

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


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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$_1$ of 0.9 liters, and 2 years ago his FEV$_1$ 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 overhelms 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 research and clinical refinement along six domains: quality of care evaluation and innovation in advanced lung disease, 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...
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 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

![Table 1. COMFORT mnemonic summarizing key therapeutic considerations](image)

| C | Call for help. Calming voice and approach amongst 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 |

![Figure 2. Customizable caregiver plan for episodes of crisis dyspnea.](image)
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 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).

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 |

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.
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 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

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References


ATS DYSPNEA CRISIS SUPPLEMENTARY METHODS DOCUMENT and EVIDENCE SUMMARY

For An Official ATS Workshop Report:
Assessment and Palliative Management of Dyspnea Crisis

May 2009 – May 2012

Title:
Supplementary Document and Evidence Summary for ATS Workshop Report:
Assessment and Palliative Management of Dyspnea Crisis

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The systematic review and evidence summary was produced 5-15-2009 for in-person ATS Workshop.
Supplementary Methods describing preparation for the 2009 Workshop:

This supplementary methods section describes in further detail the methodology and approach taken by the Ad Hoc Committee on Palliative Management of Dyspnea Crisis to develop the ATS document: An Official ATS Workshop Report: Assessment and Palliative Management of Dyspnea Crisis. In summary, we conducted a preliminary needs assessment and ATS member survey, conducted a comprehensive search of the medical literature for guidelines and published articles in the twenty year period from 1990-2009 to develop a synthesis of data that guided participants’ discussions and subcommittee discourse on management of dyspnea crisis, and used in-person and teleconference calls to comprehensively summarize the Ad Hoc Committees proceedings in a Workshop Report.

Workshop and document development original aims

Palliative Management of Crisis Dyspnea project was approved to focus on identification, management, and resource optimization for palliative care for acute crisis dyspnea. The overall aim of the project was to use a multidisciplinary process to amass best clinical information about acute crisis dyspnea, describe the assessment and management for acute crisis dyspnea in the palliative care phase of chronic illness, and produce a workshop report and educational products. Ad-Hoc Committee members embraced the World Health Organization (WHO) definition of palliative care: “…an approach that improves the quality of life of patients … through the prevention and relief of suffering
by means of … assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The synthesis of data was designed to guide participants’ discussions and subcommittee discourse on management of dyspnea crisis. The reviewers of the articles were the 4 co-chairs of the Ad Hoc Committee chosen by solicitation from the 3 sponsoring assemblies and project organizers. All of the participants were vetted for potential conflicts of interest according to the policies and procedures of the ATS.

Specific Aims:

1. Guided by available literature, workshop participants will frame and address key issues related to “crisis dyspnea” management.

2. Interdisciplinary workshop participants will develop a summary document describing the underlying clinical principles and ethical underpinnings that guide cost effective crisis dyspnea management in end-of-life care patients who choose to forgo life-saving interventions.

3. Interdisciplinary workshop participants will describe the assessment and management of acute crisis dyspnea and consider an algorithm for assessment and management of dyspnea crisis.

4. Interdisciplinary workshop participants will identify areas for future research including implementation research related to optimizing recognition and treatment for acute crisis dyspnea.
Identification of need / current scope of the problem / existing protocols:

We developed a 3 item survey and queried active ATS members in the Behavioral Science Assembly (n=348), Nursing Assembly (n=213) and Clinical Problems Assembly (n=4042) in the Spring of 2009 to assess the following:

1. Have you encountered out-patients who are in the palliative care/hospice phase of their illness who have experienced acute crisis dyspnea resulting in calling 911 or going to an ER?
2. How frequently do you see the clinical situation of acute crisis dyspnea?
3. Does your practice/facility have a protocol or policy to guide clinical practice and management of acute crisis dyspnea?

We had 109 people respond; response rate overall was 2.3%. Overall, 78 of 109 respondents indicated encountering out-patients in palliative care/hospice phase of their illness who have experienced acute crisis dyspnea resulting in calling 911 or going to an emergency room (75%). Most respondents indicated having seen the clinical situation of acute crisis dyspnea weekly (19%), monthly (41%), or yearly (38%). Only 10 respondents indicate that their practice/facility had any protocol or policy to guide clinical practice and management of acute crisis dyspnea (9.6%). Of these, few provided any concrete guidance or algorithms to assist providers in the community setting; 3 protocols and policies were summarized during the in-person workshop meeting and were used in development of the preliminary management algorithm that was drafted for consensus input.
Primary and targeted outcomes

We targeted the literature search to identify existing data on interventions for the management of crisis dyspnea (see ATS methods checklist in table 1). We anticipated a focus in the medical literature on specific pharmacological and non-pharmacological treatments that primarily evaluated efficacy on the basis of palliative relief or improvement in dyspnea. We used this explicit outcome to guide our evaluation of the literature, but did not try to limit the systematic search by any criteria to focus on this primary aim as we were interested in secondary benefits, harms, and burdens that might be associated with crisis dyspnea management. We further anticipated that other types of interventions or strategies beyond specific symptom-focused therapies would be important in the overall management of crisis dyspnea, e.g. assessment tools applicable to the palliative community setting, ethical discussions regarding balance of benefits and burdens at the end of life, utilization and health care system coordination and approaches to optimizing patient preferences, and other modalities aimed at management for crisis dyspnea. The workgroup co-chairs recognized the a priori difficulty in identifying a single desirable measure of benefit for the retrieval and evaluation of evidence to guide crisis dyspnea management. We established that patient-family preferences are paramount in responding to this clinical entity and recognize that preferences are not often included in research studies. Further, we acknowledge that literature to understand and guide management across setting and situations with its intrinsic complexities limit synthesis and anticipated that preparatory care interventions might be amongst the most important to ensure good outcomes and optimal care of patients experiencing crisis dyspnea.
**Systematic literature review**

For the evidence-based systematic literature searches, we used the following definition of acute crisis dyspnea “the onset of severe, acute dyspnea which overwhelms the patient and caregivers ability to achieve symptom relief; it can occur suddenly and often without reversible or disease-specific etiology,” focusing on acute crisis dyspnea as a very specific clinical situation that occurs in the community setting for patients with end-stage underlying lung or heart disease. We initially considered acute crisis dyspnea to be a specific clinical situation that occurs mostly in the community setting for patients with end-stage underlying lung or heart disease. We further restricted the definition primarily toward patients who have articulated care goals that are primarily focused on comfort with preferences to forego life-saving interventions like endotracheal intubation or intensive care management.

We conducted literature searches in Medline, EMBASE, CINAHL, Cochrane Database of Systematic Reviews, the Database of Reviews of Effects (DARE), Cochrane Central Register of Controlled Clinical Trials (CCRCT), National Institute for Clinical Excellence (NICE), and guidelines.gov. The searches were conducted in April 2009 and were limited to published articles in the English language focusing specifically on guidelines and published articles in the twenty year period from 1990-2009. A publication date limit of 1990-2009 was placed in all databases with the exception of guidelines.gov, in which records are only available from 1997-2009. The main concepts
for (a) dyspnea or breathlessness and (b) palliative or end-of-life care (PEOLC) were combined using an extensive list of keywords and subject heading terms.

The reviewers of the articles were the 4 co-chairs of the Ad-Hoc Committee chosen by solicitation from the 3 sponsoring assemblies and project organizers. The synthesis of data guided participants’ discussions and subcommittee discourse on management of dyspnea crisis. Periodic search refreshes were done in April annually preceding ATS meetings (2010, 2011, and 2012). No additional relevant articles were identified that addressed the particular situation of crisis dyspnea. Although discussion of new publications related to dyspnea was not possible in a workshop setting, co-leaders included relevant publications in this report and all of the committee members had the opportunity to comment and approve.

**Specific search terms**

We employed the follow strategy combining palliation or anticipated care settings with the symptom of dyspnea. Palliative and end of life care searches used:


Anticipated settings used:
home care services/standards OR home nursing/st OR hospice care/st OR "nursing assistance" OR nursing homes/st OR residential facilities/st OR intensive care units/st OR life support care/st OR "home care" OR hospice* OR "nursing homes"[tiab] OR "nursing home"[tiab] OR "intensive care"[tiab] OR icu[tiab] OR icus[tiab] OR "place of death" OR health care facilities, manpower and services OR caregiver* OR caregivers OR "care giving" OR family[mh] OR family[tiab] OR families[tiab] OR "social services" OR "social support"

AND

Search symptom dyspnea used:

dyspnea[ti] OR "dyspnea" OR “breathing discomfort” OR "physical breathing comfort" OR "breathing symptom distress" OR "dyspnea burden" OR "dyspnea symptom management" OR "dyspnea relief" OR "relieve dyspnea" OR "relieve dyspnea"

The search identified 1291 references (see figure for article flow). Article abstracts with complete citations were imported into a Reference Manager database and word document files were made for workshop four co-chairs to evaluate citations for inclusion and exclusion determination. Subsets of references were created within the database to identify systematic reviews (n=49), clinical trials (n=132), guidelines (n=22), and all other publication types (n=1082). Bibliographies including citation information and abstracts were generated for review.

A two level inclusion process was used, first selecting articles to retrieve from exclusion determinations made with abstract (or title/citation if no abstract available) in the database and then second on the result of review of the full article and grading of the level of evidence and applicability to the project. No articles were identified that specifically addressed the clinical syndrome of crisis dyspnea or catastrophic dyspnea. For this reason, the workshop co-chairs focused efforts on reviewing and summarizing available evidence from systematic evidence-based reviews (SEBRs) of palliative care
management for dyspnea targeting symptom and whole patient management for which available evidence synthesis was identified. We were guided by the methods described by the publications from the AHRQ Evidence-based Practice Centers, the National Institute for Health and Clinical Excellence, and the Center for Evidence-Based Medicine.¹⁻³ Four reviewers evaluated systematic evidence-based reviews (SEBRs) using a modified tool for the assessment of multiple systematic reviews (AMSTAR) that was adapted to stratify the quality of evidence along categories consistent with the Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) hierarchy, i.e., high, moderate, low, very low.¹⁻⁵

The synthesis of data guided participants’ discussions and subcommittee discourse on management of dyspnea crisis. We approached the evaluation and grading of the evidence in the existing SEBRs to answer 3 main questions:

- were the SEBRs relevant to crisis dyspnea management?
- were the existing SEBRs of sufficient quality to inform our current project?
- can we assess the balance of benefit / burden of interventions and produce gradable consensus recommendations for crisis dyspnea management?

Once we determined that the evidence summarized for particular modalities for palliative care of dyspnea in general was relevant and sufficient in quality, we extracted key finding as they related to the management of crisis dyspnea along with characterizable benefits, undesirable effects or burdens, and uncertainty. We summarized the identified data from our systematic review in a table of key findings date May 13, 2009 (see table 3) with
grading of the strength of the evidence to inform benefit/burden of crisis dyspnea
managements with appropriate linkage to relevant outcomes in the community
management of this syndrome. This summary table formed part of the briefing materials
for the in-person workshop at ATS in May 2009.

At the conference on May 15, 2009, we reviewed the data, received supplementary
presentations from experts in the field on the topic of assessment and community
coordination for response in crisis dyspnea, and we began the process of developing
recommendations for management where sufficient evidence existed and identified other
important aspects relevant to palliative management of crisis.

Guided by the systematic evidence review, presentations in the morning session of
Workshop, and subsequent discussions, members developed and refined a consensus
definition for the novel clinical entity of dyspnea crisis and 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. We
queried the Workshop participants and engaged in open discussion to identify candidate
statements related to domains that included pertinent considerations for measurable and
meaningful outcomes, benefits/burdens, and comprehensive management. At the
workshop, we convened subgroups to continue to work on these relevant domains during
the ensuing period of workshop funding that are summarized in the main Workshop Report.

Following the Workshop, conclusions and recommendations were refined via email 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.
Table 1. ATS Methods Checklist for Workshop Reports

<table>
<thead>
<tr>
<th>Methods checklist</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Panel assembly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Included experts for relevant clinical and non-clinical disciplines</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Included individual who represents the views of patients and society at large</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Included a methodologist with appropriate expertise (documented expertise in conducting systematic reviews to identify the evidence base and the development of evidence-based recommendations)</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Literature review</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Performed in collaboration with librarian</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Searched multiple electronic databases</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Reviewed reference lists of retrieved articles</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Evidence synthesis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Applied pre-specified inclusion and exclusion criteria</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Evaluated included studies for sources of bias</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Explicitly summarized benefits and harms</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>• Used modified AMSTAR to report systematic reviews</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>• Used GRADE to describe quality of evidence</td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>Generation of recommendations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Used GRADE to rate the strength of recommendations</td>
<td></td>
<td>N/A</td>
</tr>
</tbody>
</table>
Table 2. Evidence Table from 2009 Systematic Reviews *

<table>
<thead>
<tr>
<th>Reference</th>
<th>Dyspnea management areas addressed</th>
<th>Evaluation of SEBR methods</th>
<th>Summary of Evidence / Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bausewein, 2008⁶</td>
<td>non-pharmacological interventions in cancer and non-cancer</td>
<td>High</td>
<td>in general low burden related to therapies; possible benefit across categories: Relaxation Techniques - 4 RCT with small samples- 2 high quality, others low not enough data 1) Decreased dyspnea only at session or immediately after, no persistence of the decrease in dyspnea 2) Relaxation techniques either taught chronically with application to acute or in an acute situation have not been studied</td>
</tr>
<tr>
<td>Ben-Aharon, 2008⁷</td>
<td>interventions in cancer-related dyspnea</td>
<td>Low</td>
<td>suggests non-pharmacologic Rx may be of value with low burden; see Booth / Viola for redundant pharmacological interventions</td>
</tr>
<tr>
<td>Booth, 2008⁸</td>
<td>pharmacological interventions in cancer</td>
<td>High</td>
<td>benefit in morphine, O2 only in hypoxic pts, midazolam may be an adjunct to morphine; no support for routine corticosteroid use; promethazine may benefit but quality evidence very low</td>
</tr>
<tr>
<td>Corner, 2003⁹</td>
<td>PO / IV opioids</td>
<td>Low</td>
<td>summarized in other review of opioids</td>
</tr>
<tr>
<td>Cranston, 2008¹⁰</td>
<td>oxygen in any chronic illness</td>
<td>Moderate</td>
<td>two studies found improvement in dyspnea, others did not; individual dosing and judging of effectiveness suggested as best practice</td>
</tr>
<tr>
<td>Dorman, 2007¹¹</td>
<td>measurement scales for palliative dyspnea assessment</td>
<td>High</td>
<td>studies of low to very low evidence and problems in synthesizing; 29 scales identified with validity data in PC; 6 quantify severity of breathlessness, 4 descriptors, 19 functional impact. No one tool best: NRS, modified Borg, CRQ-D, and CDS most suitable</td>
</tr>
<tr>
<td>Engstrom, 2007¹²</td>
<td>palliative sedation</td>
<td>Low</td>
<td>15 articles of low to very low quality; palliative sedation is administered to &lt;40% of dying patients during their...</td>
</tr>
</tbody>
</table>

* ATS Crisis Dyspnea Workshop
last 4 days of life. Main indications: agitation, dyspnea, pain. 3 main themes: 1. Important factors leading to the administration of sedation; 2. Attitudes to sedation at the EOL; 3. Nurses' experience of sedation. Professionals have positive attitudes towards it but the public regards it close to "euthanasia". Recommendations that the decision to use it should be individualized to the patient and family.

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Intervention</th>
<th>Evidence Level</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gallagher, 2004</td>
<td>oxygen in any advanced disease</td>
<td>Moderate</td>
<td>Individual dosing and judging of effectiveness suggested as best practice with mixed results.</td>
</tr>
<tr>
<td>Gysels, 2007</td>
<td>psychosocial aspects of dyspnea</td>
<td>Low</td>
<td>Qualitative review with 22 articles, including 19 from COPD. Interviews with pts, family caregivers, nurses. Only 4/22 studies applied to acute dyspnea. Inconsistent results depending upon the research questions posed. A major finding is that dyspnea is a burden on informal caregivers. Authors concluded that dyspnea is a complex symptom that should be approached holistically from a nursing and PC perspective.</td>
</tr>
<tr>
<td>Generali, 2004</td>
<td>nebulized furosemide in cancer</td>
<td>Low</td>
<td>Limited data on use of nebulized furosemide inconsistent benefit in 25 patients.</td>
</tr>
<tr>
<td>Jennings, 2002</td>
<td>opiates in any terminal disease</td>
<td>High</td>
<td>Most studies moderate to high level grade evidence; 18 studies included: 13 studies had sufficient detail to permit meta-analysis -- demonstrated a beneficial effect on breathlessness [SMD:-0.31; 95% CI -0.50-0.13]. Nine of the studies examined the use of oral or parenteral opioids - significant effect for the non-nebulized forms of opioid delivery (SMD: -0.40; 95% CI: -0.63, -0.17) but not for the nebulized forms (SMD: -0.11; 95% CI: -0.32, 0.10).</td>
</tr>
<tr>
<td>Joyce, 2004</td>
<td>nebulized opioids in dyspnea</td>
<td>Moderate</td>
<td>Unable to combine data; studies mostly low to very low quality; not support use: 20 articles with subjective.</td>
</tr>
<tr>
<td>Author</td>
<td>Study Description</td>
<td>Evidence Level</td>
<td>Summary</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------</td>
<td>----------------</td>
<td>---------</td>
</tr>
<tr>
<td>Lorenz, 2008</td>
<td>Broad palliative care review</td>
<td>High</td>
<td>Summarized dyspnea assessment and broad range of interventions for palliative care; basis of the American College of Physicians palliative care guideline.</td>
</tr>
<tr>
<td>Pan, 2000</td>
<td>Non-pharmacological interventions</td>
<td>Moderate</td>
<td>Low / very low evidence: in general low burden related to therapies – possible benefits.</td>
</tr>
<tr>
<td>Plonk, 2005</td>
<td>Terminal care last week of life</td>
<td>Low</td>
<td>General review of common clinical management issues with some regard to system approach.</td>
</tr>
<tr>
<td>Roberts, 2008</td>
<td>Non-pharmacological interventions in advanced disease</td>
<td>Moderate</td>
<td>In general low burden related to therapies – possible benefit.</td>
</tr>
<tr>
<td>Thomas, 2006</td>
<td>Organization of care at end of life</td>
<td>High</td>
<td>Highlights complexities of end of life continuum and care; notes importance of community teams, place of death, advance planning, education to nurses and family.</td>
</tr>
<tr>
<td>Uronis, 2008</td>
<td>Oxygen</td>
<td>Low</td>
<td>General review with mixed benefit except in hypoxia.</td>
</tr>
<tr>
<td>Uronis, 2008</td>
<td>Oxygen in mild/non-hypoxemic pts</td>
<td>Moderate</td>
<td>In cancer only 1 of 5 small trials found significant decrease in dyspnea with O2 compared to air; in COPD only 1 of 5 studies found dyspnea significantly decreased with oxygen.</td>
</tr>
<tr>
<td>Viola, 2008</td>
<td>Cancer dyspnea care</td>
<td>High</td>
<td>High quality review with 3 studies high grade; most low grade – clear benefit in morphine, midazolam may be an adjunct to morphine; no support for routine corticosteroid use.</td>
</tr>
<tr>
<td>Adams, 2007</td>
<td>Exclude</td>
<td></td>
<td>Off topic (not PEOLC, ambulatory); COPD care model.</td>
</tr>
<tr>
<td>Bradley, 2007</td>
<td>Exclude</td>
<td></td>
<td>Off topic (not PEOLC, ambulatory); O2 in COPD.</td>
</tr>
<tr>
<td>Reference</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); O2 in COPD</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>---------</td>
<td>---------------------------------</td>
<td></td>
</tr>
<tr>
<td>Bradley, 2005</td>
<td>Exclude</td>
<td>Off topic; withdrawal of mechanical ventilation</td>
<td></td>
</tr>
<tr>
<td>Campbell, 2007</td>
<td>Exclude</td>
<td>Off topic; malignant mesothelioma therapy</td>
<td></td>
</tr>
<tr>
<td>Dundar, 2007</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); education in COPD</td>
<td></td>
</tr>
<tr>
<td>Jennings, 2003</td>
<td>Exclude</td>
<td>Duplicate</td>
<td></td>
</tr>
<tr>
<td>Jennings, 2001</td>
<td>Exclude</td>
<td>Duplicate</td>
<td></td>
</tr>
<tr>
<td>Jennings, 1999</td>
<td>Exclude</td>
<td>Duplicate; Pub type = letter</td>
<td></td>
</tr>
<tr>
<td>Joyce, 2008</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); lung cancer</td>
<td></td>
</tr>
<tr>
<td>Lorenz, 2006</td>
<td>Exclude</td>
<td>Off topic; quality measurement</td>
<td></td>
</tr>
<tr>
<td>Lorenz, 2006</td>
<td>Exclude</td>
<td>Duplicate</td>
<td></td>
</tr>
<tr>
<td>Lorenz, 2008</td>
<td>Exclude</td>
<td>Duplicate</td>
<td></td>
</tr>
<tr>
<td>Maltoni, 2005</td>
<td>Exclude</td>
<td>Off topic (not dyspnea focus); cancer prognosis</td>
<td></td>
</tr>
<tr>
<td>McCrory, 2003</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); bronchodilators in COPD</td>
<td></td>
</tr>
<tr>
<td>Miller, 2001</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); treatment ASL/MND</td>
<td></td>
</tr>
<tr>
<td>Nonoyama, 2007</td>
<td>Exclude</td>
<td>Off topic (ambulatory); O2 in COPD exercise</td>
<td></td>
</tr>
<tr>
<td>Polosa, 2002</td>
<td>Exclude</td>
<td>Off topic; interstitial disease (duplicative in Jennings)</td>
<td></td>
</tr>
<tr>
<td>Salman, 2003</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); rehab in COPD</td>
<td></td>
</tr>
<tr>
<td>Sola, 2004</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); quality of life in cancer</td>
<td></td>
</tr>
<tr>
<td>Solano, 2006</td>
<td>Exclude</td>
<td>Off topic (may be useful for background)</td>
<td></td>
</tr>
<tr>
<td>Thomas, 2005</td>
<td>Exclude</td>
<td>Off topic (Not acute dyspnea); PC in general</td>
<td></td>
</tr>
<tr>
<td>Ung, 2006</td>
<td>Exclude</td>
<td>Off topic; brachytherapy in NSCLCA</td>
<td></td>
</tr>
<tr>
<td>Uronis, 2007</td>
<td>Exclude</td>
<td>protocol for review only – no data</td>
<td></td>
</tr>
<tr>
<td>van’t, 2002</td>
<td>Exclude</td>
<td>Off topic (ambulatory); NIV in COPD</td>
<td></td>
</tr>
<tr>
<td>Vigano, 2000</td>
<td>Exclude</td>
<td>Off topic; prognosis in cancer</td>
<td></td>
</tr>
<tr>
<td>Walters-Julia,</td>
<td>Exclude</td>
<td>Off topic (not PEOLC); steroids in COPD</td>
<td></td>
</tr>
</tbody>
</table>
* Abbreviations used in table include:
SEBR – systematic evidence based review
RCT – randomized controlled trial
IV – intravenous
PO – oral
NRS – numerical rating scale
CRQ-D – Chronic Respiratory Questionnaire-Dyspnea
CDS – Cancer Dyspnoea Scale
EOL – end of life
COPD – chronic obstructive pulmonary disease
SMD – standard mean difference
CI – confidence interval
PRISM – Policy Responsive Integrated Strategy Model
PEOLC – palliative and end-of-life care
PC – palliative care
NSCLCA – non-small cell lung cancer
NIV – non-invasive ventilation
Table 3. Evidence Summary Used at the In-Person Workshop at ATS in May 2009 #

(see attached document)

# Abbreviations used in table include:
IV – intravenous
PO – oral
SMD – standard mean difference
SEBR – systematic evidence based review
Rx – pharmaceutical agent
NS – normal saline
CA – cancer
RCT – randomized controlled trial
COPD – chronic obstructive pulmonary disease
CHF – congestive heart failure
CAM – complementary and alternative medicine
CRQ – Chronic Respiratory Questionnaire
PLB – pursed lip breathing
NRS – numerical rating scale
CDS – Cancer Dyspnoea Scale
PC – palliative care
EOL – end of life

note – the number in column 2 following the lead author/year refers to the reference manager unique identifier to allow the table to track back to the systematic review database
REFERENCES

Reference List


34. Jennings AL, Davies AN, Higgins JP, Broadley K. Opioids for the palliation of breathlessness in terminal illness. [Review] [70 refs]. *COCHRANE DATABASE SYST REV* 2001;CD002066.


42. Miller RG. Examining the evidence about treatment in ALS/MND. [Review] [12 refs]. *Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders* 2001;2:3-7.


51. van't HA, Kwakkel G, Gosselink R. The acute effects of noninvasive ventilatory support during exercise on exercise endurance and dyspnea in patients with chronic
obstructive pulmonary disease: a systematic review (Structured abstract).


Figure Article Flow: Crisis Dyspnea (1990 to 2009)

1. Total references after de-duplication: n=1291
2. Systematic Evidence Based Reviews (SEBRs): n = 49
   - 138 RCT/CCT
   - 22 Guidelines
   - 1082 Other publication types
3. Abstracts excluded by co-chair expert reviewer process: n=28
   - 22 off-topic
   - 5 re-publications
   - 1 covered by other review
4. No articles addressed the particular situation of crisis dyspnea in our search
   - SEBRs were used to inform the available recommended therapies
   - other studies supported the consensus discussions
5. Periodic search refreshes were done in April annually preceding ATS meetings (2010, 2011, and 2012). No additional relevant articles were identified that addressed the particular situation of crisis dyspnea.
6. Total SEBRs reviewed: n = 21
7. Articles summarized in evidence table at the 2009 ATS Workshop: n= 21
8. Articles excluded: n= 1242 (note some were included in proceedings by individual writing sub-groups during the post Workshop deliberations)
9. Total number of articles specifically cited in the ATS Workshop Proceedings: n = 44