Breathlessness in advanced disease 1: definitions, epidemiology and pathophysiology

Nurses are likely to encounter people experiencing breathlessness in all healthcare settings and need to understand the significance of this distressing symptom.

**AUTHOR** Donna Barnes, PG Cert Health and Social Care (Palliative), RN, is a staff nurse in palliative care, Nightingale Macmillan Unit, Royal Derby Hospital.


This first in a two part unit on breathlessness only to performance status (a measure of health looking at domains including ability to ambulate, care for self and level of consciousness) (Twycross et al, 2009).

Nurses need to be aware of treatment options to support breathless patients, as the impact on an individual and their family can be profound. Krishnasamy et al (2001) note healthcare staff need to understand the impact of breathlessness from the patient’s perspective. In their study, participants described feeling “alone and isolated”, while breathless episodes were described as “suffocating” and near death. The stigma attached to breathlessness associated with smoking may lead to guilt and reluctance to seek help (Gysels and Higginson, 2009).

The wider social impact of breathlessness includes restrictions on functional capacity that limit patients’ ability to work (Gysels and Higginson, 2009), causing dependence on others and the state.

The associated loss of independence and social role can lead to feelings of anger and frustration (Twycross et al, 2009). Other psychological responses, such as chronic anxiety and depression, further increase the healthcare burden (Renwick, 2001).

**BACKGROUND**

Breathlessness has been described as a lay term (Bausewein et al, 2007), but one that accurately describes the patient experience (Esmond, 2003). The medical term dyspnoea literally means “disordered breathing” (Renwick, 2001) but is used clinically to describe the symptom of breathlessness. “Short of breath”, “chest tightness” and “chooking” are also used by patients to describe their symptoms (Uronis et al, 2008).

The American Thoracic Society (ATS, 1999) definition captures the multidimensional nature of breathlessness as a “subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity”. According to the ATS (1999), breathlessness has “multiple physiologic, psychological, social and environmental factors” and may lead to “secondary physiologic and behavioural responses”.

**SIGNIFICANCE OF BREATHLESSNESS**

Breathlessness is a common symptom in my clinical area of inpatient palliative care nursing. It occurs in advanced malignant and non-malignant disease, and affects those with active, progressive disease and limited prognosis (Bausewein et al, 2007).

Breathlessness is associated with a range of health problems, such as chronic lung disorders, heart disease and lung cancer, and can occur at various points in the disease trajectory. This means nurses caring for patients in a variety of settings – including the community, residential care and general hospitals, as well as palliative care units – are likely to encounter many patients experiencing this symptom.

Although intractable symptoms of any nature are challenging, the management of breathlessness can lead to anxiety for nurses. Tarzian (2000) studied breathlessness from the nurses’ perspective and identified that they were profoundly affected by the distress breathlessness caused patients. Participants commented that they were disturbed by patients’ fear and wanted to “breathe for them” (Tarzian, 2000).

**EPIEMIOLOGY**

Rates of breathlessness are highest in lung cancer and chronic obstructive pulmonary disease, but the symptom is also common in other cancers and non-malignant diseases (Simon et al, 2010; Dorman et al, 2009). Its prevalence is increasing, particularly in older people, due to an increase in cardiopulmonary disease (Booth et al, 2004).

Box 1 highlights common diseases associated with the symptom.

**PATHOPHYSIOLOGY**

Breathlessness does not always have organic causes (Booth et al, 2004) and psychosocial factors can precipitate, exacerbate or maintain the symptom (Davis, 2005). Its subjective nature and the lack of correlation between objective measurements of lung function and the sensation of breathlessness, make research into the symptom difficult (Esmond, 2003).

In health, breathing is controlled by respiratory centres in the brain stem and regulated primarily by arterial carbon dioxide and oxygen (Twycross et al, 2009). The respiratory centres respond to information received from various sensory receptors (Dorman et al, 2009). These processes are outlined in Box 2.

**LEARNING OBJECTIVES**

I Identify the wider psychosocial impact of breathlessness for patients and those close to them.

I Understand the role of neuromechanical dissociation in advanced breathlessness.
Chemical stimulation
- Nociceptors in the chest wall respond to chemical changes such as increased lactate, potassium ions and bradykinin which alert the central nervous system to alterations in respiratory function (Esmond, 2003).
- Central chemoreceptors in the medulla are highly sensitive to increased arterial carbon dioxide (Twycross et al, 2009).
- Peripheral chemoreceptors in the carotid and aortic bodies are sensitive to low arterial oxygen (Jantarakupt and Porock, 2005).

Emotional stimulation
Higher centres in the brain can respond to emotional distress in the absence of pulmonary abnormalities so breathlessness can sometimes occur without any lung pathology (Jantarakupt and Porock, 2005).

**BOX 2. MECHANISMS FOR THE HEALTHY CONTROL OF BREATHING**

I Neural stimulation.
- Mechanoreceptors in the respiratory muscles respond to lung inflation (Esmond, 2003).
- Juxtaglomerular cells are stimulated by inflammatory mediators and congestion in the alveoli (Esmond, 2003).
- Irritant receptors in the epithelium of the small airways respond to inhalation of noxious substances (Jantarakupt and Porock, 2005).

Neuromechanical dissociation
Advanced disease may cause changes that increase the work of breathing and/or reduce the ability of the respiratory system to meet ventilatory requirements. This can be related to:
- The primary disease, for example cancer or a neuromuscular disorder;
- The treatment, such as radiation or chemotherapy;
- Any concurrent disorders, such as COPD or heart failure;
- General debility (Twycross et al, 2009).

These may lead to one or a combination of the following:
- Respiratory muscle abnormality;
- Increased airway resistance, for example in COPD the bronchioles are narrowed so a greater effort is required to overcome the resultant increased resistance in the airways;
- Decreased lung and chest wall compliance, for example in pulmonary fibrosis;
- Reduced ventilatory efficacy leading to hypercapnia or hypoxia, for example in respiratory failure;
- Increased ventilatory drive may be caused by fear, anxiety or depression (Twycross et al, 2009; Jantarakupt and Porock, 2005; Esmond, 2003).

The body tries to respond to these changes by regulating pressure, airflow or movement of the lungs and chest wall (Twycross et al, 2009). When the mechanical response cannot meet demands, a mismatch or “neuromechanical dissociation” occurs (Twycross et al, 2009).

This increased effort without increased ventilation contributes to the sensation of breathlessness (Esmond, 2003). Once a threshold of intensity has been reached, the sensation becomes unpleasant, triggering an emotional response and behavioural changes such as stopping activity or seeking help (Twycross et al, 2009). Anxiety has a key role, as rising panic further aggravates breathlessness via the autonomic nervous system, creating a vicious cycle that becomes increasingly difficult to control (Davis, 1997).

**CONCLUSION**
There is evidence that breathlessness is becoming increasingly prevalent, which means that many more nurses can expect to work with a growing number of patients and carers who will be affected by this symptom. Healthcare professionals need to explain interventions to patients and carers and support them to manage the symptom more independently.

Part two of this unit, to be published next week, looks at the management of breathlessness, including assessment and common treatments.

**REFERENCES**

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