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Distress with Breathing in People with Lung Cancer: A Systematic Review

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ABSTRACT

While the prevalence of shortness of breath has been reported to be as frequent as pain in people with lung cancer, less attention has been paid to the distress associated with this symptom (dyspnea). This systematic review of the literature was undertaken to investigate how this symptom has been assessed and whether breathlessness in people with lung cancer is distressing. Using a pre-determined search strategy and inclusion criteria, thirty-one primary studies were identified and included in this review. A variety of outcome measures have been used to assess the experience of dyspnea with domains including intensity, distress, quality of life, qualitative sensation and prevalence. The distress associated with breathlessness appears to be variable, with some studies reporting it to be the most distressing sensation, while others report lower levels of distress. Overall the studies reflect a high prevalence of dyspnea in lung cancer patients, with subjects experiencing a moderate level of dyspnea intensity and interference with activities of daily living. Overall, the findings of this review indicate that dyspnea was a common symptom experienced by people with lung cancer with varying degrees of intensity and unpleasantness. Thus, if dyspnea and pain are both distressing sensations for people with lung cancer, this has potential implications for both clinical and academic areas, with regards to both management strategies and further research.

BACKGROUND

There are currently in excess of 1.3 million people worldwide affected by lung cancer.¹ Lung cancer is the leading cause of cancer death in the United States, with an estimated 565,650 people dying from lung cancers in 2008.² Up to ninety percent of lung cancer is related to active cigarette smoking, with the remaining ten percent mainly caused by passive smoking and exposure to medical radiation and environmental factors such as asbestos and silica.¹ People with lung cancer experience symptoms which vary between individuals, resulting in a range of symptoms which people might find distressing.³ There are several common signs and symptoms associated with lung cancer, which can be classified as a result of the primary tumour, intra-thoracic spread, distant metastases, paraneoplastic syndromes or they may be non-specific symptoms.³ The most common signs and symptoms relating to a primary lung tumour, and therefore corresponding to early stage disease, are: cough, dyspnea (distress with breathing or breathing discomfort) haemoptysis (coughing up blood) and chest discomfort. Non-specific symptoms such as weight-loss or fatigue are also common in the initial stages of lung cancer.³

Pain and dyspnea have been reported to be common distressing symptoms in people with cancer. Beckles et al (2003) report that while 6 to 25% of people with lung cancer will experience bone pain and 20 to 49% will experience chest pain, somewhere between 3 and 60% will experience dyspnea.³ While the incidence of dyspnea in people with lung cancer has been reported to be at least as frequent as pain, its presence is underappreciated and potentially not scrutinized or investigated to the same extent.⁴ For example, a preliminary search of the database Scopus reveals almost twice as much literature addressing pain and

pain management in people with lung cancer, compared with that of dyspnea. The purpose of this paper is to systematically review primary studies of people with lung cancer in order to answer two specific questions:

1. *Which outcome measures have been used to assess breathlessness?*
2. *What evidence is there that breathlessness is distressing?*

SYSTEMATIC SEARCH STRATEGY

A systematic search process was undertaken to identify peer reviewed publications specifically investigating the sensation of breathlessness in people with lung cancer. When developing the review question, the PICO structure was used. PICO is an acronym for population, interventions, comparisons and outcomes.⁵ The population of interest was adults with lung cancer, of any type or stage. Studies were limited to observation or epidemiological studies. As the intent of the systematic review was not to explore the evidence for management strategies for breathlessness, no intervention or comparator was specified for this question. The outcome of interest was data on the sensation of dyspnea or breathlessness. Three groups of search terms were identified. The first group of search terms included lung cancer and lung neoplasms, the second: dyspnea and breathlessness; and third: distress, perception and sensation. Each term within a group was separated by "or" and each group was separated by "and". The database search was undertaken between late February and early March 2008. The databases (Ovid) Medline and Embase, Cochrane Library, CINAHL, PsycINFO and Scopus were searched using the default settings except in Ovid, where 'advanced search' was used. Table 1 presents the citations retrieved using the search strategy, and those which were retained in each database.

Table 1: Retrieved and retained citations in each database

Database	Date of Search	Retrieved citations	Retained citations
MEDLINE	26/02/08	339	2
EMBASE	26/02/08	418	8
Cochrane Library	26/02/08	137	0
CINAHL	28/02/08	186	13
PsycINFO	28/02/08	174	2
Scopus	02/03/08	391	6

During the first wave of the search, citations were retained if they met the following five criteria:

1. Must refer to distress/perception/sensation of dyspnea/breathlessness or symptoms, rather than psychological distress in the abstract or title
2. Must not refer to any drugs for the treatment of breathlessness/dyspnea
3. Subjects: must include lung cancer
4. Language of publication: English
5. Publication: peer reviewed journal article (no grey literature)

The search identified 143 articles where the title met the inclusion criteria. When information in the abstract for each citation was reviewed, 36 citations were excluded as they did not meet the inclusion criteria. Full text versions of citations were retrieved for the remaining 107 articles meeting the inclusion criteria or where abstracts were ambiguous and could not be confidently excluded from the review. Upon retrieval of the full versions, articles were included within the systematic review if they met the following four criteria (second wave of review):

1. Must meet the above five criteria on review of the full-text article
2. Must not be a study investigating an intervention for the management of breathlessness (except cohort studies which included an intervention as part of the normal treatment (e.g. surgery, chemotherapy or radiotherapy) and were not compared to a control group (i.e. not explicitly an intervention study)
3. Report original primary, data (continuous ratio, categorical, nominal scales or text) on the presence of dyspnea (intensity/qualitative sensation /severity/associated distress)
4. Data specific to people with lung cancer data must be able to be extracted

Thirty-one articles were retained which satisfied the above criteria. Table 2 details each of the studies included in the review in terms of research design, sample size and stage of cancer.

Table 2: Characteristics of the articles retained in the second wave of the search strategy

Article	Research design	Sample size (n =)	Lung cancer stage
Tishelman et al 2007 ⁶	Longitudinal	400	I-IV
Broberger et al 2007 ⁷	Longitudinal	46	Not reported
Hench et al 2007 ⁸	Longitudinal	105	Not reported
Hirakawa et al 2006 ⁹	Observational	33 (26%)	Not reported
Tanaka et al 2002a ¹⁰	Observational	157	IIIA-IV and recurrent
Heedman and Strang 2001 ¹¹	Longitudinal	60 (14%)	Not reported
Smith et al 2001 ¹²	Observational	120	I-IV
Hopwood and Stephens 1995 ¹³	Observational	819	Not reported
Sarna 1993 ¹⁴	Observational	69	Not reported
Brown et al 1986 ¹⁵	Longitudinal	30	Limited + extensive disease + stage III
Lai et al 2007 ¹⁶	Qualitative descriptive	11	IIIB and IV
Broberger et al 2005 ¹⁷	Longitudinal	85	Not reported
Oh 2004 ¹⁸	Cross-sectional	106	I-IV
Kuo and Ma 2002 ¹⁹	Descriptive correlation	73	Majority stage IV, others not reported
Tanaka et al 2002b ²⁰	Observational	171	III, IV or recurrent stage
Tanaka et al 2002c ²¹	Observational	171	III, IV or recurrent stage
Kurtz et al 2002 ²²	Longitudinal	228	Early and late stage disease
Lutz et al 2001 ²³	Observational	69	IV, extensive stage, locally recurrent
Tishelman et al 2000 ²⁴	Longitudinal	26	Not reported
Kurtz et al 2000 ²⁵	Cross-sectional	129	Early and late stage disease
O'Driscoll et al 1999 ²⁶	Prospective RCT	52	Not reported
Lobchuk et al 1997 ²⁷	Observational	41	Limited and extensive disease, stages I-IV
Sarna and Brecht 1997 ²⁸	Observational	60	Advanced stage
Sarna 1995 ²⁹	Observational	65	Not reported
McCorkle and Quint-Benoiel 1983 ³⁰	Longitudinal	67	Not reported
Chan et al 2005 ³¹	Longitudinal	27	Advanced stage
Clayson et al 2005 ³²	Qualitative	15	Not reported
Tishelman et al 2005 ³³	Longitudinal	400	I-IV
Akechi et al 2002 ³⁴	Longitudinal	129	III-IV
Dudgeon et al 2001 ³⁵	Observational	37 (4%)	Not reported
Langendijk et al 2000 ³⁶	Observational	262	I-IV

RCT = Randomised Controlled Trial

I, II, III(B), IV = Cancer stages 1, 2, 3(B), 4

APPRAISAL OF POTENTIAL BIAS

Each article was appraised for potential bias using a four point checklist devised especially for use in this review. Four key points were identified which could potentially affect the believability of the dyspnea data:

1. Subjects needed to have a definite diagnosis of lung cancer
2. Reliability and validity needed to be reported or cited for the dyspnea outcome measure
3. The assessment method needed to be described adequately to permit repeatability
4. The data needed to represent the lung cancer patients (i.e. minimal missing data)

Table 3 presents the results of the appraisal process. A shaded cell indicates the study fulfilled the criterion whereas an unshaded cell indicates it was unclear from the detail provided in the study as to whether the criterion was satisfied. Only nine of the 31 articles satisfied the four criteria. All of the studies met the first criteria of a diagnosis of lung cancer. Twenty-four articles reported the reliability and validity of the instrument used to assess dyspnea and seventeen studies reported a complete or near complete data set. Large amounts of missing data have the potential to bias the study's results and influence the believability of the data. The least satisfied criterion occurred in the description of the assessment method; with only sixteen studies providing sufficient detail to allow for replication. Thus bias potentially exists for the reliability and validity of assessment tools for dyspnea

and for the replicability of the studies. A single study satisfied only one criterion, with the majority of studies satisfying all or most of the criteria. Therefore confidence can be placed to some extent in the accuracy of the believability of the dyspnea data.

Table 3: Appraisal of potential bias within studies (n=31).

Article	Lung cancer	Tool	Method	Data
Tishelman et al 2007 ⁶				
Broberger et al 2007 ⁷				
Henoch et al 2007 ⁸				
Hirakawa et al 2006 ⁹				
Tanaka et al 2002a ¹⁰				
Heedman and Strang 2001 ¹¹				
Smith et al 2001 ¹²				
Hopwood and Stephens 1995 ¹³				
Sarna 1993 ¹⁴				
Brown et al 1986 ¹⁵				
Lai et al 2007 ¹⁶				
Broberger et al 2005 ¹⁷				
Oh 2004 ¹⁸				
Kuo and Ma 2002 ¹⁹				
Tanaka et al 2002b ²⁰				
Tanaka et al 2002c ²¹				
Kurtz et al 2002 ²²				
Lutz et al 2001 ²³				
Tishelman et al 2000 ²⁴				
Kurtz et al 2000 ²⁵				
O'Driscoll et al 1999 ²⁶				
Lobchuk et al 1997 ²⁷				
Sarna and Brecht 1997 ²⁸				
Sarna 1995 ²⁹				
McCorkle and Quint-Benoiel 1983 ³⁰				
Chan et al 2005 ³¹				
Clayson et al 2005 ³²				
Tishelman et al 2005 ³³				
Akechi et al 2002 ³⁴				
Dudgeon et al 2001 ³⁵				
Langendijk et al 2000 ³⁶				

Grey: satisfied criterion, White: unclear if criterion satisfied

OUTCOME MEASURES FOR BREATHLESSNESS

Eighteen separate outcome measures were used to assess breathlessness in the 31 studies (Table 4). Studies using different types of questionnaires and interviews were grouped under the collective terms of 'questionnaire' or 'interview'. Several composite outcome measures included a number of different discrete outcome measures. For example the Edmonton Symptom Assessment Scale (ESAS) consists of nine separate Visual Analogue Scales (VAS). Table 4 presents the outcome measures used to assess the sensation of breathlessness

Table 4: Outcome measures for the sensation of breathlessness within the studies retained for the review

Article	ESAS ¹	C30 ²	LC13 ³	TSSD ⁴	FL ⁵	CDS ⁶	VAS ⁷	SDS ⁸	RSCl ⁹	DAG ¹⁰	Q11	I12	SES ¹³	DNS ¹⁴	VRS ¹⁵	LCSS ¹⁶	GBS ¹⁷	AQEL ¹⁸	
Tishelman et al 2007 ⁶																			
Broberger et al 2007 ⁷																			
Henoch et al 2007 ⁸																			
Hirakawa et al 2006 ⁹																			
Tanaka et al 2002a ¹⁰																			
Heedman and Strang 2001 ¹¹																			
Smith et al 2001 ¹²																			
Hopwood and Stephens 1995 ¹³																			
Sarna 1993 ¹⁴																			
Brown et al 1986 ¹⁵																			
Lai et al 2007 ¹⁶																			
Broberger et al 2005 ¹⁷																			
Oh 2004 ¹⁸																			
Kuo and Ma 2002 ¹⁹																			
Tanaka et al 2002b ²⁰																			
Tanaka et al 2002c ²¹																			
Kurtz et al 2002 ²²																			
Lutz et al 2001 ²³																			
Tishelman et al 2000 ²⁴																			
Kurtz et al 2000 ²⁵																			
O'Driscoll et al 1999 ²⁶																			
Lobchuk et al 1997 ²⁷																			
Sarna and Brecht 1997 ²⁸																			
Sarna 1995 ²⁹																			
McCorkle and Quint-Benoliel 1983 ³⁰																			
Chan et al 2005 ³¹																			
Clayson et al 2005 ³²																			
Tishelman et al 2005 ³³																			
Akechi et al 2002 ³⁴																			
Dudgeon et al 2001 ³⁵																			
Langendijk et al 2000 ³⁶																			

¹Edmonton Symptom Assessment Scale, ²EORTC-QLQ-C30, ³EORTC-QLQ-LC13, ⁴Thurstone Scale of Symptom Distress, ⁵Free-listing, ⁶Cancer Dyspnea Scale, ⁷Visual Analogue Scale, ⁸Symptom Distress Scale, ⁹Rotterdam Symptom Checklist, ¹⁰Dyspnea Assessment Guide, ¹¹Questionnaire, ¹²Interview, ¹³Symptom Experience Scale, ¹⁴Dypnea Numerical Scale, ¹⁵Verbal Rating Scale for Dyspnea, ¹⁶Lung Cancer Symptom Scale, ¹⁷Grade of Breathlessness Scale, ¹⁸Assessment of Quality of Life at the End of Life

DEGREE OF DISTRESS ASSOCIATED WITH THE SENSATION OF BREATHLESSNESS IN PEOPLE WITH LUNG CANCER

The following section collates and reports the degree of distress with the sensation of breathlessness in people with lung cancer. The eighteen dyspnea outcome measures were grouped into similar domains. Table 5 presents the five domains for dyspnea assessment, and the outcome measures which fall under each category. Several outcome measures are listed in two or more domains as they satisfy multiple criteria. However outcomes were also listed in several or alternate columns to which they were originally intended. For example, the VAS and VRS have the ability to measure the intensity of dyspnea, however as the intensity wasn't reported in the study, data was only able to be extracted on the presence of dyspnea and thus was classified under an

alternate heading for which it was originally designed.³⁵ Whether the data obtained from studies using a longitudinal design is based on baseline measures or averaged over several time periods is also reported.

Table 5: Outcome measures categorized according to the mode of dyspnea assessment

Domain	Outcome measure
Symptom intensity	Visual Analogue Scale (VAS), Edmonton Symptom Assessment Scale (ESAS), Dyspnea Numerical Scale (DNS), Grade of Breathlessness Scale (GBS), European Organization for the Research and Treatment of Cancer questionnaire (EORTC-QLQ-C30 and EORTC-QLQ-LC13), Assessment of Quality of Life at the End of Life questionnaire (AQEL)
Quality of life	Questionnaires
Symptom distress	Thurstone Scale of Symptom Distress (TSSD), Cancer Dyspnea Scale (CDS), Symptom Distress Scale (SDS), Free-listing
Symptom prevalence	Lung Cancer Symptom Scale (LCSS), Questionnaire, Symptom Experience Scale (SES), Rotterdam Symptom Checklist (RSCL), Verbal Rating Scale for Dyspnea (VRS), VAS, Interview, Dyspnea Assessment Guide (DAG)
Interview	Interview, Free-listing

Symptom Intensity

Visual analogue scales (VAS). Four studies assessed resting dyspnea using a visual analogue scale (VAS) anchored with 'no dyspnea' to 'maximum dyspnea'. The mean VAS data in each study was 39.54, 73.3, 8.44 and 45.0 (Brown et al 1986, Lai et al 2007, Chan et al 2005, Heedman and Strang 2001 respectively). Overall the mean VAS across studies was 41.6mm. Overall this indicates a moderate intensity of dyspnea; however the individual VAS results for the four studies convey markedly varied reports of dyspnea intensity (i.e. ranging from very low (8.44mm), to quite high (73.3mm)).

Dyspnea Numerical Scale (DNS). Using the DNS, both Tanaka et al (2002a and 2002c) reported a median DNS score to be 2 out of 10 (range 0-9). Tanaka et al (2002c) reported the mean DNS score to be 2.2 out of 10, while the mean score was not reported for Tanaka et al (2002a). Overall this indicates a low intensity of dyspnea.

Grade of Breathlessness Scale (GBS). Using the GBS, Brown et al (1986) reported the mean dyspnea score to be 3.64 on a 0 (no shortness of breath) to 5 (too breathless to leave the house) scale (baseline measure). This indicates a moderate-high intensity of dyspnea.

European Organization for the Research and Treatment of Cancer questionnaire (EORTC-QLQ-C30, EORTC-QLQ-LC13), Assessment of Quality of Life at the End of Life questionnaire (AQEL). These three outcome measures assess quality of life via questionnaires; however they have been included in the 'symptom intensity' section as the breathlessness components of the quality of life questionnaires by themselves do not convey quality of life. The average dyspnea score for the three studies, assessed using the EORTC-QLQ-C30 and LC13 was 46 (0-100 scale), where a higher score indicates a greater degree of symptoms (and a likely poorer quality of life). These results signify moderate degree of dyspnea (Table 6). Henoch et al 2007 used the AQEL to assess quality of life at the end of life. Individual dyspnea scores were reported to be 8.5 (1-10 scale) (averaged over 5 time periods), whereby higher scores indicate less symptom burden. This indicates a rather low dyspnea burden.

Table 6: Individual dyspnea scores as assessed by the EORTC-QLQ-C30 and LC13

Mean Dyspnea score (0-100)	Tishelman et al 2007 ⁶	Broberger et al 2007 ⁷	Langendijk et al 2000 ³⁶	Henoch et al 2007 ⁸
EORTC-QLQ-C30	53 (average 6 time periods)	63 (average 3 time periods)	38 (average 3 groups, C30 and LC13 not differentiated between)	
EORTC-QLQ- LC13	39 (average 6 time periods)	39 (average 3 time periods)		
AQEL				8.5 (averaged over 5 time periods)

Quality of life

Questionnaires: Tanaka et al (2002a and 2002c) used 'interference' questionnaires to investigate the impact of dyspnea on activities of daily living. Tanaka et al (2002a) reported that 52 percent (n = 81) of subject's dyspnea interfered with any physical domain, while 23 percent (n = 36) interfered with any psychological domain. Tanaka et al (2002c) reported that dyspnea interfered with at least one daily life activity in 55 percent of patients (n = 94).

Symptom Distress

Thurstone Scale of Symptom Distress (TSSD). Interestingly, of the four studies assessing distress associated with dyspnea using the TSSD, the majority report dyspnea to be ranked as the number one distress-causing symptom in lung cancer (Table 8). Tishelman et al 2007 (in all 6 time periods), Broberger et al 2005 (average over several time periods) and Tishelman et al 2005 (baseline) all reported dyspnea to have a TSSD ranking of one, while Tishelman et al 2000 (baseline) reported dyspnea to have a TSSD ranking of two.

Cancer Dyspnea Scale (CDS). Three studies used the multidimensional CDS to assess dyspnea, with two reporting median values (Tanaka et al 2002a and 2002b) and two reporting mean values (Tanaka et al 2002b and Henoch et al 2007). The combined average total dyspnea score was 7 (out of 48), with median 7, indicating a less severe dyspnea experience. Henoch et al 2007 (baseline measure) reported a mean CDS score of 5.80, while Tanaka et al 2002b reported a mean score of 8 and median score of 7. Similarly, Tanaka et al 2002a reported a median CDS score of 7.

Symptom Distress Scale (SDS). The ten studies using the SDS to assess distress associated with dyspnea reveal a combined average score of 2.1 out of 5 (Table 7). This indicates a moderate level of distress associated with dyspnea overall.

Table 7: Individual SDS scores

SDS score	Sarna et al 1993 ¹⁴	Broberger et al 2005 ¹⁷	Oh 2004 ¹⁸	Kuo and Ma 2002 ¹⁹	Tishelman et al 2000 ²⁴	Lobchuk et al 1997 ²⁷	Sarna and Brecht 1997 ²⁸	Sarna 1995 ²⁹	McCorkle and Quint-Benoliel 1983 ³⁰	Tishelman et al 2005 ³³
	1.9	2.2 [#]	2.48	0.81	2.31 [*]	2.22	1.80	1.78	1.88 [*]	3.6 [*]

*baseline measure, #averaged over several time periods

Using the SDS, four of the ten studies specified a rank for dyspnea with the average being seven, on a scale of 1 to 13 (Sarna et al 1993: Rank 8, Broberger et al 2005: Rank 7 (averaged over several time periods), Lobchuk et al 1997: Rank 5.5 and Sarna and Brecht: Rank 7).

Free-Listing (FL) Free-Listing is a structured approach allowing identification of relevant issues without imposing researchers' assumptions and was used in order to ascertain the patient's most distressing symptoms.⁷ Patients most frequently reported fatigue, pain and dyspnea as those concerns causing them the most distress at both baseline and 6 months follow-up.⁷

Symptom Prevalence

A variety of outcomes were used to report on the prevalence of dyspnea. Table 8 presents the percentage of subjects within each study reported the presence of dyspnea. The average prevalence reported by studies included in this review was 70.5 percent, with a range of 50 to 87 percent. This indicates a high prevalence of dyspnea (Table 8).

Table 8: Dyspnea prevalence

Outcome measures	% of subjects (n=)						
	LCSS	Questionnaire	SES	VAS and VRS	Interview	RSCL	DAG
Lutz et al 2001 ²³	73 (60)						
Hirakawa et al 2006 ⁹		82 (27)					
Kurtz et al 2002 ²²			56 (228)*				
Kurtz et al 2000 ²⁵			61 (79)				
Chan et al 2005 ³¹				59 (27)*			
Dudgeon et al 2001 ³⁵				84 (37)			
Clayson et al 2005 ³²					50 (7)		
Akechi et al 2002 ³⁴					66 (59) †		
Hopwood and Stephens 1995 ¹³						87 (819)	
Smith et al 2001 ¹²							87 (115)

*Baseline measure, †estimated from graph, ‡averaged over several time periods

Interview

The studies which included interviews as an outcome measure assessed many different aspects of dyspnea. These included: the physical and emotional sensations (language) of dyspnea, thoughts, feelings and experiences with dyspnea, causes of dyspnea, the effect of dyspnea on the person's life and their management of dyspnea. While it was not the primary purpose these studies, Brown et al (1986), O'Driscoll et al (1999), Clayson et al (2005), Lai et al (2007), Broberger et al (2007) and Tishelman et al (2005) report on the language used to describe dyspnea. All six studies obtain dyspnea descriptors via interviews, using words volunteered by subjects and /or words selected from a pre-existing list of breathlessness descriptors. Wilcock et al (2002) is the only study to date which has investigated the language of breathlessness using lung cancer patients, using the 'endorsed' descriptor method.³⁷ It should be noted that the Wilcock et al (2002) article was not identified during the systematic search nor did any of the studies included within the review refer to this study. The volunteered descriptors in Lai et al (2007) and Tishelman et al (2005), reported below, are not verbatim from the article, but instead have been classified into breathlessness categories by the review authors. All other studies using volunteered language have taken subject's descriptors and grouped them into similar categories in order to report them (some also reporting the original descriptors as well). Table 9 highlights the most commonly reported dyspnea descriptors in the seven studies.

Table 9: Most commonly reported dyspnea descriptors in the seven studies including data on the language of breathlessness

Brown et al 1986 ^{15*} (2 time periods)	O'Driscoll et al 1999 ^{26*}	Clayson et al 2005 ^{32*}	Lai et al 2007 ^{16*}	Broberger et al 2007 ⁷ (2 time periods)	Tishelman et al 2005 ³³ (several time periods)	Wilcock et al 2002 ^{37#}
Short of breath	Shortness of breath	Fighting for breath	Labour	Decreased breathing capacity	Frightening	I feel out of breath
Difficulty breathing	Panic	Gasping for air	Suffocating	Short of breath	Distress	I cannot get enough air
Hard to move air	Feeling of impending death		Tight			
Tired or fatigued	Fear/fright		Can't breathe			
			Awful			

*Volunteered descriptors, #Endorsed descriptors

With the exception of the endorsed descriptors in Wilcock et al's (2002) study which do not have an affective component, four out of the six studies on language report both physical and affective terms to describe dyspnea. ³⁷ The physical descriptors conveying 'shortness of breath', 'difficulty breathing' and/or 'labour' type words are common to most studies. With the exception

of 'frightening', the affective terms used to describe dyspnea differ between studies; however all of the terms indicate considerable distress associated with the sensation of dyspnea. Inaccurate categorizing, generalisation when reporting the data and differences in sample size and research design may account for differences between the terms used to describe dyspnea in the above studies.

DEGREE OF DISTRESS ASSOCIATED WITH THE SENSATION OF BREATHLESSNESS IN PEOPLE WITH LUNG CANCER (ANALYSED ACCORDING TO STAGE).

The studies included within this systematic review fall into two groups: those reporting on all stages of lung cancer (I-IV), or those only reporting on advanced stage lung cancer (III, IV or extensive disease). The studies were further analysed to determine whether any relationship existed between the stage of lung cancer, and the level of distress associated with dyspnea. Table 10 outlines the studies including subjects with all types of lung cancer, and the corresponding degree of dyspnea unpleasantness; low, moderate or high as reported in previous sections. Table 11 outlines the studies including only subjects with late stage lung cancer, and the subsequent degree of dyspnea unpleasantness.

Table 10: Degree of unpleasantness with dyspnea in studies including subjects with all stages of lung cancer

Article	Data group	Outcome measure	Data	Degree of unpleasantness
Tishelman et al 2007 ⁶	Intensity, Distress	EORTC-C30 and LC13 and TSSD	C30 = 53 LC13 = 39 TSSD = 1	Moderate
Smith et al 2001 ¹²	Prevalence	DAG	87% (n = 115)	High
Oh 2004 ¹⁸	Distress	SDS	2.48	Moderate
Kurtz et al 2002 ²²	Prevalence	SES	56% (n = 228)	Moderate
Kurtz et al 2000 ²⁵	Prevalence	SES	61% (n = 79)	High
Lobchuk et al 1997 ²⁷	Distress	SDS	2.22	Moderate
Tishelman et al 2005 ³³	Distress, Interview	TSSD, SDS, volunteered language	TSSD = 1 SDS = 3.6 Frightening, distress	High
Langendijk et al 2000 ³⁶	Intensity	EORTC-C30 and LC13	C30 + LC13 = 38	Moderate

Table 11: Degree of unpleasantness with dyspnea in studies including subjects with late stage lung cancer

Article	Data group	Outcome measure(s)	Data	Degree of unpleasantness
Tanaka et al 2002a ¹⁰	Intensity, distress, quality of life	DNS, CDS, Q	DNS = 2 (median) CDS = 7 (median) Q = 52% (n = 81)	Low to moderate
Brown et al 1986 ¹⁵	Intensity, Interview	VAS, GBS, volunteered language	VAS = 39.54 GBS = 3.64 Short of breath Difficulty breathing Hard to move air Tired or fatigued	Moderate
Lai et al 2007 ¹⁶	Intensity, Interview	VAS, volunteered language	VAS = 73.3 Labour Suffocating Tight Can't breathe Awful	High
Kuo and Ma 2002 ¹⁹	Distress	SDS	0.81	Low
Tanaka et al 2002b ²⁰	Distress	CDS	7 (median)	Low
Tanaka et al 2002c ²¹	Intensity, Quality of Life	DNS, Q	DNS = 2 (median) Q = 55% (n = 94)	Low to moderate
Lutz et al 2001 ²³	Prevalence	LCSS	73% (n = 60)	High
Sarna and Brecht 1997 ²⁸	Distress	SDS	1.80	Low
Chan et al 2005 ³¹	Intensity	VAS	8.44	Low
Akechi et al 2002 ³⁴	Prevalence	I	66% (n = 59)	High

From the tables 10 and 11, it can be seen that the studies reporting on subjects with all stages of lung cancer generally had moderate-high degree of unpleasantness associated with dyspnea. Conversely, the studies reporting on subjects with advanced lung cancer generally had a larger spread of unpleasantness, ranging from low to high. This suggests that there is no clear relationship between the stage of cancer and level of distress, contrary to notion that the as the more advanced the lung cancer, the higher the distress associated with dyspnea becomes.

SUMMARY OF FINDINGS FOR THE SYSTEMATIC REVIEW

It is clear a variety of different outcome measures were used to assess the experience of dyspnea, and that varying results were obtained, regarding the intensity, prevalence and distress associated with dyspnea. No clear relationship existed between the stage of lung cancer and the degree of distress associated with breathing. Overall the studies report a high prevalence of dyspnea in lung cancer patients, with subjects experiencing a moderate level of dyspnea intensity and interference with activities of daily living. Distress associated with breathing appears to be variable, with some studies reporting dyspnea to be the most distressing sensation, while others report lower levels of distress. The language used to describe the qualitative sensation of dyspnea involved both physical and affective words. Physical descriptors conveying 'shortness of breath', 'difficulty breathing' and/or 'labour' type words were common to all studies, however with the exception of 'frightening' the affective terms used to describe dyspnea differ between studies; although all of the affective terms used indicate considerable distress associated with the sensation of dyspnea. However, taking into account the prevalence, intensity and distress of dyspnea, the general consensus appears to be that the experience of dyspnea in people with lung cancer is common with varying degrees of intensity, but involves considerable unpleasantness. Thus if dyspnea and pain are both distressing sensations for people with lung cancer, this has potential implications for both clinical and academic areas, with regards to both management strategies and further research.

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