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REVIEW

Measurement of breathlessness in advanced disease: A systematic review

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Summary

Background: There is a plethora of assessment tools available to measure breathlessness, the most common and disabling symptom of advanced cardio-respiratory disease. The aim of this systematic review was to identify all measures available via standard search techniques and review their usefulness for patients with advanced disease.

Methods: A systematic literature search was performed in Medline. All studies focusing on the development or evaluation of tools for measuring breathlessness in chronic respiratory disease, cardiac disease, cancer, or MND were identified. Their characteristics with regard to validity, reliability, appropriateness and responsiveness to change were described. The tools were then examined for their usefulness in measuring significant aspects of breathlessness in advanced disease.

Results: Thirty-five tools were initially identified, two were excluded. Twenty-nine were multidimensional of which 11 were breathlessness-specific and 18 disease-specific. Four tools were unidimensional, measuring the severity of breathlessness. The majority of disease-specific scales were validated for chronic obstructive pulmonary disease (COPD), few were applicable in other conditions. No one tool assessed all the dimensions of this complex symptom, which affects the psychology and social functioning of the affected individual and their family—most focused on physical activity.

Conclusion: As yet there is no one scale that can accurately reflect the far-reaching effects of breathlessness on the patient with advanced disease and their family. Therefore, at present, we would recommend combining a unidimensional scale (e.g. VAS) with a

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disease-specific scale (where available) or a multidimensional scale in conjunction with other methods (such as qualitative techniques) to gauge psychosocial and carer distress for the assessment of breathlessness in advanced disease.

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Introduction

Breathlessness is a complex symptom affecting many dimensions of a patient's life reducing not only patients' activity and functional capacity, but also causing distress and discomfort. Despite the many advances that have taken place in cardio-respiratory medicine in recent years, the breathlessness that accompanies advanced disease frequently remains intractable causing distress and disability for patients and anxiety and social isolation for their close family. There is a need for carefully developed studies with clearly defined research questions and appropriate measurement tools to evaluate ways of improving patients' breathlessness. Historically, most of the work on the measurement of breathlessness has been conducted by respiratory clinicians and physiologists, therefore most measures have been developed for patients with chronic pulmonary disease^{1,2} and are suitable for use only in a clinical setting. To date, palliative care studies have focused on the management of breathlessness rather than its assessment, but improving the management of breathlessness requires assessment tools, which are sensitive enough to accurately assess the effect of interventions intended to relieve the symptom.¹

Patients experience different sensations with various intensities when they describe breathlessness. The American Thoracic Society (ATS) stresses that breathlessness is a subjective symptom, like pain, which can only be described and interpreted by the patient and therefore any assessment should be patient-reported.³ Severity, character, time course and triggers have also to be taken into account as the course of breathlessness varies with different disease trajectories such as cancer, chronic obstructive pulmonary disease (COPD) or motor neurone disease (MND). Further measurable aspects are symptom frequency, severity and distress and the symptom's impact on function, psychological, social and spiritual well-being.

The aim of this paper is to identify and systematically review the literature for instruments regularly used to measure the sensation of breathlessness in chronic conditions such as COPD, cancer, chronic heart failure and MND. A second aim is to relate these tools to the specific situation of patients with advanced disease and identify those measures that could be used by patients near the end of life.

The review focuses on measures of the sensation of breathlessness. Health-related quality-of-life measures,

domain-specific measures and general symptom scales such as the Memorial Symptom Assessment Schedule,⁴ the Edmonton Symptom Assessment Schedule (ESAS)⁵ and the Support Team Assessment Schedule (STAS),⁶ which are also regularly used with breathless patients are not the subject of this review. In addition, pulmonary function and exercise testing are not included because they do not assess the severity of the feeling of being breathless (i.e. the sensation) but rather the impact of breathlessness on functional capacity (exercise testing) or the physiological consequences of the underlying illness causing breathlessness.

Methods

Definition of breathlessness

There are a variety of definitions of breathlessness ranging from two words (e.g. "laboured breathing") to whole paragraphs, but no consensus exists on a single one. The ATS has defined breathlessness, or dyspnoea, as "a subjective experience of breathing discomfort that is comprised of qualitatively distinct sensations that vary in intensity".³ For the purpose of this review the ATS definition will be used and we will refer to 'breathlessness', as opposed to 'dyspnoea', as this is the term patients use.

Definition of advanced disease

"Advanced" stages of disease are often not clearly defined. Generally the term "advanced" is connected with active and progressive disease and a limited prognosis. Prognostication in advanced disease relates to different factors such as symptoms, performance status and disease trajectory. As disease trajectories vary depending on whether the patient is suffering from malignant or non-malignant disease,⁷ advanced stages have to be defined independently for every disease. Breathlessness is known to be one of the symptoms that increase towards the dying phase in cancer patients.^{8–10}

Literature search

A systematic literature search was performed.¹¹ MEDLINE (1966–August 2005 week 1) was searched using OVID with the following search terms: dyspnoea/dyspnea (MeSH exploded and keyword) or breathlessness (keyword) AND outcome measures (keyword) or outcome assessment (health care) (exploded) or treatment outcome (keyword) or treatment outcome (exploded) or psychometrics (keyword) or psychometrics (exploded) or questionnaires (keyword) or questionnaires (exploded) or medical audit (exploded) or audit measures (keyword) or outcome (keyword) or quality of health care (exploded). The reference lists of all retrieved studies and review articles were searched for further relevant articles.

Selection criteria

The following criteria for the selection of studies were used: studies focusing on the development or evaluation of

instruments measuring the sensation of breathlessness in chronic respiratory disease, cardiac disease, cancer or MND. Measurement could relate to severity, intensity or exercise capacity, and be uni- or multidimensional. Multidimensional tools were included if they were breathlessness specific or disease specific. Similarly, measures assessing quality of life were included if they contained questions relating to breathlessness and were clearly related to one of the above-mentioned conditions. General health-related measures, domain-specific measures or general symptom measures were not included as was information on breathlessness and posture because it did not seem relevant to this review.

Data extraction and analysis

Identified measures were first evaluated according to the criteria listed in Table 1. These criteria are relevant for psychometric testing of outcome measures, as used in other reviews.^{12,13} In a second step the identified measures were examined according to their potential for use in patients with advanced disease. The following criteria were adopted: (1) content of the measure regarding breathlessness (severity, frequency, intensity and distress) and symptoms/factors (physical, function, psychosocial and spiritual) and (2) administration of the measure (self-administration, time, validated in advanced disease, frequency of use). The frequency of use was evaluated with a cut-off point of five studies indicating frequent use.

Results

The search yielded 6330 references. Seventy-three studies were identified that reported either the development and/or validation of 35 instruments measuring breathlessness. We excluded two instruments, the COPD Activity Rating Scale¹⁴ and the Breathing Problems Questionnaire,¹⁵ as they mainly measured functional impairment of patients with breathlessness and did not contain any questions evaluating breathlessness itself.

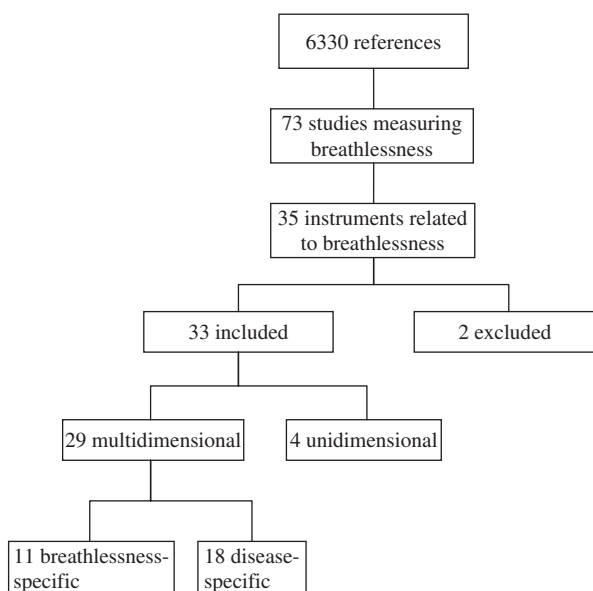
Of the remaining measures, 29 were multidimensional, of which 11 were breathlessness-specific and 18 were disease-specific. Four were unidimensional, measuring the severity of breathlessness (Fig. 1). The psychometric properties of the included measures are shown in Appendix A.

Unidimensional tools

Three types of unidimensional instruments are commonly used in the measurement of breathlessness (Appendix A): visual analogue scales (VAS), numerical rating scales (NRS) and the Modified Borg Scale. Unidimensional tools measure breathlessness in general or on exercise (e.g. Oxygen Cost Diagram and Modified Borg Scale^{16,17}) and are often used to describe the severity of breathlessness in exercise tolerance tests. Many tools developed for patients with advanced disease use VAS (e.g. ESAS⁵), NRS or categorical scales (e.g. STAS⁶). All unidimensional measures are self-administered and quick to complete. The VAS, the Modified Borg Scale and the Oxygen Cost Diagram are frequently used (more than

Table 1 Criteria for the evaluation of breathlessness measures.

Validity	
Content validity	Does the measure cover domains of importance to patients and caregivers?
Criterion validity	Does the measure correlate with superior measures or predicted futures outcomes?
Construct validity	Do the results confirm expected pattern of relationships or hypotheses?
Reliability	
Internal consistency	Do individual items within measure correlate with each other and with total scores?
Test–retest reliability	Does the measure produce same results when applied under same conditions at different times?
Responsiveness to change and acceptability	
	Does the measure discriminate between differing degrees of disease severity?
	Has the measure demonstrated change in clinical trials or follow-up studies?
	Are observed scores well distributed around scale midpoint, with low floor and ceiling effects?
Appropriateness	
	Is the measure suitable for use in clinical audit in a variety of settings?
	Is the amount of time needed for completion acceptable?

**Figure 1**

five studies) in studies including patients suffering from breathlessness.

VAS

The VAS is widely used in the measurement of breathlessness as well as other symptoms, e.g. pain, at a specific point in time. Numerous studies have established its validity, whether as a measure of breathlessness or other sensations^{18–22}; however, comparison of studies is difficult due to the use of different formats, lack of specification of formats, small sample numbers and the use of the scale to measure different variables,¹ e.g. different aspects of breathlessness such as ‘breathlessness’, ‘distress due to breathlessness’ or ‘bother caused by breathlessness’. Heys-

Moore²³ validated a VAS relating to the preceding 24h (VAS₂₄). There are no apparent criteria or standard principles that guide the consistent use of the VAS by different observers.²⁴ 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.¹ It is not suitable, however, for comparing breathlessness in different patients, nor would it be satisfactory for summarising or comparing the conditions of groups of patients.²⁴ Dudgeon compared a VAS with a verbal rating scale for dyspnoea and showed that the two scales had a strong correlation to the point of redundancy.²⁵

Oxygen-cost diagram

The oxygen-cost diagram (OCD) is a variation of the VAS.¹⁶ Guyatt described the diagram as ‘simple and easy to administer’²⁶; however, Mahler and Wells reported initial difficulties with patients’ lack of understanding of how to use it.²⁷ Ambrosino and Porta noted that not all patients engaged in all the activities depicted along the line.²⁴ In addition, the measure relies heavily on ambulatory activities so it is of limited use for assessing patients who are breathless at rest. It offers no advantages over the VAS¹ and its responsiveness and validity are unproven.²⁶ The OCD has been widely used in patients with pulmonary disease but not in patients with advanced cancer or other diseases.

NRS

From pain management it is known that NRSs are easier to use for patients than VASs.²⁸ In the measurement of breathlessness, ratings on the NRS are highly correlated with VAS ratings.²⁹ The NRS has been shown to be a more repeatable measure than the VAS, therefore requiring smaller sample sizes to detect a change in breathlessness.³⁰ Subratty developed an NRS for the assessment of breathlessness in chronic heart failure and related it to a list of

activities; however, it has only been tested in eight patients.³¹

Modified Borg Scale

The Borg Scale was developed to assess the rate of perceived exertion.³² Later the instrument was used to measure the intensity of the sensation of breathlessness (originally in healthy subjects on exercise); now the Modified Borg Scale is the format most commonly used.^{17,32} Although not a true ratio scale, it has been described as such to enable statistical calculations¹ but is more appropriately described as a categorical scale³³ or a 'category scale with ratio properties'.³⁴ Wilson and Jones demonstrated that Modified Borg Scale scores are more reproducible than VAS scores between tests and within the period of a single exercise test.¹⁸ The Borg Scale has, in comparison to the VAS, the advantage that it can be used over the phone. Ambrosino and Porta recommended using a modified Borg score for each level of effort during a scalar test, and comparing the severity of breathlessness at comparable time periods (isotime) or at similar work intensities (iso-load).²⁴ Further work is required to assess its usefulness in patients with advanced cancer.^{1,34}

Breathlessness-specific tools

We identified 11 breathlessness-specific tools (Appendix A), covering the following domains: magnitude of task^{23,35,36}; magnitude of effort and functional impairment³⁵; symptoms associated with breathlessness³⁷⁻⁴⁰; activities of daily living and fear of overexertion⁴¹; breathlessness during physical activity, speaking activity and speaking during physical activity⁴²; sense of effort, sense of anxiety, sense of discomfort⁴³; frequency, timing, triggers, coping strategies, limitations, feelings⁴⁰; intensity, temporal, constrictive pressure, pain, sound quantity, dry sound, wet sound, energy, air quantity, respiratory effort, loss of power, fear, depression, dread, suffocation, illness.²³ Of these tools only the Modified MRC Dyspnoea Scale and the Baseline/Transition Dyspnoea Index are used in more than five studies.

All but five of the breathlessness-specific tools have been validated in patients with pulmonary disease, predominantly COPD. Only one scale, the Feinstein Index of Dyspnoea, has been validated for patients with chronic heart failure.³⁸ The Cancer Dyspnoea Scale (CDS⁴³), the Dyspnoea Exertion Scale and the Dyspnoea Assessment Questionnaire²³ have been validated for patients with cancer. The Breathlessness Assessment Guide was developed for patients with lung cancer.⁴⁰

Six of these measures are self-administered: the Breathlessness Cough and Sputum Scale (BCSS³⁹), the Chronic Lung Disease Severity Index,³⁷ the University of California St. Diego Shortness of Breath Questionnaire,⁴¹ the University of Cincinnati Dyspnea Questionnaire⁴² and the CDS.⁴³ Feinstein's Index of Dyspnoea,³⁸ the Breathlessness Assessment Guide⁴⁰ and the Baseline Dyspnoea Index/Transition Dyspnoea Index (BDI/TDI)³⁵ are administered by an interviewer but a self-administered computerised format of the BDI has been developed.⁴⁴ Two measures, the MRC Dyspnoea Scale³⁶ and the University of Cincinnati Dyspnoea Questionnaire,⁴² have a format that allows either self-administration or

interviewer administration. The tools contain between three and 30 items, and the reported completion time varies from 30 s (Medical Research Council (MRC) Dyspnoea Scale³⁶) to 5-10 min (University of Cincinnati Dyspnoea Questionnaire⁴²).

Most breathlessness-specific tools have been successfully tested for validity and reliability in patients with COPD with the exception of the Breathlessness Assessment Guide,⁴⁰ which has not yet undergone formal psychometric testing. Responsiveness and appropriateness have not been shown for all scales. The MRC Dyspnoea Scale is too insensitive to capture relevant changes in breathlessness following an intervention^{45,46} whereas the BDI/TDI have been specifically developed to measure changes from the baseline condition.³⁵ The BDI/TDI was found to obtain valid, responsive measures of acute changes in quality of life and breathlessness associated with a COPD exacerbation.⁴⁷ The BCSS showed discriminative quality and was responsive to change, as was the CDS.^{39,48} Stoller et al. developed a Modified Baseline Dyspnoea Index to provide more precise criteria for the ratings by differentiating between home and work functional impairment.⁴⁹ However, it does not demonstrate any advantage to Mahler's index when using the tool to assess breathlessness in patients with end stage disease who are no longer able to work.¹

Disease-specific dyspnoea tools

We identified 18 multidimensional disease-specific tools (Appendix A) of which the Chronic Respiratory Disease Questionnaire (CRQ⁵⁰) is one of the most widely used measures for quality of life in chronic respiratory disease.⁵¹ Most of them aim to assess the quality of life of patients with respiratory disease by covering the varying combinations of some of the following domains: emotional and mental function, mastery, coping skills, concerns, depression, anxiety^{50,52-59}; symptoms such as cough, sputum, breathlessness, fatigue^{50,52,53,53,60}; physical activity^{52,55-57,61-64}; impact on daily life^{50,53,58,60}; self-care, domestic, leisure^{53,61,65}; social activity and limitations^{53,55,58,59}; sexual functioning,⁶⁶ environmental stimuli;⁵⁷ treatment satisfaction⁵⁶ and quality of life.⁶³

The identified measures cover between eight and 164 items, with a completion time of between 2 min (Clinical COPD Questionnaire (CCQ)⁵²) and 15-25 min (CRQ⁵⁰). Seven of the measures are self-administered: St. George's Respiratory Questionnaire, Seattle Obstructive Lung Disease Questionnaire (SOLDQ), CCQ, Pulmonary Function Status Scale (PFSS), 10-item Respiratory Illness Questionnaire (RIQ-MON 10), VAS8, MND Dyspnoea Rating Scale (MDRS)^{52,54,56,59,60,66,67}. The Lung Cancer Symptom Scale (LCSS) consists of two scales, one for the patient and one for the health-care professional.⁶³ In this group, the CRQ, the St. George's Respiratory Questionnaire, The Seattle Obstructive Lung Disease Questionnaire, the LCSS and the Revised ALS Functional Rating Scale (ALSFRS-R) were used in more than five studies.

The CRQ is an interviewer-administered questionnaire but Schünemann et al. showed that the self-administered version maintains validity and responsiveness relative to the interviewer-administered version.⁵¹ The CRQ is one of

Table 2 Breathlessness measures and advanced disease.

Type, name (and abbreviation) of measure	Content of measure									Administration of measure				
	Breathlessness				Symptoms/factors					Self-admin.	Validated in advanced disease	Time	Frequency of use	
	Severity	Frequency	Intensity	Distress	Physical	Functional	Psychological	Social	Spiritual					
<i>Unidimensional measures</i>														
Visual Analogue Scale (VAS) ^{19,21,22}	X										X	X	Seconds	X
Oxygen Cost Diagram (OCD) ¹⁶	X							X			X		1–2 min	X
Modified Borg Scale ¹⁷	X										X		No information	X
Numerical Rating Scale (NRS) ²⁹	X										X		No information	
<i>Breathlessness-specific measures</i>														
Modified MRC dyspnoea scale ³⁶											X		30 s	X
Baseline/Transition Dyspnoea Index (BDI/ TDI) ³⁵	X												Observer = 5 min; self-admin = no info	X
Breathlessness, Cough and Sputum Scale (BCSS) ³⁹					X	X					X		No information	
Chronic Lung Disease severity index (CLD) ³⁷		X	X		X	X					X		No information	
University of California St. Diego (UCDS) Shortness of Breath Questionnaire ⁴¹	X					X	X				X		No information	
University of Cincinnati Dyspnoea Questionnaire ⁴²		X				X					X		5–10 min	
Feinstein's Index of Dyspnoea ³⁸	X				X	X							Few minutes	
Cancer Dyspnoea Scale (CDS) ⁴³	X			X			X				X	X	140 s	
Breathlessness Assessment Guide ⁴⁰	X	X		X	X	X		X			X	X	No information	
Dyspnoea Exertion Scale ²³						X					X	X	No information	
Dyspnoea Assessment Questionnaire ²³			X	X							X	X	No information	

<i>Disease-specific measures</i>											
Chronic Respiratory Disease Questionnaire (CRQ) ⁵⁰	X	X		X	X	X	X			First 15–25 min (max 30), repeat 10–15 (max 20)	X
St. George's Respiratory Questionnaire (SGRQ) ⁶⁰		X		X	X	X	X	X		No information	X
MRC Respiratory Symptoms Questionnaire ³⁶				X	X				X	No information	
ATS-DLD-78 questionnaire ⁶⁸				X	X				X	No information	
Seattle Obstructive Lung Disease Questionnaire (SOLDQ) ⁵⁶	X	X		X	X	X	X		X	5–10 min	X
Pulmonary Functional Status Scale (PFSS) ⁶⁶	X				X	X	X		X	15 min	
London Chest Activity Daily Living Scale ⁶⁵	X				X			X			
Pulmonary Function Status & Dyspnoea Questionnaire (PFSDQ) ⁶¹	X	X	X			X		X	X	First 17 min, repeat 15	
Modified PFSDQ (PFSDQ-M) ⁶²	X	X	X		X	X			X	First 7 min, repeat 6	
Airways Questionnaire 20 (AQ20) ⁵⁷				X	X	X			X	2.5 ± 0.9 min	
Clinical COPD Questionnaire (CCQ) ⁵²		X		X	X	X	X		X	2 min approx.	
Respiratory Quality of Life Questionnaire (RQLQ) ⁵⁸	X			X	X	X	X		X	No information	
Quality of Life for Respiratory Illness Questionnaire (QOL-RIQ) ⁵⁵	X			X	X	X	X		X	No information	
10-Item Respiratory Illness Questionnaire-monitoring 10 (RIQ-MON 10) ⁵⁹	X				X	X	X		X	Couple of minutes	
VAS8 ³³	X			X	X	X	X		X	<5 min	
Lung Cancer Symptom Scale (LCSS) ⁶³	X			X	X				X	Patients = first 8 min, X repeat 3–5; observer = 2 min	
MND Dyspnoea Rating Scale (MDRS) ⁵⁴	X	X	X	X	X	X	X		X	10 min	
Revised ALS Functional rating Scale (ALSFRS-R) ⁶⁴				X	X				X	No information	X

the few instruments that focus on breathlessness from the patient's point of view and its impact on quality of life, demonstrating potential value as a tool in the initial assessment of breathlessness. However, repeated use may not detect small changes, limiting its application to patients who develop breathlessness in their last few days.¹

The MRC Respiratory Symptoms Questionnaire and the ATS DLD-78 questionnaire are mainly used to assess the prevalence of pulmonary disease in epidemiological studies⁶⁸; however, they seem to be too coarse to demonstrate reliable changes in breathlessness following intervention.⁴⁵

Measurement of breathlessness in advanced disease

Table 2 shows how the identified measures relate to their use in patients with advanced disease. Of the 33 instruments evaluated, most are self-administered. Only three are designed for use by an interviewer (BDI/TDI, Chronic Respiratory Questionnaire, Breathlessness Assessment Guide),^{35,50} of which two (BDI/TDI, CRQ) have a self-administered version developed later.^{35,69} The severity of breathlessness is measured in 25 instruments, the frequency in ten, the distress in seven and the intensity in four. Physical symptoms, predominantly other respiratory symptoms related to breathlessness such as cough or wheeze, are included in 17 of the measures. The majority of the instruments (28/33) contained questions related to the functional status of the patient. Fifteen covered psychological dimensions and 11 covered social dimensions. None of the instruments included questions regarding the spiritual dimension of breathlessness. Four breathlessness-specific instruments were found to be validated for patients in a palliative care setting: the CDS, the Breathlessness Assessment Guide, the Dyspnoea Exertion Scale, and the Dyspnoea Assessment Questionnaire.^{23,40,43} However all of these were only for patients with malignant disease and have not been tested in non-malignant progressive conditions. Twenty-one of the identified measures were quick to fill in, most of them taking between 5 and 10 min. Ten measures have been published in more than five studies.

Discussion

This is the first systematic review of the measurement of the sensation of breathlessness in advanced disease (non-cancer specific). We identified 33 instruments measuring breathlessness either unidimensionally, symptom specifically or disease specifically. All measures but three met the criteria of validity, reliability, responsiveness and appropriateness. For the three measures missing psychometric data, in one it had not been tested (Breathlessness Assessment Guide)⁴⁰ and for the others the data are not available (Dyspnoea Exertion Scale, Dyspnoea Assessment Questionnaire).²³

From this review, it appears that there is no established gold standard for the assessment of the impact of breathlessness in advanced disease. However, it remains unlikely that any one instrument could be developed that would be suitable for the clinically diverse population experiencing this symptom in advanced disease. Instead, instruments must be chosen from the existing pool by reference to a series of operational criteria: the definition of breath-

lessness being used, the setting of the study, temporal factors, diagnostic group, disease staging and the sensitivity required of the instrument.

The lack of a universal definition of breathlessness, or dyspnoea, has led to different and sometimes conflicting results and conclusions.¹ Many studies, particularly those with cancer patients, do not state the definition they are using^{9,70,71}; however, a clear definition of breathlessness is necessary for both the researcher and the patient. The definition of the ATS is now widely used by many researchers. Associations between different sensations of breathlessness and specific underlying diseases have been investigated; whilst no two conditions were linked to the same group of descriptors, one group of descriptors could be associated with more than one condition.^{2,72} It has also been demonstrated that patients who deny being *short of breath* will, on direct questioning, respond positively to other descriptors.² Whichever definition is chosen for use by researchers in a particular study it needs to be comprehensible to patients yet tightly defined for accurate measurement.

Available tools

Many tools are available for the measurement of breathlessness. However, this review confirms that there is no single instrument that encompasses all the components of the sensation of breathlessness.⁷³ Different measures cover one or more dimensions or aspects of breathlessness. Scales developed for research rather than clinical measurement provide valuable information on the perception of breathlessness, its impact on day-to-day life and factors which exacerbate the symptom,³⁵ but many are not sensitive enough to detect small but significant changes that may occur in the symptom in a patient with advanced disease. In addition, a minimally clinically important difference has been described for only some of these tools and for others this information is not available. The unidimensional and most of the breathlessness-specific tools are more suitable for repeated measures than disease-specific tools as they take only a short time to complete and have been shown to be sensitive to change (see Appendix A). Disease-specific measures are useful for the characterisation of patients as they cover various aspects related to breathlessness.

The assessment tool should be chosen for the specific research question being asked. In addition, the circumstances in which measurement is made must be clearly defined: is breathlessness to be measured on exertion or at rest? How is exertion defined? Over what period of time is the measurement made? The following partially literature-derived scenarios suggest how to combine tools according to the research question: (i) in a RCT to determine the efficacy of oral morphine in relieving the sensation of breathlessness in patients dyspnoea was measured on a VAS with "no breathlessness" at 0 mm and "worst possible breathlessness" at 100 mm as anchors, and exercise tolerance was measured on the modified scale of the MRC⁷⁴; (ii) in another RCT that assessed the short-term clinical impact of ambulatory oxygen over 12 weeks in dyspnoeic COPD patients, dyspnoea was measured with a modified Borg scale pre- and post-walk and the Chronic Respiratory

Questionnaire⁷⁵; and (iii) for an ongoing epidemiological study to describe the course of breathlessness over time in COPD and cancer patients, a Modified Borg Scale is used in combination with qualitative in-depth interviews to capture both the severity of dyspnoea and the personal experience of patients.

Population and conditions

Most instruments were validated for patients with pulmonary disease, only a few were developed for patients with cancer. Despite breathlessness being a common symptom in chronic heart failure and MND, we identified only one measure for the former and two for the latter condition. Some tools are derived from instruments for patients with asthma (AQ20, QoL-RIQ),^{55,76} or are validated in a variety of pulmonary conditions (SGRQ, PFSDQ, BDI/TDI, CLD severity index)^{35,37,40,61} but there is a lack of instruments that could apply to a group of breathless patients with different conditions. This makes research into a mixed patient group challenging with regard to the choice of the measurement tool. In addition, many measures for pulmonary conditions are mainly validated in a predominantly male population (BDI/TDI, CLD severity index, CDS, CRQ, PFSDQ, SOLDQ, PFSS),^{35,37,43,50,56,61,66} which reflects the fact that COPD, in particular, affects more men than women. However, it has been shown that women perceive higher levels of breathlessness compared to men despite the same level of ventilatory impairment.^{77,78} The generalisability of these measures to a wider population could, therefore, be questioned.

Most of the existing tools were not developed in the palliative care setting and are not validated for patients with advanced disease.

Unidimensional tools

Tools such as the VAS or the Modified Borg Scale appear simple to use at first glance.³⁵ Some patients will have used VAS scales in pain management, but some still find them difficult to use and confusing. Furthermore, there is insufficient evidence to give unequivocal guidance and it has yet to be defined what a clinically meaningful change is on a VAS in breathlessness in COPD and cancer patients.⁷⁹ From the measurement of breathlessness in decompensated chronic heart failure and asthma it has been established that a 2.11 cm change for the former and a 2.2 cm change for the latter condition on a 10 cm VAS is meaningful.^{80,81} However, a consensus statement from a recent meeting of specialists researching breathlessness defined the best guess as a 10% change (1 cm) in a VAS from baseline, or a 1-point change in the BORG as a reasonable minimum for current use.⁷⁹

Breathlessness-specific tools

Breathlessness-specific tools have the advantage of being, on average, much shorter and therefore easier for patients to complete than disease-specific tools. Some only cover aspects of breathlessness (MRC Dyspnoea Scale, BDI/TDI)^{35,36}; others include symptoms related to breathlessness such as cough and wheeze, which are typical for COPD

patients but not applicable in patients suffering from other conditions. Only one instrument considers the impact of breathlessness on speech (University of Cincinnati Dyspnoea questionnaire),^{42,82} however speech, in this questionnaire, is related to physical activity and daily activities, which may not be applicable to patients in the advanced stage of their disease.

The breathlessness-specific tools for patients with cancer are all validated in a palliative care setting and in consequence do not rely so much on functional status items but on effort, discomfort, anxiety, frequency, triggers or coping strategies. Unfortunately, the instrument that covers most aspects and dimensions of breathlessness, the Breathlessness Assessment Guide,⁴⁰ has not undergone the usual psychometric testing examining validity and reliability of the tool. In addition, its focus is on assessment rather than responsiveness to treatment. Two further tools for cancer patients have not been disseminated to a wider audience as they have only been published within an MD thesis and have not been validated in a standard way.²³

Disease-specific tools

Disease-specific tools cover different aspects of the influence of breathlessness and the underlying disease on a patient's quality of life. Most disease-specific questionnaires are similar, but each focuses on subtly different dimensions or components deemed to be major concerns of patients.⁴⁶ The majority of disease-specific tools are developed for patients in COPD with the aim of showing treatment effects in pulmonary rehabilitation and bronchodilator therapy. As breathlessness reduces mobility, daily activities and self-care, these domains are included in most of the instruments validated for COPD patients. The functional domain also plays a role in the two MND instruments; however, function in this circumstance is related to much simpler tasks such as talking, eating and dressing as patients' functioning might be affected by paralysis.

Exertion and function

In earlier stages of a disease, breathlessness is experienced on exertion; later it is also experienced at rest. However, exertion needs to be clearly defined for the patient group under study, e.g. exertion could be defined as ten flights of stairs or as the movement from the bed to the chair. Those who might be breathless for small movements might also be breathless at rest. Most instruments examining functional status are not applicable for such patients as the examples used for physical functioning include "walking uphill" or "heavy shopping" or "getting dressed" rather than small movements around the bed or even "no movement at all". In general, measuring breathlessness during exercise is applicable to patients with stable COPD, but it is not useful in advanced disease or terminal care.⁴⁶

Measurement of breathlessness in advanced disease

Despite breathlessness being a frequent symptom towards the end of life, only few measures have been developed and validated for patients in this situation. There are more

breathlessness-specific than disease-specific measures for patients in palliative care. The available instruments are either developed for the use in cancer (CDS, Breathlessness Assessment Guide, Dyspnoea Exertion Scale, Dyspnoea Assessment Questionnaire)^{23,40,43} or in MND.^{54,64} Despite the fact that most tools have been developed for patients with COPD there are none that have been explicitly validated in patients in advanced disease. This might reflect the difficulty of prognosis in COPD and the fact that these patients tend not to decline as steadily as cancer patients.

With regard to the criteria important for symptom measurement in palliative care, most instruments are self-administered. However, some of them are quite lengthy and therefore difficult for very ill patients to complete.

As already noted, measures rely heavily on functional domains. No measure covers all dimensions important for symptom control; however, breathlessness cannot be regarded as an isolated symptom.¹ In COPD patients, breathlessness is often accompanied by other related respiratory symptoms, such as cough or wheeze, which are reflected in many tools developed for COPD. These symptoms might not play such an important role in patients suffering from cancer. Instead, cancer patients might experience many other symptoms. Some of the cancer-specific tools such as the LCSS and the Breathlessness Assessment Guide take account of this.

Breathlessness is closely related to anxiety. However, anxiety is only included in half of the breathlessness- and disease-specific questionnaires. Surprisingly, the impact of breathlessness on patients' social lives is covered in an even smaller number of questionnaires. However, it is known from qualitative research in breathless patients that loss of social life plays an important role for the patients.⁸³ As the experience of breathlessness also touches existential issues it is disappointing that not one of the instruments covers this dimension. Even the distress caused by breathlessness is only covered in seven instruments. Distress should be given greater consideration, especially in patients with advanced disease who are close to death.

Recent research⁸⁴ has uncovered the effect of intractable breathlessness on those caring for or living with the patient with this condition. Carer distress is one way of assessing this and is not included in any of the instruments reviewed here.

Conclusion

Although 33 tools for assessing breathlessness were identified, none were comprehensive or responsive enough to be recommended for use in isolation to measure the sensation of breathlessness, its impact on the quality of life of patients with advanced disease and their family, nor its response to treatment strategies. However, we can make the following general recommendations:

- For general clinical questions (e.g. effectiveness of medication) a VAS or the Modified Borg Scale are most useful.
- Alternatively, if the focus is more on quality of life, then a multidimensional tool (such as the CRQ for COPD patients or the LCSS) is preferable.
- Breathlessness-specific questionnaires are more likely to consider the sensation of breathlessness and the impact on function, e.g. the CDS focuses on the sensation and the distress of breathlessness.
- In research, it is sensible to combine unidimensional and QOL- or breathlessness-specific questionnaires, the latter especially if there is a wish to examine the sensation of breathlessness and its impact on function.
- In addition, it is well worth considering whether a mixed methods approach could be used e.g. a unidimensional scale and a qualitative interview for experience and contextual factors.

Further validation and comparison of the tools reviewed may provide researchers and clinicians with useful means to help the pressing need to complete research in this complex area.

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Appendix A. Supplementary Materials

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.rmed.2006.07.003](https://doi.org/10.1016/j.rmed.2006.07.003).

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