

Measurement of dyspnoea in the clinical rather than the research setting

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Purpose of review

Refractory dyspnoea is a common and difficult to treat symptom in advanced disease. Accurate assessment helps to guide treatment and prognosis.

Recent findings

The absence of commonly agreed assessment tools has been a significant barrier to improving care through inhibition of clinical research and limitation of clinicians' ability to assess the effectiveness of their interventions. Two recently published systematic reviews on measurement tools for breathlessness identified a variety of tools but none could be recommended as gold standard. Validation of these tools in palliative care seems more appropriate than development of new tools. For clinical purposes, the combination of a unidimensional tool to assess dyspnoea severity and a multidimensional tool to evaluate the impact on a person's quality of life seem most appropriate. This review discusses the present evidence and puts forward a strategy for assessment and measurement of the symptom in clinical practice.

Summary

Despite a variety of measurement tools none can be recommended as gold standard for the assessment of dyspnoea. A combination of unidimensional and multidimensional tools seems to be the best for clinical assessment. Measurement of dyspnoea has to be seen in context with the person's history, physical examination and diagnostic tests.

Keywords

assessment, breathlessness, dyspnoea, measurement, outcomes, palliative care

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Introduction

Dyspnoea is one of the most common and distressing symptoms of advanced malignant and nonmalignant disease, reaching 90% in people with cancer [1] and 95% in people with Chronic Obstructive Pulmonary Disease (COPD) [2]. It is a complex multidimensional symptom affecting every facet of the person's life and indeed having devastating effects on carers [3]. There is no single universally used and commonly effective treatment to palliate breathlessness, which often requires a combination of pharmacological and nonpharmacological treatments to ameliorate it. Therapeutic nihilism about the management of dyspnoea in advanced disease was common until recently. There is increasing research and clinical interest in improving the accuracy of assessment of this complex symptom to help evaluate the interventions available to relieve it and to aid prognostication [4] with the recognition that end-of-life care in this group is often inadequate, partly because of poor planning and communication [5].

Clinical assessment of dyspnoea

Accurate clinical assessment of dyspnoea (also referred to as breathlessness) is important

- (1) to help make a clear diagnosis of the causes(s) of the symptom,
- (2) to understand the impact of the symptom on the individual,
- (3) to establish an appropriate management plan.

Regular, standardized assessment of the severity of this distressing symptom is not yet considered mandatory in clinical practice yet without this there can be no accurate assessment of the effectiveness of interventions and necessary changes of treatment. It has been acknowledged that clinicians have to become more familiar with available measurement tools [6*].

History

A comprehensive clinical history is an important part of assessing dyspnoea and should include the following points in addition to standard practice:

- (1) pattern of breathlessness (onset, aggravating factors, characteristics);
- (2) presence of other symptoms and their importance compared to breathlessness;
- (3) impact on a person's quality of life including physical activities (e.g. walking), ability to self-care, social life and psychological status;

- (4) current symptomatic treatments for breathlessness (e.g. handheld fan) and their efficacy for that person;
- (5) adverse effects of any treatments used currently or in the past;
- (6) all comorbidities;
- (7) the person's understanding and interpretation of the symptom.

The carer's psychological and social status, support available to them and their hopes and fears about the condition need separate assessment as these will have a significant effect on the patient's condition.

It is particularly important to distinguish whether the underlying cause of breathlessness is irreversible or potentially reversible. Any recent or acute escalation of breathlessness may indicate a new potentially treatable disorder (e.g. pulmonary emboli) or exacerbation of the underlying condition, for example COPD, or escalation of underlying disease (e.g. interstitial lung disease) indicating the need for end-of-life care or an alteration in the treatment regimen.

Verbal descriptors of dyspnoea

Dyspnoea comprises a number of qualitatively different sensations [7] and attempts have been made to link descriptors of breathlessness with distinct pathophysiological processes. This has been done with partial success in COPD [8^{*}] but not in cancer [9] in which a significant amount of overlap has been described between the same descriptors and different pathophysiologies. Thus, this line of enquiry may not be especially useful in either clinical assessment or research.

Measurement of dyspnoea

Dyspnoea is a subjective symptom so the person's report of severity is the most accurate measure. Note however, this may be affected on a day-to-day basis by other factors (e.g. psychological or social changes) and 'response shift'. Objective measures such as respiratory rate, oxygen saturation or lung function tests do not correlate with the subjective experience of people. The discrepancy between intensity of breathing discomfort and disease severity has been acknowledged [7]. Accurate measurement would differentiate between people with different levels of dyspnoea and capture changes resulting from treatment or over time [10].

Numerous assessment tools are available for measuring dyspnoea, but recent systematic reviews [11^{**},12^{**}] have demonstrated that none can be regarded as a 'gold standard' achieving accurate, comprehensive assessment of dyspnoea in all settings or for all diseases. Most have been validated in chronic respiratory illness, but not in

cancer or palliative care settings [11^{**}] and further validation is required. Selecting the most appropriate scale depends therefore on the context and purpose of measurement [12^{**}].

Essential information about measurement of dyspnoea should include whether it was made during or after exercise (the latter being carefully defined), the period over which the measurement was made (e.g. over last week, now or over last 24 h) and the severity of dyspnoea at best, at worst and on average.

Measurement tools for dyspnoea

The tools described in this review are those that seem most suitable for clinical practice. A wider overview of all available tools for measurement can be found in the two recently published systematic reviews [11^{**},12^{**}].

Unidimensional tools

Three types of unidimensional instruments are commonly used in the measurement of dyspnoea: visual analogue scales (VASs), numerical rating scales (NRSs) and the modified Borg scale. Unidimensional tools measure the sensory component or general severity of breathlessness either averaged over a period of time or at a point in time, for example after exercise. All unidimensional measures are self-administered taking only a few moments to complete.

Visual analogue scale

The VAS is a horizontal or vertical line, usually 100-mm long that is widely used in the measurement of symptoms such as breathlessness and pain, at a specific point in time. A clear description of the sensation being measured must be given such as 'breathlessness', 'distress due to breathlessness' or 'effort of breathing'. Clear anchors are defined at each end of the VAS such as 'not breathless at all' to 'extremely breathless' or 'not breathless' to 'breathlessness as bad as it can be'. The person indicates a level of dyspnoea by marking the line between anchor points and the distance from the left side or the bottom of the scale is measured. As breathlessness is a sensation that can change between measurements, the VAS is most suited to within-subject repeated measurement as it has the sensitivity required to measure minute changes [13] and has been shown to be reproducible in the same person on different days. It is neither suitable, however, for comparing breathlessness in different people, nor would it be satisfactory for summarizing or comparing the conditions of groups of people [14].

Numerical rating scale

From pain management it is known that NRSs are easier to use for people than VASs [15]. In the measurement of breathlessness, ratings on the NRS are highly correlated

with VAS ratings [16]. The NRS has been shown to be a more repeatable measure than the VAS [17]. Healthy subjects preferred the NRS to the VAS during exercise [18]. The NRS and Borg scales, unlike the VAS, can be used over the phone. In one study, the NRS was more repeatable than the VAS in participants with cancer [17].

Modified Borg scale

The modified Borg scale is a categorical scale similar to a NRS but descriptive terms (severe, moderately severe, etc.) are used to anchor responses [19]. The modified Borg scale has ratio properties [20] but is not strictly linear [21]. It is possible that larger changes are more likely to be observed at the higher end of the scale in which there are larger numerical intervals between word anchors for symptom severity [21]. Modified Borg scale scores are more reproducible than VAS measurements between tests and within the period of an exercise test [22]. Ceiling effects have been described in dyspnoea measurements using the modified Borg scale as the levels of dyspnoea people choose are triggered by the verbal anchors with people choosing the numbers by the anchors [23].

Medical Research Council scale

The Medical Research Council (MRC) scale is a simple categorical scale grading the effect of breathlessness on daily activities [24,25]. It can be either self-reported or interviewer-administered with reported completion times of 30 s [24]. The sensitivity is too coarse to demonstrate reliable changes in breathlessness following an intervention [10]. Nonetheless, the MRC scale is widely used in clinical settings in the United Kingdom as a preliminary assessment.

Multidimensional tools

Multidimensional tools assess the impact of breathlessness on various domains such as activities of daily living, emotional and mental functioning, sense of mastery or other person related outcomes, in contrast with unidimensional tools. There are almost 30 multidimensional tools available [11**], most being used in research.

Chronic Respiratory Disease Questionnaire

The Chronic Respiratory Disease Questionnaire (CRQ) is a 20-item questionnaire that examines people's outcomes focusing on four dimensions: dyspnoea (five self-selected items), fatigue (four items), emotional function (seven items) and mastery or feeling of control over the disease (four items) [26]. For the self-selected dyspnoea items, each person is asked to select the five most important activities associated with breathlessness from a list. They then rate their breathlessness associated with each activity over the past 2 weeks on a Likert-like scale

from 1 (extremely short of breath) to 7 (not at all short of breath) [26]. The individual scores are added to obtain an overall CRQ dyspnoea score (range 5–35), then divided by 5 (for the five activities) to provide a mean score (range 1–7). A higher score represents a better 'quality of life'. The CRQ has been developed and evaluated for COPD [27,28] but has not yet been evaluated in people with cancer.

The CRQ is one of the few instruments focusing on breathlessness and its impact on quality of life from the person's standpoint. It was originally 'interviewer-administered' but a self-administered version now exists [29]. It takes 10–25 min when first used [30] but 10–15 min subsequently [31].

Motor Neurone Disease Dyspnoea Rating Scale

The Motor Neurone Disease Dyspnoea Rating Scale (MDRS), modelled on the CRQ, comprises 16 questions covering dyspnoea, fatigue, emotional function and mastery [32]. It lists a smaller number of activities in the dyspnoea domain than the CRQ being suited for people 'with exercise-limiting limb weakness'. Low scores indicate minimal and high scores maximal symptoms. People identify five activities of daily living that cause breathlessness and then quantify the severity of dyspnoea on a five-point Likert scale. The MDRS can be either self-administered or completed with assistance and takes about 10 min to complete [32]. As people with cancer are often limited in their activities, some centres started to use the MDRS in this person group as it fits their situation better. It has not, however, been validated in people with cancer.

Cancer Dyspnoea Scale

The Cancer Dyspnoea Scale (CDS) is composed of 12 items covering the sensations of effort, anxiety and discomfort [33]. The participant rates the severity of each on a scale from 1 (not at all) to 5 (very much). The maximum total score is 48: with up to 20 points for effort, 16 for anxiety and 12 for discomfort. A higher score reflects more severe dyspnoea. The CDS usually takes a few minutes to complete [33].

The use of scales in clinical work

Using scales in clinical work is much more problematic. Time constraints in routine out-patients appointments or domiciliary consultations need to be remembered. Questionnaires involving extensive lists of questions that need to be completed by people may be unhelpful when building a therapeutic relationship between clinician and a person disabled by breathlessness. If completed questionnaires are not studied by the clinician and the questions already asked within them repeated in the consultation then people are likely to wonder why they

invested energy in filling them in and lose confidence in the consultation. Many people worry about the 'correct way' to answer questionnaires and often need help with the unidimensional scales (e.g. the VAS) the first time they use them. Nevertheless, clinical assessment of dyspnoea needs to be standardized as this is done in pain management [15]. Higginson and Carr [34] give some useful recommendations that should be considered when introducing measures into clinical practice such as choice of measure, introduction to staff and regular review.

As people with advanced illness normally suffer from multiple symptoms first short general measures such as the Memorial Symptom Assessment Scale (MSAS) [35] or the Palliative Outcome Scale (POS) [36,37] can help to screen for severe problems that then could be investigated in more detail.

For the overall severity of dyspnoea, a unidimensional scale such as the VAS, NRS or the Borg scale seems to be most suitable [11^{••},12^{••}]. These scales are also helpful to assess treatment effects but there is an ongoing discussion how the minimal clinically important differences (MCIDs) are best defined. For the Borg scale changes greater than 2 units appear to be associated with more powerful interventions such as pulmonary rehabilitation whereas changes with less intensive interventions such as oxygen supplementation or drug therapy seem to be associated with lower changes in the order of 1.0 unit with more moderate effect sizes [21]. There are limited data to allow recommendations for the VAS but it is suggested that a change in VAS of approximately 10–20 is associated with a modest level of symptom change in people with chronic lung disease [21].

If the impact of breathlessness on quality of life is the main interest, the CRQ seems to be most helpful. Alternatively, the dyspnoea and mastery subscale of the CRQ can be used or the MRDS. The existing studies evaluating the MCID for the CRQ consistently show estimates around 0.5 on all domains of the CRQ [29].

Physical examination

A comprehensive examination should be used to check for reversible problems such as pleural effusions or infection or exacerbations of heart failure, for example. The person's psychological status is also important as anxiety and depression are common in chronic illness and can both precipitate and exacerbate breathlessness.

Diagnostic tests

In general, diagnostic tests in palliative care should be used circumspectly and only if the results can be acted on

to help the person. Previous investigations often provide valuable information.

A variety of pulmonary function tests such as spirometry or oxygen saturation are available. Spirometry is widely used both in research and in clinical settings and also in some studies in palliative care settings [38–40]. Nevertheless, dyspnoea measures are at best moderately correlated with pulmonary function [41,42]. They are exhausting for people in a palliative care setting and therefore of limited usefulness [43].

Exercise tolerance measures

As dyspnoea is often connected with physical activity exercise tolerance measures can help to assess the exercise capacity of people and in combination with a measure such as the Borg scale the severity of breathlessness can be evaluated. Various exercise tests are now being validated for people with advanced disease such as the shuttle walking test [38] or specifically developed for this person group such as the reading numbers aloud test for people being breathless at rest or on minimum exertion [39] or the upper limb exercise test [44]. These tests are, however, too burdensome and time consuming for use in clinical practice and are more helpful in the research setting.

Conclusion

Clinical assessment of breathlessness plays an important role in the management of this devastating symptom. Besides the medical history and physical examination, measurement of dyspnoea should become mandatory in clinical practice. Various tools for measurement of dyspnoea exist but none of the existing tools can be recommended as the gold standard. A unidimensional scale can be used to assess the severity of breathlessness and a multidimensional tool such as the CRQ for assessing the impact of breathlessness on quality of life. As in advanced illness people have many symptoms, a generic palliative measure that assesses a person's outcomes may also be useful. Clinicians should familiarize themselves with some measurement scales and include them in their daily practice.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 143).

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