IJAHSP
The Internet Journal of Allied Health Sciences and Practice
http://ijahsp.nova.edu

A Peer Reviewed Publication of the College of Allied Health & Nursing at Nova Southeastern University
Dedicated to allied health professional practice and education
http://ijahsp.nova.edu Vol. 6 No. 1 ISSN 1540-580X

The Language of Dyspnoea: A Systematic Review

Ashleigh Garrard, BPhys (Hons)[1]
Marie Williams, PhD[2]

1. School of Health Sciences, University of South Australia
2. Associate Professor, School of Health Sciences, University of South Australia

CITATION: Garrard, AK., Willams, M. The language of dyspnoea: A systematic review. *The Internet Journal of Allied Health Sciences and Practice*. Jan 2008, Volume 6 Number 1.

ABSTRACT

Dyspnoea is an uncomfortable conscious awareness of breathing. Since the late 1980s, studies on the language used to describe the sensation of breathlessness have emerged in order to understand mechanisms and differences between chronic diseases. This systematic review aimed to consider primary studies of the language of breathlessness in order to describe the evolution of this field, methodological approaches, key findings and, identify areas which require further investigation. A systematic search process was used to identify thirty-five primary studies. This field of study has evolved rapidly over the past eighteen years. Descriptions of the sensation of breathlessness have been acquired by subjects either selecting a descriptor statement from a pre-existing list (endorsed) or describing the sensation in their own words (volunteered). Three common inventories have been used by the majority of studies to obtain qualitative descriptors of breathlessness. Studies have generally focused upon on physical descriptors of the sensation, though the need for similar studies in the affective domain has been acknowledged. Clear associations between descriptions of breathlessness and medical conditions have been reported, though consistency between studies is equivocal. Further investigations are required to confirm the consistency of the language of breathlessness within people with the same medical conditions, reliability between occasions of assessment (subject in the same state of breathlessness), consistency between recalled descriptions and reality of the experience, changes in the qualitative sensation of breathless over the natural history of chronic diseases, impact of interventions of the sensation of breathlessness, and differences between adults and children.

Introduction

The mechanisms responsible for breathlessness and dyspnoea are complex. The most recent neurophysiological model for dyspnoea (the dyspnoea neuromatrix) proposes that conscious experience of the sensation of breathlessness requires "…integration of respiratory afferent activity, respiratory motor drive, affective state, attention, experience, and learning."[1] Although peripheral physiological receptors are responsible for the physical sensation of breathlessness via input to the sensory cortex, distress or discomfort with breathing is centrally modulated by limbic (threat and fear) and higher cognitive centres (experience, memory, expectation).[2,3] Von Leupoldt & Dahme (2005) have proposed the affective domains and central processing of pain and dyspnoea share a common cortical and sub-cortical network.[4] Therefore, like pain, affective and physical sensations may be reflected in the language used to describe the experience of dyspnoea.

The language of breathlessness is a relatively new area of investigation which first emerged during the late 1980s.[5] Early studies confirmed that qualitatively different sensations exist when breathlessness is induced using a variety of methods in healthy young people, suggesting that different mechanisms underpin different sensations of breathlessness.[5] Distress with breathing or dyspnoea, is a common symptom of a number of chronic medical conditions. However, it appears that the qualitative sensation of breathlessness differs between medical conditions, presumably due to differences in underlying mechanisms.[6-9] In essence, dyspnoea is not a generic sensation experienced or described in the same way regardless of the underlying cause. Dyspnoea is

commonly evaluated in terms of severity (visual analogue scales or Borg's perceived rate of exertion), resulting functional impairment (Medical Research Council scale) or its impact on quality of life (St George Respiratory Questionnaire). However, studies of the language which describes the quality of the breathlessness sensation provide a different dimension and have implications for understanding the neurophysiology of sensation-perception and improving diagnosis and treatment regimens for the management of dyspnoea.

The purpose of this paper is to systematically review primary studies of the language of breathlessness in order to describe the evolution of this field, methodological approaches, key findings, and identify areas which require further investigation.

The Language of Breathlessness

A systematic search process was undertaken to identify peer reviewed publications specifically investigating the language used to describe the sensation of breathlessness or dyspnoea. This review aimed to include papers specific to the language of breathlessness, rather than those which investigate the broad areas of dyspnoea mechanisms, management or impact. Three groups of search terms (and truncations) were identified. These were based on common medical and scientific terms for distress with breathing and key words used in studies of the language of breathlessness presented within a recent narrative review article.[10] The first group of search terms included breathless, breathlessness, dyspnea, and dyspnoea; the second group included language, word (truncation), descriptor (truncation), and the third group included perception, sensation, and memory. Each term within a group was separated by "or" and each group was separated by "and."

Results of the database search conducted in February 2007 are presented in Table 1. Eight databases were selected to cover a broad range of literature. Minor limits were placed on some database searches to allow more precise identification of the studies most likely to investigate the language of breathlessness or dyspnoea. Hand searching of the reference lists of retrieved articles was also undertaken.

TABLE 1 Database Search Results

Database	Limits	Fields	Date of Search	Retrieved Citations	Retained Citations
Scopus	Article and Review	All	8/2/2007	290	48
PubMed	Nil	All	8/2/2007	24	22
Medline (OVID)	Nil	All	8/2/2007	28	20
Web of Science (Web of Knowledge)	Articles	Advanced Search: Topic Search	8/2/2007	25	14
Psychinfo (EBSCOhost)	Peer Reviewed	All	8/2/2007	5	3
Psychinfo (Cambridge Scientific Abstracts)	Peer Reviewed	All	8/2/2007	45	4
CINAHL (EBSCOhost)	Peer Reviewed	All	9/2/2007	11	5
Academic Search Elite (EBSOChost)	Peer Reviewed	All	12/2/2007	5	4

The title and abstracts of all citations retrieved during the initial search were reviewed and retained only if they met four criteria. Criteria A:

1. Must refer to language, descriptors or words to describe dyspnoea/breathlessness in the abstract or title or make reference to specific breathlessness descriptors from Simon et al. (1989), Simon et al. (1990) or Mahler et al. (1996)[5-7]
2. Language of publication: English
3. Subjects: must have a respiratory condition
4. Publication: journal article (no grey literature)

Full versions of the articles were retrieved for citations meeting Criteria A and for citations where abstracts were unavailable or ambiguity existed. Upon retrieval of full versions, articles were included within the review if they met the following three criteria. Criteria B:

1. Confirmed Criteria A on full review of paper
2. Report original primary data or a systematic review (no narrative reviews)
3. Studies must have reported primary or secondary data from human subjects who either volunteered words to describe the sensation of breathlessness or subjects selected or endorsed words / statements from a list of breathlessness descriptors.

The full versions of fifty-six articles were retrieved after the application of Criteria A. However, only thirty-five of these met both Criteria A and B for inclusion within this review (Table 2). Of the twenty-one articles excluded, one did not meet Criteria A on retrieval of the full article (part 1 of Criteria B), fifteen were narrative reviews (part 2 of Criteria B) and five did not meet part 3 of Criteria B.

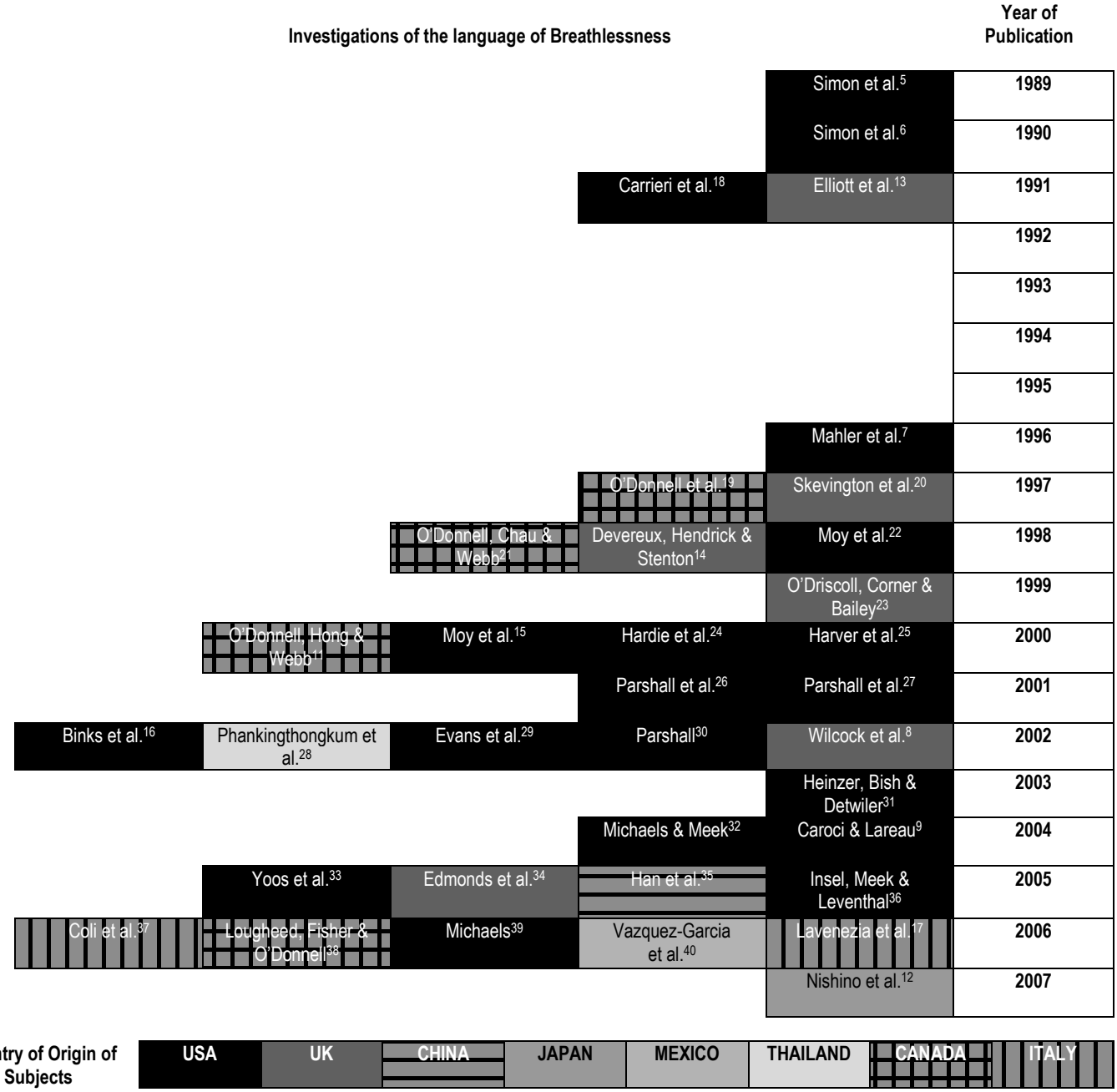
This review will be presented in the following order; evolution of studies of the language of breathlessness, methods of acquiring descriptions of the sensation of breathlessness and development of breathlessness descriptor lists, associations between descriptions of breathlessness and medical conditions, impact of culture and age and how the consistency of the language of breathlessness has been evaluated.

Evolution of Investigations into the Language of Breathlessness

Over the past 18 years, an increasing number of primary papers have been published in this field (n= 35) (Table 2). No systematic reviews were identified. This field of study is based on the concept that dyspnoea, like pain, consists of a number of qualitatively different and distinct sensations, rather than a generic sensation with varying intensities.[5] It has been suggested that the words used to describe these sensations reflect specific peripheral, physiological mechanisms and these descriptions can therefore aid in the diagnosis and management of medical conditions.[5] This concept has been explored by inducing breathlessness in healthy subjects using different physiological mechanisms, by reviewing the words used to describe breathlessness by people with different medical conditions or by associating different descriptors with the specific physiological mechanisms involved in diseases such as asthma. [5-8, 11-17]

Four main studies pioneered this field of investigation.[5-7,13] The first was Simon et al. (1989) who induced breathlessness via eight different mechanisms in a group of healthy subjects.[5] In order to determine whether different words were associated with different physiological mechanisms subjects were requested to choose descriptors (from a predetermined list) that best described their breathlessness sensation.[5] After establishing this relationship, Simon et al. (1990) sought to determine whether people with various medical conditions differed in the way breathlessness was described.[6] Shortly following this, in Britain, Elliott and colleagues repeated components of those studies by Simon et al. (1989) and Simon et al. (1990), using a larger sample size and a more extensive descriptor list. [5,6,13] Less compelling results were reported regarding language and it association with medical conditions, however Elliott et al. (1991) reported that descriptors were chosen consistently on different occasions.[13] Five years later, Mahler and colleagues also repeated components of the earlier studies but with larger sample sizes.[7] This area of research has since gained momentum (Table 2) and expanded into investigations on the impact of age and cultural diversity of the language of breathlessness.

TABLE 2 Evolution of Investigations into the Language of Breathlessness



Methods of Acquiring Descriptions of the Sensation of Breathlessness & the Development of Breathlessness Descriptor Lists

Two data collection methods have been used by studies in this field. The original and most common technique has been to invite people to select (endorse) statements from a previously developed list. This technique was used by 31 of the 35 studies included in this review. The majority of studies have used descriptor lists developed by Simon et al. (1989), Simon et al. (1990) or Mahler et al. (1996) (Table 3) or have made minor modifications to these.[5-7] The initial list of 19 breathlessness descriptor statements created by Simon et al. (1989) was compiled from patients with cardiopulmonary conditions and a group of college students with

induced breathlessness.[5] This same team of researchers (Simon et al. 1990) modified the list in order to decrease replication and improve the discriminate ability between medical conditions.[6] Mahler et al. (1996) made minor modifications to Simon et al.'s (1990) descriptor list after gaining the input from patients regarding their understanding and the clarity of the descriptors.[6,7]

Within the original studies, individual descriptor statements have been categorised into groups using a descriptive statistical method (*cluster analysis)*. Groupings are based on the number of times individual descriptors are endorsed by subjects in the sample. Categories are formed by grouping descriptors which are frequently endorsed by the same subject.[41] In studies on the language of breathlessness, these categories are referred to as *clusters*. As Table 3 demonstrates, the initial three studies responsible for the most commonly used descriptor lists have progressively confirmed and refined the language clusters and the related individual descriptor statements.[5-7]

TABLE 3 Comparison of Three Commonly used Descriptor Lists

DESCRIPTOR LISTS & CLUSTER MODIFICATIONS					
Simon et al. (1989)[5]		**Simon et al. (1990)[6]**		**Mahler et al. (1996)[7]**	
CLUSTER	**DESCRIPTOR**	**CLUSTER**	**DESCRIPTOR**	**CLUSTER**	**DESCRIPTOR**
Rapid	I feel that my breathing is rapid	**Rapid**	I feel that my breathing is rapid	**Rapid**	My breathing is rapid
Exhalation	My breath does not go out all the way	**Exhalation**	My breath does not go out all the way	**Exhalation**	My breath does not go out all the way
Shallow	My breath does not go in all the way	**Shallow**	My breath does not go in all the way	**Inhalation**	My breath does not go in all the way
	I cannot take a deep breath		My breathing is shallow	**Shallow**	My breathing is shallow
	My breathing is shallow	**Work**	My breathing requires effort	**Work / Effort**	My breathing requires effort
Work	My breathing requires effort		My breathing requires more work		My breathing requires work
	My breathing requires more work	**Hunger**	I feel out of breath		I feel out of breath
Hunger	I feel a hunger for more air		I cannot get enough air		I cannot get enough air
	I cannot get enough air		I feel a hunger for more air	**Air hunger**	I feel a hunger for air
Suffocating	I feel that I am smothering	**Suffocating**	I feel that I am smothering	**Suffocating**	I feel that I am smothering
	My chest feels tight		I feel that I am suffocating		I feel that I am suffocating
	I feel that I am suffocating	**Tight**	My chest feels tight	**Tight**	My chest feels tight
	I feel that my breathing stops		My chest is constricted		My chest is constricted
	My chest is constricted	**Heavy**	My breathing is heavy	**Heavy**	My breathing is heavy
Heavy	My breathing is heavy		I feel that I am breathing more	**Breathing more**	I feel that I am breathing more
	I feel that I am breathing more	**Key**			
Gasping	I feel out of breath	Cluster OR descriptor eliminated by Simon et al. (1990)			
	I am gasping for breath	Descriptor moved to different cluster by Simon et al. (1990) or Mahler et al. (1996)			
Concentration	My breathing requires more concentration	Newly developed cluster or descriptor by Simon et al. (1990) or Mahler et al. (1996)			
		Descriptor modified by Mahler et al. (1996)			

The comprehensiveness and correctness of the endorsed breathlessness descriptor statements in their description of the sensation of breathlessness has been confirmed by various researchers. The initial studies in this area sought the opinions of patients with breathlessness, healthy people with induced breathlessness, the retrospective view of the investigators, and health care professionals to ensure the list's content was suitable.[5-7,13] The validity of Mahler and colleagues descriptors has also been confirmed by healthy, young, non-breathless subjects.[7,25] More recent studies have compared the patient's own words

(volunteered descriptors) with those from the predetermined endorsed list to confirm content validity.[9, 27, 30, 32, 39] However, in the study by Michaels (2006), it is not clear whether subjects are confirming quality or intensity of the sensation of breathlessness.[39]

Five research groups have developed completely new lists (Table 4).[12,13,20,35,40] These groups aimed to establish more comprehensive lists of breathlessness descriptors, which may be appropriate to wider groups of people with breathlessness or different languages.[12,13,20,35,40] Physical sensations dominate the content of the original descriptor lists (Table 3). However, later studies have included a small number of statements which reflect affective or emotional sensations or have identified these in subject's own volunteered responses.[18,20,23,26,31] Interestingly, where this has been done, common affective themes (panic, fear, anxiety) and descriptors of fatigue have been identified. Despite an increasing awareness of the involvement of the limbic system and other higher cortical centres in the sensation of dyspnoea, the majority of more recent studies continue to focus on physical descriptors.[12,17,37,38]

The second, less common approach used to obtain descriptors of breathlessness has been to ask people to volunteer descriptions of the sensation in their own words. Table 4 presents the data collection method (endorse, volunteer or both) for studies included in this review. Six studies collected only volunteered descriptions while 17 of the 35 studies used this method in conjunction with selection of descriptions from a pre-developed list (endorsed). In many cases where volunteered descriptions have been solicited, these have been prospectively sought to confirm the validity of the descriptor lists. Details concerning the diversity and frequency of volunteered descriptions were rarely reported in these studies.

TABLE 4 Data Collection Methods in Studies on the Language of Breathlessness^

	Endorsed						Subject Volunteered Words
	Simon et al. (1989)[5]	Simon et al. (1990)[6]	Elliott et al. (1991)[13]	Mahler et al. (1996)[7]	Developed new list	Other **	
Carrieri et al. (1991)[18]							RA
Skevington et al. (1997)[20]							NV
O'Donnell et al. (1997)[19]							NV
Moy et al. (1998)[22]							NV
O'Donnell et al. (1998)[21]							NV
Devereux, Hendrick & Stenton (1998)[14]							NV
O'Driscoll, Corner & Bailey (1999)[23]							QA & RA
Harver et al. (2000)[25]							NV
Hardie et al. (2000)[24]							RA
Moy et al. (2000)[15]							NV
O'Donnell, Hong & Webb (2000)[11]							NV
Parshall et al. (2001)[26]							RA
Parshall et al. (2001)[27]							CVEL & RCP
Binks et al. (2002)[16]							NR
Wilcock et al. (2002)[8]							NV
Parshall (2002)[30]							CVEL
Evans et al. (2002)[29]							RCP
Phankingthongkum et al. (2002)[28]							RA
Heinzer, Bish & Detwiler (2003)[31]							QA
Caroci & Lareau (2004)[9]							CVEL & RCP
Michaels & Meek (2004)[32]							CVEL & RCP
Insel, Meek & Leventhal (2005)[36]							NV
Han et al. (2005)[35]							DNQ
Yoos et al. (2005)[33]							RA
Edmonds et al. (2005)[34]							QA
Vazquez-Garcia et al. (2006)[40]							DNQ
Lavenezia et al. (2006)[17]							NV
Michaels (2006)[39]							CVEL
Lougheed, Fisher & O'Donnell (2006)[38]							NV
Coli et al. (2006)[37]							NV
Nishino et al.(2007)[12]							NV

^ Note: Studies which developed the original descriptor lists (Simon et al. 1989, Simon et al. 1990, Elliot et al. 1991 and Mahler et al. 1996) are not included in the table[5-7,13]

** Other: Some or all of endorsed descriptors used were from an other source or unstated origin

Key for Endorsed Tool used

Exact List
Modified Version of Original List

Key for Reporting Volunteered Words

QA = Qualitative approach
RA = Reported and Analysed
RCP = Reported common phrases only
DNQ = Used only to develop new questionnaire
CVEL = Support content validity of endorsed list
NR = Asked of subjects but not reported in results
NV = No volunteered words reported

A quantitative framework has been used in the majority of studies to establish associations between disease conditions and combinations of descriptor categories. A small number of studies used qualitative methodologies to explore the content and meaning of phrases used by people to describe their dyspnoea experience.[23,31,34] Patients with heart failure tended to describe their physical limitations and coping strategies for breathlessness.[34] This is in contrast to groups of patients with chronic obstructive pulmonary disease and lung cancer who commonly expressed descriptions of strong affective sensations including fear, anxiety, panic, frustration, helplessness, and a feeling of impending death. [23,31]

In summary, studies of the language of breathlessness have predominantly employed quantitative frameworks which focus upon the selection of physical descriptions (endorse rather than volunteer). Face validity has been confirmed for common inventories of physical descriptors. Clusters have been determined for grouping similar physical descriptors. Few studies have obtained volunteered descriptions or investigated affective descriptors of the sensation.

Consistency of the Language of Breathlessness

Overall, few studies specifically investigated aspects of the consistency of the language of breathlessness. Table 5 presents studies investigating or including an aspect of reliability. Only a small number of these studies explicitly assessed whether the same subjects selected the same descriptors on each occasion.[5,6,32] Studies concerning reliability can be divided into different categories. Only one study reported stable internal or within-questionnaire reliability of the language of breathlessness. The second group of studies explored the test-retest reliability while subjects were in a constant state of breathlessness (recalling descriptors while at rest on both occasions or breathlessness was induced on both occasions). Also using test-retest methods, two studies have compared recalled descriptors of breathlessness at rest with those given by subjects during a state of acute breathlessness.[7,16]

Three studies used test-retest methods to investigate the variability of the language of breathlessness between timeframes where the sensation was likely to differ — that is, during an acute symptomatic episode and during a non-acute period.[27,30,32] This probable variation in the language of breathlessness is due to the likelihood that the language used to describe the sensation of breathlessness will change to reflect the different physical and affective symptom states between acute and non acute periods. For example, the words used to describe the sensation of dyspnoea from recall at rest before and after a hospital admission were compared in two studies and as expected, a low correlation was reported (Table 5).[27, 30] Similarly, Michaels & Meek (2004) reported differences across a four week time frame where, each week subjects recalled words to describe their most intense period of breathing discomfort.[32] Again, it was likely that this sensation would not be identical between weeks due to day to day variability in symptom state and a low correlation was reported (Table 5).[32]

TABLE 5: Consistency of the Language of Breathlessness

Study	Number	State of Breathlessness	Time Between Tests	Acceptable Reliability** YES=√	Acceptable Reliability** NO=x
Studies which Tested Internal Consistency					
Elliott et al. (1991)[13]	194 (of 194)	Recall at rest	Within the same questionnaire		**x**
Studies which tested the repeatability of breathlessness descriptor selection: subjects in a constant state of breathlessness					
Simon et al. (1989)[5^]	30 (of 30)	Recall at rest	2 hours approx.	√	
Elliott et al. (1991)[13]	194 (of 194)	Recall at rest	2 hours at least		**x**
Mahler et al. (1996)[7^#]	16 (of 218)	Recall at rest	4-15 days	√	
Parshall et al. (2002)[30]	104 (of 104)	Recall at rest *(acute symptomatic period))*	1 hour at least		**x**
		Recall at rest *(Non acute period)*	1 hour at least		**x**
Han et al. (2005)[35]	328 (of 328)	Recall at rest	2 hours at least		**x**
Vazquez-Garcia et al. (2006)[40]	10 (of 104)	Recall at rest	1-2 days		**x**
Studies which tested the repeatability of descriptor selection: comparing recalled descriptors with descriptors during actual breathlessness					
Mahler et al. (1996)[7#]	16 (of 218)	Recall at rest Vs Breathless	4-15 days	√	
Binks et al. (2002)[16]	15 (of 15)	Recall at rest Vs Breathless	Same day		**x**
Studies which tested the repeatability of breathlessness descriptors: comparing descriptors from an acute episode with those from a non acute period					
Parshall et al. (2001)[27]	34 (of 36)	Recall at rest *(from 1 week prior)* V Recall at rest *(Decided to go to ED*	Same day		**x**
Parshall (2002)[30]	104 (of 104)	Recall at rest *(from 1 week prior)* V Recall at rest *(Decided to come to ED)*	Less than 1 hour		**x**
Michaels & meek (2004)[32∞]	11 (of 11)	Recall at rest *(most intense breathlessness ever)* V Recall rest *(most intense breathlessness weekly)*	Weekly		**x**

****Criteria for Acceptable Reliability:** reported reliability based the same subject selecting the same descriptor on each occasion AND one of the following: ^ =mean % agreement of ≥ 75% OR # = a significant correlation coefficient (p≤ 0.05) OR ∞ = if selecting descriptors on a weekly basis 50% of subjects had 75% reselection of baseline descriptor.

In summary, the language used to describe the sensation of breathlessness (endorsed) is reproducible when subjects are in a constant state of breathlessness (recall at rest or experimentally induced). Descriptions of breathlessness differ between stable and acute medical states in the same subject and differ over time presumably as a result of symptom state.

Association between Descriptions of Breathlessness and Medical Conditions

Associations have been reported between specific combinations of endorsed descriptor clusters and different pathologies. That is, different pathologies are represented by unique patterns of language clusters. While a number of studies reported differences in the language of breathlessness between medical conditions, it was unclear how consistently people with the same medical condition described the sensation of breathlessness between studies included in this review. To explore this issue, a secondary analysis of studies which used one of the descriptor lists of Simon et al. (1989), Simon et al. (1990) or Mahler et al. (1996), either in their original form or with very minor modifications, was undertaken.[5-7] Data were extracted for reports of significant associations between medical conditions and specific language clusters. Only conditions which had been investigated by two or more studies were reviewed. If authors reported only the frequency of endorsed descriptor selection by subject group, clusters which had a frequency of endorsement of greater or equal to 50 percent from the subject cohort were determined to be associated with the subject group (Table 6).

A minority of studies reported statistical associations.[6-8] The majority of studies reported the frequency of descriptor selection only.[12,15,19,21,30,38] Table 6 indicates that there were no two (or more) studies which demonstrated the exact same combination of

TABLE 6 Associations Between Medical Conditions And Breathlessness Descriptor Clusters across Investigations of the Language of Breathlessness

Study & Sample Size	Specific Subject Details	Breathlessness Descriptor Clusters									
		Rapid	Inhalation	Exhalation	Shallow	Work /Effort	Suffocating	Breathing more	Hunger	Heavy	Tight
Simon et al. (1990)[6] N=16	COPD					■			■		
Mahler et al. (1996)[7] N=85	COPD					■					
O'Donnell, Berkley, Chau & Webb (1997)[19] N=12	COPD		■			■				■	
Wilcock et al. (2002)[8] N=34	COPD								■		■
Parshall (2002)[30] N=104	COPD: AE	■	■	■	■	■	■	■	■	■	■
	COPD: WBE	■		■	■	■	■		■	■	■
Caroci & Lareu (2004)[9] N=30	COPD					■					
Simon et al. (1990)[6] N=7	ASTHMA			■		■					■
Mahler e al. (1996)[7] N=56	ASTHMA					■					■
Moy et al. (1998)[22] N=25	ASTHMA: PreB										■
	ASTHMA: PostB					■		■			
Moy et al. (2000)[15] N=8	ASTHMA: ER					■					
	ASTHMA: M					■					■
Wilcock et al. (2002)[8] N=37	ASTHMA					■			■		■
Lougheed, Fisher & O'Donnell (2006)[38] N=116	ASTHMA: M20%↓		■			■					■
	ASTHMA: MDM		■	■		■				■	■
Simon et al. (1990)[6] N=9	ILD					■					
Mahler et al. (1996)[7] N=37	ILD	■				■					
O'Donnell, Chau & Webb (1998)[21] N=12	ILD	■	■			■				■	
Wilcock et al. (2002)[8] N=29	ILD	■				■			■		
Simon et al. (1990)[6] N=5	CHF	■									
Mahler et al. (1996)[7] N=17	CHF		■	■		■					
Wilcock et al. (2002)[8] N=30	CHF					■			■		■
Caroci & Lareu (2004)[9] N=30	CHF					■			■		
Simon et al. (1990)[6] N=5	NMD				■	■	■				
Mahler et al. (1996)[7] N=6	NMD	■	■			■					

N=Sample Size, COPD=Chronic obstructive pulmonary disease, ILD=Interstitial lung disease, CHF=Congestive Heart Failure, NMD=Neuromuscular disease, PVD=Pulmonary vascular disease, AE= Acute Exacerbation, WPE=Week prior to Exacerbation, PreB=Pre Bronchodilator, PostB=Post Bronchodilator, ER=External Resistors, M=Methacholine inhalation, M20%↓=Mechacholine with 20% decrease in FEV_1, MDM=Maximum Dose of Methacholine

breathlessness descriptor clusters by subjects of the same medical condition. This suggests a number of possibilities. First, the language of breathlessness may not be specific to the labels given to different medical conditions but may reflect features of chronic respiratory disease such as impairment level or the affective component of dyspnoea. Alternatively, many of the subject groups were very small and therefore may not be a true representation of the given population. In addition, while subjects may have been allocated to one medical condition they may have had concomitant conditions. Furthermore, no consistent mathematical method was used across the studies determining associations between subject groups and descriptor clusters, which may affect the reproducibility of unique cluster combinations.

One further possibly exists which may explain this lack of consistency. The symptom state of subjects when assessing the language used to describe the sensation of breathlessness differed between studies in this review. This discrepancy may have influenced the responses provided and would therefore to some extent explain the inconsistencies in associations between medical conditions and cluster patterns between studies. Depending on the aim of the investigation, studies have considered descriptors chosen by subjects while asymptomatic for breathlessness (the sensation of breathlessness recalled while at rest), with induced breathlessness (immediately following an exercise, methacholine or carbon dioxide challenges) and during acute asthmatic episodes or exacerbations of chronic obstructive pulmonary disease (Table 7).

TABLE 7 Subject Symptom State at Interview in Language of Breathlessness Investigations

	STATE OF BREATHLESSNESS AT INTERVIEW			
	Breathless		Recall at rest	Other
	Induced	Spontaneous occurrence		
Simon et al. (1989)[5]	■			
Simon et al. (1990)[6]			■	
Elliott et al. (1991)[13]			■	
Carrieri et al. (1991)[18]			■	
Mahler et al. (1996)[7]	■		■	
Skevington et al. (1997)[20]		■	■	
O'Donnell et al. (1997)[19]	■			
Moy et al. (1998)[22]		■		^
O'Donnell et al. (1998)[21]	■			
Devereux, Hendrick & Stenton (1998)[14]	■			
O'Driscoll, Corner & Bailey (1999)[23]		■	■	
O'Donnell, Hong & Webb (2000)[11]	■			
Harver et al. (2000)[25]			■	
Hardie et al. (2000)[24]	■		■	
Moy et al. (2000)[15]	■			
Parshall et al. (2001)[26]			■	
Parshall et al. (2001)[27]			■	
Binks et al. (2002)[16]	■		■	
Wilcock et al. (2002)[8]			■	
Parshall (2002)[30]			■	
Evans et al. (2002)[29]	■			
Phankingthongkum et al. (2002)[28]				#
Heinzer, Bish & Detwiler (2003)[31]			■	
Caroci & Lareau (2004)[9]			■	
Michaels & Meek (2004)[32]			■	
Insel, Meek & Leventhal (2005)[36]			■	
Edmonds et al. (2005)[34]			■	
Han et al. (2005)[35]			■	
Yoos et al. (2005)[33]			■	
Vazquez-Garcia et al. (2006)[40]	■	■	■	
Lavenezia et al. (2006)[17]	■		■	
Coli et al. (2006)[37]	■		■	
Lougheed, Fisher & O'Donnell (2006)[38]	■			
Nishino et al. (2007)[12]	■			

Key

^ = requested descriptions of the sensation of breathlessness following bronchodilator inhalation

= requested descriptors of breathlessness after the viewing of video footage of a breathlessness episode

If a person describes their breathlessness when they are not suffering from the sensation, a number of factors may confound the person's recall. Several studies have reported that recalling a breathlessness experience involves both physical and negative, affective sensations.[18,20,23,26,31] When the sensation is recalled physical and affective components of sensation may be influenced by previous or "worst experiences," or the degree of anxiety or catastrophising associated with the sensation.[42] Alternatively, if the sensation is induced, consideration must be given to whether the inducing method will create a dyspnoea sensation identical to that regularly experienced. If the language used to describe the sensation of dyspnoea is specific to the physiological mechanism causing it, then using a method which mimics the usual dyspnoea-causing mechanism in the specific population would appear important. For example, exercise is a significant limiting factor in people with COPD, so this would seem to be an appropriate method of inducing breathlessness for this population.[43] Similarly, if an episode of bronchoconstriction is the cause of breathlessness in asthmatics, the same principles apply.

In summary, previous studies report that descriptions of breathlessness discriminate between chronic medical conditions. Comparisons of medical conditions between studies show little consistency (cluster profile). This lack of consistency may reflect differences in methodology, subject demographics (diagnosis, concomitant diseases or severity) or symptom state during assessment.

Cultural and Age Differences in the Language of Breathlessness

The majority of studies in this field have been conducted in English speaking countries (United States of America and the United Kingdom). Four studies were identified, one from each of, Thailand, China, Mexico, and Japan, as well as one which compared the language of African and Caucasian Americans. Different cultures have a unique interpretation of language. Culture may influence the language used to describe the breathlessness experience, both between and within countries.[12,24,28,35,40] The use of culturally specific descriptors is important in order to allow people with breathlessness to accurately describe their sensation in familiar and recognisable terms. Studies in Thai, Chinese, Mexican, and Japanese have demonstrated that the direct English translation of descriptors into other languages is not always appropriate.[12,28,35,40] These studies identified that the common English descriptor lists (Table 2) included a number of statements which once translated, were unfamiliar expressions in the given language. It was also acknowledged that literal translation of the primarily physical descriptors of the common English descriptor lists (Table 5) does not permit the sizable affective component of descriptions from Chinese and Mexican-Spanish populations.[35,40] Similarly, different cultures within the same nationality do not always use the same vocabulary to describe the sensation of breathlessness. Hardie and colleagues reported stark differences between the common volunteered descriptors used by asthmatic African-Americans and Caucasian Americans.[24]

Age has the potential to pose another confounder to the language of breathlessness. Three studies to date have reported the language used by children to describe asthma sensations.[18,28,33] People with asthma, regardless of their age, appear to endorse similar terms, yet volunteer distinctly different ones. As the methods and specific interviewing processes used were not identical between the studies of asthmatic children and asthmatic adults, it is difficult to draw conclusions based on these comparisons.[6-8,18,22,28,33,38] No study has directly compared descriptors of breathlessness between adults and children.

In summary, people of different cultures, both within and between countries, use different terminology to describe the sensation of breathlessness, and as a result, direct translation of the common English descriptor lists, without modification, is inappropriate. Although age seemingly has the potential to affect the language used by people to describe the sensation of breathlessness, limited research has been conducted to explore this.

Conclusion and future directions

While the language of breathlessness is still a relatively new field of investigation, there has been rapid growth since its inception in the late 1980s. The qualitative sensations of breathlessness have been assessed by two primary methods. The original and most common technique was for subjects to select (endorse) statements from an inventory. The most frequently used inventories are derived from the original studies of the language of breathlessness, which have had their construct validity confirmed.[5-7] A minority of studies request volunteered words or phrases to describe the sensation of breathlessness either as the sole method of data collection or in conjunction with endorsed descriptor selection. People with breathlessness consistently describe (endorse descriptors) the sensation when under similar conditions during assessment (recall sensation at rest or breathlessness induced experimentally). Differences in the qualitative sensation of breathlessness between chronic medical conditions have been reported by individual studies. However, consistency in describing the sensation of breathlessness by people with the same medical conditions between studies appears equivocal. This lack of consistency may reflect differences in methodology of studies, subject demographics (diagnosis, concomitant diseases or severity), symptom state during assessment, culture, age and potentially gender. Further investigations are required to confirm the consistency of the language of breathlessness within people with the same medical conditions, reliability between occasions of assessment (subject in the same state of

breathlessness), consistency between recalled descriptions and reality of the experience, changes in the qualitative sensation of breathless over the natural history of chronic diseases, impact of interventions of the sensation of breathlessness, and differences between adults and children.

Significant energy has been spent by researchers on exploring and confirming relationships between specific physical descriptors and physiological mechanisms resulting in a well-delineated somatic vocabulary of breathlessness. The precise mechanisms underlying the way in which cognition, memory, expectation, emotion, personality, and other psychological factors modulate the perception of breathlessness are yet to be confirmed. However, the language used to describe the experience of breathlessness may provide a means of understanding the central processes involved in the development of this sensory experience. While the current descriptor lists provide a standard and consistent method of collecting data on the language of breathlessness, these predominantly focus upon physical sensations. When subjects are asked to describe the sensation of breathlessness in their own words, a range of affective descriptors have been volunteered which are not reflected in common breathlessness descriptor inventories. Affective sensations are fundamental in the dyspnoea experience, and ongoing research is required to map and explore the affective component of the language of breathlessness.[44] In general, current clinical strategies address the physical domain of the sensation of breathlessness by decreasing the work of breathing or increasing cardiorespiratory function. Potentially, strategies which specifically target the perceptual domain of breathlessness, such as cognitive behavioural therapy, may alter the affective domain of this sensation.

References

1. O'Donnell DE, Banzett RB, Carrieri-Kohlman V, Casaburi R, Davenport PW, Gandevia SC, et al. Pathophysiology of dyspnea in chronic obstructive pulmonary disease. *Proc Am Thorac Soc*. 2007;4:145-68.
2. Liotto M, Brannan S, Egan G, Shade R, Madden L, Abplanalp B, et al. Brain responses associated with consciousness of breathlessness (air hunger). *Proc Natl Acad Sci U S A*. 2001;98:2035-40.
3. Martinez-Moragon E, Perpina M, Belloch A. Does experience influence perception of dyspnoea?. *Arch Bronconeumol*. 2006;42:171-4.
4. Von Leupoldt A, Dahme B. Cortical substrates for the perception of dyspnea. *Chest*. 2005;128(1):345-54.
5. Simon P, Schwartzstein RM, Woodrow Weiss J, Lahive K, Fencl V, Teghtsoonian M, et al. Distinguishable sensations of breathlessness induced in normal volunteers. *Am Rev Respir Dis*.1989;140:1021-27.
6. Simon P, Schwartzstein RM, Woodrow Weiss J, Fencl V, Teghtsoonian M, Weinberger SE. Distinguishable types of dyspnea in patients with shortness of breath. Am Rev Respir Dis. 1990;142:1009-14.
7. Mahler D, Harver A, Lentine T, Scott JA, Beck K, Schwartzstein RM. Descriptors of breathlessness in cardiorespiratory disease. *Am J Respir Crit Care Med*. 1996;154:1357-63.
8. Wilcock A, Crosby V, Hughes A, Fielding K, Corcoran R, Tattersfield AE. Descriptors of breathlessness in patients with cancer and other cardiorespiratory diseases. *J Pain Symptom Manage*. 2002;23(3):182-89.
9. Caroci A, Lareau S. Descriptors of dyspnea by patients with chronic obstructive pulmonary disease versus congestive heart failure. *Heart Lung*. 2004;33(2):102-10.
10. Scano G, Stendardi L, Grazzini M. Understanding dyspnoea by its language. *Eur Respir J*. 2005;25:380-85.
11. O'Donnell DE, Hong HH, Webb KA. Respiratory sensation during chest wall restriction and dead space loading in exercising men. *J Appl Physiol*. 2000;88:1859-69.
12. Nishino T, Isono S, Ishikawa T, Shinozuka N. An additive between different qualities of dyspnea produced in normal subjects. *Respir Physiol Neurobiol*. 2007;155:14-21.
13. Elliott M, Adams L, Cockroft A, Macrae KD, Murphy K, Guz A. The language of breathlessness. *Am Rev Respir Dis*. 1991;144:826-32.
14. Devereux G, Hendrick DJ, Stenton SC. Perception of respiratory symptoms after methacholine-induced bronchoconstriction in a general population. *Eur Respir J*. 1998;12:1089-93.
15. Moy ML, Woodrow Weiss J, Sparrow D, Israel E, Schwartzstein RM. Quality of dyspnea in bronchoconstriction differs from external resistive loads. *Am J Respir Crit Care Med*. 2000;162:451-5.
16. Binks A, Moosavi SH, Banzett RB, Schwartzstein RM. "Tightness" sensation of asthma does not arise from the work of breathing. *Am J Respir Crit Care Med*. 2002;165:78-82.
17. Laveneziana P, Lotti P, Coli C, Binazzi B, Chiti L, Stendardi L, et al. Mechanisms of dyspnoea and its language in patients with asthma. *Eur Respir J*. 2006;27(4):742-7.
18. Carrieri V, Kieckhefer G, Jason-Bjerklie S, Souza J. The sensation of pulmonary dyspnea in school-age children. *Nurs Res*. 1991;40(2):81-5.
19. O'Donnell DE, Bertley JC, Chau LKL, Webb KA. Qualitative aspects of exertional breathlessness in chronic airflow limitation. *Am J Respir Crit Care Med*. 1997;155:109-15.

20. Skevington S, Pilaar M, Routh D, MacLeod RD. On the language of breathlessness. *Psychol Health*. 1997;12:677-89.
21. O'Donnell DE, Chau LKL, Webb KA. Qualitative aspects of exertional dyspnea in patients with interstitial lung disease. *J Appl Physiol*. 1998;84(6):2000-9.
22. Moy ML, Latin ML, Harver A, Schwartzstein RM. Language of dyspnea in assessment of patient with acute asthma treated with nebulized albuterol. *Am J Respir Crit Care Med*. 1998;158:749-53.
23. O'Driscoll M, Corner J, Bailey C. The experience of breathlessness in lung cancer. *Eur J Cancer Care (Engl)*. 1999;8:37-43.
24. Hardie G, Janson S, Gold WM, Carrieri-Kohlman V, Boushey HA. Ethnic Differences. Word descriptors used by African-American and white asthma patients during induced bronchoconstriction. *Chest*. 2000;177(4):935-43.
25. Harver A, Mahler DA, Schwartzstein RM, Baird JC. Descriptors of breathlessness in healthy individuals. *Chest*. 2000;118:679-90.
26. Parshall M, Welsh JD, Brockopp DY, Heiser RM, Schooler MP, Cassidy KB. Dyspnea duration, distress, and intensity in emergency department visits for heart failure. *Heart Lung*. 2001;30(1):47-56.
27. Parshall M, Welsh JD, Brockopp DY, Heiser RM, Schooler MP, Cassidy KB. Reliability and validity of dyspnea sensory quality descriptors in heart failure patients treated in an emergency department. *Heart Lung*. 2001;30(1):57-65.
28. Phankingthongkum S, Daengsuwan T, Visitsunthorn Thamlikitkul V, Udompunthuruk S, Vichyanond P. How do Thai children and adolescents describe asthma symptoms?. *Pediatr Allergy Immunol*. 2002;12:119-24.
29. Evans K, Banzett RB, Adams L, McKay L, Frackowiak RSJ, Corfield DR. BOLD fMRI identifies limbic, paralimbic and cerebellar activation during air hunger. *J Neurophysiol*. 2002;88:1500-11.
30. Parshall M. Psychometric characteristics of dyspnea descriptor ratings in emergency department patients with exacerbated chronic obstructive pulmonary disease. *Res Nurs Health*. 2002;25:331-44.
31. Heinzer M, Bish C, Detwiler R. Acute dyspnea as perceived by patients with chronic obstructive pulmonary disease. *Clin Nurs Res*. 2003;12(1):85-101.
32. Michaels C, Meek PM. The language of breathing among individuals with chronic obstructive pulmonary disease. *Heart Lung*. 2004;33(6):390-400.
33. Yoos H, Kitzman H, McMullen A, Sidora-Arcoleo, Anson E. The language of breathlessness: do families and health care providers speak the same language when describing asthma symptoms?. *J Pediatr Health Care*. 2005;19:197-205.
34. Edmonds P, Rogers A, Addington-Hall JM, McCoy A, Coats AJS, Gibbs JSR. Patient descriptions of breathlessness in heart failure. *Int J Cardiol*. 2005;98:61-6.
35. Han J, Zhu Y, Li S, Chen X, Put C, Van de Woestijne KP et al. Respiratory complaints in Chinese. *Chest*. 2005;127:1942-51.
36. Insel KC, Meek PA, Leventhal H. Differences in illness representation among pulmonary patients and their providers. *J Health Psychol*. 2005;10(1):147-62.
37. Coli C, Picariello M, Stendardi L, Grazzini M, Binazzi B, Duranti R, et al. Is there a link between the qualitative descriptors and the quantitative perception of dyspnea in asthma?. *Chest*. 2006;130(2):436-41.
38. Lougheed MD, Fisher T, O'Donnell DE. Dynamic hyperinflation during bronchoconstriction in asthma: implications for symptom perception. *Chest*. 2006;130(4):1072-81.
39. Michaels C. Content validity and the language of breathing. *Heart Lung*. 2006;35(6):405-11.
40. Vazquez-Garcia J, Balcazar-Cruz Ca, Cervantes-Mendez G, Mejia-Alfaro R, Cossio-Alcantara J, Ramirex-Venegas A. Descriptors of breathlessness in Mexican Spanish. *Arch Bronconeumol*. 2006;42(5):211-17.
41. Dawson B, Trapp RG. *Basic & Clinical Biostatistics*, 4th ed, New York: Lange Medical Book / McGraw-Hill; 2004.
42. Sutton K, Cooper M, Pimm J, Wallace L. Anxiety in chronic obstructive pulmonary disease: the role of illness specific catastrophic thoughts. *Cognit Ther Res*. 1999;23(6):573-85.
43. Ambrosino N, Scano G. Topical Review. Measurement and treatment of dyspnoea. *Respir Med*. 2001;95:539-47.
44. Schwartzstein RM. Language of Dyspnea. In: Mahler DA, O'Donnell DE, editors. *Dyspnea Mechanisms, Measurement and Management*. Boca Raton: Taylor and Francis; 2005.p.115-45.