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Does the Sensation of Breathlessness Change Over Time in People with Chronic Obstructive Pulmonary Disease? A Systematic Review

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ABSTRACT

The aim of this systematic review was to identify and appraise studies which tracked changes in the sensation of breathlessness, as described in terms of intensity, unpleasantness, its effect on impairment levels or quality of life, over two or more years in people with COPD. Four major databases were searched. Twelve studies were included for full analysis. These studies were a mix of observational and experimental in their design, and were found to have high methodological quality. Subjects in the studies were, overall, severely impaired at the start of the two year period, according to level of airflow restriction. Impairment levels did not change dramatically over the two year period (mean decrease of 2%). Thirteen outcome measures were identified within the studies. Modest improvements over the two year period were noted using tools which measure breathlessness intensity and self-reported impairment levels when forms of management were implemented. No clear conclusions could be drawn about changes in quality of life over two years for people with COPD. No studies have reported changes in the quality of the sensation of breathlessness over a minimum two-year period. There is a distinct lack of longitudinal studies tracking changes in the qualitative sensations of breathlessness.

INTRODUCTION

The last two decades have seen a new wave of research into the sensation of breathlessness. What was previously thought of as a generic sensation commonly experienced by people with respiratory, cardiac, and neuromuscular conditions is now accepted to be as complex and multidimensional as pain. Breathlessness is commonly experienced by people with chronic obstructive pulmonary disease (COPD), and longitudinal studies into the disease frequently use a variety of verified measurement tools to track changes in the intensity or severity of subjects' breathlessness, their degree of airflow obstruction, and their exercise capacity.[1-3] Yet it is only relatively recently that the research and clinical fields have begun to see the benefits of exploring not only the intensity, but also the *quality* of the sensation of breathlessness.

Contemporary neural imaging studies confirm that different neuronal pathways are responsible for the processing of affective (unpleasantness) and sensory (intensity) domains of dyspnoea, and consequently, future studies exploring dyspnoea have been encouraged to use separate visual analogue scales for both unpleasantness and intensity of dyspnoea.[4-7] The McGill Pain Questionnaire requires people to select words from a number of domains in order to describe the qualitative sensations of their pain experience. In a similar way, researchers working in the area of breathlessness / dyspnoea have considered the language that people use to describe this sensation as a means of identifying and exploring the qualitative affective domain rather than

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simply the intensity of breathlessness. The language used by people to describe the sensation of breathlessness has been shown to reflect underlying pathobiological mechanisms causing the sensation.[8] People with COPD can be distinguished from people without the disease through a unique gathering of words and phrases describing the sensation.[9] This evidence would suggest that there is a place for tools which also measure the quality of the sensation, and these tools could then be used longitudinally to track changes in the sensation over a period of time.

Breathlessness is the most common symptom of COPD. In general, epidemiological studies investigating morbidity/mortality for COPD consider changes over three to five years and give priority to physiological outcomes such as pulmonary function parameters and body mass index as predictors for life expectancy. While epidemiological studies of people with COPD commonly report either the presence or intensity of this symptom, it is unclear to what extent the qualitative domain has been explored and whether changes in this symptom are evident within shorter timeframes. A systematic search of the literature was undertaken to identify studies which reported longitudinal changes in the sensation of breathlessness for people with chronic obstructive pulmonary disease (COPD). The aim was to identify which assessment tools have been used to monitor the sensation of breathlessness (intensity, unpleasantness, or impact upon daily life), and whether the sensation of breathlessness changed over two years in people with COPD.

Using the PICO framework, a specific question was formulated for the systematic search. The population (P) of interest was people with COPD. The aim was to assess changes in the sensation of breathlessness over time with natural progression of the disease. The effect of interventions (I) for COPD management was not a specific focus of the review. Studies which included trials of medication or intervention such as pulmonary rehabilitation were included, as these forms of treatment could be considered "usual care" for people with COPD. However, studies in which the sole intervention was surgical (such as lung volume reduction or lung transplant surgery) were excluded, as these interventions were likely to alter the normal course of the disease and subsequent changes in breathlessness. No comparison (C) group was sought. The outcome measures (O) from which data was extracted were tools which reported intensity, quality or daily impact of breathlessness. These had to be measured on at least two occasions, two years apart from each other.

METHODOLOGY

Two basic groups of search terms were employed in the search. The first group concerned the identifying feature of the target population; a diagnosis of COPD. The second group of terms aimed to identify study designs which were likely to report data over the course of at least two years on a variety of respiratory related outcomes including the sensation of breathlessness. In order to ascertain as broad a scope of each term as possible, the MeSH database was accessed and used through PubMed, and Boolean commands were included where possible. A final list of the terms selected for searching is shown in Table 1.

TABLE 1: Search terms for systematic review of the literature

Group 1 (COPD)	Group 2 (change over time)
• Chronic Obstructive Airway* Disease • Chronic Obstructive Lung Disease • Chronic Obstructive Pulmonary Disease • COAD • COPD • Chronic Airflow Obstruction* • Obstructive Lung Disease* "OR" in between each term	• Longitudinal Stud* • Longitudinal Survey* • Follow-Up Stud* • Follow Up Stud* • Follow-Up Survey* • Follow Up Survey* • Followup Stud* • Followup Survey* • Prospective Stud* • Cohort Stud* • Concurrent Stud* • RCT • Intervention Stud* "OR" in between each term

Four major databases were searched. These four were selected as they were of relevance to the topic and were deemed to be large enough to encompass the majority of literature on the topic. The search yielded 4183 abstracts.

In each database, citations were retained if the title clearly met the following three criteria (criteria 1):

1. Indicated that the study included subjects with COPD

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2. Studies reported on change in respiratory impairment, with a follow-up period of 2 years or more.
3. Title did not contain enough information to discern whether or not points 1 and 2 were present.

Four hundred and fifty seven (457) abstracts for citations which met the initial three criteria were retrieved (if possible), and a second set of criteria (criteria 2) was then applied. Studies which did not meet more than one of the criteria were excluded on the basis of the first criterion point they did not meet. Citations were retained if:

1. Studies included subjects with a diagnosis of COPD at the initial collection of data, as defined by a forced expiratory volume in one second less than 70% of predicted value (FEV_1% predicted <70) [61 citations excluded]
2. Studies contained data collected at least 2 years apart [21 citations excluded]
3. Studies included primary outcome measures of quality (descriptions, words, unpleasantness rating), intensity (eg. VAS, Borg) and/ or respiratory related impairments (perceived respiratory related impairment (eg. Medical Research Council dyspnoea scale) or respiratory related quality of life (eg. St George Respiratory Questionnaire) [130 citations excluded]
4. Title/abstract of the article did not contain enough information to discern whether or not points 1, 2 and 3 were present

Two hundred and forty four (244) full text versions of each citation meeting the second inclusion criteria were retrieved and a third and final set of criteria were applied (criteria 3):

1. Studies included subjects with a diagnosis of COPD at the initial collection of data (clinically verified: mean FEV_1% predicted <70) [36 citations excluded]
2. Studies reported changes over a period of 2 or more years [59 citations excluded]
3. Studies included primary outcome measures of quality (descriptions, words), intensity (eg. Visual analogue scales, Borg's rate of perceived exertion scale), respiratory related impairments (eg. Medical Research Council scale for breathlessness), and/or quality of life (eg. St George Respiratory Questionnaire) [64 citations excluded]
4. Any interventional methods used within studies were non-surgical in nature (ie. exclude lung volume reduction/ transplant surgery etc) [21citations excluded]
5. Studies contain primary data on the sensation of breathlessness (quality or intensity) (ie. no narrative reviews) [49 citations excluded]

Table 2: Results of the systematic search.

Database	Limits	Number of articles	Retained (criteria 1)	Retained (criteria 2)	Retained (criteria 3)
PubMed	Language (English)	3351	337	180	13
CINAHL	Nil	455	56	29	1
Academic Search Elite	Nil	123	17	8	1
Scopus	Language (English); Type (Articles and Reviews)	254	47	27	0

RESULTS

From the 4183 abstracts initially obtained from the systematic search of the four databases, 12 articles were included for full analysis after removal of duplicates between databases. All studies were published between 1995 and 2007. While the search strategy included studies which reported longitudinal data for two or more years, for consistency of analysis and reporting data between studies, only data for a two year period were extracted regardless of whether studies collected data over a longer time period. Five of the studies were observational, while the remaining 7 studies were interventional. The Lewis Olds Williams (LOW) critical appraisal tool was used to appraise the interventional studies for potential methodological bias. [10] Each item in the LOW tool has three possible answers: "Yes", "No" and "Can't Tell", with the first response designating a score of 1, and the latter two a score of 0. The Critical Appraisal Skills Programme 2004 (CASP) instrument for cohort studies was used to assess the observational studies for methodological bias. This instrument consists of 12 questions, with ten of these allowing a "Yes", "No" or "Can't tell" response.

Appraisal of the 12 articles revealed that results from the studies appeared believable with the majority of studies have few issues with potential bias (average score 7/9). Table 3 presents the results of the critical appraisal of each study according to the specific scoring criteria.

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TABLE 3: Critical appraisal of studies

Study Type													
Interventional studies									Observational studies				
LOW critical appraisal point	van Schayck et al 1995 [11]	Guell et al 2000 [12]	Spencer et al 2001 [13]	Clini et al 2002 [14]	Ries et al 2003 [1]	Cote and Celli 2005 [15]	Naunheim et al 2006 [16]	Modified checklist: The Critical Appraisal Skills Programme 2004 (CASP)	Miravitlles et al 2004 [17]	Hesselink et al 2006 [18]	Mahler et al 1995 [19]	Cote, Dordelly and Celli 2007 [20]	Oga et al 2007 [21]
Focused issue	√	√	√	√	√	√	√	**Focused issue**	√	√	√	√	√
Acceptable recruitment	X	√	√	√	√	√	√	**Appropriate method**	√	√	√	√	√
Sufficient number	?	√	?	√	?	?	?	**Acceptable recruitment**	√	√	√	√	√
Control group	√	√	√	√	√	√	X	**Exposure accurately measured**	√	√	√	√	√
Subjects managed acceptably	√	√	?	√	√	X	√	**Outcome accurately measured**	√	√	√	√	√
Unbiased outcome measures	√	√	√	√	√	?	√	**Confounded factors accounted for**	√	√	?	√	√
Confounding factors accounted for	√	√	√	√	√	√	X	**Adequate follow up of subjects**	√	√	√	√	√
Effect size calculated	√	√	√	√	√	√	√	**Precise results**	√	√	?	?	?
Acceptable results	√	√	√	√	√	√	√	**Acceptable results**	√	√	√	√	√
								Applicable to general population	√	√	?	√	√
KEY: LOW= Lewis Olds Williams; √= Yes; X= No; ?= Can't tell								**Results fit with other evidence**	√	√	√	√	√

TABLE 4: Interventional methods used in the studies

Study	Interventional method							
	Nil	*Surgery (eg. lung volume reduction)*	*Non-invasive positive pressure ventilation*	*Pulmonary rehabilitation*	*Long term oxygen therapy*	*Drug*	*Placebo*	*Other*
van Schayck et al 1995						■		
Mahler et al 1995	■							
Guell et al 2000	■			■				
Spencer et al 2001						■	■	
Clini et al 2002			■		■			
Ries et al 2003								■
Miravitlles et al 2004	■							
Cote and Celli 2005	■							
Hesselink et al 2006	■							
Naunheim et al 2006		■						■
Cote, Dordelly and Celli 2007	■							
Oga et al 2007	■							

The interventional methods used within the studies are reported in Table 4. Whilst the methods of intervention may have an impact on the results obtained through the various outcome measures, many of the treatments used within the studies are currently considered "usual care" for COPD, and subjects involved in the observational studies may have been under similar management. The decision to exclude studies in which surgery was the form of intervention was decided on as the impact of surgery on outcome measures is frequently dramatic and not representative of the normal progression of COPD. In the study by Naunheim et al (2006), surgical intervention was trialled against a more "usual" form of management. Only the data of the latter group was extracted and analysed.[16]

Subjects

The Global Initiative for Chronic Lung Disease (GOLD) stages classification of COPD is as follows: [22]

All have a forced expiratory volume in one second$_1$ to forced vital capacity ratio (FEV/FVC) < 0.70, plus

- Stage 1 (Mild): $FEV_1 \geq 80\%$ predicted
- Stage 2 (Moderate): $50\% \leq FEV_1 < 80\%$ predicted
- Stage 3 (Severe): $30\% \leq FEV_1 < 50\%$ predicted
- Stage 4 (Very Severe): $FEV_1 < 30\%$ predicted or $FEV_1 < 50\%$ predicted plus chronic respiratory failure

Table 5 presents the mean baseline FEV_1% predicted for the 12 studies within the review, the subsequent classification of subjects according to the GOLD criteria, and the changes in airways obstruction reported over each 2 year period. Two studies did not report airways obstruction as a percentage of the predicted value, but rather as a volume (litres).[1,20] Taking average values for FEV_1% predicted, this places the majority of subjects within the 12 studies in the "severe" category at commencement of the 2 year time frame.

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TABLE 5: Classification of subjects within studies according to the GOLD classification

Study	Baseline FEV_1% predicted (unless otherwise indicated)	Mean change in FEV_1 over 2 years
van Schayck et al 1995	70 ± 16 (**moderate**)	1.46L decrease
Mahler et al 1995	1.28 ± 0.59 litres	0.07L increase
Guell et al 2000	31 ± 12 (PR group) (**severe**) 39 ± 14 (nil intervention group) (**severe**)	1% increase (PR group) 2.5% decrease (nil intervention group)
Spencer et al 2001	50 ± 15 (moderate)	Not reported
Clini et al 2002	28 ± 11 (NPPV group) (**very severe**) 31 ± 11 (LTOT group) (**severe**)	0.5% increase (NPPV) 0.2% decrease (LTOT)
Ries et al 2003	1.07 ± 0.43 litres (PR maintenance) 1.14 ± 0.42 litres (control)	0.06L decrease (PR maintenance) 0.07L decrease (control)
Miravitlles et al 2004	33 ± 8 (**severe**)	"no significant difference"
Cote and Celli 2005	33 ± 9 (Pulmonary Rehab group) (**severe**) 30 ± 9 (no intervention group) (**very severe**)	0.02L decrease (PR group) 0.16L decrease (no intervention group)
Hesselink et al 2006	61 ± 16 (**moderate**)	3.17% decrease
Cote, Dordelly and Celli 2007	40 ± 15 (exaerbators) (**severe**) 49 ± 16 (non-exacerbators) (**severe**)	6.6% decrease (exacerbators) 3.6% decrease (non-exacerbators)
Naunheim et al 2006	27 ± 7 (**very severe**)	Not reported
Oga et al 2007	46 ± 1.3 (**severe**)	1.8% decrease

KEY: NPPV= non-invasive positive pressure ventilation; LTOT= long term oxygen therapy; PR= pulmonary rehabilitation

Changes in Impairment

Across all of the studies within the review, changes in FEV_1% predicted or an equivalent marker were minor (a mean 2% decrease over two years). The majority of studies, including interventional studies, reported minor deteriorations in airway obstruction over a two year period, as measured by FEV_1 in litres or FEV_1% predicted. However, these changes were often very small, and not statistically significant. As a result of this analysis, the results have been reported across all studies rather than separately for intervention and observational studies. The most dramatic change observed was that of the group people prone to multiple repeated infections or exacerbations of their lung disease ("exacerbators") within the 2007 study by Cote and colleagues, presenting a 7% decrease in the predicted value (FEV_1% predicted) over a two year period.[20]

Outcome Measures Used to Monitor Changes in the Sensation of Dyspnoea

Thirteen different measures were used by the 12 studies to assess and monitor changes in the sensation of breathlessness or related-impairments. Several studies used multiple tools, resulting in a total of 25 outcome measures for subjects across the studies. Table 6 gives a brief description of each of the tools used to assess changes (improvement or deterioration) in breathlessness over a two year period. Table 7 presents the measures used within each study and the changes observed over the two year period.

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TABLE 6: Description of tools used to measure breathlessness

Domain of measurement	Tool	Description
Perceived intensity of breathlessness	Borg Perceived Rate of Exertion scale	A 0 to 10 scale with some numbers accompanied by descriptions of perceived rate of exertion. A *higher* score indicates a worse perception of rate of exertion.
	Visual Analogue Scale (VAS)	10cm line, only markers being 0 (no problems) and 10 (worst). Number of cm from zero marked as score. A *higher* score indicates a worse degree of dyspnoea.
	University of California, San Diego Shortness of Breath Questionnaire (UCSD SOBQ)	24 activities listed. Rate each from 0 (not breathless at all) to 5 (maximally breathless). Overall score of between 0 and 120 produced. A *higher* score indicates a worse degree of dyspnoea.
Perceived severity of breathlessness	Baseline Dyspnea Index/ Transitional Dyspnea Index (BDI/ TDI)	The BDI rates dyspnoea in three categories: functional impairment, magnitude of task, magnitude of effort. Each is graded (0 to 4), scores are added together to produce overall score between 0 and 12. A *higher* score indicates a worse degree of dyspnoea. The TDI rates changes in each of the three categories, grading each (-3 to +3) to produce an overall transition score between –9 and + 9.
Perceived severity of respiratory-related impairment	(Modified) Medical Research Council scale for dyspnoea (MRC/ MMRC)	MRC is 1 to 5 scale with descriptions corresponding with each grade. MMRC is same set of descriptions, but scale is instead 0-4. Subject asked to pick description that best applies to them. A *higher* score indicates a worse degree of dyspnoea.
Generic quality of life	Quality of life for respiratory illness questionnaire (QOL-RIQ)	55 questions on seven subscales. For each item on 7-point Likert scale, subjects nominate degree to which they are troubled due to pulmonary complaints, resulting in an overall score between 7 and 49. A *higher* score indicates worse quality of life.
	Short Form 36 Health Survey (SF-36)	36 item multiple choice questionnaire; produces scores in eight domains; overall score of 0 to 100 is produced. A *lower* score indicates worse health-related quality of life.
	Chronic Respiratory Questionnaire (CRQ)	20 questions in four areas: dyspnea (5 questions), fatigue (4 questions), emotional functioning (7 questions), and mastery (4 questions). Subjects rate each domain on a 7-point scale ranging from 1 (maximum impairment) to 7 (no impairment). A *lower* score indicates worse health-related quality of life.
	Inventory of Subjective Health (ISH)	21 item questionnaire with questions relating to several areas, including tiredness, heart and chest problems, gastric problems, and headache. A total score of between 0 and 21 is produced. A *higher* score indicates worse health-related quality of life.
	Quality of Well Being (QWB)	A 4 item interviewer-administered questionnaire with questions in four areas: Symptom/complex, mobility, physical activity, and social activity. An overall score between 0 and 1 is produced. A *lower* score indicates worse health-related quality of life.
	Rand 36-Item Health Survey	Similar to the SF-36. Includes 36 questions in eight domains, with the addition of a question regarding change in health. An overall score of between 5 and 40 is produced. A *higher* score indicates worse health-related quality of life.
	Maugeri Foundation Respiratory Failure Questionnaire (MRF-28)	21 item, self-administered questionnaire, with items in 3 domains: daily activity, cognitive function and invalidity. Produces an overall score of 0 to 100. A *higher* score indicates worse health-related quality of life.
Respiratory related quality of life	Saint George Respiratory Questionnaire (SGRQ)	76 item multiple choice questionnaire; produces scores in three domains; an overall score of 0 to 100 is produced. A *higher* score indicates worse health-related quality of life.

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TABLE 7: Measures used to track changes in breathlessness over 2 years (changes reported in individual scale of each measure)

Tool	van Schayck et al 1995	Mahler et al 1995	Guell et al 2000	Spencer et al 2001	Clini et al 2002	Ries et al 2003	Miravitlles et al 2004	Cote and Celli 2005	Hesselink et al 2006	Naunheim et al 2006	Cote, Dordelly and Celli 2007	Oga et al 2007
Borg						**0.5**↓* **0.6**↓^						
VAS			**4.1**↓* **0.5**↓^									
USCD SOBQ						7.3↑* 10.6↑^						
BDI/ TDI		**0.7**↓				0.2↑* **0.1**↓^						
MRC/ MMRC			**1.8** ↓* no change^		**0.9**↓* 0.1↑^			**0.14**↓* 0.38↑^			0.33↑E **0.12**↓non-E	0.28↑
QOL-RIQ									**0.89**↓			
SF-36				*Physical* 1.72 ↓* 2.62 ↓^ *Mental* 1.32 ↓* 2.28 ↓^								
CRQ			*Dyspnoea domain* **1** ↑* no change^			6.4↓* 11.4↓^						0.24↓
ISH	1.2↑											
QWB						0.12↓* 0.11 ↓^						
Rand						*Physical* 4.5↓* 3↓^ *Mental* 0.4↓* 2↓^						
MRF-28					**4**↓* 6↓^							
SGRQ				no change* 1.4↑^	**4**↓* **5**↓^		**3.79**↓			4↑	7 ↑E 1 ↑non-E	3.74↑

KEY: Borg= Borg Perceived Rate of Exertion scale; VAS=Visual Analogue Scale; USCD SOBQ= University of California, San Diego Shortness of Breath Questionnaire; BDI/TDI= Baseline Dyspnea Index/ Transitional Dyspnea Index; MRC/MMRC= Medical Research Council scale for dyspnoea/ Modified Medical Research Council scale for dyspnoea; QOL-RIQ= Quality of life for respiratory illness questionnaire; SF-36= Short Form 36 Health Survey; CRQ= Chronic Respiratory Questionnaire; ISH= Inventory of Subjective Health; QWB= Quality of Well Being; Rand= Rand 36-Item Health Survey; MRF-28= Maugeri Foundation Respiratory Failure Questionnaire; SGRQ= Saint George Respiratory Questionnaire; shaded cells= interventional study; **bold font**= improvement; ↑= increase in value; ↓= decrease in value; *= interventional group; ^= control / placebo group; E= exacerbators; Non-E= non exacerbators.

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DISCUSSION

Individual studies have previously assessed longitudinal changes in various domains for people with COPD.[1-3] Despite this, a systematic review focusing specifically on changes in dyspnoea or breathlessness could not be identified. The aim of this review was to summarise evidence concerning the variety of outcome measures and changes in intensity, quality, or life impact of dyspnoea for people with COPD over a two year period.

COPD Severity and Changes over Time in Pulmonary Function

Within the 12 studies included in this review, there was little change with respect to disease progression. Where extractable, the change in FEV_1% predicted, as a measure of airways obstruction, was noted. In most of the studies, there was an average mean decrease in FEV_1, but the change was often negligible.

One factor that may have influenced this finding is that most of the subjects within the reviewed studies fell within the "severe" grouping, according to the GOLD classification. It must be remembered that these people represent the *surviving* subgroup of the COPD population. Many others with a similar or greater degree of physiological impairment would have died. It may be that these subjects had already reached a plateau in terms of disease progression and potentially adapted to this level of disease, and that if subjects with a lesser initial level of impairment were followed, the changes observed over a two year period may have been more dramatic. The fact that only studies which reported changes over an exact two year period (regardless of whether data for longer durations of study were available) were included will also have influenced the results with regard to changes in impairment. The small changes in airways obstruction may be indicative of the fact that two years is not a long enough period of time to observe significant changes in the level of impairment in people with COPD unless there are frequent exacerbations of the disease.

Outcome Measures Used to Monitor Changes in the Sensation of Dyspnoea

Overall, results concerning changes in the sensation of dyspnoea (intensity, severity or quality), its related impairments, and quality of life for people experiencing it were inconclusive. The measures used to track changes over 2 years can be grouped into three main categories, and will be discussed in terms of the most commonly used outcome measures for each category. It must be kept in mind that in most cases, the statistical significance of the changes in the outcome measures within individual studies was not reported.

Measures of Intensity

Three main measures were used to track changes in the intensity of breathlessness: the VAS, the Borg, and the UCSD SOBQ. Each of these were used only once across the 12 studies. The VAS was used by Guell and colleagues (2000) in an interventional study.[12] These authors reported small improvements in the intensity of dyspnoea experienced by subjects in both the intervention (pulmonary rehabilitation) and the control group. These gains were significantly more for the pulmonary rehabilitation group, and accompanied by a small decrease in airways obstruction. Similarly, using the Borg scale, Ries and colleagues (2003) noted small but not significant improvements in intensity for both intervention (pulmonary rehabilitation follow up) and control groups.[1] Conversely, the UCSD SOBQ, also used by Ries et al, noted a non-significant increase in the intensity of breathlessness. This UCSD SOBQ requires subjects to rate intensity across a number of tasks. It may be that the more multidimensional nature of this tool is a more accurate representation of the dyspnoeic experience than a unidimensional tool such as the VAS or Borg. In summary, it appears that people with severe COPD who undertake pulmonary rehabilitation report less intense breathlessness over a two year period, while people with severe COPD who do not undertake pulmonary rehabilitation report more intense breathlessness over a two year period.

Measures of Respiratory-Related Impairment

A form of the Medical Research Council scale for dyspnoea (either the original or modified version) was also a common tool throughout five studies. [12, 14, 15, 20-21] The (M)MRC scale requires subjects to rate the degree to which dyspnoea impacts on daily life. The tool was used with nine groupings of subjects, and four of these demonstrated improvements over the two year period (and one no change) using a version of the MRC scale. Three of the four groups in which improvement was noted were recipients of an intervention of some kind. Yet, only one mean improvement was more than a whole grade on the (M)MRC scale. This suggests that minor improvements in self-reported respiratory-related impairment can be seen over two years for people with COPD who receive some form of management. For people who receive no treatment, respiratory-related impairment seems to remain unchanged or slightly worsen.

Measures of Quality of Life

The SGRQ was used in six of the studies, on nine groups of subjects in total. [13, 14, 16, 17, 20] In three of the nine groups of subjects assessed within these studies, improvement was observed over the two year period. In five groups, health-related quality of life

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deteriorated. One group had no change over the two year period. The greatest change observed was a 7-point increase (deterioration) in the "exacerbators" group within Cote, Dordelly and Celli's 2007 study.[20] According to Jones and colleagues (1991), this reflects a moderate change and therefore deterioration in the quality of life for subjects. [23] All other changes in SGRQ scores across the studies are considered to be of less significance. This demonstrates that overall, no clear conclusions could be drawn about changes in the effect of dyspnoea on quality of life over two years using the SGRQ.

In this review, both interventional and observational study designs were included. While studies with only surgical interventions were excluded, and only "usual care" forms of intervention accepted, the interventional methods may have influenced the rate of change in both airways obstruction, and more importantly, the sensation of dyspnoea. Contrary to what may have been expected for people with this progressive terminal disease, a large number of studies reported minor improvements in the sensation of dyspnoea over a two year period. Forty six outcome measurements were reported across the 12 studies (due to the use of multiple tools and subject groups within each study). Sixteen of these displayed improvement, despite minimal change in physiological impairment (FEV_1). The majority of improvements were noted in interventional studies. This suggests that the interventions were having an effect on the sensation of breathlessness. However, it may also be a reflection on the coping mechanisms employed by people with chronic breathlessness. Perhaps improvements in the face of deteriorating or unchanging physical condition reflect habituation of the individual to their physiological state. It may be that the intensity of breathlessness or the impact of the sensation on daily activities and quality of life was seen to improve because subjects learned not to put themselves in breathlessness-provoking situations.

There are a number of clinical implications arising from this review. Breathlessness is one of the most common and disabling symptoms of COPD. While a substantial body of high level research confirms the benefits of pharmacological approaches and pulmonary rehabilitation for people with COPD, in the real world environment, it is not uncommon to find health professionals offering optimal pharmacological management to people with severe airflow obstruction but expressing concern or reticence in referring people to pulmonary rehabilitation programmes. The majority of studies in this review included people with severe airflow obstruction (FEV_1 30 to 50% predicted) and the findings indicated that, unless people suffer frequent respiratory exacerbations, access to "usual care" (optimal pharmacological management and pulmonary rehabilitation) is likely to result in, at worst, little deterioration and at best, small improvements in the sensation (intensity and impact) of breathlessness over a two year period. For people with COPD and health professionals working with people with COPD, these findings should encourage referral and participation in both aspects of "usual care." The variety of outcome measures used to assess and monitor breathlessness make it difficult to descriptively compare between studies and make statistical processes, such as meta-analysis, impractical. In addition, the findings from recent neural images studies indicate that two discretely different domains exist for the sensation of breathlessness; affective (unpleasantness) and sensory (intensity).[4] To date, outcome measures used to capture the experience of breathlessness attend to intensity and the behaviour impacts of breathlessness, rather than the affective or qualitative sensation. Clinicians and researchers intending to assess the sensation of breathlessness should consider using tools which assess both of these domains through either simple visual analogue scales for intensity and unpleasantness or more comprehensively through structured interviews for the language of breathlessness.[5-7, 24]

CONCLUSION

The aim of this systematic review was to identify which assessment tools have been used to monitor the sensation of breathlessness and whether the sensation of breathlessness changed over two years in people with COPD. The studies included within this review reported on three broad groups of outcome measures: intensity, respiratory-related impairment, and quality of life. As neural images studies have only been published in the past year indicating that breathlessness has two discrete neural pathways for intensity and unpleasantness, it was not surprising that no longitudinal studies included within this review specifically assessed the qualitative sensation of unpleasantness.

In terms of changes across a two year period, this systematic review found that for people with predominantly severe airflow obstruction and physiological impairment, as measured by FEV_1, did not change significantly over a two year period. Similarly, little to no change was observed in the intensity of breathlessness, its impact on activities of daily living and on general quality of life.

The findings suggest that the sensation of breathlessness does not change significantly over a two year period for people with severe COPD. Many of the studies included in this review trialled a variety of interventions with subject groups, and as such, the findings in regards to change in impairment levels and the sensation of breathlessness may be partly attributable to the interventional methods, many of which are considered best practice or usual care for this group (optimal pharmacological management and pulmonary rehabilitation). Most outcome measurement tools employed within the studies were unidimensional

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in nature, or measured the effects of the sensation on activities of daily living or quality of life. As such, little is known about whether or how the qualitative sensation of breathlessness changes over time in people with chronic pulmonary disease.

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