Breathlessness in the community: part 1 — assessment

Janelle Yorke

Breathlessness causes emotional and physical distress and social isolation for both patients and their families. Refractory breathlessness, i.e. that which persists even when measures to optimise the underlying condition have been implemented, is one of the most distressing symptoms experienced by patients with advanced life-limiting illnesses. This two-part series describes the experience of refractory breathlessness in patients with advanced disease living in the community, and provides guidance for their care. This, the first part in the series, outlines the experience of breathlessness and how community nurses can accurately assess patients. The second part of this series (available in the next issue of Journal of Community Nursing) will outline management techniques.

**KEYWORDS:** Breathlessness ● Advanced disease ● Assessment

Breathlessness is common in community clinical practice, especially for community nurses providing supportive and palliative care in the advanced stages of disease. The prevalence and severity of refractory breathlessness — one of the most distressing symptoms experienced by patients with advanced life-limiting illnesses (Booth et al., 2003; Solano et al., 2006) — increases as death approaches and patients are generally sedated. However, there is little evidence that palliative care interventions improve breathlessness at end of life.

The advanced stage of a disease is often not clearly defined. Generally, the term ‘advanced’ is connected with progressive disease and a limited prognosis (Bausewein et al., 2007). Prognosis in advanced disease relates to different factors such as symptoms and disease trajectory.

**THE EXPERIENCE OF BREATHLESSNESS**

As highlighted by the American Thoracic Society’s (ATS, 2012) definition, breathlessness is multidimensional. Physical and psychological mechanisms are involved in a person’s perception of, and response to, breathlessness and the experience of breathlessness itself is complex. It is a subjective and distressing symptom and its precise mechanisms are not completely understood, although it is widely acknowledged as a multidimensional construct, similar to the experience of intractable pain (Banzett and Moosavi, 2001; Von Leupoldt and Dahme, 2005).

Although breathlessness is common in advanced cardiopulmonary conditions, the illness trajectory from diagnosis to death — and, therefore, the everyday experience of breathlessness — is different. In patients with lung cancer, for example, the onset of breathlessness is typically rapid (Booth et al., 2003), with refractory breathlessness developing in previously ‘well’ patients. This can be especially frightening for patients and their families. In advanced cancer, however, breathlessness is usually due to the direct effects of a tumour on the lungs, metastatic involvement or pleural effusion.

One large study identified breathlessness as an independent predictor for shorter survival (median survival was 19 days) in cancer patients (Quinten et al., 2008). In contrast, patients with a chronic condition such as obstructive pulmonary disease (COPD) or heart failure develop refractory breathlessness late in the course of their disease — the increase in breathlessness severity generally develops over a period of years.

**BREATHLESSNESS — DEFINITION**

The term ‘breathlessness’ is generally applied to describe the subjective experience of breathing discomfort. The most widely accepted definition is proposed by the American Thoracic Society (ATS, 2012), defining breathlessness as ‘a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience is derived from interaction among multiple physiologic, psychological, social, and environmental factors and may induce secondary physiological and behavioural responses’.

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Prolonged exposure to breathlessness is associated with a 'resetting' of the patient’s perception of it and his or her internal response — known as a 'response shift' (Schwartz and Sprangers, 1999). Thus, a patient with cancer approaching end of life may find the sudden onset of refractory breathlessness more distressing and harder to tolerate than a patient with an advanced chronic condition (White, 2013). Nonetheless, end-of-life issues and patient needs are likely to be similar regardless of the underlying diagnosis.

Breathlessness per se can only be perceived by the person experiencing it (ATS, 2012). It is a subjective experience and assessment of the individual patient is paramount in providing appropriate symptom management.

**Causes of breathlessness**

Breathing is predominately an involuntary neuromuscular mechanism controlled by the respiratory centre, which is located in the brain stem. The primary function of respiration is to meet metabolic needs and maintain blood-gas and acid-base homeostasis (Booth et al, 2008). Under normal circumstances people have little awareness of the mechanics of breathing. However, in illness a person’s normal physiological processes are disrupted leading to a mismatch between what the body requires and what the respiratory centre can provide (O'Donnell et al, 2007) — this can lead to the uncomfortable respiratory sensation known as breathlessness.

Breathlessness in advanced disease is related to a number of factors (Table 1). The particular contribution of each of these varies between patients. However, the immediate cause of breathlessness is largely attributable to the increased effort involved in breathing during exertion or at rest. Patients with cancer who are receiving community palliative care reported that everyday activities such as walking slowly (47.8%) and talking or eating (56.5%) could significantly worsen breathlessness (Roberts et al, 1993).

<table>
<thead>
<tr>
<th>Table 1: Causes of breathlessness in advanced disease</th>
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<tbody>
<tr>
<td>Infection/pneumonia</td>
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<tr>
<td>Cancer affecting the lung — primary or secondary</td>
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<tr>
<td>Anaemia</td>
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<tr>
<td>Hypoxia/hypercapnia</td>
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<td>Anxiety/panic</td>
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<tr>
<td>Pain</td>
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<td>Pulmonary embolism</td>
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<td>Pulmonary congestion</td>
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Therefore, it is reasonable to assume that emotions, both positive and negative, play an important role in a person’s perception of, and reaction to, breathlessness.

Perception of breathlessness

Breathlessness involves the perception of the sensation as well as a person’s reaction to it (ATS, 2012). Brain-imaging techniques have been used to identify the structures involved in the perception of breathlessness. These images show the development of emotional and cognitive structures similar to those found in pain perception and other unpleasant experiences. In particular, the amygdala — part of the limbic system associated with emotions — is activated during laboratory-induced breathlessness (Von Leupoldt and Dahme, 2005), with participants describing the feeling as ‘terrifying’ even though they were able to stop the experiment at any time.

![Breathlessness-anxiety cycle.](image)

Therefore, it is reasonable to assume that emotions, both positive and negative, play an important role in a person’s perception of, and reaction to, breathlessness.

Clinically, however, there is often uncertainty about the contribution of emotion to breathlessness. There is evidence to suggest that breathlessness in advanced disease can trigger anxiety (Dudgeon and Lertzman, 1998); while other studies suggest that anxiety precipitates breathlessness (O’Driscoll et al, 1999).
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References:


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Graphical Three panel figure and text: Because I simply don’t have space for asthma

Practical efficacy

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Patients will often experience a cycle of breathlessness and anxiety (Figure 1). Patient education about breathlessness should include detail about its effect on the parts of the brain where people ‘feel’ and ‘interpret’ experiences, as understanding what causes anxiety can help to reduce the impact of breathlessness.

Similarly, the presence of anxiety and depression in patients with cardiorespiratory illness is higher than in the general population (Yohannes et al, 2010), highlighting the importance of including an assessment of psychological well-being along with any assessment of symptoms such as breathlessness.

When assessing breathlessness, the community nurse should address it as a multidimensional problem in which the emotional experience of breathlessness is inseparable from the sensory experience and the causative biological mechanisms. This requires a holistic assessment to be performed.

For the nurse, the contribution of emotion to the experience of breathlessness has important implications. The connection between breathlessness and anxiety means that any assessment should include both factors. If untreated, anxiety can further exacerbate breathlessness — the aim is to help the patient develop techniques to break the breathlessness-anxiety cycle.

Common signs of anxiety include:
- Irritability
- Agitation
- Difficulty in ‘breathing in’
- Palpitations
- Dry mouth
- ‘Butterflies’ in the stomach
- Dizziness
- Sweating.

All of the above may be heightened in a patient experiencing breathlessness, especially during an acute episode. It is important to discuss this with the patient, as knowing what to expect can often lessen any associated anxiety and distress, enabling the patient and carer to implement management techniques.

**ASSESSMENT OF BREATHELESSNESS IN ADVANCED DISEASE**

Increasing breathlessness in advanced disease is likely to be due to general worsening of the underlying condition or an exacerbation of factors such as bacterial or viral infection, or a cardiac event. If breathlessness is refractory and the patient is approaching the end of life, symptom management should be instigated.

When assessing a patient’s breathlessness, community nurses can use validated questionnaires to measure its severity over time as well as its response to treatment. Questionnaires usually focus either on the direct severity of breathlessness, or how it limits the patient’s activities or quality of life. Most breathlessness questionnaires have been developed and validated to measure COPD, and caution should be used when using questionnaires in different patient groups.

A number of systematic reviews have focused on using questionnaires to assess breathlessness, including studies into advanced disease (Bausewein et al, 2007) and palliative care (Dorman et al, 2007). In reality, the measurement of breathlessness at end of life may not be practical — however, it is to be hoped that the community nurse will be familiar enough with the patient at this stage to recognise it.

**Tools to assess breathlessness**

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to assess breathlessness must be short and easy for the patient and community nurse to use. A numerical rating scale (NRS) can be practical, especially in advanced disease (Dorman et al, 2007), but can be used to assess breathlessness intensity or distress in any patient group. It will also be familiar to many nurses involved in the assessment of pain.

The Dyspnoea-12 has also been validated in a variety of conditions (including COPD, heart failure, asthma and interstitial lung disease) and is simple and easy to use (Yorke et al, 2010; 2011a,b). It comprises 12 items that assess breathlessness severity using descriptors of its physical and emotional components, e.g. ‘My breathing requires more work’; ‘I cannot get enough air.’ Each item is rated as ‘none’ (0); ‘mild’ (1); ‘moderate’ (2); or ‘severe’ (3).

The value of the Dyspnoea-12 is that it provides a separate score for the physical and emotional components of breathlessness, which may help nurses to identify which aspects of breathlessness management may be most helpful in individual cases. For instance, it may not be possible to decrease the severity of the physical impact of breathlessness, but interventions that focus on psychological aspects (such as associated distress and anxiety) may help to reduce the severity of the emotional component.

Both of the tools mentioned above use self-report, however, nearness to death may interfere with the ability to self-report breathlessness, as declining consciousness and/or cognition are common consequences of being at the end of life. This may lead to under-recognition and too extensive or too little treatment (Campbell et al, 2010).

The Respiratory Distress Observation Scale (RDOS) was developed to help clinicians assess respiratory distress in patients who are not able to self-report. It incorporates eight observer-rated parameters:

- Heart rate
- Respiratory rate
- Accessory muscle use
- Paradoxical breathing pattern
- Restlessness
- ‘Grunting at end’ — expiration
- Nasal flaring
- Fearful facial display.

Each parameter is scored from 0–2 points and the points are added, with total scores ranging from 0–16. Higher scores indicate severe distress (Campbell 2008; Campbell et al, 2010). Although early evaluations of the RDOS have been promising, further research is needed to determine its clinical usefulness in the community end-of-life setting.

Underlying cause
When assessing a patient who is experiencing breathlessness, the starting point remains accurate diagnosis of the underlying cause so that disease-specific management can be started — at the same time, interventions that will improve symptom control need to be considered (Yorke and Roberts, 2013). It is important to take a clear clinical history, including:

- Past medical history
- Drug and allergy history
- Family history
- Personal and social history

In advanced disease, it is unlikely that a full history will be provided by the patient. If the patient is not known to the assessing clinician, he or she may need to rely on the patient’s clinical notes and family members and/or carers. However, whenever possible the medical history and, in particular, recent experiences of breathlessness and how the current episode is different/similar, should be sought from the individual patient.

Patients with underlying cardiorespiratory conditions, including cancer, endure persistent and progressive breathlessness. This is compounded by acute exacerbations, which can worsen any symptoms. These exacerbations can be caused by viral or bacterial infections, complications in the patient’s underlying condition.
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Breathlessness remains a devastating symptom, which, in the author's opinion, is rarely managed as well as it could be. Managing breathlessness in the community is an important yet often difficult task. A broad range of interventions and a holistic patient assessment are needed to ensure that the right approach is used. By using appropriate assessment tools and simple interventions, much can be done to improve the symptoms of patients requiring community-based palliative care.

REFERENCES