

# Dyspnea in lung cancer patients: a systematic review

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**Abstract:** Dyspnea is a common and distressing symptom experienced by 19%–51% of patients with advanced cancer. Higher incidences are reported in patients approaching end of life. While the prevalence of dyspnea has been reported to be as frequent as pain in people with lung cancer, less attention has been paid to the distress associated with dyspnea. This review of the literature was undertaken to investigate how dyspnea has been assessed and whether breathlessness in people with lung cancer is distressing. Using a predetermined search strategy and inclusion criteria, 31 primary studies were identified and included in this review. Different outcome measures were used to assess the experience of dyspnea, with domains including intensity, distress, quality of life, qualitative sensation, and prevalence. 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, and others reporting lower levels of distress. 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.

**Keywords:** breathlessness, distress, neoplasm, scale, fatigue

## Introduction

Lung cancer, the most common cause of cancer-related death in men and women, is responsible for 1.3 million deaths worldwide annually.<sup>1</sup> Mortality from lung cancer remains very high worldwide. 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.<sup>2</sup> People with lung cancer experience symptoms which vary between individuals, resulting in a range of symptoms which people might find distressing.<sup>3</sup> There are several common signs and symptoms associated with lung cancer, which can be classified as a result of the primary tumor, intrathoracic spread, distant metastases, paraneoplastic syndromes, or nonspecific symptoms.<sup>3</sup> The most common signs and symptoms relating to a primary lung tumor, and therefore corresponding to early stage disease, are nonspecific symptoms such as weight loss or fatigue. Cough, dyspnea (distress with breathing or breathing discomfort), hemoptysis (coughing up blood), and chest discomfort are also common in the initial stages of lung cancer.<sup>3</sup>

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Pain and dyspnea have been reported to be common distressing symptoms in people with cancer. Beckles et al report that while 6%–25% of people with lung cancer will experience bone pain and 20%–49% will experience chest pain, somewhere between 3% and 60% will experience dyspnea.<sup>3</sup> While the incidence of dyspnea in people with lung cancer is reported to be at least as frequent as pain, its presence is underappreciated and potentially not analyzed or investigated to the same extent.<sup>4</sup> For example, a preliminary search of the Scopus database 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 review primary studies of people with lung cancer in order to answer two specific questions:

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

## 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<sup>5</sup> (population, interventions, comparisons, and outcomes) structure was used. 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 included lung cancer and lung neoplasms; the second, dyspnea and breathlessness; and the 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 2009. The Ovid MEDLINE, Embase, Cochrane Library, CINAHL, PsycINFO, and Scopus databases 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 from each database.

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

1. The abstract or title refers to distress/perception/sensation of dyspnea/breathlessness or symptoms, rather than psychological distress.
2. It does not refer to any drugs for the treatment of breathlessness/dyspnea.
3. Subjects include those with lung cancer.
4. Language of the publication is English.
5. The publication is a peer-reviewed journal article (not gray 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. It meets the above five criteria on review of the full-text article.
2. It is not a study investigating an intervention for the management of breathlessness, except for cohort studies which include an intervention as part of the normal treatment (eg, surgery, chemotherapy, or radiotherapy) and were not compared with a control group (ie, not explicitly an intervention study).
3. It reports 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 are able to be extracted.

Thirty-one articles were retained that 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 1** Retrieved and retained citations from each database

Database	Date of search	Retrieved citations	Retained citations
MEDLINE	26/02/2009	339	2
Embase	26/02/2009	418	8
Cochrane Library	26/02/2009	137	0
CINAHL	28/02/2009	186	13
PsycINFO	28/02/2009	174	2
Scopus	2/3/2009	391	6

**Table 2** Characteristics of the articles retained from the second wave of the search strategy

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

**Abbreviation:** RCT, randomized controlled trial.

## Appraisal of potential bias

Each article was appraised for potential bias using a four-point checklist devised especially for use in this review. The following four key points were identified that 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 (ie, 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. Nine of the 31 articles satisfied the four criteria. All of the studies met the first criterion of a diagnosis of lung cancer. Twenty-four articles reported the reliability and validity of the instrument used to assess dyspnea, and 17 studies reported a complete or near complete dataset. 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 16 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 <sup>6</sup>	X	X	X	X
Broberger et al <sup>7</sup>	X	X	X	X
Henoch et al <sup>8</sup>	X	X	O	X
Hirakawa et al <sup>9</sup>	X	O	O	X
Tanaka et al <sup>10</sup>	X	X	X	X
Heedman and Strang <sup>11</sup>	X	O	O	X
Smith et al <sup>12</sup>	X	X	X	O
Hopwood and Stephens <sup>13</sup>	X	O	O	X
Sarna <sup>14</sup>	X	X	X	O
Brown et al <sup>15</sup>	X	X	O	O
Lai et al <sup>16</sup>	X	X	X	X
Broberger et al <sup>17</sup>	X	X	O	O
Oh <sup>18</sup>	X	X	X	X
Kuo and Ma <sup>19</sup>	X	X	O	O
Tanaka et al <sup>20</sup>	X	O	X	X
Tanaka et al <sup>21</sup>	X	X	X	X
Kurtz et al <sup>22</sup>	X	X	X	X
Lutz et al <sup>23</sup>	X	X	O	O
Tishelman et al <sup>24</sup>	X	X	O	X
Kurtz et al <sup>25</sup>	X	O	X	X
O'Driscoll et al <sup>26</sup>	X	X	O	O
Lobchuk et al <sup>27</sup>	X	X	O	O
Sarna and Brecht <sup>29</sup>	X	X	O	O
Sarna <sup>28</sup>	X	X	X	X
McCorkle and Quint-Benoliel <sup>30</sup>	X	X	X	O
Chan et al <sup>31</sup>	X	X	X	X
Clayson et al <sup>32</sup>	X	O	X	O
Tishelman et al <sup>33</sup>	X	X	X	O
Akechi et al <sup>34</sup>	X	O	O	O
Dudgeon et al <sup>35</sup>	X	X	O	X
Langendijk et al <sup>36</sup>	X	X	O	O

**Abbreviations:** X, satisfied criterion; O, unclear whether criterion satisfied.

## Outcome measures for dyspnea

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 analog scales (VAS). Table 4 presents the outcome measures used to assess the sensation of breathlessness.

## Domains of dyspnea assessment

The following section collates and reports the degree of distress with the sensation of breathlessness in people with lung cancer. The 18 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 alternative columns to which they were originally intended. For example, the VAS and the Verbal Rating Scale for dyspnea (VRS) have the ability to measure the intensity of dyspnea; however, as the intensity was not reported in the study, data were only able to be extracted on the presence of dyspnea and thus were classified under an alternative heading for which they were originally designed.<sup>35</sup> Whether the data obtained from studies using a longitudinal design are based on baseline measures or averaged over several time periods is also reported.

## Symptom intensity VASs

Four studies assessed resting dyspnea using a VAS anchored with “no dyspnea” to “maximum dyspnea”.<sup>11,15,16,31</sup> Overall, these four

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

Article	ESAS <sup>a</sup>	C30 <sup>b</sup>	LC13 <sup>c</sup>	TSSD <sup>d</sup>	FL <sup>e</sup>	CDS <sup>f</sup>	VAS <sup>g</sup>	SDS <sup>h</sup>	RSCL <sup>i</sup>	DAG <sup>j</sup>	Q <sup>k</sup>	I <sup>l</sup>	SES <sup>m</sup>	DNS <sup>n</sup>	VRS <sup>o</sup>	LCSS <sup>p</sup>	GBS <sup>q</sup>	AQEL <sup>r</sup>	
Tishelman et al <sup>6</sup>																			
Broberger et al <sup>7</sup>																			
Henoeh et al <sup>8</sup>																			
Hirakawa et al <sup>9</sup>																			
Tanaka et al <sup>10</sup>																			
Heedman and Strang <sup>11</sup>																			
Smith et al <sup>12</sup>																			
Hopwood and Stephens <sup>13</sup>																			
Sarna et al <sup>14</sup>																			
Brown et al <sup>15</sup>																			
Lai et al <sup>16</sup>																			
Broberger et al <sup>17</sup>																			
Oh <sup>18</sup>																			
Kuo and Ma <sup>19</sup>																			
Tanaka et al <sup>20</sup>																			
Tanaka et al <sup>21</sup>																			
Kurtz et al <sup>22</sup>																			
Lutz et al <sup>23</sup>																			
Tishelman et al <sup>24</sup>																			
Kurtz et al <sup>25</sup>																			
O'Driscoll et al <sup>26</sup>																			
Lobchuk et al <sup>27</sup>																			
Sarna and Brecht <sup>29</sup>																			
Sarna <sup>28</sup>																			
McCorkle and Quint-Benolie <sup>30</sup>																			
Chan et al <sup>31</sup>																			
Clayson et al <sup>32</sup>																			
Tishelman et al <sup>33</sup>																			
Akechi et al <sup>34</sup>																			
Dudgeon et al <sup>35</sup>																			
Langendijk et al <sup>36</sup>																			

**Notes:** <sup>a</sup>Edmonton Symptom Assessment Scale; <sup>b</sup>European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC-QLQ-C30); <sup>c</sup>European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire LC13 (EORTC-QLQ-LC13); <sup>d</sup>Thurstone Scale of Symptom Distress; <sup>e</sup>Free-listing; <sup>f</sup>Cancer Dyspnea Scale; <sup>g</sup>Visual Analog Scale; <sup>h</sup>Symptom Distress Scale; <sup>i</sup>Rotterdam Symptom Checklist; <sup>j</sup>Dyspnea Assessment Guide; <sup>k</sup>Questionnaire; <sup>l</sup>Interview; <sup>m</sup>Symptom Experience Scale; <sup>n</sup>Dypnea Numerical Scale; <sup>o</sup>Verbal Rating Scale for Dyspnea; <sup>p</sup>Lung Cancer Symptom Scale; <sup>q</sup>Grade of Breathlessness Scale; <sup>r</sup>Assessment of Quality of Life at End of Life.

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

Domain	Outcome measure
Symptom intensity	Visual Analog 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 Quality of Life Questionnaires (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

studies indicate a moderate intensity of dyspnea; however, the individual VAS results for the four studies convey markedly varied reports of dyspnea intensity.

### Dyspnea numerical scale

Using the Dyspnea Numerical Scale (DNS), Tanaka et al reported in two studies a median DNS score of 2 out of 10 (range 0–9).<sup>10,21</sup> In one of these studies, the mean DNS score was reported to be 2.2 out of 10,<sup>21</sup> while in the other study, the mean score was not reported.<sup>10</sup> Overall, this indicates a low intensity of dyspnea.

### Grade of breathlessness scale

Using the Grade of Breathlessness Scale (GBS), Brown et al 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).<sup>15</sup> This indicates a moderate–high intensity of dyspnea.

## European organization for the research and treatment of cancer quality of life questionnaire C30 and LC13, assessment of quality of life at the end of life questionnaire

The above three outcome measures assess quality of life via questionnaires; however, they have been included in the above 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 European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC-QLQ-C30) and EORTC-QLQ-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 a moderate degree of dyspnea (Table 6). Hensch et al used the Assessment of Quality of Life at the End of Life questionnaire (AQEL) to assess quality of life at end of life.<sup>8</sup> Individual dyspnea scores were reported to be 8.5 (1–10 scale) (averaged over five time periods), whereby higher scores indicate less symptom burden. This study indicates a rather low dyspnea burden.

## Quality of life Questionnaires

Tanaka et al, in two studies, used “interference” questionnaires to investigate the impact of dyspnea on activities of daily living.<sup>10,21</sup> In one of those studies, the authors reported that 52% (n = 81) of a subject’s dyspnea interfered with any physical domain, while 23% (n = 36) interfered with any psychological domain. In the other study, they reported that dyspnea interfered with at least one daily life activity in 55% of patients (n = 94).<sup>21</sup>

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

Mean dyspnea score (0–100)	Tishelman et al <sup>6</sup>	Broberger et al <sup>7</sup>	Langendijk et al <sup>36</sup>	Hensch et al <sup>8</sup>
EORTC-QLQ-C30	53 (average six time periods)	63 (average three time periods)	38 (average three groups, C30 and LC13 not differentiated between)	
EORTC-QLQ-LC13	39 (average six time periods)	39 (average 3 time periods)		
AQEL				8.5 (averaged over five time periods)

**Abbreviations:** AQEL, Assessment of Quality of Life at the End of Life questionnaire; EORTC-QLQ-C30/LC13, European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire C30/LC13.

**Table 7** Individual Symptom Distress Scale (SDS) scores

Article	SDS score
Sarna et al <sup>14</sup>	1.9
Broberger et al <sup>17</sup>	2.2 <sup>a</sup>
Oh <sup>18</sup>	2.48
Kuo and Ma <sup>19</sup>	0.81
Tishelman et al <sup>24</sup>	2.31 <sup>b</sup>
Lobchuk et al <sup>27</sup>	2.22
Sarna and Brecht <sup>29</sup>	1.80
Sarna <sup>28</sup>	1.78
McCorkle and Quint-Benoliel <sup>30</sup>	1.88 <sup>b</sup>
Tishelman et al <sup>33</sup>	3.6 <sup>b</sup>

**Notes:** <sup>a</sup>Averaged over several time periods; <sup>b</sup>Baseline measure.

## Symptom distress

### Thurstone scale of symptom distress

Interestingly, of the four studies assessing distress associated with dyspnea using the Thurstone Scale of Symptom Distress (TSSD), the majority report dyspnea to be ranked as the number one distress-causing symptom in lung cancer. Of the four studies, one by Tishelman et al<sup>6</sup> (in all six time periods), one by Broberger et al<sup>17</sup> (average over several time periods), and another by Tishelman et al<sup>33</sup> (baseline) all reported dyspnea to have a TSSD ranking of 1, while yet another by Tishelman et al<sup>24</sup> (baseline) reported dyspnea to have a TSSD ranking of 2.

### Cancer dyspnea scale

Three studies used the multidimensional Cancer Dyspnea Scale (CDS) to assess dyspnea, with two reporting median values<sup>10,20</sup> and two reporting mean values.<sup>8,20</sup> The combined average total dyspnea score was 7 (out of 48), with median 7, indicating a less severe dyspnea experience. Henoche et al<sup>8</sup> (baseline measure) reported a mean CDS score of 5.80, while Tanaka et al<sup>20</sup> reported a mean score of 8 and median score of 7. Similarly, Tanaka et al<sup>10</sup> reported a median CDS score of 7.

## Symptom distress scale

The 10 studies using the Symptom Distress Scale (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.

### Free-listing

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

## 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 reporting the presence of dyspnea. The average prevalence reported by studies included in this review was 70.5%, with a range of 50%–87%. This indicates a high prevalence of dyspnea (Table 8).

## Interview

The studies that 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 of dyspnea, causes of dyspnea, the effect of dyspnea on the person's life, and their management of dyspnea. While it was not their primary purpose, six studies report on the language used to describe dyspnea.<sup>7,15,16,26,32,33</sup> 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. An article by Wilcock et al is the only study to date that has investigated the language of

**Table 8** Dyspnea prevalence (all values in % [n])

Outcome measure	Article									
	Lutz et al <sup>23</sup>	Hirakawa et al <sup>9</sup>	Kurtz et al <sup>22</sup>	Kurtz et al <sup>25</sup>	Chan et al <sup>31</sup>	Dudgeon et al <sup>35</sup>	Clayson et al <sup>32</sup>	Akechi et al <sup>34</sup>	Hopwood and Stephens <sup>13</sup>	Smith et al <sup>12</sup>
LCSS	73 (60)									
Questionnaire		82 (27)								
SES			56 (228) <sup>a</sup>	61 (79)						
VAS and VRS					59 (27) <sup>a</sup>	84 (37)				
Interview							50(7)	66 (59) <sup>c</sup>		
RSCL									87 (819)	
DAG										87 (115)

**Notes:** <sup>a</sup>Baseline measure; <sup>b</sup>Estimated from graph; <sup>c</sup>Averaged over several time periods.

**Abbreviations:** DAG, Dyspnea Assessment Guide; LCSS, Lung Cancer Symptom Scale; RSCL, Rotterdam Symptom Checklist; SES, Symptom Experience Scale; VAS, Visual Analog Scale; VRS, Verbal Rating Scale for dyspnea.

**Table 9** Most commonly reported dyspnea descriptors in the seven studies that included data on the language of breathlessness

Article	Descriptor
Brown et al <sup>15</sup> (two time periods)	Short of breath <sup>a</sup>
	Difficulty breathing <sup>a</sup>
	Hard to move air <sup>a</sup>
	Tired or fatigued <sup>a</sup>
O'Driscoll et al <sup>26</sup>	Shortness of breath <sup>a</sup>
	Panic <sup>a</sup>
	Feeling of impending death <sup>a</sup>
	Fear/fright <sup>a</sup>
Clayson et al <sup>32</sup>	Fighting for breath <sup>a</sup>
	Gasping for air <sup>a</sup>
Lai et al <sup>16</sup>	Labor <sup>a</sup>
	Suffocating <sup>a</sup>
	Tight <sup>a</sup>
	Can't breathe <sup>a</sup>
	Awful <sup>a</sup>
Broberger et al <sup>7</sup> (two time periods)	Decreased breathing capacity
	Short of breath
	Frightening
Tishelman et al <sup>33</sup> (several time periods)	Distress
	I feel out of breath <sup>b</sup>
Wilcock et al <sup>37</sup>	I cannot get enough air <sup>b</sup>

Notes: <sup>a</sup>Volunteered descriptors; <sup>b</sup>Endorsed descriptors.

breathlessness in lung cancer patients using the “endorsed” descriptor method.<sup>37</sup> It should be noted that the 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 reported in the articles by Lai et al<sup>16</sup> and Tishelman et al,<sup>33</sup> reported below, are not verbatim from the articles, but instead have been classified into breathlessness categories by the review authors. All other studies using volunteered language have taken subjects' 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.

With the exception of the endorsed descriptors in Wilcock et al's 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.<sup>37</sup> The physical descriptors conveying “shortness of breath”, “difficulty breathing”, and/or “labor” 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 as well as generalization 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 unpleasantness with dyspnea in people with all stages of lung cancer

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 analyzed 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:

**Table 10** Degree of unpleasantness with dyspnea in studies that include subjects with all stages of lung cancer

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

Abbreviations: DAG, Dyspnea Assessment Guide; EORTC-QLQ-C30/LC13, European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire C30/LC13; SDS, Symptom Distress Scale; SES, Symptom Experience Scale; TSSD, Thurstone Scale of Symptom Distress.



**Table 11** Degree of unpleasantness with dyspnea in studies that include subjects with late stage lung cancer

Article	Data group	Outcome measure(s)	Data	Degree of unpleasantness
Tanaka et al <sup>10</sup>	Intensity, Distress, Quality of Life	DNS, CDS, Q	DNS = 2 (median) CDS = 7 (median) Q = 52% (n = 81)	Low to moderate
Brown et al <sup>15</sup>	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 <sup>16</sup>	Intensity, Interview	VAS, volunteered language	VAS = 73.3 Labor Suffocating Tight Can't breathe Awful	High
Kuo and Ma <sup>19</sup>	Distress	SDS	0.81	Low
Tanaka et al <sup>20</sup>	Distress	CDS	7 (median)	Low
Tanaka et al <sup>21</sup>	Intensity, Quality of Life	DNS, Q	DNS = 2 (median) Q = 55% (n = 94)	Low to moderate
Lutz et al <sup>23</sup>	Prevalence	LCSS	73% (n = 60)	High
Sarna and Brecht <sup>29</sup>	Distress	SDS	1.8	Low
Chan et al <sup>31</sup>	Intensity	VAS	8.44	Low
Akechi et al <sup>34</sup>	Prevalence	I	66% (n = 59)	High

**Abbreviations:** CDS, Cancer Dyspnea Scale; DNS, Dypnea Numerical Scale; GBS, Grade of Breathlessness Scale; I, interview; LCSS, Lung Cancer Symptom Scale; Q, questionnaire; SDS, Symptom Distress Scale; VAS, Visual Analog Scale.

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.

From Tables 10 and 11, it can be seen that the studies reporting on subjects with all stages of lung cancer generally had a 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 the notion that the more advanced the lung cancer, the higher the distress associated with dyspnea becomes.

## Conclusion

It is clear that a variety of different outcome measures was used to assess the experience of dyspnea and that varying results were obtained regarding the intensity, prevalence, and distress associated with dyspnea. 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 involves both physical and affective words. Physical descriptors conveying “shortness of breath”, “difficulty breathing”, and/or “labor” 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 is a distressing sensation for people with lung cancer, this has potential implications for both clinical and academic areas with regards to both management strategies and further research.

## Disclosure

The authors declare that they do not have any financial relationship/interest in a commercial organization that could pose a conflict of interest.

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