Dyspnea Review for the Palliative Care Professional: Assessment, Burdens, and Etiologies

Arif H. Kamal, M.D.,1 Jennifer M. Maguire, M.D.,2 Jane L. Wheeler, MSPH,1 David C. Currow, M.P.H.,3 and Amy P. Abernethy, M.D.1,3

Abstract

Background: Dyspnea is a common symptom experienced by many patients with chronic, life-threatening, and/or life-limiting illnesses. Although it can be defined and measured in several ways, dyspnea is best described directly by patients through regular assessment, as its burdens exert a strong influence on the patient’s experience throughout the trajectory of serious illness. Its significance is amplified due to its impact on family and caregivers.

Discussion: Anatomic and physiologic changes associated with dyspnea, and cognitive perceptions related to patients and the underlying disease, provide insights into how to shape interventions targeting this oppressive symptom. Additionally, as described in the concept of “total dyspnea,” the complex etiology and manifestation of this symptom require multidisciplinary treatment plans that focus on psychological, social, and spiritual distress as well as physical components. Several validated assessment tools are available for clinical and research use, and choice of method should be tailored to the individual patient, disease, and care setting in the context of patient-centered care.

Conclusion: This article, the first in a two-part series, reviews the identification and assessment of dyspnea, the burden it entails, and the underlying respiratory and nonrespiratory etiologies that may cause or exacerbate it.

Introduction

The word “dyspnea” is derived from the Greek roots dys, meaning difficult, and pneuma meaning breath. Dyspnea, or breathlessness, is a common and oppressive symptom experienced by many patients throughout the trajectory of life-limiting illness. Dyspnea may be related to the illness, its comorbidities, therapy for either, or hypoxia. Often it is the result of a combination of all these. Dyspnea may occur at rest or with activity, may be continuous, intermittent or have a pattern of acute-on-chronic experiences and effects those with and without primary cardiopulmonary disorders alike. As breathing is a primal sensation of life, its disturbance creates a visceral sense of dread that, itself, incurs suffering. Dyspnea is a reason for consultation in over 10% of palliative care inpatient consultations and is the fourth most common reason for palliative care patients to visit the emergency department. In this first of a two-part series on dyspnea for the palliative care professional, we review the burden, pathophysiology, and measurement of dyspnea. The next review will appraise both pharmacologic and nonpharmacologic options for dyspnea management.

Definitions

The American Thoracic Society defines dyspnea as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary.” In more colloquial terms, dyspnea is an uncomfortable breathing sensation that is subjective and difficult to define by the outsider; patients “know it when they feel it.” Table 1 lists examples included in dyspnea assessment questionnaires to describe the symptom. Descriptors used by patients to express degrees of dyspnea or breathlessness fall into the general categories of difficulty with air movement (“I feel that my breathing is more rapid.” “My breath does not go out all the way.”), increased effort (“I feel that I am breathing more.” “I feel hunger for more air.”), and general distress (“I feel I am suffocating.”

1Department of Medicine, Division of Medical Oncology, Duke University Medical Center, Durham, North Carolina.
2Department of Medicine, Division of Pulmonary Diseases and Critical Care Medicine, University of North Carolina, Chapel Hill, North Carolina.
3Department of Palliative and Supportive Services, Division of Medicine, Flinders University, Bedford Park, South Australia, Australia. Accepted June 3, 2011.
Dyspnea is experienced at some point by most patients with advanced cancer, heart failure, and chronic lung disease. Dyspnea is either an element of the disease course or a component of the final stages of most etiologies that cause significant morbidity and mortality in the United States. Dyspnea is experienced at some point by most patients with advanced cancer, heart failure, and chronic lung disease and in the last 3 days of life in the imminently dying. Dyspnea is a risk factor for hospitalization in patients with lung cancer and for in-hospital death, independent of underlying illness, for anyone with advanced disease who is enrolled in home-based health care. Significant associations have been reported between dyspnea and decreased patient and family well-being and increased staff anxiety, highlighting the impressive effect of this one symptom on the patient, his/her support network, and the health care delivery system.

Not surprisingly, dyspnea is frequently included as a component of prognostic models of death from pulmonary and nonpulmonary disease. Two decades ago, Carpenter et al. reported that symptoms of breathlessness are a predictor of death from all causes over a period of 27 years—even when the symptom was episodic. The Bode Scale, a tool used to determine prognosis of COPD patients over 1 to 3 years, has as its only patient-experienced component the measurement of dyspnea on a scale from 0–4. The Mortality Risk Index Score incorporates dyspnea as an important part of the 6-month assessment of prognosis in elderly, nursing home residents. The Palliative Prognostic Score, a tool to stratify patients into groups based on predicted 30-day survival, also uses the presence of dyspnea as an integral part of its survival prediction.

**Etiologies of Dyspnea**

PATTERNED after the concept of total pain first described by Dame Cicely Saunders in the 1960s, the concept of “total dyspnea” creates a framework for understanding dyspnea etiology in a way that captures its full impact on the patient and caregiver. Encompassing the four domains of physical, psychological, interpersonal, and existential distress, total dyspnea is a significant part of the symptom experience of patients with life-altering illness.

**Burden and Consequences in Advanced Disease**

Dyspnea is a significant factor for hospitalization in patients with lung cancer and for in-hospital death, independent of underlying illness, for anyone with advanced disease who is enrolled in home-based health care. Significant associations have been reported between dyspnea and decreased patient and family well-being and increased staff anxiety, highlighting the impressive effect of this one symptom on the patient, his/her support network, and the health care delivery system.

**Table 1. Patient Descriptors of Dyspnea**

<table>
<thead>
<tr>
<th>I feel…</th>
<th>My…</th>
<th>I cannot…</th>
</tr>
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<tbody>
<tr>
<td>That I am smothering</td>
<td>Breathing requires effort</td>
<td>Take a full breath</td>
</tr>
<tr>
<td>That my breath stops</td>
<td>Chest feels tight</td>
<td>Get enough air</td>
</tr>
<tr>
<td>That I am suffocating</td>
<td>Breathing is fast</td>
<td>Stop thinking about my breathing</td>
</tr>
</tbody>
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“I feel that I am smothering.” This symptom may be constant (i.e., continuous dyspnea) or present in episodes (i.e., breakthrough dyspnea) as described in a cohort of cancer patients by Reddy et al. Breakthrough dyspnea was the predominant type, with over 80% of patients reporting short spells of breathlessness interrupting long symptom-free periods throughout the day. Continuous dyspnea was reported by only 39% of patients. On average, breakthrough episodes occurred 5–6 times per day and lasted less than 5 minutes, indicating that tailored treatment paradigms with quick onset of action are needed to counteract this more common type.

Although dyspnea has traditionally been described in the medical literature by physiologic measures, there is a growing acknowledgment that it is ultimately a patient-centered symptom that does not necessarily correlate with findings of hypoxia, hypercarbia, or tachypnea. Correspondingly, patient-reported experience of the symptom has become the standard for assessment, and an increasingly accepted method for determining its severity and impact. Because of its many correlates with the patient’s underlying disease, demographic background, comorbid symptoms, and emotional state, each patient’s experience of dyspnea becomes as unique to the individual as is their journey with life-limiting illness.

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dyspnea describes the patient’s experience of the symptom from multiple perspectives that, synergistically, combine to shape the symptom and to determine its impact (Fig. 1). A mnemonic encompassing these various biopsychosocial components is presented in Figure 2. This approach is wholly consistent with the multidisciplinary nature central to palliative care.

Physiologically, dyspnea results from three main abnormalities: increased load requiring greater respiratory effort (e.g., obstruction), an increase in the proportion of respiratory muscle required to maintain a normal workload (e.g., weakness), and an increase in ventilator requirements (e.g., fever, anemia). The anatomic condition and underlying disease giving rise to dyspnea may be pulmonary obstruction (COPD, reactive airways, cough/secretions, mass lesions), pulmonary restriction (fibrosis or other interstitial disease, effusions, fibrosis, infections, kyphosis, obesity), perfusion/oxygenation mismatch (anemia, pulmonary hypertension, heart failure, pulmonary embolism), and fatigue/weakness (multiple sclerosis, amyotrophic lateral sclerosis, cancer fatigue). Although abnormalities can often be measured, imaged, or assumed based on underlying disease, etiologies of dyspnea are often related to systemic effects of illness. For example, data from the National Hospice Study reported that 24% of patients with no known cardiopulmonary process (e.g., local cancer involvement, pleural effusions, pulmonary infections) experience dyspnea. Additionally, in hospice patients with no known cardiopulmonary disorder, both prevalence and severity of dyspnea increase significantly as death approaches. In such cases, systemic changes such as asthenia and cachexia, both of which are present in greater than 80% of people with advanced cancer, are postulated as etiologies.

Other nonanatomic correlates of dyspnea include affect and spiritual and existential distress. Patient anxiety and panic both play an important role in the development of dyspnea and, in turn, are exacerbated by its presence—setting up a pernicious spiral of cause and symptom (Fig. 3). The association between symptoms of breathlessness and anxiety, particularly panic attacks, is well-documented. This association bears notice given the high prevalence of anxiety in palliative care populations. One recent study reported that 22% of patients in an inpatient palliative care unit met Hospital Anxiety and Depression Scale (HADS) criteria for anxiety. It has also been observed that, compared to control patients, patients with underlying anxiety or panic disorders have an exaggerated experience of dyspnea. Additionally the effect of spiritual distress on dyspnea has been recently described.

The central nervous system (CNS) also plays a critical role in the perception of dyspnea. In the accepted neurophysiologic model, it is thought that dyspnea arises when sensory receptors involved with respiration are activated, sending an afferent impulse to the CNS; the CNS then directs an efferent impulse toward the muscles of respiration. Mismatch between these signals may contribute to dyspnea through modulation of any of these systems. It has been postulated since 1985 that endogenous opioids, known as endorphins, may attenuate the dyspnea sensation at the CNS level. An important recent investigation antagonizing endogenous endorphins in opioid-naive volunteers has added to the understanding of the efficacy of exogenous opioids as the mainstay of global therapy for dyspnea. Mahler et al. conducted an investigation measuring beta-endorphin levels at rest and post-exercise in 17 patients with COPD undergoing a 10-minute treadmill exercise test. Patients were given either intravenous saline or naloxone, measured for beta-endorphin serum levels, and queried for numerical rating score of dyspnea. A threefold increase in serum beta-endorphin levels was observed from rest to postexercise. Mean ratings of dyspnea throughout exercise were significantly higher in patients when they received naloxone. This recent proof of concept suggests that further studies are warranted to identify ways in which the endogenous opioid effect on dyspnea can be accentuated.

Additionally, increasing investigations with positron emission tomography (PET) and functional magnetic resonance imaging (fMRI) have added to the knowledge of how dyspnea activates cortical and cerebellar systems.

**Measurement of Dyspnea**

Various validated measurement tools are available to assist the palliative care professional in quantitatively and

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**FIG. 1.** Elements of the biopsychosocial model of “total dyspnea.”

**FIG. 2.** Mnemonic of the biopsychosocial elements of dyspnea.
Overview of a rational approach to dyspnea.

Recent attention has been drawn to the need for a practical assessment tool that describes the patient’s experience of dyspnea and is useful in the clinical setting as well as for research purposes. While several validated scales are used in the research setting to measure the impact of dyspnea on HRQOL, most of these are too long and arduous to be practical in routine clinical care. To better reflect the patient’s experience rather than focusing on physiologic parameters, Tanaka et al. developed the Cancer Dyspnea Scale, a 12-item multidimensional dyspnea scale for patients with cancer to assess effort, anxiety, and discomfort. Originally validated in a Japanese population, it has subsequently been validated in Swedish-speaking and English-speaking cohorts. This effort represents a step forward in incorporating the patient’s symptom experience into dyspnea assessment, but falls short of assessing the full impact of dyspnea. To date, no single assessment tool considers all of the various components of this multifaceted symptom and its impact on people.

Ultimately, when selecting assessment measures in palliative care, the clinician must take into account the goals of care, purpose of the assessment, ease of administration, and patient burden, with the aim of gathering useful information while not detracting from quality of life by being tedious, distressing, intensive, or complicated. In clinical practice, the most fruitful way of measuring experience is simply to ask, intervene, follow up, and ask again — using the same scale each time (Figure 3). Clinically, a straightforward standardized scale (e.g., 0–10 NRS) alone or as a part of a longer symptom list (e.g., ESAS) is likely best. More complex tools (e.g., Cancer Dyspnea Scale) have not yet demonstrated their role in clinical practice, but in the research setting they can help identify etiologies and document change in complex outcomes in response to therapies. Additionally, the evolving understanding that most dyspnea is intermittent, as opposed to continuous, means that a thorough assessment involves questioning both the patient’s current symptom burden and experiences over the last 24 hours.

Conclusion

Dyspnea, a complex and commonly experienced symptom, worsens in prevalence and intensity for many palliative care patients. Its dramatic effects on independence and quality of life make prompt recognition and characterization of underlying causes and comorbidities paramount. Various tools to measure dyspnea are available to the clinician and researcher, but often the most useful and well-received are those that are short, to the point, and used regularly to monitor symptom status. Most importantly, the actual words of the patient reflect the true meaning of dyspnea, its burden, and the impact of therapeutic interventions. The field of palliative care is expanding and the patient population evolving. An increasing proportion of inpatient palliative care consultations are being performed on patients without cancer, such as individuals receiving advanced therapies for COPD and heart failure. As the population of those with life-limiting illnesses referred to palliative care grows, further research and clinician education are critical; we must continue to refine and improve our understanding of, ability to recognize, and capacity to effectively treat this disabling symptom.

In a subsequent article, we will explore pharmacologic and nonpharmacologic interventions for dyspnea.

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Address correspondence to:
Amy P. Abernethy, M.D.
Duke University Medical Center
Box 3436
Durham, NC 27710
E-mail: abernethy@duke.edu