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Which measurement scales should we use to measure breathlessness in palliative care? A systematic review

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Introduction: There is no universally accepted measurement scale to assess breathlessness in adult palliative care patients. This significantly hampers clinical practice and research into effective interventions. The aim is to systematically identify and appraise breathlessness measurement scales, which are validated for use in palliative care or which show potential for use. **Methods**: We undertook systematic searches of electronic databases (Cochrane databases 2005, MEDLINE 1966–2005, OLDMEDLINE 1950–1965, EMBASE 1980–2005, PsycINFO 1872–2005, AMED 1985–2005, CINAHL 1982–2005, SIGLE 1980–2005) with follow-up searches (reference lists of included papers, hand-searches of relevant journals). The basic search strategy was 'breathlessness (etc.) AND measurement (scales, validation etc.) AND palliative care/cardiac failure/respiratory disease/neoplasm etc.', modified for each database, without language restriction. Patient-based scales with evaluations of at least two psychometric characteristics were included. Exercise-based tests were excluded. Scales were appraised with particular emphasis on construct validity and responsiveness. **Results**: We identified 29 scales: six to measure breathlessness severity, four to assess breathlessness descriptions, and 19 to measure functional impact of breathlessness. **Severity**: The Numeric Rating Scale (NRS) and modified Borg Scale have been evaluated in COPD (the NRS has also been evaluated in cancer). Both require further assessment of responsiveness and test-retest reliability over time intervals relevant to palliative care. Visual Analogue Scales have also been evaluated, but require larger sample sizes than NRS for evidence of intervention effectiveness. **Descriptions**: The Japanese Cancer Dyspnoea Scale (CDS) has been evaluated in patients with cancer, but requires further assessment of construct validity and responsiveness. **Functional impact**: The Chronic Respiratory Questionnaire dyspnoea subscale (CRQ-D) has been evaluated in chronic lung diseases and heart failure; the MND Respiratory Scale is similar. CRQ-D has face and construct validity, test-retest reliability and responsiveness, and shows promise for palliative care. **Conclusion**: The NRS, modified Borg, CRQ-D and CDS appear most suitable for use in palliative care, but further evaluation is required before adopting any scale as standard. This review has been registered with the Cochrane collaboration and will be published and updated as a Cochrane review. *Palliative Medicine* 2007; **21:** 177–191

Key words: dyspnea; evaluation studies; palliative care; psychometrics

Introduction

Breathlessness is a common and distressing symptom in advanced cancer, end stage heart failure, and chronic lung disease. Estimates of prevalence in terminally ill patients range from 29 to 74%, increasing in the last weeks of life.[1] There is no universally accepted measurement scale, and this hampers clinical practice and research to evaluate the effectiveness of interventions for breathlessness. A Cochrane review of the effectiveness of opioids for breathlessness noted the absence of a standard outcome measure and the difficulties of pooling results.[2] In the UK, the National Institute for Health and Clinical Excellence (NICE) and the National Cancer Research Institute (NCRI) have stressed the importance of defining robust outcome measures which are responsive and appropriate to individuals throughout the course of their illnesses.[3,4]

The ideal measurement scale is valid, reliable, and responsive;[5] Table 1 includes more detailed descriptions of these criteria. Recommendations for evaluating scales are described in more detail in a statement from the Scientific Advisory Committee of the Medical Outcomes Trust.[6]

Appendices are available online at: http://pmj.sagepub.com

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Table 1 Inclusion criteria

Types of participants	
Adult patients (>18 years) suffering from breathlessness, whose disease is not responsive to curative treatment	Includes patients with advanced cancer, end-stage cardiac failure or respiratory failure, progressive neuromuscular degenerative conditions, such as motor neurone disease, and end-stage renal failure
Types of scales	
Quantitative measurement of breathlessness, or impact of breathlessness on function	Scales may have been developed primarily for clinical or for research purposes. May include *subscales* of breathlessness measurement provided the paper gives psychometric data relating to that individual subscale
Patient-based measurement	Either patient- or observer-completed on the basis of patient's answers to fixed, closed questions
Psychometric evaluation	Demonstration of *at least two* criteria:
Content validity	Breadth of scope of the scale; to what extent does it appear to capture the relevant aspects of the construct of breathlessness; are there important gaps?[5]
Construct validity, including convergent validity, discriminant validity	How well scale is related to other measures of same construct; lack of correlation with dissimilar or unrelated constructs or variables[5]
Test-retest reliability	How consistent an individual's test scores are over a defined time period, assuming the severity of breathlessness remains constant[5]
Internal consistency	How closely related are different items in the scale; eg, Cronbach's alpha or Intraclass Correlation Coefficient (high Cronbach's alpha suggests item redundancy and low Cronbach's alpha suggests poor consistency of items or potentially different constructs contained within the scale)[5]
Responsiveness	Ability to detect clinically meaningful change for individuals; ability to detect change in the measured construct, measured as an effect size statistic; 'the ratio of a signal (the real change over time that has occurred) to noise (the variability in scores seen over time that is not associated with true change in status)'[6]
Factor analysis	For a scale comprising several items, a way of grouping them into factors which may tap into a particular construct; Eigenvalues can give an estimation of the extent to which particular and separate factors account for the variance in the data derived from use of the scale[5]
Criterion validity	For example, for a shortened version of a scale, concurrent validity with the longer version of the scale which has already been validated; need to ensure that sufficient data exist to support the use of the criterion measure[5]

Some reviews of instruments available for assessment of breathlessness are available.[7,8] The review by Bowling is not systematic in search or appraisal, and does not focus specifically on the potential application to palliative care settings. The systematic review by Bausewein *et al*.,[8] focuses on patients with advanced disease, but is limited to MEDLINE. We set out to systematically review the scales to measure breathlessness in order to determine which have evidence of validity, reliability and responsiveness, and which appear to be most appropriate for use in palliative care.

Methods

Methods for conducting systematic reviews of the effectiveness of *interventions* have been well described.[9,10] We applied the principles to systematically reviewing *scales* for measuring breathlessness.

Search strategy

We carried out systematic searches of the electronic databases: Cochrane databases (2005; including CENTRAL (Cochrane Central Register of Controlled Trials), CDSR (Cochrane Database of Systematic Reviews), CDMR (Cochrane Database of Methodology Reviews), CMR (Cochrane Methodology Register), DARE (Database of Abstracts of Reviews of Effectiveness), HTA (Health Technology Assessment database), NHS EED (National Health Service Economic Evaluation Database)), MEDLINE (1966–2005), OLDMEDLINE (1950–1965), EMBASE (1980–2005), PsycINFO (1872–2005), AMED (Allied and Complementary Medicine 1985–2005), CINAHL (Cumulative Index to Nursing and Allied Health Literature 1982–2005), SIGLE (System for Information on Grey Literature in Europe 1980–2005). To complement this, we also hand-searched the most commonly encountered journals (*Chest* and *Respiratory Medicine*), and reference lists of review articles.[11–16] Standard textbooks in palliative care,[17–20] symptom measurement,[7] and dyspnoea,[21] and included papers were also used to identify any relevant papers. Searches were performed on 1 August 2004 and updated on 1 September 2005.

The basic search strategy was 'breathlessness' AND 'measurement' AND 'respiratory disease/heart failure/cancer/palliative care etc.', using MeSH and keywords appropriate to each database. The search strategy for MEDLINE is available online (Appendix A), and full

strategies for the other databases are available on request. No language restriction was imposed.

We designed the search strategy to aim for high recall of potentially relevant papers, rather than high precision (ie, we aimed for sensitivity rather than specificity).

SD reviewed all titles and abstracts; AE independently assessed 10% of the titles and abstracts. We obtained potentially relevant papers for further scrutiny and decided on inclusion or exclusion on the basis of the criteria below, achieving a consensus after discussion in cases of disagreement (SD, AE and AB). We carried out follow up searches for identified instruments to check for reports of their development and other evaluation work.

Criteria for inclusion and exclusion of scales

We included patient-based scales to measure breathlessness, ie, quantitative measurements of the patient's subjective sensation of breathlessness, either for clinical or research purposes. Scales had to have evaluation of at least two of the following psychometric characteristics (see Table 1):

- content validity
- construct validity, eg, including convergent validity, discriminant validity
- test-retest reliability
- internal consistency
- responsiveness
- factor analysis
- criterion validity

Primary criteria used to evaluate scales were construct validity and responsiveness. Construct validity is defined by how well the scale is related to other measures of same construct (convergent validity), and the lack of correlation with dissimilar or unrelated constructs or variables (discriminant validity). For the purposes of this review, responsiveness is defined as the ability to detect change in the measured construct, measured as an effect size statistic: 'the ratio of a signal (the real change over time that has occurred) to noise (the variability in scores seen over time that is not associated with true change in status)',[6] although we note there are many other definitions in the literature.[22,23] Change scores alone or correlations with changes in other measures were classified as longitudinal construct validity rather than formal statistics of responsiveness.[24]

Secondary criteria included face validity, development and content validity, factor analysis, test-retest reliability, internal consistency, respondent and administrative burden (the time and effort required to complete the scale, reading level, evidence that the scale does not place undue burden on the respondent, resources needed, training issues for administration).[6]

Purely qualitative assessments were not included, although they can be important to gain a full understanding of the patient's experience of breathlessness. We excluded scales which were based only on an observer's estimation of the patient's breathlessness, since correlations are imperfect (Table 2).[25,26]

The included scales were examined to see if likely categories of types of scales were evident. The following categories did appear evident, and were agreed among the authors (SD, AE, AB) prior to data extraction: overall severity of breathlessness, descriptions of the quality of breathlessness, and functional limitations or breathlessness associated with activities of daily living. All scales were then classified into one of these categories by SD and AE during data extraction.

Data extraction

Data extraction was carried out by SD, recorded on a specifically designed proforma, and checked by AE. We extracted data concerning the study participants, the measurement scale(s) used, the process of scale

Table 2 Exclusion criteria

Types of participants	
Population not medically defined	For example, occupationally defined (studies of factory workers) or epidemiological surveys of samples of the general population
Less than 10 subjects	Since unlikely to yield robust, generalisable psychometric results
Types of scales	
General symptom screen	Without specific psychometric data relating to assessment of breathlessness component
Physiological or functional 'performance-based' measurements	Such as FEV_1/SaO_2/6 minute walk etc. (since not measurements of *breathlessness* as such; may be limited by other constraints, eg, fatigue, limb weakness or neurological deficit)
Incorporated into exercise tests	Measurements of breathlessness associated with exercise, such as measurements during treadmill tests (since unlikely to be applicable to palliative care population; may be limited by other constraints, eg, fatigue, limb weakness or neurological deficit; review focuses on subjective perceptions of breathlessness not functional measures)
Evaluation	
Qualitative outcomes	Such as quotations from interviews with patients; not included other than in the context of scale development or acceptability

development and psychometric evaluations, as listed above (see inclusion criteria, Table 1).

Results

The initial search of electronic databases gave 15 671 titles (MEDLINE 5662, EMBASE 4261, CINAHL 2256, PsycINFO 1139 and AMED 680, CENTRAL 1654, SIGLE 19). Some 13 512 references were imported into EndNote (discarding duplicates) (see Appendix B, available online). Of the 1391 titles and abstracts assessed by both SD and AE, the percentage concordance was 97.6%, and the kappa coefficient was 0.65 (indicating good agreement between reviewers).

Principal findings

In this systematic review, we have identified 29 partially validated scales to make quantitative measurements of the subjective sensation of breathlessness:

a) Six scales to measure the overall severity of breathlessness;
b) Four scales to describe the quality of breathlessness;
c) 19 scales to measure the functional impairment caused by breathlessness associated with activities of daily living.

A further 19 scales were considered but excluded from the review, for example because they were insufficiently specific to breathlessness measurement (and did not contain a relevant subscale) or because there was insufficient published psychometric evaluation.

Scales with evidence of validity, reliability and acceptability in palliative care

Descriptions of each scale are shown in Table 3, and the available validity, reliability and acceptability data are summarised in Tables 4–7. None of the identified scales have been fully assessed in palliative care. However, we judged the potential suitability for use in palliative care practice and research based on good data within these broad aspects, and comprehensiveness across them, as follows.

Scales to measure the severity of breathlessness

Summaries of the available evaluation data are shown in Table 4, with additional detail available online in Appendix C (breathlessness 'right now', over the previous week or over the previous four weeks). The Numeric Rating Scale (NRS) or modified Borg Scale appear most promising one-dimensional scales, but need further evaluation of responsiveness; test-retest reliability is variable for the modified Borg Scale.

The NRS or modified Borg scale are similar one-dimensional measurements of severity. The modified Borg Scale has theoretical advantages over the NRS: it was conceived as a ratio scale, in which a rating of '4' signifies breathlessness twice as severe as '2', and '8' twice as severe as '4', and so on. The verbal descriptors of the modified Borg Scale allow for some comparison between individuals; an individual who rates their breathlessness as 'very severe' is likely to be describing a more extreme sensation than an individual who rates their breathlessness as 'slight'. In a study of mechanically-ventilated patients, the NRS was more popular than the modified Borg Scale;[27] an assessment in a palliative care setting would be helpful. The NRS may be better suited to being read aloud to patients who are unable to complete a written questionnaire, for example because of cognitive impairment, fatigue, visual impairment, or, indeed, severe acute breathlessness.

The exact phrasing of the question is important, since it has an effect on psychometric properties. For instance, Wilcock *et al*. demonstrated that asking about 'worst breathlessness over the past 24 hours' (from 'not breathless at all' to 'breathlessness as bad as you can imagine') was associated with lower standard deviation of the difference between two tests, 1–8 days apart, when compared with questions about breathlessness 'right now', 'average breathlessness over the past 24 hours' and 'bother over the past 24 hours'.[28] Therefore, smaller sample sizes would be needed to detect a change in breathlessness of 25%, for 'worst breathlessness over the past 24 hours' compared with the other items. Corresponding sample sizes needed when using the Visual Analogue Scales (VAS) were consistently higher than when using the NRS.[28]

When using the NRS as a screening tool for breathlessness interfering with daily activities, Tanaka *et al*. recommend using 0/1 out of 10 as the threshold for further evaluation. This has a sensitivity of 98%,[53] and a specificity of 54%.[53]

Scales to describe the quality of breathlessness

A summary of validity and reliability data is shown in Table 5 (additional detail is available online in Appendix D). The Japanese Cancer Dyspnoea Scale (CDS) appears promising,[29] with evidence of construct validity and test-retest reliability. However, there is no evidence of responsiveness, and it requires evaluation in its English language version.[29] The minimal clinically important difference in scores is not defined,[29] although a score of 8 out of 48 is reported to correspond to significant breathlessness.[53] The Dyspnea Descriptor Questionnaires

Table 3 Descriptions of scales to measure breathlessness

Scales to measure the overall severity of breathlessness		
VAS	Visual Analogue Scales[50] (horizontal HVAS or vertical VVAS)	Straight lines, usually 100 mm long, labelled with verbal anchors at each end; Aitken recommends transforming scores to achieve a normal distribution before using parametric methods[51]
NRS	Numeric Rating Scale[52] or Dyspnoea Numeric Scale[53]	Usually 0–10; labelled with verbal anchors (eg, 'nothing at all' to 'maximal')
mBorg	Modified Borg Scale[54,56]	Original Borg Scale 0–20, to rate perceived exertion; modified to 6–20;[56] subsequent modifications 0–10. Conceived as a ratio scale (8 signifies twice as much breathlessness as 4, and so on). Verbal anchors throughout the range, so scores can be compared between individuals (ranging from 'very, very light' to 'maximal')
Global SOB	Global Shortness of Breath question[58]	'How much shortness of breath have you had during the past 4 weeks?' from 1 (none) to 6 (very severe)
Faces	Faces Scale[27]	Series of six pictures of faces with expressions from 'happy' to 'distressed'; the patient selects the face which best represents the degree of breathlessness at the time. Scores range from 0 ('least dyspnoea') to 5 ('worst possible dyspnoea')
Descriptions of breathlessness		
CDS	Cancer Dyspnoea Scale[29]	Twelve-item questionnaire to assess 'breathing difficulty in past few days'. Rating of sense of effort (five items), sense of anxiety (four items), sense of discomfort (three items). Evaluated in Japanese, not in English
DDQ (heart failure)	Dyspnea Descriptor Questionnaire (heart failure)[31]	Thirteen-item questionnaire, based on Simon *et al.* descriptors,[58] eg, 'It took a lot of effort to breathe', 'I felt out of breath'
DDQ (COPD)	Dyspnea Descriptor Questionnaire (COPD)[30]	Sixteen item questionnaire (reduced to seven items); based on Simon *et al.* descriptors,[58] eg, 'I felt that I was suffocating', 'my breathing required work'
DAQ	Dyspnoea Assessment Questionnaire[59]	Forty-three descriptors of breathlessness sensations in 16 groups; patient ticks all that apply; various scoring methods
Scales to measure the functional impact or limitations associated with breathlessness		
ALSFRS-R	Amyotrophic Lateral Sclerosis Functional Rating Scale – revised (Respiratory subscale)[60]	Three items relating to dyspnoea, orthopnoea, respiratory insufficiency (including use of assisted ventilation). Each graded on a scale from 0 to 4 with verbal descriptors
ATS-DLD-78	American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale[61]	Five questions (yes/no) to grade breathlessness on exertion, eg, when walking; very similar to MRC/WHO scales
BCSS	Breathlessness, Cough and Sputum Scale (breathlessness subscale)[62]	'How much difficulty did you have breathing today?', rated from 0 ('none') to 4 ('severe: almost constant, present even when resting'); to be completed at end of each day
CHQ-D	Chronic Heart Failure Questionnaire – dyspnea subscale[63]	Patient chooses the five most important activities which have made them short of breath in the previous two weeks; 26 listed activities as prompts; each activity rated 1 (extremely short of breath) to 7 (not at all short of breath)
CLASP	Cardiovascular Limitations and Symptoms Profile[44]	Six item subscale concerning breathlessness in previous two weeks. Includes frequency, difficulty lying flat, and impact of shortness of breath
CLD	Chronic Lung Disease Severity Index[64]	Two item subscale. Frequency of breathlessness in previous three months (1 never to 4 all of the time); activity which typically provokes breathlessness (eg, vigorous activity, or light activity)
CRQ-D; CRQ-SAI-D	Chronic Respiratory (Disease) Questionnaire – dyspnea subscale,[32] (CRQ interviewer-administered; CRQ-SAI self-administered)	Patient chooses the five most important activities which have made them short of breath in the previous two weeks; 25 listed activities as prompts; each activity rated 1 (extremely short of breath) to 7 (not at all short of breath)
CRQ-SAS-D; CRQ-IAS-D	CRQ Standardised dyspnea questions;[65] (CRQ-SAS self-administered; CRQ-IAS interviewer-administered)	As for CRQ-D, but five standardised activities are used (includes emotion, basic care needs, walking, chores, social activities)
EORTC-QLQ; LC13 breathlessness subscale	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Lung Cancer supplement (breathlessness subscale)[66]	Three items (yes/no) regarding breathlessness at rest, walking, and climbing stairs

Table 3 (*Continued*)

LCADL	London Chest Activity of Daily Living Scale[45]	Breathlessness during the previous few days, while doing 15 activities (self care, domestic, physical, leisure domains), graded 0–5; extent to which breathlessness affects normal activities of daily living (a lot, a little, not at all)
MDRS-D	Motor Neurone Disease Dyspnoea Rating Scale – dyspnoea subscale[33]	Patient chooses five activities which have made them short of breath in the previous two weeks; 13 listed activities as prompts; each activity rated 0 (not at all short of breath) to 4 (extremely short of breath)
MRC	Medical Research Council Dyspnoea Scale[67]	Grade 1 (not troubled with breathlessness, except on strenuous exertion) to 5 (too breathless to leave home, or breathless after undressing). Various modifications since original development[68–71]
OCD	Oxygen cost diagram[72]	Vertical line 100 mm long, marked with activities in proportion to their oxygen cost. Patient indicates the point at which their breathlessness prevents them from doing further activity
PFSDQ-M	Pulmonary Functional Status and Dyspnea Questionnaire-modified version[73]	General dyspnea survey: five items, including rating of severity of breathlessness 'most days in the past year', 'today', 'with most day-to-day activities'; dyspnea with 10 activities including self care, walking and climbing stairs
Rand	Rand Instrument: shortness of breath battery from the Medical History Questionnaire[74]	Includes five items to rate breathlessness on exertion (similar to MRC/WHO/ATS), two items about orthopnoea, two items about 'enlarged heart or heart failure'
$SGRQ_{activity}$	St George's Respiratory Questionnaire (activity subscale)[42]	Sixteen items (of 76 for entire questionnaire); true/false questions regarding breathlessness with listed activities
SS (SOBS)	Symptom Scale (Shortness of Breath Subscale)[75]	Frequency, severity, ease with which symptoms occur, and interference graded 1–6; treatment of breathlessness graded 1–4
UCDQ	University of Cincinnati Dyspnea Questionnaire[49]	Thirty item questionnaire, listing physical and speech activities, graded from 1 (not at all short of breath) to 5 (always short of breath or cannot do) or 9 (not interested)
UCSD SOBQ	University of California San Diego Shortness of Breath Questionnaire (new version)[43]	Twenty-four item questionnaire, listing 21 activities; breathlessness doing each activity in previous week rated from 0 (not at all breathless) to 5 (maximally or unable to do because of breathlessness); three items concerning limitations imposed by breathlessness or fear of it

Table 4 Scales to measure the overall severity of breathlessness ('right now', over the previous week or over the previous four weeks): summary

Scale	Patient groups	Context	Face validity	Content validity	Factor analysis	Construct validity	Discriminant validity	Test-retest	Internal consistency	Responsiveness	Acceptability	Time to complete
HVAS	Asthma, COPD; ventilated	ED, OP, PR, CCU/ITU	●	–	N/A	●	variable	●	N/A	–	(●)	●
VVAS	Acute asthma, COPD; ventilated	ED/IP; OP, CCU/ITU	●	–	N/A	●	●	●	N/A	–	(●)	●
NRS	Cancer; COPD	OP; home	●	–	N/A	●	●	●	N/A	–	●	●
Modified Borg	COPD; RLD; asthma	OP	●	–	N/A	●	●	? variable	N/A	–	●	●
Global SOB	COPD	OP/RCT	●	–	N/A	(●)	–	–	N/A	●	–	–
Faces scale	Ventilated	CCU/ITU	?	–	N/A	(●)	–	●	N/A	–	(●)	–

●, Evaluation work; (●), limited evaluation work;?, may be suitable; CCU, coronary care unit; COPD, chronic obstructive pulmonary disease; ED, emergency department; ITU, intensive therapy unit; N/A, not applicable; OP, out-patient; RLD, restrictive lung disease.

Table 5 Scales to describe the quality of breathlessness: summary

Scale	Patient groups	Context	Face validity	Content validity	Factor analysis	Construct validity	Discriminant validity	Test-retest	Internal consistency	Responsiveness	Acceptability	Time to complete
CDS	Cancer	OP, IP	●	●	●	●	–	●	●	–	●	●
DDQ 1	HF	ED	●	●	●	–	–	●	●	–	–	–
DDQ 2	COPD	ED	●	●	●	–	–	●	●	–	(●)	–
DAQ	Cancer	Hospice	●	●	–	(●)	–	–	–	–	●	–

●, Evaluation work; (●), limited evaluation work; –, no data available; COPD, chronic obstructive pulmonary disease; ED, emergency department; HF, heart failure; IP, in-patient; OP, out-patient.

Table 6 Domains addressed by scales and subscales to measure functional limitations due to breathlessness

Scale (see text for full scale title)	At rest	Mobility/ walking/ stairs	Dressing/ undressing; showering/ bathing/hygiene	Positional lying flat/ bending	Housework/ shopping	Eating	Leisure/ sport/ social	Speech	Emotional, eg, angry upset	Sex	Interference with life	Patient selects activity	Frequency of breathlessness
ALSFRS-R	●	●	'Eating, bathing, dressing'	●	–	–	–	–	–	–	–	–	–
ATS-DLD-78, Fletcher, MRC, WHO	–	●	●	–	–	–	–	–	–	–	–	–	–
Rand instrument	–	●	●	●	–	–	–	–	–	–	–	–	–
BCSS	●	–	●	–	'Light activity'	–	–	–	–	–	–	–	–
CLASP breathlessness	–	–	–	●	–	–	–	–	–	–	●	–	●
CLD	●	●	–	–	–	–	–	–	–	–	–	–	●
CRQ-D, CHQ-D	–	●	●	●	●	●	●	●	●	–	–	●	–
CRQ-SAS,-IAS	–	●	'Basic needs'	–	●	–	●	–	●	–	–	–	–
EORTC; QLQ-LC13	●	●	–	–	–	–	–	–	–	–	–	–	–
LCADL	–	●	●	●	●	–	●	●	–	–	●	–	–
MDRS	–	●	●	●	●	●	●	●	●	–	–	●	–
OCD	–	●	–	–	–	–	–	–	–	–	–	–	–
PFSDQ-M	–	●	●	–	●	–	–	–	–	–	●	–	●
SGRQ activity	●	●	●	–	●	–	●	–	–	–	–	–	–
SOBS	–	●	–	–	–	–	–	–	–	–	–	–	●
UCDQ	–	●	●	–	●	●	●	●	–	–	–	–	●
UCSD; SOBQ	●	●	●	●	●	●	–	–	–	●	–	–	–

●, At least one item in subscale relates to listed domain; NB for CRQ-D and MDRS, only the five most important activities are chosen.

Table 7 Scales to measure the functional limitations and impact of breathlessness: summary

Scale	Patient groups	Context	Face validity	Content validity	Factor analysis	Construct validity	Discriminant validity	Test-retest	Internal consistency	Responsiveness	Acceptability	Time to complete
ALSFRS-R	MND	Trial	? (MND)	–	●	●	–	–	●	–	–	–
ATS-DLD subscale	COPD, asthma	OP	X	–	–	●	–	●	●	–	●	●
Modified MRC	COPD, ILD, asthma, other	OP	X	–	–	●	●	–	–	–	●	●
Modified MRC	COPD	OP	X	–	–	●	–	●	–	–	●	●
Rand	H failure, resp disease	OP	X	–	–	●	–	?	–	●	?	●
BCSS subscale	COPD	RCT	X	–	–	●	●	●	N/A	●	●	–
CLASP	IHD	OP	?	? unpublished	–	(●)	–	?	–	–	●	●
CLD	Chronic lung disease	OP	X	●	●	●	–	–	●	–	?	–
CRQ-D	COPD, ILD, CF, AAT, MND	OP, IP, RCT, PR	●	●	For whole CRQ	●	●	●	●	●	●	?
CHQ-D	H failure	RCT, OP	●	●	For whole CHQ	●	●	●	●	●	●	?
MDRS	MND	OP	●	●	●	●	–	–	●	–	●	●
EORTC; QLQ-LC13	Lung cancer	RCT	X	–	–	(●)	(●)	●	●	–	?	–
LCADL	COPD	OP, home	●	●	–	●	●	●	●	–	–	–
OCD	Resp disease, COPD, H failure	OP	X	–	N/A	●	–	?	N/A	X	?	●
PFSDQ	COPD	PR	?	●	–	●	●	–	●	–	?	?
PFSDQ-M	COPD	PR	?	●	●	●	?	●	●	-	●	●
$SGRQ_{activity}$	COPD, asthma, Br'ectasis	OP, PR	?	●	–	●	●	●	●	●	●	●
SOBS	IHD/treadmill	OP	?	–	–	(●)	–	–	●	–	–	–
UCDQ	Asthma, sarcoid, COPD, fibrosis	OP, laboratory	●	●	●	●	–	●	●	–	●	●
UCSD SOBQ, (initial and new versions)	COPD, asthma, CF, Lung tplt	PR, OP, PR trial	●	●	–	●	–	●	●	?, (small effect size)	●	●, for initial version

●, Evaluation data available; (●), limited evaluation work; ?, evaluation data available, may be satisfactory; –, evaluation data unavailable; AAT, $Alpha_1$-antitrypsin deficiency; Br'ectasis, bronchiectasis; CF, cystic fibrosis; COPD, chronic obstructive pulmonary disease; H failure, heart failure; IHD, ischaemic heart disease; ILD, interstitial lung disease; IP, in-patient; Lab, exercise laboratory; Lung tplt, lung transplant; N/A, not applicable; OP, out-patient; PR, pulmonary rehabilitation programme; RCT, randomised controlled trial; Resp., responsiveness; X, evaluation data available but unsatisfactory.

(DDQ) developed for COPD,[30] and heart failure,[31] may be useful to assess the quality of breathlessness, but may not be suitable to assess the effects of interventions for breathlessness, and have no evidence of construct validation or responsiveness. They need evaluation in a palliative care context.

Scales to measure functional impairment caused by breathlessness

We identified 19 scales to measure the functional impact or limitations due to breathlessness. Table 6 shows which functional domains are assessed by each scale, and Table 7 summarises the available validity and reliability data, with additional detail online in Appendix E. Some scales allow the patient to select the most important functional areas or activities (eg, the dyspnoea subscales of the Chronic Respiratory Questionnaire (CRQ-D),[32] and the Motor Neurone Disease Dyspnoea Rating Scale (MDRS-D)[33]).

The CRQ-D appears to be a useful, patient-centred instrument, which has evidence of validity, reliability and responsiveness.[32] It has been validated in a variety of settings.[34–39] The minimal clinically important difference in scores for a group of patients is reported as 0.5 on each seven-point Likert scale.[40] One of the main potential problems with its use in a clinical setting is the time it takes to complete: 15 or 25 minutes for the entire questionnaire (it is unclear how long it takes to complete the dyspnoea subscale).[32] It seems most appropriate for patients who are not acutely short of breath. It may be possible to reduce the number of items on the dyspnoea subscale:[41] validity and reliability were maintained with fewer items in each subscale. The MDRS-D is, in effect, an adaptation of the CRQ; it is modified for patients with limb weakness which limits activities.[33] It has not been evaluated to the same extent as the CRQ-D itself, but shows promise for palliative care.

An advantage (particularly in palliative care) is the patient-centred nature of these scales; the CRQ-D and MDRS-D ask the patients themselves to select the five most important activities for them. Using this sort of scale in the clinical context could serve a useful role in defining patient-centred goals for improvement in breathlessness.

The St George's Respiratory Questionnaire activity subscale ($SGRQ_{activity}$)[42] and the University of California San Diego Shortness of Breath Questionnaire (UCSD SOBQ, new version)[43] have evidence of validity, reliability and responsiveness, and may be suitable for ambulatory patients. The Cardiovascular Limitations and Symptoms Profile (CLASP)[44] breathlessness subscale, London Chest Activities of Daily Living (LCADL),[45,46] Pulmonary Functional Status Dyspnea Questionnaire modified version (PFSDQ-M),[47,48] and University of Cincinnati Dyspnea Questionnaire (UCDQ),[49] have some evidence of validity and reliability, but responsiveness has not been reported.

Discussion

Breathlessness is a multifaceted construct, and there is no gold standard or criterion measure. The choice of the most appropriate measurement scale depends on the purpose for which it is intended, and the available resources. Most of the scales included in this systematic review have been evaluated in chronic respiratory disease, yet breathlessness is also common in advanced cancer and heart failure. None of the identified scales has been fully validated in a palliative care setting, but several scales appear to show promise for use in this context.

Strengths and weaknesses

We have conducted a thorough search of the available literature concerning validity and reliability of breathlessness measurement scales. The area is not well indexed, and it may be possible to further refine the search strategies to improve efficiency of future systematic reviews.

Although we performed follow up searches for each included scale, we did not contact authors to check for other evaluation work.

The lack of consistency in the reporting of scale development, particularly responsiveness, which has numerous definitions (25 different definitions in one review[23]) hampers review and interpretation of scales in this field, as in others.

Implications for further research and clinical practice

With so many existing scales, it seems sensible to spend time validating them rather than developing new scales. If possible, such evaluation work could be incorporated into other studies.

Scales should be evaluated as recommended by the Scientific Advisory Committee of the Medical Outcomes Trust.[6] Evidence of face and construct validity, test-retest reliability and responsiveness are particularly important for evaluative scales. It would be useful to compare recommended scales directly, for instance, the NRS and modified Borg Scale, in a palliative care setting. Subscales may not have identical psychometric properties when used in isolation from the rest of the scale (for instance CRQ-D or $SGRQ_{activity}$[5]), so these require full evaluation if intended for separate use. However, there are potential

advantages to using the scales in their original format, if the other domains addressed by the scale are also relevant (eg, the CRQ also assesses fatigue, emotion and mastery).[32] The CDS should be evaluated in its English language version.[29]

Conclusion: scales which are most suitable for palliative care

Selecting the most appropriate scale to measure breathlessness depends on the context and purpose. The NRS or modified Borg Scale seem most suitable to measure the overall severity of breathlessness, CDS to assess the quality of breathlessness, and CRQ-D to measure the functional impairment caused by breathlessness. All require further evaluation in a palliative care setting before being adopted as standard.

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This review has been registered with the collaboration and will be published and updated as a Cochrane review.

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