Identification and assessment of breathlessness in clinical practice: a systematic review and narrative synthesis.

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ABSTRACT

Context

Breathlessness is common in chronic conditions but often goes unidentified by clinicians. It is important to understand how identification and assessment of breathlessness occurs across healthcare settings, to promote routine outcome assessment and access to treatment

Objective

To summarise how breathlessness is identified and assessed in adults with chronic conditions across different healthcare settings.

Methods

This is a systematic review and descriptive narrative synthesis (PROSPERO registration: CRD42018089782). Searches were conducted on Medline, PsycINFO, Cochrane Library, Embase and CINAHL (2000-2018) and reference lists. Screening was conducted by two independent reviewers, with access to a third, against inclusion criteria. Data were extracted using a bespoke proforma.

Results

Ninety-seven studies were included; conducted in primary care (n=9), secondary care (n=53) and specialist palliative care (n=35). Twenty-five measures of identification and 41 measures of assessment of breathlessness were used. Primary and secondary care used a range of measures to assess breathlessness severity, cause, and impact for people with chronic obstructive pulmonary disease (COPD). Specialist palliative care used measures assessing broader symptom severity and function with less focus on overall quality of life (QoL). Few studies were identified from primary care.

Conclusion

Various measures were identified, reflective of the setting's purpose. However, this highlights missed opportunities for breathlessness management across settings; primary care is particularly well-placed to diagnose and support breathlessness. The COPD approach (where symptoms and QoL are part of disease management) could apply to other conditions. Better documentation of holistic patient-reported measures may drive service improvement in specialist palliative care.

249/250 words

Key words: dyspnea, breathlessness, chronic breathlessness syndrome, identification, assessment, patient reported outcome measures

INTRODUCTION

Breathlessness is defined by the American Thoracic Society as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (1).

Breathlessness is common in the general population (2) and in people with cardiorespiratory conditions and cancer;(3, 4) relevant in all healthcare settings. Breathlessness has a widespread impact on the patient and their family.(5-7) It is associated with poor quality of life,(8) poor survival(9) and increased emergency care and hospital admissions(10-12) with increased hospital length of stay and in-hospital adverse events.(13, 14) Recognition that breathlessness may be persistent and disabling despite optimal treatment of the causative medical condition, has led to recent naming and defining of chronic breathlessness syndrome.(15)

Evidence-based interventions and clinical frameworks to aid assessment of breathlessness (16) and assessment and management of chronic breathlessness are available.(17) Access to, and use of, these may improve patient and family experience, support clinicians to be more effective, and lessen pressure on the health system and resources. The identification and assessment of breathlessness in all clinical settings is therefore important, but not conducted systematically in clinical practice (18) and tends not to be reported by patients routinely.(19) As patients usually appear comfortable at rest, practitioners may not identify this symptom (20) without specific enquiry.(21) Therefore, breathlessness is all too often ‘invisible’,(19, 21) and unmanaged in clinical practice in spite of its negative impact.

A number of tools or tests can be used in clinical practice to identify the presence or measure breathlessness severity and the impact on the individual’s physical and mental quality of life or functional status, as well as the cause of the breathlessness (22-24). However, little is known about how these are used in clinical practice across healthcare settings and how they vary according to the main purpose of care; 1) primary care for initial presentation, referral and ongoing management of disease and symptom management of chronic breathlessness; 2) secondary care for diagnosis and ongoing management of disease and symptom management of chronic breathlessness; and 3) palliative care for symptom management of chronic breathlessness, maintenance of function and support for other symptoms or concerns in advanced disease.

Routine outcome measurement of problems like breathlessness can help to drive service improvement.(25) Clinical audits and research can help to demonstrate service effectiveness or identify areas for improvement. As management of long-term conditions is an increasing necessity across nations, outcome measurement can help provide evidence to clinical commissioners of the need for resources.(25)

We therefore reviewed the published literature presenting data on the identification and assessment of breathlessness in clinical practice, across health care settings.

METHODS

This systematic literature review and descriptive narrative synthesis was reported in accordance with Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines (26). The protocol is registered on PROSPERO (CRD42018089782).

Information Sources and Search Strategy

A search strategy was formulated using MeSH headings and keywords in relation to breathlessness and patient reported outcomes (Supplementary File 1). A sensitive (retrieving higher results), rather than specific (more precise, less results) approach was taken, to retrieve as many results as possible.

Five databases, MEDLINE(Ovid), PsycINFO (Ovid), Cochrane Library, Embase (Ovid) and CINAHL (EBSCO), were searched between 2000 and 19 February 2018 and reference lists of relevant articles hand searched. A date filter of 2000 was set to ensure results were relevant to current clinical practice.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were established to identify the range of measures used to identify and assess breathlessness across healthcare settings, as reflected by primary research studies conducted in routine clinical practice (Table 1).

Study Selection

Titles and abstracts were reviewed against the inclusion criteria by two independent researchers (HE, UN) with recourse to JC and MJ in the case of disagreement. Where decisions could not be made from the titles and abstracts, full texts were retrieved, and the same process followed. Full texts were then sourced and reviewed by the same two independent reviewers, with arbitration to JC and MJ if disagreement occurred. Independent second reviewing included 10% of title/abstract and full texts with high levels of agreement.

As effectiveness outcomes of studies were not being considered, no formal quality assessment was conducted. However, it was noted whether or not any measures found had been psychometrically validated.

Data Extraction

Data were extracted using a piloted form to collect: author, title, year, setting, geographic location, study design, sample size, age, health conditions, and measures of identifying and assessing breathlessness. Many studies did not report population age range, but only the mean and standard deviation which were all >18 years. We have therefore made an assumption that the population was adult. Individual study outcomes were not collected, as this did not address our research question. The first 10% of data extraction (consecutive papers) were checked for accuracy and consistency by UN. There were no disagreements and so no further double data extraction was conducted.

Study Settings

Included studies were grouped by health care setting, reflective of their purpose:

i) Primary care; this included general practice and long-term care facilities assuming most received their medical care from community services. This setting is commonly associated with initial presentation, referral, and ongoing care.

ii) Secondary care; this included all studies set in hospital-based services, whether secondary or tertiary care, such as outpatients, inpatients, emergency departments and rehabilitation services. This is associated with diagnosis and ongoing management.

iii) Specialist palliative care (SPC); this included specialist palliative care services whether provided in community, hospital, or hospice settings. Commonly associated with symptom management, maintenance of function and holistic support in advanced disease.

Categorisation of Measures Identifying and Assessing Breathlessness

Measures were categorised and described as those able to identify: the presence or absence of breathlessness; those that assessed the symptom severity; those that assessed the impact of the symptom; and tests to help assess the underlying cause of the symptom. Some were able to both identify presence/absence and measure aspects of the symptom. For example, the Visual Analogue Scale tests both presence/absence and the amount of breathlessness, and the modified Medical Research Council [mMRC] scale could identify presence/absence and gave a measure of the impact on physical exertion. Where a measure/test could be counted in more than one category, they were counted in both.

Description was used to present the included studies and narrative synthesis was used to analyse the findings. Included studies were grouped by study setting, noting the primary diagnosis of study participants. Measures of identification and assessment of breathlessness were grouped by their purpose (symptom severity, impact of symptom, cause of symptom) and by study setting. It was not possible to distinguish between measures identifying breathlessness and chronic breathlessness specifically. Therefore, throughout the manuscript, we refer to breathlessness. However, in circumstances where breathlessness is *likely* to be chronic, for example in COPD pulmonary rehabilitation or palliative care, where treatment of underlying cause is likely to have been optimised, we infer chronic breathlessness as appropriate.

RESULTS

Included Studies

The search strategy returned 19,062 articles. Three additional articles were identified through reference searching (n=19,065). Duplicates (n=6,561) were removed and two independent authors (HE and UN) screened the remaining 12,504 articles by title and abstract, of which 12,356 were excluded. Following full text review and discussion, 97 articles were included (See Figure 1 for PRISMA flowchart and Appendix C for reference list of included studies).

General Characteristics of Studies

Studies were conducted from 2000 – 2018, the numbers per year increasing with time. Studies were conducted in North America (n=49 [50.5%]); Europe (n=38 [39.2%]; 15 from the UK [15.5%]), Asia (n = 9 [9.3%]) and one from Australia [1%]. All studies were observational and included case note assessment/chart reviews/medical records review (n=36 [37%]), retrospective cohort/studies (n=30 [31%]), longitudinal/prospective cohort studies (n=11 [11.3%]), audits/clinical audits (n=6 [6.2%]), evaluations/service evaluations (n=5 [5.2%]), cross-sectional studies (n=3 [3.1%]), database review (n=3 [3.1%]), descriptive analysis (n=2 [2.1%]) and case-series study (n=1 [1%]) (Supplementary File 2). Studies varied widely in their sample size, ranging from seven to 67,362 participants.

Health Care Setting

Most studies reporting approaches to the identification and assessment of breathlessness were in the secondary care (n=53 [54.6%]) setting, followed by SPC (n=35 [36.1%]). Very few studies were in the primary care setting (n=9 [9.3%]) [Figure 2].

Primary Health Conditions

Most included studies reported the identification and assessment in the context of a diagnosis of COPD (Chronic obstructive pulmonary disease; n=31 [32%]) or cancer (n=30 [31%]). Of the others, the most common were studies reporting a range of primary medical conditions (n = 17 [17.5%]), interstitial lung diseases (n = 7 [7.2%]) or heart failure (n = 4 [4.1%]).

Measures of Identification of Presence or Absence of Breathlessness

Of the 97 studies, 93 (95.9%) reported at least one breathlessness measure or other method of enquiry of identifying breathlessness in clinical use. There were 25 distinct measures of identifying breathlessness reported by included studies (Appendix B). The top three most frequently used measures were the MRC or mMRC (Medical Research Council

Dyspnoea Scale, or modified version) [used in 27 studies (27.8%)], ESAS (Edmonton Symptom Assessment Scale, or variant) [n=22 (22.7%)], and BORG (or variant) [n=13 (13.4%)]. Only two measures were used across all three health care settings; CAT (COPD Assessment Test) [primary care n=2 (2.1%), secondary care n=4 (4.1%), SPC n=1 (1%)], and where breathlessness was identified but the method was not described [primary care n=1 (1%), secondary care n=7 (7.2%), SPC n=3 (3.1%)].

In addition, some studies only used clinician assessment (history/examination/observation) (n=9; 9.3%), patient volunteered symptom (n=4; 4.1%) or where breathlessness was identified but the method was not described (n=11; 11.3%).

Measures of Assessment of Breathlessness (symptom severity, impact of symptom, cause of symptom)

Of the 97 studies, 85 (87.6%) reported at least one measure of assessing breathlessness (symptom severity, impact, or cause). There were 41 distinct measures in clinical use across settings (Appendix B). The most common measures reported overall were LFM (Lung Function Measurements) [used in 41 studies (42.3%)], MRC [n=27 (27.8%)] and ESAS [n=22 (22.7%)]. Only two measures were used across all health care settings; LFM [primary care n=8 (8.2%), secondary care n=30 (30.9%), SPC n=3 (3.1%)] and CAT [primary care n=2 (2.1%), secondary care n=4 (4.1%), SPC n=1 (1%)].

Measures of the symptom severity were most common (studies n=70; 72.2%); followed by measures of the impact of breathlessness such as quality of life, patient concerns or functional status (n=55; 56.7%); and lastly, measures of the underlying cause/diagnosis of breathlessness (n=47; 48.5%). A summary of symptom severity, impact, and cause measures of assessment by health care settings can be found in Table 2 (see Appendices A and B for detailed lists).

Validation of Measures

Of the measures used for both identification and assessment of breathlessness, the majority were validated tools (n=26), some were adaptations or simplified versions of scales, and many were medical tests (n=13).

DISCUSSION

Most published literature since 2000 regarding the identification and measurement of breathlessness in clinical practice is from the secondary care and palliative care setting. Fewer than one in ten studies were from primary care. Nearly all studies used some form of identification of presence or absence of the symptom. However, the pattern of symptom severity assessment, impact of symptom and diagnostic tests varied by clinical setting, in part reflecting the setting's purpose. Thus, primary care and secondary care studies reported a pattern consistent with diagnosis, disease management/monitoring and ongoing patient care, and in palliative care, of improving quality of life through symptom management in those with diagnosed advanced diseases of many aetiologies and multiple symptoms.

Measures by setting

Primary Care

The few papers in primary care might be explained by its sheer range of clinical concerns, however, given the prevalence of breathlessness this still raises the question of a gap in clinical practice. One to two percent of primary care consultations are reported as due to breathlessness, but is likely to be an underestimate.(27-29) Around one in ten of the general population have limiting breathlessness experienced for at least three months over the past six months.(2) In people commonly attending primary care, breathlessness prevalence is much higher: about a third of older adults (30) and most with advanced chronic conditions (e.g. COPD).(4) Primary care is an excellent setting to identify, assess, manage the disease and the symptom of chronic breathlessness (30) given that most chronic condition management takes place here (31) if primary care is well developed.

The Quality and Outcomes Framework in UK primary care includes payments if a target proportion of people with COPD and mMRC ≥3 are offered pulmonary rehabilitation.(32) In this context, breathlessness is likely to be chronic, given the assumption that optimisation of COPD treatment will occur prior to or alongside pulmonary rehabilitation. However, patients with breathlessness due to other causes, e.g. heart failure, are not included in this process, and other breathlessness interventions are not mandated for those with COPD. Our included primary care studies were in the context of COPD, raising a concern that many with breathlessness due to other causes are potentially unknown, unassessed, and unmanaged. If breathlessness is not systematically sought and assessed in primary care, then manageable suffering may go unnoticed. A recent British Lung Foundation general public online survey, “The Breath Test”, showed that a third of 365,043 respondents who were worried about their breathing (MRC grade 3 to 5) had not sought medical advice, and of those that had, 58% had not found the advice helpful.(33)

Suboptimal identification and management of breathlessness in primary care has consequences for the wider health system, especially for urgent care. Around a third of patients conveyed by ambulance to the emergency department are discharged home without hospital admission.(12) A recent systematic review found that breathlessness was the symptom general practitioners found the most difficult to address and were reluctant to prescribe opioids for severe COPD related chronic breathlessness despite its potential benefit, preferring to admit patients to hospital.(34)

Improved community-based care, including crisis plans (35) and self-management skills (36, 37), may prevent at least some urgent hospital attendance.

Secondary Care

Secondary care had the most included studies with symptom severity, impact, and cause of breathlessness measured. This is expected given that medical conditions causing breathlessness managed in this setting are common. A number of studies in this setting were from pulmonary rehabilitation services where walk tests, BORG and MRC scales (38-41), found in our included studies, are part of standard patient monitoring.(42, 43)

The pattern of measurements is consistent with the investigative, diagnostic and disease management/monitoring purpose in this setting. Most studies were in respiratory conditions such as COPD, with a few in cancer. However, breathlessness is common in other conditions such as heart disease, which has a similar clinical disease severity classification (New York Heart Association Class).(44) However, only eight studies within this setting included patient groups other than respiratory or cancer, which may indicate that breathlessness is less likely to be addressed as a clinical target in other conditions.

The importance of patient-reported outcome measures (PROMS) is increasingly recognised in oncology practice with recent work showing better patient survival when PROMS are embedded in routine practice and used in patient-clinician decision making.(45)

In general, high breathlessness NRS scores predict hospital admission from the emergency department (10-12), longer length of hospital stay, in-hospital adverse events (13, 14), and can be measured routinely.(14) However, in secondary care, other than with pulmonary rehabilitation, whilst there is evidence that breathlessness is identified and measured in COPD to inform classification of disease severity, treatment choice and to monitor response to treatment, there does not appear to be a specific clinical concern in the symptom as a *therapeutic target,* i.e. for chronic breathlessness. A recent cohort study of optimally treatment people with COPD estimated that just over half had chronic breathlessness syndrome with little evidence that this was being addressed.(46) This is despite the availability of evidence-based treatments or full recognition of its widespread impacts.

The revised Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria requires symptoms (MRC), broader impact (CAT) and exacerbations to be assessed along with spirometry, to classify stage of disease, guide COPD management and monitor progress (47). This approach could be used in other conditions.

Specialist Palliative Care

The high number of studies found in the palliative care setting reporting measures of breathlessness identification and assessment is expected in the context of a population with advanced illness receiving disease management and support with a focus on prevention, relief of suffering, and enhancement of quality of life through symptom control.(48) Unsurprisingly, diagnostic and pathophysiological tests were rarely reported although optimisation of disease treatment, and diagnosis of new conditions remain important in palliative care. However, the clinical focus of chronic breathlessness syndrome in this setting is highly likely, given that optimal treatment is usually optimised prior to a referral to palliative care.

Holistic clinical assessment is a core competency of the palliative care clinical practice curriculum (48) and forms the content of first palliative care consultations. However, implementation of standardised documentation of such assessment has been slow. Notable exceptions, such as the Palliative Care Outcome Collaborative (PCOC) in Australia, are seen. Most Australian palliative care services contribute core outcome sets for national benchmarking, using the feedback as a stimulus for service improvement, showing year on year improvement in patient report outcomes.(25) Recent initiatives, such as the Outcome

Assessment and Complexity Collaborative (OACC) – a suite of outcome measures used within palliative care to measure and improve care for patients, families and caregivers (49), derived from the PCOC, are beginning to be implemented in areas of the UK and elsewhere.

A number of breathlessness measurement approaches were identified often as part of broader symptom – such as the ESAS (50-71) - or more recently as part of holistic assessments of patient concerns - such as the Patient Outcome Scale Symptom Module (POSs) (72), indicating that holistic measures may be growing.(49) Nearly half of the studies had a broad measure of performance/functional status (Appendix B). Although in the context of overall symptom assessments, breathlessness-specific quality of life impacts would not be expected, patient-reported holistic concerns were few.

Effective implementation of routine outcome measurement would be helpful to drive service improvement and provide evidence of clinically effective services for commissioners.

STRENGTHS AND LIMITATIONS

Breathlessness identification and assessment in the included studies from around the world was within the context of routine clinical practice rather than selected trial populations to provide generalisable findings. The literature was broad with robust methods to minimise selection bias. Inclusion of studies where breathlessness was measured both as a primary outcome and also as part of a full symptom assessment enabled patterns of assessment across a range of settings to be seen.

The major limitation with regard to answering our question is the use of published literature only. If health services have implemented routine identification and assessment but have not published findings, then this knowledge is unrepresented. Some healthcare settings have a stronger culture of publication than others e.g. secondary more than primary care and therefore good practice in primary care have been missed. Secondly, included papers were limited to English, and finally, most studies were either retrospective or used routine medical records with recording inaccuracies common with such designs.

Implications for clinical practice and research

In all healthcare settings, measurement of breathlessness is important because it is common, associated with poor clinical outcomes, and there are interventions which benefit patients (73). There are clinically feasible tools available to identify and assess the wider impact of breathlessness (14) both at initial assessment, and on follow-up to assess effectiveness of interventions. The importance of breathlessness as an indicator of disease severity – as for COPD – along with a focus on breathlessness as an ongoing therapeutic target, could be incorporated in the management of other chronic conditions. Routine documented serial measurement of holistic patient concerns is important, including in services where holistic assessment is a core component of care. Systematic documentation allows benchmarking of services, illustrates service effectiveness, drives service improvement, informs service funding, and provides representative data to address clinically relevant research questions. Routine assessment of breathlessness is also required to identify chronic breathlessness syndrome, which may not be volunteered by the patient themselves.

Prospective research is needed to determine tailored-to-setting core outcome measurement sets, how best to implement core clinical outcome measures routinely in all healthcare settings, and how to use them to drive improvements in care. Use of routinely collected clinical data provides a rich source to interrogate to identify current practice gaps e.g. an analysis of England's primary care Clinical Practice Research Database showed that lung cancer, rather than COPD, drove access to palliative care services for people with respiratory conditions highlighting an inequity in care.(74) Further trials could test if breathlessness identification and management in primary care - and first responder - based interventions will reduce inappropriate emergency hospital care. A better understanding of patient and clinician experience of identification and assessment of breathlessness particularly in the primary care setting, where it sits as one problem among many, would help inform future work.

CONCLUSIONS

Patterns of acute and chronic breathlessness identification and assessment vary across healthcare settings in routine clinical practice. Mostly, the patterns reflect the purpose of the health services involved but highlight missed opportunities. Firstly, primary care is well placed to seek and diagnose causes of breathlessness at an early stage and initiate and support ongoing symptom management. Secondly, routine use of simple breathlessness severity scores should be embedded into all clinical practice to identify patients in need of evidence-based interventions. Thirdly, patient-reported measures should be used serially in all settings to monitor management and ensure that breathlessness remains a visible therapeutic target rather than a signpost to diagnosis and prognosis only.

AUTHOR CONTRIBUTIONS

HE was responsible for the design of the study, collection, and analysis of the data, and drafting and revision of the manuscript. MJ and JC supervised the project and contributed to study design, analysis and re-drafting of the paper. UN acted as second reviewer, screening records, and extracting data along with revisions to the manuscript. All authors approved the final draft.

DISCLOSURE/CONFLICTS OF INTEREST

The authors have nothing to disclose.

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APPENDIX A - DIFFERENT TYPES OF BREATHLESSNESS ASSESSMENT MEASURES

Symptom severity measures of breathlessness: Tools n=17, Studies n=70	**Measures of the impact of breathlessness (on wider factors): Tools n=20, Studies n=55**	**Measures of the cause/diagnosis of breathlessness: Tools n=12, Studies n=47**
BDI/TDI	*BDI/TDI*	Bronchoscopy
BORG Scales	*BORG Scales*	CTS
Categorical scale (0 = none, 1 = mild, 2 = moderate, 3 = severe)	BPQ	Doppler echocardiography (2D)
ESAS Scales	CAT (COPD)	ECG (Electrocardiogram)
McCorkle Symptom Distress Scale	CCQ (COPD)	Echocardiogram
MDASI	*MDASI*	High sensitive C-reactive protein
NRS	CRQ (Chronic Respiratory Diseases)	Imaging (CT, MRI, Chest X-Ray, HRCT)
Patient Outcome Scale Symptom Module	Functional Capacity Scale	LFM
Quantitative Scale	KPS Scales	VATS
Respiratory symptom scales (adapted from MRC and RSQ)	*NYHA*	*NYHA*
Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))	LINQ	*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))*
MRC Scales	*MRC Scales*	Waveform capnography (ETCO2)
SAS	Palliative Care Assessment Tool	
Unknown - dyspnea assessed	Palliative Prognostic Score	
UCSD	*UCSD*	
VAS	Palliative Performance Scale	
Rotterdam symptom checklist	*Rotterdam symptom checklist*	
	SGRQ (Respiratory Diseases)	
	STAS (Schedule for Team Assessment)	
	Walk tests	

BDI/TDI: Baseline and Transition Dyspnea Index; Borg Scales (Borg, MBS, Borg RPE); BPQ: Breathing Problems Questionnaire; CAT: COPD Assessment Test; CTS: Canadian Thoracic Screening Questionnaire; CCQ: Clinical COPD Questionnaire; CRQ: Chronic Respiratory Disease Questionnaire; ESAS: Edmonton Symptom Assessment Scale (ESAS; Modified ESAS); KPS: Karnofsky Performance Status (Karnofsky Performance Status; Australian modified Karnofsky Performance Status); LINQ: Lung Information Needs Questionnaire; LFM: Lung Function Measurements; MDASI: MD Anderson Symptom Inventory; MRC: Medical Research Council Dyspnea Scale (MRC, mMRC, emRC); NRS: Numerical Rating Scale; NYHA: New York Heart Association Functional Classification; SAS: Symptom Assessment Scale; SGRQ: St. George's Respiratory Questionnaire; STAS: Schedule for Team Assessment); UCSD: University of California San Diego Shortness of Breath Questionnaire; VATS: Video Assisted Thoracic Surgery; VAS: Visual Analogue Scale; Walk tests (ESWT; ISWT, 6MWD, 6MWT, Shuttle/Treadmill Walk Test).
Italics are used if measures are found in more than one category.

APPENDIX B – DIFFERENT TYPES OF BREATHLESSNESS IDENTIFICATION AND ASSESSMENT MEASURES ACROSS HEALTH CARE SETTINGS

Symptom severity measures of breathlessness: Tools n=17, Studies n=70	**Primary care**	**Secondary Care**	**SPC**	**Total**
Medical Research Council Dyspnoea Scales[*1]*	6	21		n=27
Edmonton Symptom Assessment Scales*[2]		4	18	n=22
BORG[*3]*		13		n=13
Visual Analogue Scale*		1	3	n=4
*University of California San Diego Shortness of Breath Questionnaire**		3		n=3
McCorkle Symptom Distress Scale*			2	n=2
Symptom Assessment Scale*			2	n=2
*Baseline and Transition Dyspnoea Index**		1		n=1
Categorical scale (0 = none, 1 = mild, 2 = moderate, 3 = severe)*			1	n=1
*MD Anderson Symptom Inventory**		1		n=1
Numerical Rating Scale*		1		n=1
Patient Outcome Scale Symptom Module*			1	n=1
Quantitative Scale		1		n=1
Respiratory symptom scales (adapted from the MRC Respiratory Symptoms Questionnaire and Dyspnoea Scale*			1	n=1
*Rotterdam symptom checklist**			1	n=1
Unknown - dyspnea assessed		1		n=1
*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))**		1		n=1
Total number of measures used	*n=6*	*n=48*	*n=29*	*n=83*
Total number of distinct measures	*n=1*	*n=11*	*n=8*	*n=20*
Total number of studies using measures of severity of breathlessness	***n=6***	***n=38***	***n=26***	*n=70*
Number of studies as a proportion of total (97) studies	*6.2%*	*39.2%*	*26.8%*	
Measures of the impact of breathlessness (on wider factors): Tools n=20, Studies n=55	**Primary care**	**Secondary Care**	**SPC**	
Medical Research Council Dyspnoea Scales[*1]*	6	21		n=27
Walk tests[4]		19		n=19
BORG[*3]*		13		n=13
COPD Assessment Test*	2	4	1	n=7
St. Georges Respiratory Questionnaire*		7		n=7
KPS Scales[5]			6	n=6
Palliative Performance Scale			4	n=4

*University of California San Diego Shortness of Breath Questionnaire**		3		n=3
Chronic Respiratory Diseases Questionnaire		2		n=2
New York Heart Association Functional Classification		2		n=2
Palliative Prognostic Score			2	n=2
Schedule for Team Assessment			2	n=2
*Baseline and Transition Dyspnoea Index**		1		n=1
Breathing Problems Questionnaire		1		n=1
Clinical COPD Questionnaire*	1			n=1
Functional Capacity Scale			1	n=1
Lung Information Needs Questionnaire	1			n=1
*MD Anderson Symptom Inventory**		1		n=1
Palliative Care Assessment Tool*			1	n=1
*Rotterdam symptom checklist**			1	n=1
Total number of measures used	*n=10*	*n=74*	*n=18*	*n=102*
Total number of distinct measures	*n=4*	*n=11*	*n=8*	*n=23*
Total number of studies using impact measures of breathlessness	***n=6***	***n=33***	***n=16***	*n=55*
Number of studies as a proportion of total (97) studies	*6.2%*	*34.0%*	*16.5%*	
Measures of the cause/diagnosis of breathlessness: Tools n=12, Studies n=47	**Primary Care**	**Secondary Care**	**SPC**	
Lung Function Measurements[6]	8	30	3	n=41
Imaging (CT, MRI, Chest X-Ray, HRCT)		5		n=5
New York Heart Association Functional Classification		2		n=2
Bronchoscopy		1		n=1
Canadian Thoracic Society Screening Questions*	1			n=1
Doppler echocardiography (2D)		1		n=1
ECG (Electrocardiogram)		1		n=1
Echocardiogram		1		n=1
High sensitive C-reactive protein		1		n=1
*Van Den Bongard's Score (none (0), slight (1), severe (2) and high-grade stenosis with cyanosis or stridor (3))**		1		n=1
Video Assisted Thoracic Surgery		1		n=1
Waveform capnography (ETCO2)		1		n=1
Total number of measures used	*n=9*	*n=45*	*n=3*	*n=57*
Total number of distinct measures	*n=2*	*n=11*	*n=1*	*n=14*
Total number of studies using cause/diagnosis measures of breathlessness	***n=8***	***n=36***	***n=3***	*n=47*
Number of studies as a proportion of total (97) studies	*8.2%*	*37.1%*	*3.1%*	

[1] Includes MRC, mMRC (modified mRC) and eMRC (extended MRC).

[2] Includes ESAS and Modified ESAS.
[3] Includes BORG, Modified BORG and BORG RPE (Rate of Perceived Exertion).
[4] Includes 6MWD (6 minute walk distance), 6MWT (6 minute walk test), ESWT (Endurance Shuttle Walk Test), ISWT (Incremental Shuttle Walk Test), Shuttle Walk Test and Treadmill Walk Test.
[5] Includes KPS and AKPS.
[6] Includes FEV1, FEV% pred, FEV1%, FEV1% pred, FVC, FVC%, FVC% pred, FEV/FVC, FEV1/FVC, FEV1/FVC%, FEV1/VC, FEV1/VC%, VC, VC% pred, TLC, TLC%, TLC% pred, TLCO, TLCO% pred, DLCO, DLCO%, DLCO% pred, DLCO/VA%, KCO% pred, RV, RV% pred, RV/TLC, RV/TLC%, RV/TLC% pred, FRC% pred, IC% pred, IC/TLC%, PaO2, PaCO2, pH, PEFR, SaO2, SO2, SpO2, MIP, MEP, MVV% pred.
* Measures used for both identification and assessment
Italics are used if measures are found in more than one category.

APPENDIX C – REFERENCE LIST OF INCLUDED STUDIES

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Table 1: Inclusion and Exclusion Criteria

Inclusion
• All observational quantitative and qualitative study designs (that use routinely collected data within the context of routine clinical practice [primary, secondary, emergency], for example service evaluations, clinical audits, chart reviews, or similar) • Primary research • Any health setting (e.g. primary care, secondary care, community care). • Studies published since 2000 • Adults (18+) with breathlessness (studies including adults and children were included if the adult population data can be adequately extracted) • Adults with breathlessness due to any chronic illness or disease (apart from those listed in the exclusion criteria; studies that have any of these excluded conditions along with any 'chronic illness or disease' only included if the 'chronic illness or disease' data can be adequately extracted)
Exclusion
• Case histories, commentaries, opinion pieces, conferences presentations, and other grey literature • Systematic reviews • Experimental studies (Randomised Controlled Trials (RCT), quasi-experimental) for example, interventions of breathlessness assessments/measures or of breathlessness treatments were excluded • Anything not applied in routine clinical practice • Studies including children and/or animals • Studies not in the English Language. • Healthy adults with induced-breathlessness (e.g. recreational exercise, sports, exercise laboratory) • Adults with asthma (specific pathophysiology, treatment pathways and its own literature), hyperventilation syndrome (not due to chronic pathology), obesity (not necessarily considered as disease), sleep apnoea or other sleep related disorders (usually consequence of disease rather than a disease itself) which may present with breathlessness • Adults with breathlessness as a side effect or adverse reaction to a drug or medication, or as a result of a medical procedure • Unexplained breathlessness

Table 2: Different Types of Breathlessness Identification and Assessment across Health Care Settings Summary

Number of studies	**Primary care N = 9**	**Secondary care N = 53**	**SPC N = 35**	**Total N = 97 (100%)**
Identification	**N (%)**	**N (%)**	**N (%)**	**N = 93**
Studies using measure to identify presence/absence of breathlessness	9 (100)	51 (96.2)	33 (94.3)	93 (95.9)
Assessment of symptom severity				**N=70**
Studies using measures of breathlessness symptom	6 (66.7)	38 (71.7)	26 (74.3)	70 (72.2)
Assessment of Impact of symptom				**N=55**
Studies using impact measures of breathlessness	6 (66.7)	33 (62.3)	16 (45.7)	55 (56.7)
Measures of the cause/diagnosis of breathlessness				**N=47**
Studies using cause/diagnosis measures of breathlessness	8 (88.9)	36 (68)	3 (8.6)	47 (48.5)

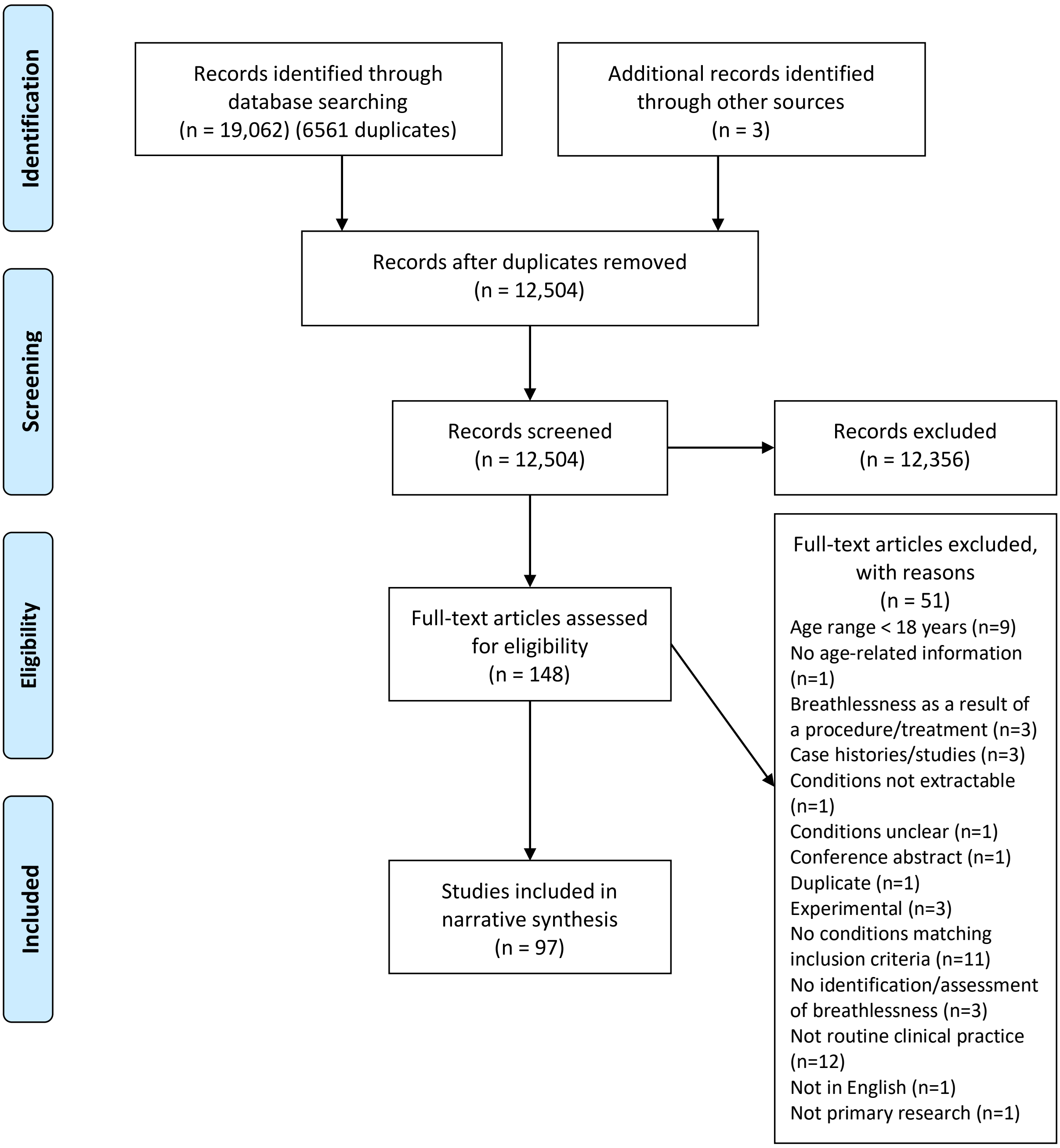

Figure 1: PRISMA Flowchart

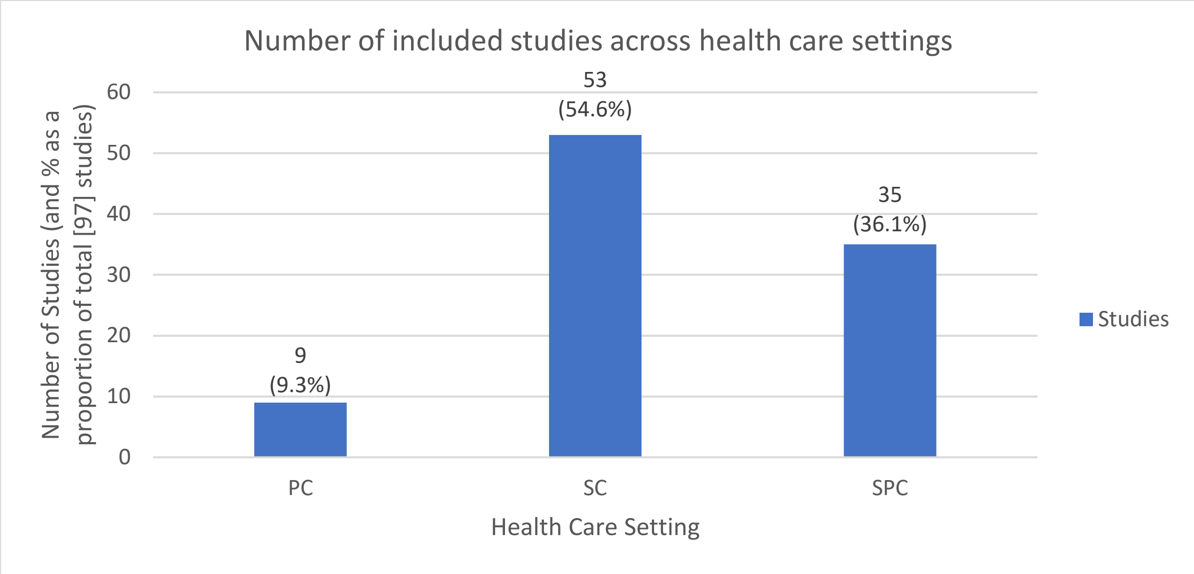

Figure 2: Number of studies by health care setting
PC – Primary care
SC - Secondary Care
SPC – Specialist palliative care