements of a comprehensive response, such as care coordination strategies, checklists, and practiced interventions. Among the key elements are emergency symptom-controlling medications, recognition by lay and professional caregivers, and organized steps to quickly and safely intervene. The current state of the science does not support a standardized emergency treatment recommendation to specifically address dyspnea crisis (clinicians should apply currently recommended care for dyspnea management as summarized in the existing literature; see the online supplement). Review of existing practice protocols emphasize the importance of developing individualized plans for dyspnea crisis based on the patients' and caregivers' previous experiences, preferences, and available treatments and resources. One approach that workshop members advanced was the "COMFORT" mnemonic that might be used in developing individualized care recommendations between patients and providers (see Table 1 and Figure 2).

When palliation is the focus of care, clarification of the indication and rationale for an intervention should be explained to the patient, family, and caregivers. To assess the effectiveness of various dyspnea treatments, it is helpful to consider an

**Table 1.** COMFORT mnemonic summarizing key therapeutic considerations

C	Call for help. Calming voice and approach among patient and caregivers
O	Observe closely and assess dyspnea for ways to respond
M	Medications to be tried (recommendations from providers for opioid/other use)
F	Fan to face may decrease shortness of breath
O	Oxygen therapy as previously found useful
R	Reassure and use relaxation techniques
T	Timing interventions to reduce dyspnea – work together – reassess – repeat

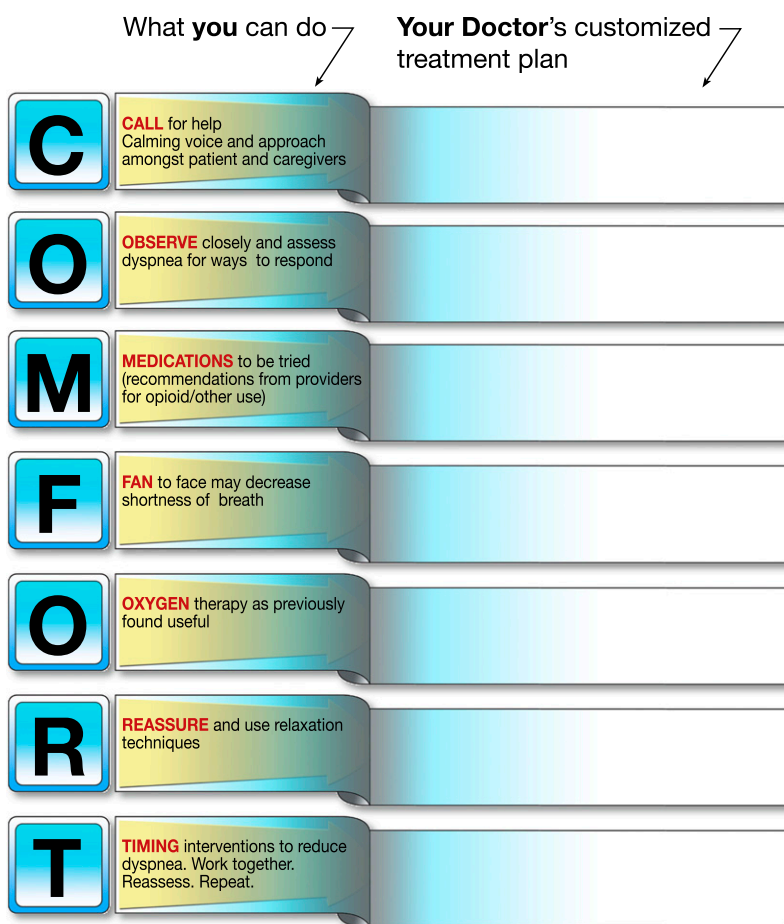
n-of-one trial (apply a palliative intervention with subsequent subjective assessment as to whether the benefit outweighs its burden). Assessments may include a patient or a primary caregiver

record or diary of dyspnea, therapy effectiveness, and modifying factors (36, 37). Close attention to other factors in the patient's environment and ways to mitigate psychosocial responses may also be important.

## Development of Patient Education and Provider Aid Products

Patients are at the center of the dyspnea crisis, yet for many family members, caregivers, and clinicians these situations are also a crisis (38, 39). Although family caregivers, nurses, emergency department (ED) personnel, and hospice personnel are the usual "first responders," there are currently no recommendations for how they should handle this emergency situation. Poor recognition of dyspnea, termed by one author the "invisibility of

## DYSPNEA CRISIS:



**Figure 2.** Customizable caregiver plan for episodes of crisis dyspnea.

breathlessness,” contributes to less widespread education and may increase the potential for caregivers to be underprepared (30). Education should be early and ongoing and should involve patients, families, caregivers, and all members of the health team, including medical assistants, acute care staff, palliative care teams, and hospice personnel.

### Patients, Caregivers, and Families

Dyspnea crisis education for patients, caregivers, and families should be initiated at the time of diagnosis and reinforced throughout the course of the patient's illness. Individualized or tailored patient education including action plans for the patient and caregivers are essential. Techniques for managing dyspnea crisis should be anticipated and taught before a dyspnea crisis and reinforced at every encounter, with possible practice of “rituals for dyspnea crises” to heighten patient and caregivers' sense of control and self-efficacy (38, 39). Acute exacerbations can be an opportunity for the professional healthcare provider to teach patients and caregivers what to expect, and what actions are appropriate, and to help the patient practice care plans. We recommend that the ATS and other organizations develop templates and patient education materials to enhance dissemination and implementation of dyspnea crisis management Targets that might be included in education are suggested in Table 2 and may be aided by Figure 2.

### Education for Healthcare Professionals

Education for healthcare professionals also needs to take an interdisciplinary approach to assessing and managing patients who are experiencing dyspnea crisis. Educational topics should include: self-reporting measurement tools, measurement of distress related to dyspnea, nonpharmacologic and pharmacologic interventions, the COMFORT acute treatment aid (*see* Table 1), noninvasive positive pressure ventilation, invasive mechanical ventilation, and nonmedical treatment strategies. A dyspnea management checklist and algorithms for essential steps in care and comfort during dyspnea crisis could be helpful for providers. Education about the prevention, assessment, and treatment of dyspnea crisis needs to be accessible to healthcare providers at all levels, including medical and nursing school curricula,

continuing education programs that deal with end-of-life and palliative care, and ongoing orientation programs in institutions such as hospitals, nursing homes, skilled nursing facilities, and hospice care programs.

### Methods and Modes for Delivery

There are numerous avenues for teaching healthcare professionals, patients, families, and caregivers about dyspnea crisis. Methodologies considered by the Ad Hoc Committee include: web-based programs for chronic symptom management that could incorporate essential skills similar to those taught for “panic” experiences, pulmonary rehabilitation programs that could develop simulations for the patient and caregiver to practice necessary skills, dissemination of algorithms for assessment and management of the patient in dyspnea crisis, education sheets or scripts for caregivers and healthcare providers outlining appropriate strategies for patients experiencing dyspnea crisis, periodic practice exercises of treatment skills, and development of video training or resources for dyspnea management that might also target instructions on pursed lip breathing and other nonpharmacological strategies.

### Enhancing Implementation with Audit and Quality Improvement

A number of recent guidelines and task forces have identified assessment of dyspnea as underdeveloped in clinical practice and suggest that performance measures should be part of the approach to improving care across cardiopulmonary disorders associated with this symptom (3, 8, 9, 13, 14, 40, 41). Reliable and responsive quality metrics will be needed to support implementation of the assessment and care management recommendations suggested by this report; existing metrics recommend at a minimum assessing dyspnea in critically and/or chronically ill patients (currently approved quality metrics can be found at the National Quality Measures Clearinghouse at <http://www.qualitymeasures.ahrq.gov/>). Following the basic tenet that “you can't improve what you don't measure,” we advocate an emphasis on patient-centered quality of care enhancement and recognize the need

**Table 2.** Components for patient education in dyspnea crisis

Basic facts about causes and triggers of dyspnea crises
How to identify signs and symptoms that are an indication of a dyspnea crisis
How to recognize and measure changes from baseline for both intensity of dyspnea and an affective component (anxiety or distress)
Breathing retraining including pursed lip breathing, slowed pattern of breathing, prolonged exhalation, and posture modification
Relaxation techniques, mindfulness meditation, guided imagery and distraction strategies (e.g., music, TV, reading by self or caregiver)
Appropriate and individualized use of oxygen, ventilation, and/or fans
Use of a written action plan that includes appropriate administration and dosing of medications and stepwise titration regimens

for implementation aids to support practice improvement for dyspnea crisis.

In addition to publication of this Workshop Report, teaching, dissemination, and implementation aids will be needed to produce changes in practice. The education subgroup in collaboration with the ATS Education Committee will develop and disseminate specific provider and patient/caregiver aids (*see* Figure 2). The Working Group acknowledged potential barriers to the more widespread use of opioids and calls attention to efforts and advocacy currently underway to advance appropriate implementation of dyspnea care recommendations into clinical practice. Although multiple tools have been identified for assessing dyspnea, there remains no consensus for the optimal assessment strategy. We recommend that clinicians regularly assess both dyspnea intensity and the distress associated with the dyspnea. We also recommend that quality metrics be used to enhance recognition and practice improvement toward these goals (3, 8, 9, 13, 14, 23, 24, 40, 41).

### Directions for Future Research

Calls for appropriately designed studies have been made by two Institute of Medicine committees, an NIH Consensus panel, the National Hospice and Palliative Care Organization, and the Hospice and Palliative Nurses Association (42–45). However, the kinds of randomized clinical trials common to palliative phases of illness are difficult to conduct

**Table 3.** Potential study questions posed by committee members

Care coordination	<ol style="list-style-type: none"> <li>1. Does a written, interdisciplinary plan of care decrease utilization of inappropriate resources for the treatment of episodes of dyspnea crisis?</li> <li>2. Does the use of electronic records facilitate efficient transfers of patient information between different levels or settings of care?</li> </ol>
Communication	<ol style="list-style-type: none"> <li>1. Does the use of a written "Dyspnea Management Checklist" decrease the incidence of acute episodes of dyspnea?</li> <li>2. Does identification and avoidance of patient-identified precipitants of dyspnea decrease the frequency of acute episodes of dyspnea?</li> </ol>
Utilization	<ol style="list-style-type: none"> <li>1. Does the use of an interdisciplinary treatment plan decrease the incidence of readmission for episodes of acute dyspnea in chronically ill patients?</li> <li>2. What is the frequency of chronically ill patients being admitted to an inappropriate level of care for dyspnea crisis and what might prevent this?</li> <li>3. Does the anxiety of dyspnea crisis lead to extensive testing in the hopes of identifying reversible factors; does this lead to more aggressive care at the end of life and do written care plans mitigate this experience?</li> </ol>
Therapy	<ol style="list-style-type: none"> <li>1. Do palliative care interventions improve symptom management for patients with advanced diseases who are not within 6 months of death?</li> <li>2. Do palliative care evaluations and interventions improve symptom management and health-related quality of life for patients and caregivers with advanced diseases receiving care in emergency departments?</li> </ol>

and may not reflect ideal methodology in this setting. Other designs that incorporate qualitative elements to understand patient and caregiver perspectives are also appropriate. For the individual patient, an n-of-one study can be justified, and trial designs that include variations on that approach may well advance the field (3, 14, 37). The Workshop members recognize that approaches are needed that advance reliable measures of dyspnea across cognitive states; non-disease-directed treatments of dyspnea and its sequelae; and optimal initiation dose, dosing interval, titration schedule, and delivery route of medications. In addition to the need for differently designed studies, we have identified several gaps in research and practice that need to be addressed. Study questions summarized in Table 3 remain key areas relevant to management of dyspnea crisis.

## Conclusions

Patients with advanced cardiac and lung diseases may suffer from unrelenting dyspnea and are at risk of experiencing dyspnea crises. Such crisis events may occur despite optimal conventional

pharmacological and nonpharmacological therapies. The participants in this ATS Workshop have developed a working definition of this entity and hope to advance the recognition and attention to assessment and management with this report. We emphasize that practitioners should not underestimate the profound psychosocial impact that dyspnea has on the quality of life of both patients and their families. Patients and families living with dyspnea need clinicians to understand both their chronic illness and their palliative care needs. Patients who do not want to use mechanical ventilation, in particular, need effective ways to manage their symptoms during dyspnea crisis. Improved education about how to plan for and manage episodes of dyspnea crisis will give clinicians, patients, and family caregivers important tools and guidance to handle these crisis situations. ■

These guidelines were prepared by an *ad hoc* committee of the Behavioral Science, Nursing, and Clinical Problems assemblies

### Members of the Committee:

RICHARD A. MULARSKI, M.D., M.S.H.S. MCR  
(Co-chair)

LYNN F. REINKE, Ph.D., A.R.N.P. (Co-chair)  
VIRGINIA CARRIERI-KOHLMAN, R.N., D.N.Sc.

(Co-chair)

MARK D. FISCHER, M.D. (Co-chair)

MARGARET L. CAMPBELL, Ph.D., R.N.

(Subcommittee co-leader)

GRAEME ROCKER, M.A., M.H.Sc., D.M.

(Subcommittee co-leader)

ANN SCHNEIDMAN, M.S., C.N.S., R.N.

(Subcommittee co-leader)

SUSAN S. JACOBS, R.N., M.S. (Subcommittee

co-leader)

ROBERT ARNOLD, M.D.

JOSHUA O. BENDITT, M.D.

SARA BOOTH, M.D.

IRA BYOCK, M.D.

GARRETT K. CHAN, R.N., Ph.D.

J. RANDALL CURTIS, M.D., M.P.H.

DORANNE DONESKY, Ph.D., R.N.

JOHN HANSEN-FLASCHEN, M.D.

JOHN HEFFNER, M.D.

RUSSELL KLEIN, M.D.

TRINA M. LIMBERG, B.S., R.R.T.

HAROLD L. MANNING, M.D.

R. SEAN MORRISON, M.D.

ANDREW L. RIES, M.D., M.P.H.

GREGORY A. SCHMIDT, M.D.

PAUL A. SELECKY, M.D.

ROBERT D. TRUOG, M.D.

ANGELA C. C. WANG, M.D.

DOUGLAS B. WHITE, M.D., M.A.S.

### ATS Documents, Development, and Implementation Committee Liaison:

MICHAEL GOULD, M.D., M.S.

**Author disclosures:** M.L.C. reported receiving textbook royalties from McGraw-Hill (amount unspecified). R.A. reported receiving textbook royalties from Cambridge University Press (up to \$1,000), Johns Hopkins University Press (up to \$1,000), and Oxford University Press (up to \$1,000). S.B. reported receiving textbook royalties from Oxford University Press (amount unspecified). J.H.-F. reported receiving textbook royalties from American College of Physicians and UpToDate (amounts unspecified). J.H. reported holding stocks or options in Entovita (\$1-999). R.A.M., L.F.R., V.C.-K., M.D.F., G.R., A.S., S.S.J., J.O.B., I.B., G.K.C., J.R.C., D.D., R.K., T.M.L., H.L.M., R.S.M., A.L.R., G.A.S., P.A.S., R.D.T., A.C.C.W., and D.B.W. reported that they had no relevant commercial interests.

**Acknowledgment:** The Ad Hoc Committee acknowledges the assistance of the ATS members Jerry Krishnan, M.D., Ph.D. and Michael Gould, M.D., M.S.; the expert editorial guidance by Kevin Wilson, M.D.; the aid by ATS staff Judy Corn, Eileen Larsson, Miriam Rodriguez, Jessica Wisk, and Lance Lucas; and they are grateful to the officers and membership of the ATS Behavioral, Nursing, and Clinical Problems Assemblies for their support and encouragement. The Committee also acknowledges participation in deliberations and reviews by Kathleen O. Lindell, Ph.D., R.N. and Suzanne C. Lareau, R.N., M.S. of the ATS Patient and Family Education Committee; and by Paula Meek, Ph.D., R.N.; Huong Nguyen, Ph.D., R.N.; Karen Mularski, M.D.; and Catherine Simpson, M.Div.



## References

- American Thoracic Society. Dyspnea: mechanisms, assessment, and management. A consensus statement. *Am J Respir Crit Care Med* 1999;159:321–340.
- National Consensus Project. Clinical practice guidelines for palliative care: 2004 [Accessed March 9, 2012]. Available from: <http://www.nationalconsensusproject.org>.
- Mahler DA, Selecky PA, Harrod CG, Benditt JO, Carrieri-Kohlman V, Curtis JR, Manning HL, Mularski RA, Varkey B, Campbell M, et al. American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest* 2010;137:674–691.
- Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, Levy M, Mularski RA, Osborne ML, Prendergast TJ, et al.; ATS End-of-Life Care Task Force. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *Am J Respir Crit Care Med* 2008;177:912–927.
- Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, Morton SC, Hughes RG, Hilton LK, Maglione M, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med* 2008;148:147–159.
- Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, Calverley PM, Gift AG, Harver A, Lareau SC, et al.; American Thoracic Society Committee on Dyspnea. An official American Thoracic Society statement: update on the mechanisms, assessment, and management of dyspnea. *Am J Respir Crit Care Med* 2012;185:435–452.
- National Priority Partnership. Palliative and end-of-life care [Accessed May 30, 2012]. 2010. Available from: [http://www.qualityforum.org/Topics/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](http://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx).
- Mularski RA, Curtis JR, Billings JA, Burt R, Byock I, Fuhrman C, Mosenthal AC, Medina J, Ray DE, Rubenfeld GD, et al. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. *Crit Care Med* 2006;34:S404–S411.
- Marciniuk DD, Goodridge D, Hernandez P, Rocker G, Balter M, Bailey P, Ford G, Bourbeau J, O'Donnell DE, Maltais F, et al.; Canadian Thoracic Society COPD Committee Dyspnea Expert Working Group. Managing dyspnea in patients with advanced chronic obstructive pulmonary disease: a Canadian Thoracic Society clinical practice guideline. *Can Respir J* 2011;18:69–78.
- Kamal AH, Maguire JM, Wheeler JL, Currow DC, Abernethy AP. Dyspnea review for the palliative care professional: assessment, burdens, and etiologies. *J Palliat Med* 2011;14:1167–1172.
- Kamal AH, Maguire JM, Wheeler JL, Currow DC, Abernethy AP. Dyspnea review for the palliative care professional: treatment goals and therapeutic options. *J Palliat Med* 2012;15:106–114.
- National Quality Forum (NQF). Addressing national priorities [Accessed May 12, 2012]. 2010. Available from: <http://www.qualityforum.org/>.
- Heffner JE, Mularski RA, Calverley PM. COPD performance measures: missing opportunities for improving care. *Chest* 2010;137:1181–1189.
- Mularski RA, Campbell ML, Asch SM, Reeve BB, Basch E, Maxwell TL, Hoverman JR, Cuny J, Clauser SB, Snyder C, et al. A review of quality of care evaluation for the palliation of dyspnea. *Am J Respir Crit Care Med* 2010;181:534–538.
- Bausewein C, Booth S, Gysels M, Kühnrich 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.
- Mularski RA, Reinke LF, Carrieri-Kohlman V, Fischer MD. Dyspnea Crisis: A consensus definition for a novel entity [abstract]. *Chest* 2010;138:233A.
- Schünemann HJ, Jaeschke R, Cook DJ, Bria WF, El-Solh AA, Ernst A, Fahy BF, Gould MK, Horan KL, Krishnan JA, et al.; ATS Documents Development and Implementation Committee. An official ATS statement: grading the quality of evidence and strength of recommendations in ATS guidelines and recommendations. *Am J Respir Crit Care Med* 2006;174:605–614.
- Atkins D, Best D, Briss PA, Eccles M, Falck-Ytter Y, Flottorp S, Guyatt GH, Harbour RT, Haugh MC, Henry D, et al.; GRADE Working Group. Grading quality of evidence and strength of recommendations. *BMJ* 2004;328:1490.
- Whitlock EP, Lin JS, Chou R, Shekelle P, Robinson KA. Using existing systematic reviews in complex systematic reviews. *Ann Intern Med* 2008;148:776–782.
- Chan KS, Morton SC, Shekelle PG. Systematic reviews for evidence-based management: how to find them and what to do with them. *Am J Manag Care* 2004;10:806–812.
- Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, Porter AC, Tugwell P, Moher D, Bouler LM. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC Med Res Methodol* 2007;7:10–18.
- World Health Organization. WHO definition of palliative care, 2005 [Accessed May 12, 2012]. Available from: <http://www.who.int/cancer/palliative/definition/en/>.
- Bausewein C, Farquhar M, Booth S, Gysels M, Higginson IJ. Measurement of breathlessness in advanced disease: a systematic review. *Respir Med* 2007;101:399–410.
- Dorman S, Byrne A, Edwards A. Which measurement scales should we use to measure breathlessness in palliative care? A systematic review. *Palliat Med* 2007;21:177–191.
- Antonelli Inc. Marra C, Giordano A, Calcagni ML, Cappa A, Basso S, Pagliari G, Fuso L. Cognitive impairment in chronic obstructive pulmonary disease: a neuropsychological and spect study. *J Neurol* 2003;250:325–332.
- Campbell ML, Templin T, Walch J. Patients who are near death are frequently unable to self-report dyspnea. *J Palliat Med* 2009;12:881–884.
- Cassell EJ, Leon AC, Kaufman SG. Preliminary evidence of impaired thinking in sick patients. *Ann Intern Med* 2001;134:1120–1123.
- Campbell ML, Templin T, Walch J. A Respiratory Distress Observation Scale for patients unable to self-report dyspnea. *J Palliat Med* 2010;13:285–290.
- Booth S, Silvester S, Todd C. Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. *Palliat Support Care* 2003;1:337–344.
- Gysels MH, Higginson IJ. Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. *Palliat Support Care* 2009;7:153–162.
- McMillan SC, Small BJ. Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Oncol Nurs Forum* 2007;34:313–321.
- Truog RD, Brock DW, White DB. Should patients receive general anesthesia prior to extubation at the end of life? *Crit Care Med* 2012;40:631–633.
- Au DH, Udris EM, Engelberg RA, Diehr PH, Bryson CL, Reinke LF, Curtis JR. A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest* 2012;141:726–735.
- Abernethy AP, McDonald CF, Frith PA, Clark K, Herndon JE II, Marcello J, Young IH, Bull J, Wilcock A, Booth S, et al. Effect of palliative oxygen versus room air in relief of breathlessness in patients with refractory dyspnoea: a double-blind, randomised controlled trial. *Lancet* 2010;376:784–793.
- Horton R, Rocker G, Currow D. The dyspnea target: can we zero in on opioid responsiveness in advanced chronic obstructive pulmonary disease? *Curr Opin Support Palliat Care* 2010;4:92–96.
- Booth S, Wade R, Johnson M, Kite S, Swannick M, Anderson H; Expert Working Group of the Scientific Committee of the Association of Palliative Medicine. The use of oxygen in the palliation of breathlessness. A report of the expert working group of the Scientific Committee of the Association of Palliative Medicine. *Respir Med* 2004;98:66–77.
- Bruera E, Schoeller T, MacEachern T. Symptomatic benefit of supplemental oxygen in hypoxemic patients with terminal cancer: the use of the N of 1 randomized controlled trial. *J Pain Symptom Manage* 1992;7:365–368.



- 38 Dorman S, Jolley C, Abernethy A, Currow D, Johnson M, Farquhar M, Griffiths G, Peel T, Moosavi S, Byrne A, *et al.* Researching breathlessness in palliative care: consensus statement of the National Cancer Research Institute Palliative Care Breathlessness Subgroup. *Palliat Med* 2009;23:213–227.
- 39 Booth S, Moosavi SH, Higginson IJ. The etiology and management of intractable breathlessness in patients with advanced cancer: a systematic review of pharmacological therapy. *Nat Clin Pract Oncol* 2008;5:90–100.
- 40 Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006;15:264–271.
- 41 Qaseem A, Snow V, Shekelle P, Casey DE Jr, Cross JT Jr, Owens DK, Dallas P, Dolan NC, Forciea MA, Halasyamani L, *et al.*; Clinical Efficacy Assessment Subcommittee of the American College of Physicians. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med* 2008;148:141–146.
- 42 Field MJ, Cassel CK. Approaching death: improving care at the end of life. Washington, DC: National Academy Press; 1997.
- 43 National Institutes of Health. State-of-the-Science Conference Statement: Improving End-of-Life Care, December 6–8, 2004, Bethesda, Maryland, USA. *J Palliat Med* 2005;8:8,S1.
- 44 Campbell G, Happ MB, Hultman T, Kirchhoff KT, Mahon MM, Mayo MM, McMillan S, Raudonis B. The HPNA Research Agenda: 2009–2012. *Journal of Hospice and Palliative Nursing* 2009;11:10–18.
- 45 Foley KM, Gelband H. Improving palliative care for cancer. Washington, DC: National Academy Press; 2001.