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# Experiences of breathlessness: A systematic review of the qualitative literature

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## ABSTRACT

*Objective:* Breathlessness is one of the core symptoms in many advanced conditions. The subjective nature of the symptom has been acknowledged in many definitions, emphasizing that it can only be fully perceived and interpreted by the patients themselves.

*Aim:* To review and assess the evidence on the psychosocial nature or experience of breathlessness.

*Methods:* Relevant literature was identified through electronic and hand searches. Studies with qualitative enquiry or mixed method designs were included. The methodological quality of studies was assessed with a standard grading scale.

*Results:* Twenty-two studies were identified, 12 from the United Kingdom, 4 from the United States, 3 from Canada, 1 from Sweden, 1 from Iceland, and 1 from Finland. The nature of the studies determined the themes in which the studies were subsumed. Studies on COPD (19) outnumbered "all other conditions" (3), one of which had COPD and cancer patients and so these were analyzed separately. Within the COPD category most studies (17) considered the experience of breathlessness from the perspective of the patient, 1 study from the informal carer, and 1 from the professional carer. Most of the papers sought to understand the meaning of the symptom in the patient's daily life. The other papers demarcated separate areas of the experience of acute exacerbations and the patient's view on care. The studies explored the subjective component of breathlessness, as part of human experience and social life. The papers showed the influence of the meaning the symptom has for those affected on their ability to cope and on their management.

*Significance of results:* Although the work in this area is still dominated by research on COPD, the totality of the evidence now shows breathlessness as an intractable symptom in other advanced conditions. Practice recommendations focused on the holistic approach as part of palliative and nursing care.

**KEYWORDS:** Experience of breathlessness, Qualitative literature, Advanced disease, Systematic review, Palliative care

## INTRODUCTION

Breathlessness is a symptom that affects patients with a variety of conditions: It is a common problem

in advanced cancer and a number of nonmalignant diseases such as COPD, cardiac failure, cryptogenic fibrosing alveolitis (CFA), and various neurological conditions. A recent study that compared symptom prevalence among people with five advanced, life-limiting diseases found that breathlessness, together with pain and fatigue, is one of the core symptoms that is particularly persistent and frequent toward the end of life (Solano et al., 2004). Edmonds et al.

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(2001) showed that 78% of patients with cancer, for example, experienced breathlessness in the last year of life. Breathlessness is considered as a clinical marker for the terminal phase of illness, often interpreted as an indication to shift from curative to supportive and palliative care (Escalante et al., 2000). The number of patients suffering from breathlessness is increasing as the prognosis of people with the underlying diseases associated with breathlessness is extending due to improved medical interventions.

Breathlessness pervades all aspects of patients' lives and it is very difficult to manage. Despite treatment, many patients continue to suffer from unrelieved breathlessness. Evidence exists that, although pain was reduced when specialist palliative care was provided, breathlessness worsened as patients with cancer neared death (Higginson & McCarthy, 1989). Hopwood and Stephens (1995) also reported that medical interventions in the management of breathlessness such as steroids, opioids, oxygen, bronchodilators, anxiolytics, and palliative radiotherapy have not been sufficiently effective in alleviating the suffering caused by breathlessness. A Cochrane review (Jennings et al., 2001) has shown that opioid drugs had a small but significant effect in the treatment of breathlessness in advanced disease but adverse effects (e.g., nausea, vomiting, and constipation), which were fairly troublesome, were reported.

Breathlessness or dyspnea is defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (American Thoracic Society, 1999). Many definitions have been employed, increasingly including an element of the subjective nature of the symptom, emphasizing that it can only be perceived and interpreted by the patient him- or herself (Pierson & Hudson, 1981; Gift, 1987). Yet, it is surprising that most of the research on breathlessness is of a purely medical nature and that research has mainly approached the symptom by quantifying it with objective measurement tools. However, several studies have now shown that there is no consistent relationship between the experience of breathlessness and physiological measures (Heyse-Moore et al., 2000). Some patients experience severe dyspnea with minimal physiological changes whereas others with severe disease experience very little dyspnea (West & Popkess-Vawter, 1994).

Breathlessness can be caused by a multiplicity of factors, as it may be due to the underlying condition, the consequences of treatment, or the presence of concurrent diseases. Often, breathlessness is associated with other symptoms such as fatigue, cough, anxiety, panic, pain, headaches, nausea, numbness, and tingling alongside pain (Janson-Bjerklie et al.,

1986). This makes breathlessness a very complex phenomenon to grasp. Traditional explanations of the experience of dyspnea have focused either on the pathological and physiological basis of the symptom or on psychological processes producing its subjective manifestations. This article addresses the patients' experience of breathlessness and how patients and their carers experience this symptom in relation to personal perception and social influence. Much of what we know about this topic comes from a review by Williams (1989), who critically investigated the psychosocial research on COPD. He advocated a sociological perspective on chronic illness and disability similar to how we approach the experience of breathlessness here, as a complementary way to more conventional understandings (Williams, 1989). However, here we aim to review and assess the evidence on breathlessness not within the boundaries of COPD but as a symptom in the context of different conditions that lead to breathlessness. This has not been done before. Also, the time has come to identify work in COPD that has been published since Williams' review and consider whether the same issues are still pertinent.

## METHODS

### Identification of the Literature

Relevant studies were identified by searching

- Computerized databases: MEDLINE (1989 to March Week 2 2005), EMBASE (1989 to 2005 Week 11), CINAHL (1989 to March Week 2 2005), PsychInfo (1989 to March Week 2 2005).
- The reference lists of identified studies: these were searched for further relevant studies.
- The following journals, which were handsearched: *Palliative Medicine*, *Heart & Lung*, *Chest*, and *Social Science and Medicine*.
- The search engine of Google scholar.

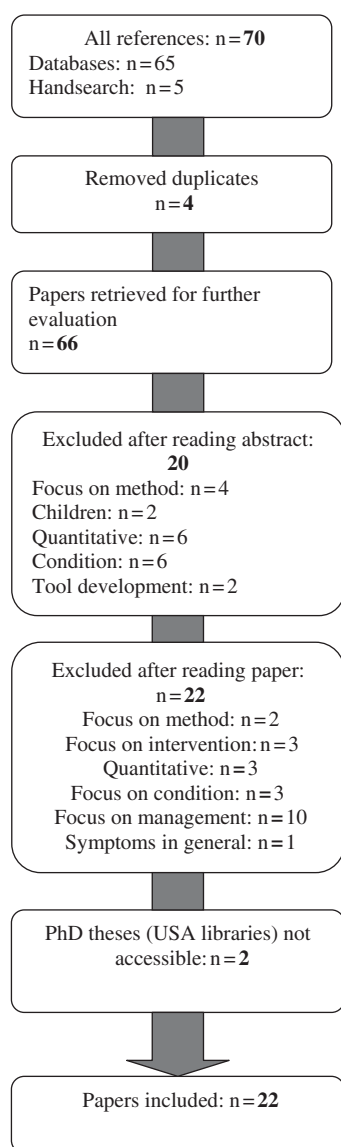
### Search strategy

We used the following keywords: Breathlessness OR, Shortness of breath OR, Dyspnea OR, Dyspnoea OR, Chronic respiratory AND Qualitative OR, Social OR Social science OR, Psychosocial OR, Psycho-social OR, Experience.

### Inclusion Criteria

We included studies on the psychosocial nature or experience of breathlessness as an irreversible

symptom of different conditions (advanced cancer and nonmalignant diseases such as COPD, cardiac failure, CFA, and neurological conditions) and studies using qualitative or mixed method designs so as to explore or interpret the phenomenon of breathlessness in terms of the meanings people bring to them. Papers were excluded in which the primary focus of the study was on research methodology, on interventions or management, on symptoms in general, on the condition rather than the symptom, on breathing problems in children, on tool development, or studies that had a quantitative study design. The process of including and excluding studies in this review is presented in a flow diagram according to QUOROM consort statement (2006) (see Fig. 1).



**Fig. 1.** Quorum flowchart showing studies included and excluded, and reasons.

## Quality Assessment

The methodological quality of the studies was independently scored by two reviewers with a standard grading scale (Hawker et al., 2002; see Table 1).

## RESULTS

### The Nature of the Evidence

We identified 70 papers as potentially relevant; of these, 22 papers met our inclusion criteria (see Fig. 1). The majority of these, 12, came from the United Kingdom. Of the other papers, 4 came from the United States, 2 from Canada, 1 from Sweden, 1 from Iceland, and 1 from Finland. The majority of the studies scored very highly on methodological quality (see Table 1).

## COPD

### *The Patient's Perspective*

*Daily Needs and Life.* Most of the studies that investigated the experience of suffering from COPD have focused on the patient's experience. All these studies formulated their research questions as looking into the problems and needs of people living with COPD, except two studies by Nicholls (2000, 2003) that focused specifically on breathlessness. The first mentioned studies endeavored to achieve an understanding of the daily impact the disease had on the lives of the people studied, whereas the latter wanted to gain insight in the role of personality in the experience of the symptom. The findings of these studies center around a few significant themes in the experience of suffering from chronic respiratory illness: the experience of illness or symptoms, its consequences, how the person affected copes with it, and the patient's opinion of his contact with the health care system. Breathlessness was found as one of the most prominent and threatening symptoms in the illness experience of COPD.

Having COPD and suffering its symptoms, especially breathlessness, is experienced as painful (Nicholls, 2003; Seamark et al., 2004), hard work (Elofsson & Ohlen, 2004), a constant struggle (Nicholls, 2003; Barnett, 2005), a continuous fight (Jonsson, 2005), taking all one's strength (Nicholls, 2003), and therefore exhausting (Nicholls, 2003). It could unexpectedly flip into acute illness; one has to be ever vigilant as life is very uncertain. It can be overwhelming, which creates the feeling of "existing" rather than "living" (Nicholls, 2003). There is a lot at stake for the patient: loss on different levels, of functional abilities (even to the level of taking care of one's personal hygiene), of jobs (O'Neill, 2002; Barnett,

**Table 1.** *The studies' methodological quality (according to the method developed in Hawker et al., 2002)*

Study	Abstract	Introduction and aims	Method and data	Sampling	Analysis	Ethics	Bias	Results	Transferability, generalizability	Implications and usefulness	Total
Barnett (2005)	4	4	3	3	4	4	4	4	3	3	36
Elofsson & Ohlen (2004)	3	3	4	3	3	4	1	4	3	4	32
Guthrie et al. (2001)	3	3	3	4	4	3	3	4	4	4	35
Jonsdottir (1998)	3	3	4	4	3	2	4	3	3	3	32
Leidy and Haase (1999)	3	4	4	4	4	4	4	4	4	4	39
Nicholls (2000)	3	4	4	2	3	1	1	2	2	2	24
Nicholls (2003)	3	4	4	4	3	4	1	4	3	4	34
O'Neill (2002)	4	4	4	4	4	3	4	4	4	4	35
Seamark et al. (2004)	4	4	4	4	4	4	3	4	4	4	38
Bailey (2001)	3	3	4	3	4	3	3	4	4	4	35
Bailey (2004)	3	3	3	2	4	4	3	4	2	3	31
De Vito (1990)	3	4	4	2	3	3	2	4	3	4	32
Nicholson and Anderson (2000)	3	4	4	4	4	3	4	4	3	4	37
Elkington et al. (2004)	4	4	4	4	3	4	1	4	4	4	36
Jones et al. (2004)	4	4	4	3	3	1	1	3	3	4	30
Jones et al. (2003)	4	4	4	4	3	1	1	4	4	3	32
Oliver (2001)	4	3	3	4	3	4	4	4	4	4	37
Bergs (2002)	3	3	3	4	4	3	4	4	3	4	35
Bailey (2004b)	4	3	4	3	4	3	3	4	3	4	35
Roberts et al. (1993)	3	4	4	4	4	3	4	4	4	4	38
Edmonds et al. (2005)	3	4	4	4	4	4	3	4	4	4	38
Booth et al. (2003)	4	4	4	4	4	2	2	4	4	4	36

Each area was rated on a 4-point scale from 1 (*very poor*) to 4 (*good*).  
Total minimum score = 10; total maximum score = 40.

2005), of social life (O'Neill, 2002; Barnett, 2005) of one's home (Elofsson & Ohlen, 2004), of intimacy (O'Neill, 2002; Barnett, 2005), of liberty, of future (Seamark et al., 2004). Patients get isolated, feel misunderstood by others, and try to live up to expectations of how to behave as a normal person (Jonsdottir, 2005). They often do not succeed in maintaining the normal image; they get frustrated (Barnett, 2005), hurt, vulnerable, and isolate themselves further (Jonsdottir, 2005) as they perceive their sickness as weakness (Jonsdottir, 2005). Breathlessness equals demise (Nicholls, 2003).

Managing symptoms requires keeping in control, not allowing the condition to become worse, and maintaining a sense of self, and this requires careful planning and surveillance. Some patients just manage to reach the level of resignation (Nicholls, 2003; Jonsdottir, 2005). Looking for a cause is part of coming to terms with one's suffering. Patients expressed regret (Elofsson & Ohlen, 2004) and anger (Nicholls, 2003) at having caused the illness themselves by their habit of smoking. In Seamark et al. (2004) it was found that the experience called for self-reflection and in Leidy and Haase (1999) activities with or on behalf of others were seen as meaningful and satisfying, similar to the concept of "connectedness" in two other studies (Elofsson & Ohlen, 2004; Jonsdottir, 2005). Positive thoughts centered around deepened faith and spirituality (Nicholls, 2003; Elofsson & Ohlen, 2004) and acceptance (Seamark et al., 2004).

Ambivalent thoughts appeared where patients' experiences with the health care system were elicited. Positive comments centered around the conscious discussion of diagnosis and prognosis, treatment options, and good relationships with the general practitioner. Although patients expressed the need for regular surveillance, the suggestion of involving specialist respiratory nurses was met with moderate enthusiasm, as yet another stranger being involved in the care of the patient (Seamark et al., 2004). This was based on previous experience with health professionals' involvement in the treatment of symptoms who were found to be distanced (Seamark et al., 2004), impersonal, aloof, and rarely constant (Nicholls, 2003). Contact with the health care system sometimes means an increased workload for patients, who can often just cope with daily life. Additional regimens could be perceived as a challenge to patients' autonomy.

Apart from the general purpose of capturing the essence of suffering from breathlessness and other symptoms caused by COPD, most of the studies had their specific emphases. Seamark et al. (2004), by jointly interviewing both the patient and his or her main carer, included a dual perspective and showed

that the carer was equally affected by the patient's disability. Jonsdottir (2005) focused on the life patterns of patients with COPD and how they coped. Nicholls (2003) explored how personality influenced breathlessness and how breathlessness affected notions of self. Elofsson and Ohlen (2004) investigated what the issues were for older people living with COPD. Leidy and Haase (1999) considered the meaning of functional performance from the perspective of patients with COPD, and O'Neill (2002) explored how women recognize and respond to symptoms of COPD.

*Experience of Acute Exacerbations.* Four studies explored the experience of acute exacerbation events of COPD by patients and their families. Two papers by Bailey (2001, 2004) were based on the same research conducted with 10 family–nurse units in two general hospitals in a Northeastern Ontario mining community. Narrative analysis as an extension of ethnographic enquiry was used to examine the interview data. One paper discussed the death stories that were told by patients and caregivers, portraying different kinds of acute dyspnoeic episodes (Bailey, 2001). From these data, two narrative genres emerged: the "near-death" story, which described a distinct moment in time when the participant thought she or he or the person she or he had been caring for had died (and been resuscitated), and the "shadow-of-death" story, which represented an incident when the storyteller feared dying or witnessing a death event. The second paper concentrated on the study's findings relating to the affective components of acute dyspnoeic episodes in COPD (Bailey, 2004). Patients described a dynamic relationship between dyspnea and emotional functioning or anxiety. As a result, an alternate understanding of the dyspnea–anxiety relationship surfaced whereby anxiety is not the underlying cause of dyspnea but, rather, a sign of long-standing or acute respiratory failure. So the "anxiety–dyspnea–anxiety cycle" may be more accurately labeled a "dyspnea–anxiety–dyspnea cycle."

Nicholson and Anderson (2000) conducted a focus group study with a small sample of patients suffering from chronic bronchitis recruited from two general practices in two industrial cities in the United Kingdom. Patients were encouraged to express the complexities of their subjective experiences, which added to existing knowledge of the day-to-day living with the condition and in particular the impact of acute exacerbations on their quality of life. Smoking cessation as a therapeutic option in chronic bronchitis was shown to be one of the many complexities in the management of the respiratory problems where straightforward interventions and subjective behavior do not always correspond. De Vito's (1990) paper

had the dual purpose to collect recollections of a large sample of 96 patients' experiences of acute exacerbations in a hospital setting and to evoke memories of nursing behaviors during these episodes. The value of this study lies in drawing attention to the discrepancy between nurses' approaches to care for patients with a critical dyspneic episode and patients' needs in these situations, sensitizing professional carers to strategies that can be employed in an emergency situation for which there are not many other options.

Also Bailey et al. (2004) examined the acute dyspneic experience, however, from the nurses' perspective. In the context of this paper with its general purpose of providing an overview of the literature with a view to developing a research agenda into the experience of breathlessness, we opted to include this paper in the separate category of the carer's perspective: the health professional (see below).

*Experience of Care.* Four studies cover how patients with COPD experience care. Oliver (2001) investigated the perceptions and needs of a sample of COPD patients with moderate to severe impairment of respiratory function ( $FEV1 < 50\%$  of predicted) from both a primary and secondary care context. The relationship patients had with their GP was a central issue that appeared to have a significant influence upon the patients' quality of life and confidence in coping with their disease. The data suggested that this relationship was not always perceived to be helpful and a contributing factor in patients' failure to adhere to treatment, in altering health behaviors, in seeking early medical advice, and obtaining emergency admission to a hospital.

A retrospective study consisting of in-depth interviews with the bereaved carers of COPD patients used carers' accounts as proxies for the deceased's experience, thus providing an exceptional description of illness experience in the last year of life that might otherwise have been inaccessible (Elkington et al., 2004). This study provided evidence of the seriousness and severity of symptoms from which patients with COPD suffered in the last year of life. The findings revealed that there is a mismatch between patients' needs and the services that they received. It showed that additional resources such as respiratory nurse specialists, although still rarely provided, are especially valued to assist GPs in meeting patients' needs, attending to their social, psychological, and physical needs, and liaising with secondary care.

Jones et al. (2004) conducted focus groups with COPD patients who had not attended pulmonary rehabilitation investigating their perceptions of factors that influence their compliance with inhaled therapy

for COPD and their compliance with health-related behaviors related to smoking cessation, exercise, and diet. The results showed that COPD patients tend to adhere well to drug medication, which was reinforced by fear of dyspnea and feelings of vulnerability. However, lifestyle changes and ongoing management were less well maintained due to the poor quality of information they had received.

Jones et al. (2003) focused on a group of patients identified by their GPs as anticipated to die within one year. They found that poor symptom control remained an important cause of distress. They reported a low number of needs that the authors related to patients' concern about the burden they placed on their carers. Their information needs were variable, reflecting the individual ways in which patients coped with their illness.

#### *The Carer's Perspective: The Informal Carer*

One paper used a phenomenological design to understand how women caring for husbands with COPD experience their quality of life (Bergs, 2002). These women had given up work because of their husbands' illness. The study showed that women who have full-time caring responsibility for their spouses often find the situation so difficult that they are nearly at a breaking point, but at the same time, they want to keep on caring for their husbands. They believed it was their duty to care for their husbands and that being a woman has helped them manage in their caregiving role. Quality of life is here understood as the answer to the question: What gives value to our lives? The most significant value for the participants in the study was to live up to their role as caregivers.

#### *The Carer's Perspective: The Health Professional*

Only one paper approached the experience of breathlessness from the perspective of the professional carer, interpreting the caregiving stories of nurses to develop an understanding of the care they provide for individuals hospitalized for in-patient care during an acute episode of their chronic breathlessness (Bailey et al., 2004). A narrative approach to the ethnographic study findings identified a group of stories centering around emotional behavior, usual nursing care, causes of acute exacerbation events, and admission circumstances. These stories represent essentially a common COPD-illness template that influences how nurse caregivers interpret the behaviors presented by patients and as a guide in the planning of their nursing actions in case of these acute respiratory episodes. Nurses used their usual understanding to inform the care that they provided for specific patients, suggesting standardized instead of individualized care.

## Other Conditions

### *Breathlessness as a Symptom in Cancer*

Roberts et al. (1993) undertook a study to examine dyspnea during the last weeks of life as it is experienced by patients with cancer and understood by the nurses providing care. They used a triangulated approach of a pencil-and-paper survey, a chart audit of late stage cancer patients, and intensive interviews with selected patients and nurses in a metropolitan home-care hospice program. Three interrelated themes emerged: the barriers that dyspnea created throughout all aspects of living with late-stage cancer, the isolation in which patients coped with their dyspnea, and the inconsistent understanding of health professionals with regard to breathlessness. The findings from the various data sources suggested that health professionals did not consistently become involved in dyspnea management. These data supported the idea that there may be a serious discrepancy between the difficulty that breathlessness poses for patients and the low priority it is given in health care services. The nurses expressed vastly different interpretations of most elements of the frequency, effect, and implications of dyspnea in this patient group. These problems in management were complicated by the finding that patients did not tend to report breathlessness to health professionals. The study emphasized the importance of accurate assessment of dyspnea, taking into account the patients' understanding, to identify suitable and tailored management strategies as a critical foundation for patient care.

### *Breathlessness as a Symptom in Heart Failure*

One study explored patient experience of breathlessness in heart failure (Edmonds et al., 2005). The patients in this study had a diagnosis of symptomatic heart failure (New York Heart Association [NYHA] functional classes II, III, and IV) and were recruited from the hospital. Interviews suggested three main experiences of breathlessness: "everyday," which patients were able to accommodate, "worsening," which prompted hospital admission, and "uncontrollable," experienced as a symptom that even health professionals had difficulty managing. These descriptions predominantly focused on physical functioning, relating to patients' ability to manage breathlessness on a day-to-day basis. The study pointed out the need for further research into breathlessness to comparatively consider the symptom in other settings and in other conditions.

### *Comparative Research on Breathlessness*

Booth et al. (2003) investigated the effects of breathlessness comparatively in COPD and advanced

cancer. Both patient groups felt very restricted in their daily activities and reported that they were very disabled and becoming increasingly dependent because of breathlessness. Skills such as staying calm and adopting a philosophical attitude toward the symptom were described as essential in order to contain its impact. Breathlessness was found to manifest itself differently in the two conditions, which is related to differences in disease progression. Patients with COPD have a considerably longer prognosis than cancer patients, the onset of breathlessness is slower, and often they are older when they become significantly disabled. Support from different sources was highly valued but was reported to be provided inconsistently and sporadically. Most of the patients had received care from GPs and specialist respiratory nurses. This study also included interviews with the informal carers of the patients who suffered from breathlessness, documenting its devastating effect on the carers' lives.

## DISCUSSION

This article reviews the qualitative literature on the experience of breathlessness. The studies identified were considered per disease category and, as 19 out of the 22 of the studies focused on COPD, we created the category of "other conditions" in which we subsumed the studies that investigated breathlessness in the context of cancer (Roberts et al., 1993), heart failure (Edmonds et al., 2005), or comparatively in COPD and cancer (Booth et al., 2003). A further division was suggested by the available papers that considered the experience of breathlessness from the perspective of the patient, the informal carer, and the professional carer. Most of the papers sought to understand the meaning of the symptom in the patient's daily lives. The other papers clearly demarcated separate areas of how acute exacerbations were experienced and the patient's view on care. The carer's experience of breathlessness fell into the fundamentally different perspectives of the informal carer and the professional health carer.

Although these categories were mainly suggested by the nature of the studies identified for this review, they were not always clear-cut. How we divided the studies represented the content of the papers best, but the categories need to be qualified in this section, as considerable overlap still exists, and in different ways, this classification does not do justice to the studies in their totality. The paper that Booth et al. (2003) wrote illustrates this, where the emphasis lies on the comparison of the symptom in the two conditions of COPD and cancer, but this detracts attention from the discussion included on carers' concerns. By making these gaps and overlaps explicit

(see Table 2) we are convinced that this review represents the studies on the experience of breathlessness in the most sensible way, as they best contribute to the body of evidence.

What is the state of the evidence of the experience of breathlessness as studied by psycho-social research since 1989 when Williams' review on COPD was published? The limited number of UK studies dedicated to this topic, previously mentioned by Williams, now seems to have grown to half of the total studies available, showing an increased awareness of the need to explore the experiential aspects of breathlessness. However, the distribution of the studies across disease categories shows that the bulk of the research has been produced on the experience of breathlessness in COPD. In this respect not much has changed, as the research in COPD still counts as a model for conceiving the symptom in other conditions. The two other studies that have been published focusing on breathlessness in cancer and in heart failure, as well as the comparative study, show that the pattern of the symptom is definitely different in these other conditions. This calls for further work to explore whether there are important differences in patterns of breathlessness associated with other diseases.

The contribution of these papers can be seen in the exploration of the subjective component of breathlessness, which recent definitions now tend to recognize but that is still unexplored. The studies made use of innovative methodologies that have hitherto not much been experimented with in the context of a symptom that has previously been the object of pure medical interest. The papers' high score on methodological quality, however, needs to be taken with caution, as the methodology to assess the quality of qualitative studies is still developing. The studies have used the phenomenological approach, inductive grounded theory, life history, ethnographic, and narrative methodology. Here, illness realities have meaning as they are part of social life, and are not directly reducible to physiological states. The papers gave exclusive attention to the patients' (and/or carers) account and used open designs to allow for situated views to surface. The papers in this category showed the symptom of breathlessness as a complex multidimensional phenomenon, with no consistent relationship between the severity of the disease and the experience of the symptom. They showed that the patient's experience is lived as a whole.

An important point emerging from the papers is the influence of the meaning of the illness for patients on their ability to cope and to manage (Roberts et al., 1993; O'Neill, 2002). From the study material the symptom appears as clearly gendered

(O'Neill, 2002; Seamark et al., 2004). O'Neill's paper reported the specific symptom experiences of women with COPD and the mechanisms they developed accordingly to keep their problems under control. Bergs (2002) found that women caregivers for severely ill husbands derived a great deal of strength and persistence from being a woman. The significance of this becomes clear in the light of an earlier study on this topic, which found that individuals with male caregivers are more than twice as likely to enter a nursing home within a 6-month period compared with those having female caregivers (Jette, 1995). Age also appeared to be an important influencing factor in how a patient perceives an illness. A study on elderly people suffering from severe COPD found that the experience of the illness was seen as one of several conditions making life difficult. Other hardships seemed to be more related to life in old age in general. In Guthrie et al. (2001), where the quality of life of the study's sample was measured, the elderly group reported consistently worse scores when measured. This is in contrast with a study by Guyatt et al. (1987) in which older COPD patients tended to have fewer emotional problems, including depression, anger, and frustration than their younger counterparts. It is worthwhile investigating in which way age influences the experience of breathlessness. Personality is another factor mediating how patients deal with breathlessness. Nicholls (2003) study sought to understand how people with similar pathologies can be affected in such different ways that one person lives independently, self-medicates, socializes, and is mobile whereas someone else is dependent, socially isolated, depressed, and removed. Moving away from the traditional approach to focus on similarities with other chronic illnesses and to assume a linear, predictable course, this study argues that coping with chronic breathlessness is an active, complex, multidimensional process that is interwoven with the person's notion of self. Among these factors shaping the experience of breathlessness one in particular has been left unexplored: the role of culture in understanding and coping with the symptom.

One study was dedicated to the experience of caring for a husband with COPD (Bergs, 2002). The perspective of the informal carer was represented as a part of two other studies (Booth et al., 2003; Seamark et al., 2004). These studies have now identified the informal carer as an important area of research, as their findings attest of the devastating impact that breathlessness in the context of a life-threatening condition can have on them. Bergs (2002) found that women caring for spouses with COPD were continuously almost at a breaking point. They not only had to manage their spouses' symptoms, but they also had to cope with revisions in marital

**Table 2.** *Qualitative studies on the experience of breathlessness*

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
COPD						
The patient's perspective: Daily needs and life						
Barnett (2005) UK	Phenomenological approach. Data collection through unstructured interviews. Critical hermeneutic analysis	To explore the experience of living with COPD	10 COPD patients	Patients homes	<ul style="list-style-type: none"> <li>• Perception of severity and symptoms</li> <li>• Functional disabilities</li> <li>• Emotional trauma</li> <li>• Implications surrounding social loss</li> </ul>	Awareness should be raised with professionals of the difficulties of daily living with COPD. Understanding and empathy are required to manage this condition adequately.
Elofsson & Ohlen (2004) Sweden	Phenomenologic enquiry. Data collection through open interviews. Analysis by phenomenologic-hermeneutic method.	To achieve understanding of the meaning of the lived experiences of elderly persons who are severely ill with COPD and in need of everyday care.	6 patients (2 women, 4 men)	A home care service in Western Sweden	Living with COPD as hard work. Dialectic patterns: <ul style="list-style-type: none"> <li>• Resignation–contentedness</li> <li>• Loneliness–connectedness</li> <li>• Being homeless–being at home</li> </ul>	Patients are best cared for in the holistic approach of palliative care. In this kind of care the dialectic, experiences should be acknowledged.
Guthrie et al. (2001) UK	General methodology of noncomputerized qualitative analysis. Open-ended interviews following a topic guide.	To illuminate standardized outcome measures and improve the understanding of the needs of patients with severe COPD.	37 patients with severe COPD (drawn from a sample of 64 patients studied in a RCT)	Home. Interviewed at intervals (3) coinciding with follow-up assessments trial. Duration trial: 6 months	QoL was seen as depending on family relationships, freedom from fear, mobility, and independence in the activities of daily living, and the absence or successful mitigation of symptoms of concomitant disease.	Disease-specific, symptom-oriented outcome measures may miss these. Threatening approach of death recommended the extension of a palliative approach to endstage COPD

*Continued*

Table 2. Continued

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
Jonsdottir (1998) Iceland	Newman's hermeneutic dialectic method and phenomenology.	To describe the life patterns of people with COPD.	10 patients (6 men, 4 women) with COPD as their primary diagnosis	A pulmonary unit in Iceland. First and last interview 4–16 months apart.	Themes underlying life patterns: <ul style="list-style-type: none"> <li>• Resignation to the situation as it is, a way to survive.</li> <li>• Unsuccessful solutions to traumatic events.</li> <li>• Difficulties in expressing oneself and relating to others.</li> <li>• Conflict between internal needs and external expectations. Few words for breathing difficulties (about suffering).</li> <li>• Activity restrictions.</li> <li>• Participants' life pattern as a group: isolation, being closed in.</li> </ul>	There is a need for a new kind of nursing practice. This is based on the nurse–client relationship.  Newman describes the nurse as being fully present with the person, real, authentic, nonjudgmental, respecting the person's experience, seeking to know what is meaningful in the person's life, facilitating his/her choices, and unconditionally accepting the unpredictability of the unfolding life.
Leidy and Haase (1999) USA	Phenomenological approach and consensus dialogue for concept clarification.	To describe the meaning of functional performance from the perspective of patients with COPD	6 men, 6 women with moderate to severe disease; most had additional medical conditions	Pulmonary outpatient clinic in the Southeastern USA	Patients with COPD face an ongoing challenge of preserving their personal integrity (satisfying sense of wholeness). Qualities most salient to integrity: <ul style="list-style-type: none"> <li>• sense of effectiveness, being able to;</li> <li>• sense of connectedness, being with.</li> </ul>	Identifying personal integrity as a motivating and explanatory factor in day-to-day activities may be an important consideration in designing effective interventions to improve capacity, performance, and QoL.

Nicholls (2000) UK	Grounded theory framework. Data collection through life history narratives.	To address how a sufferer's self-image affects experience of breathlessness, and how the experience affects the way a sufferer's self-image develops.	A sample of adults with COPD	Not reported	Breathlessness is a unique experience that can only be interpreted by the sufferers.	A "sufferer-centered" approach should be embraced.
Nicholls (2003) UK	Phenomenological. Data collection through Life history and interviews.	To explore how a person's personality or "self" affected the way his chronic breathlessness was expressed. How the experience of breathlessness affected one's notions of "self."	5 men, 5 women with long-standing chronic breathlessness from a primary obstructive pulmonary disease	Local physiotherapy-run pulmonary rehabilitation group. Interviewed three times over successive months.	Experience: difficult to describe, stigma, guilt, physical deterioration but mentally intact. Strategies: self-care, careful avoidance of acute exacerbation, heightened responsibility, managing health professionals. Experience of health care: necessity of handing over to health care system, health professional as gatekeepers, restrictions by drugs and rehabilitation, confusing advice. Death and spirituality: experiences akin to terminal illness, patients looked for causes, then resignation, faith, relation with family. Mobility and walking: mobility = freedom. Care = work.	Good care needs attention to the experience of breathlessness.

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Table 2. Continued

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
O'Neill (2002) USA	The Common Sense model by Leventhal. Data collection by interview and symptom diary.	To explore how women recognize and respond to symptoms of COPD	21 women enrolled in pulmonary rehabilitation programs	2 pulmonary rehabilitation clinics (PRC) in the Northeastern US. Data collected over 10-month period	Identity: patients mostly had clear label for the disease. Time line: Major theme was "not getting any worse." Cause: 13 women saw smoking as the main cause, 8 as the only cause. Others: bacterial infections, TB, stress as carer. Consequences: loss of jobs, family, and social relationships; for the younger participants: loss of intimacy, sex, stigma. Coping: Behavioral methods and cognitive methods.	Symptom control is a priority. Health professionals should continue to teach methods to control it and search for new strategies for relief. Nurses are in an ideal position to recognize depression and its contribution to functional decline. The popular media can be used to raise awareness and describe coping strategies. Referral to pulmonary rehabilitation clinics should be more consistent and timely.
Seamark et al. (2004) UK	Interpretative, phenomenological through semistructured interviews	The experiences of patients with severe COPD and their carers, particularly with regard to ongoing and palliative care needs.	9 men and their carers, 1 woman. 8 interviewed in conjunction with partner (1 refused, 1 had no carer)	Semirural general practice	Losses: activities of daily living, growing dependence on carer, loss of future. Relationships with professionals: Positive and negative, role of specialist respiratory nurse. The effect on the carer: similar losses, multiple roles, illness affects both. Adaptation: difficulties mentioned. Positive: appreciation for carer, deepened faith, spirituality, "you know your real friends."	Information sharing, care surveillance is important. Utilize service in place and for the primary health care team to build on existing relationships. Further research in areas such as advanced care planning by GPs and impact of structured surveillance.

Bailey (2001) Canada	Narrative approach as extension to ethnographic inquiry.	To understand the event of an acute exacerbation episode of COPD from the perspective of patients and their family caregivers.	10 family–nurse units, 4 months	2 general hospitals in a Northeastern Ontario mining community	Two kind of stories of acute exacerbations: <ul style="list-style-type: none"> <li>• Near-death story</li> <li>• Shadow-of-death story</li> </ul>	Managing acute exacerbations requires an understanding of its experience.
Bailey (2004) Canada	Ethnographic design and narrative analysis. In-depth interviews.	To explore the affective component of dyspnea/anxiety described by COPD patients in acute illness events.	10 patient–family units of end-stage COPD patients	2 general hospitals in a Northeastern Ontario mining community	Acute dyspnea as experienced is inextricably related to anxiety and emotional functioning. Patient reported anxiety: important marker during acute exacerbation. Emic suggestion: Dyspnea–anxiety–dyspnea instead of anxiety–dyspnea–anxiety cycle.	Greater attention to patients' subjective experiences of the disease.
De Vito (1990) USA	Content analysis. Semistructured interviews.	To understand the COPD patient's experience of dyspnea and nursing actions while hospitalized.	96 adults with chronic bronchitis, emphysema or a combination, having dyspnea and hospitalized at least once for an acute exacerbation.	Hospital setting. Data collection over 9-month period	<ul style="list-style-type: none"> <li>• Fear (dyspnea–fear vicious circle).</li> <li>• Helplessness (nurse-control, leads to frustration).</li> <li>• Loss of vitality (life and death).</li> <li>• Preoccupation (breathing = effort, concentration).</li> <li>• Legitimacy.</li> </ul>	Acknowledge fear. Imitation of breathing techniques. Solemnity required. Tone of respect for a matter of life-death. Reminding of subjective aspect. Isolation, withdrawal instead of distraction.

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Table 2. Continued

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
Nicholson and Anderson (2000) UK	Thematic analysis. Focus group discussions.	The subjective perspectives of the QoL of patients with chronic bronchitis	20 sufferers, 10 men, 10 women. Age range: 30–86 years	GP practices in 2 industrial cities	Acute exacerbations were common. Panic and fear. Depending on medication. Loss of social life. Suspicion of GPs when they don't prescribe what is expected. Knowledge, belief and behavior regarding smoking do not correspond.	Greater attention to patients' subjective experiences of the disease.
The patient's perspective: Experience of care						
Elkington et al. (2004) UK	Data collection by in-depth interviews based on the retrospective approach of the VOICES questionnaire with bereaved relatives of COPD patients. Framework analysis.	To explore the experience of the last year of life of COPD patients from the perspective of the bereaved relative, focusing on symptoms and contact with health services.	28 of the 110 patients accepted interviews over a period of 4 months	Patients recruited by the ONS database of death registrations	Breathlessness was the dominant symptom. Home oxygen: benefits in terms of symptom relief and mobility; dependence on it imposed lifestyle restrictions. Variability in health service provision at community level in last year of life: from prescription only, to review by respiratory nurse specialist (RNS). RNS contact was valued in giving advice, spending time with patients, and liaising with secondary care.	The principles of palliative medicine have increasing application in noncancer conditions, including COPD. With its expertise in symptom control, palliative care may be able to offer alternative treatments to the conventional ones in respiratory medicine. The role of the RNS is important although not many are active as yet.

Jones et al. (2004) UK	Five focus groups. Thematic content analysis.	To examine patient perceptions of factors that influence their compliance with inhaled therapy and behaviors related to smoking cessation, exercise, and diet.	29 COPD patients who had not attended pulmonary rehabilitation	Patients from secondary and primary care who had not attended pulmonary rehabilitation.	Patients had low levels of intentional noncompliance with medication. Contributors to compliance are fear of dyspnea and feelings of vulnerability. Information by health professionals about lifestyle modification was poor.	COPD patients require better education to manage their disease effectively.
Jones et al. (2003) UK	Semistructured interviews	To determine the needs of patients dying in primary care from COPD	16 patients with maximal therapy for COPD	Primary care practices in North West England	Poor control of symptoms. The concern of patients of the burden they place on their carers. The need for knowledge about their illness.	The variability of information needs shows the importance of an individual approach to patients with an apparently homogeneous disease.
Oliver (2001) UK	Phenomenological approach. Piloting of semistructured interview schedule by focus groups and interviews.	To explore the perceptions and needs of COPD patients.	16 patients. Respondents included with FEV1 < 50% (moderate to severe impairment)	2 sample frames: 1. under care of GP 2. Patients who had received in-patient care previously at district general hospital	The beginning of the doctor-patient relationship: Perception by patient of relationship formed by the way that diagnosis had been given. Many experienced sense of loss after diagnosis. Agenda of consultation: Frustration and anger due to inability to explain sensations of breathlessness. Little information received and uncertain as to where to seek help.	Easier access to care is needed. Open and frank discussion with professionals so that psychological condition and coping strategies can be assessed.

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Table 2. Continued

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
					<p>Illness pathway: Disabilities experienced as a constant battle. Patients placed fine line between medical and social needs. Socially isolated due to public's poor understanding.</p> <p>Medication: Need to manage antibiotics and steroids themselves.</p> <p>Power in doctor–patient relation: Concern to be “good patient.”</p>	
The carer's perspective: Informal carer						
Bergs (2002) Finland	Phenomenological approach. Unstructured, in-depth interviews.	To describe the experience of QoL of women taking care of husbands with COPD.	6 women living with husbands with COPD, between 47 and 69 yrs with husbands who had stopped work.	Not mentioned	<p>Negative sides of caring: Own health less valued than husband's. Importance of employment. Vigilance. Weakening marital relationship. Emotional straightjacket of living with him. Too proud to ask for help. Becoming mentally worn out. Feeling of isolation.</p> <p>Positive sides: spiritual help. Need for increased social support. Determined to care to the very end. Dreadful prospect of single life.</p>	<p>Increase support and understanding of health personnel. Need for education for wives' own health.</p>
The carer's perspective: The health professional						

Bailey et al. (2004) Canada	Ethnographic narrative approach interviews.	To understand the nurse's experience of care giving for individuals hospitalized for in-patient care during an acute exacerbation.	10 nurse caregivers	2 general hospitals in a Northeastern Ontario mining community	Nurses caregiving strategies based on a preexisting template. Anxiety was seen as a "cause" of the acute distress rather than what patients understood as a "sign" of acute distress.	The need to facilitate nurses individualization of standard templates and to develop strategies to facilitate the reshaping of inaccurate templates in the presence of new knowledge.
Other conditions						
Cancer Roberts et al. (1993) USA	Lincoln & Guba's approach to naturalistic enquiry. Patient self-report surveys for a baseline measure of the frequency and nature of dyspnea. Chart audits to survey the recorded incidence and its management. Interviews.	To generate a description of the phenomenon of dyspnea in late-stage cancer.	30 patients completed the surveys. 10 patients participated in the interviews. Both lung and other cancers. Experienced some degree of breathlessness but none dyspnoeic at rest. 12 nurses were interviewed.	Four distinct but interrelated settings within a large metropolitan home-care hospice program. Data collected over a 4-month period.	Results of survey and charts: Survey showed 76.7% of patients suffering from dyspnea. Chart showed only 38.8% as evidence. Rates of dyspnea reporting: no significant difference between survey and chart for those with lung involvement (26.3%), whereas for those without lung involvement: 77.8%. Findings from interviews: 1. Dyspnea is a barrier to all aspects of daily living 2. Patients cope in isolation. Not understood by professionals, sometimes not reported by patients.	Importance of initial and ongoing nursing assessment of dyspnea for all late stage cancer patients is a critical foundation for patient care. Need for updating nurse's knowledge of dyspnea management strategies. An accepted nursing and medical standard of care is needed.

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Table 2. Continued

Reference and country of study	Theoretical perspective/ methods	Study aim	Participants	Setting	Main concepts/ themes	Practice recommendations
Cardiac failure					Findings from nurse interviews: vastly discrepant interpretations of, e.g., frequency, effect, implications of dyspnea, and hence on the benefits of its management. Inadequate assessment, gaps in nursing understanding of dyspnea and its management and inconsistencies in medical interventions.	
Edmonds et al. (2005) UK	Data collection by semistructured interviews. Analysis using a constant comparative approach with QSR Nudist 4.0.	To explore patient experience of breathlessness in heart failure.	Theoretical sampling strategy NYHA classes II, III, IV. 27 patients with chronic heart failure. All but 1 had at least 1 comorbid condition.	From outpatient cardiology and care of the elderly clinics and hospital clinics.	Three dominant experiences of breathlessness: <ul style="list-style-type: none"> <li>• Everyday: accepted as normal, not specifically identified with heart failure.</li> <li>• Worsening: everyday coping strategies failed, leading to hospital admission.</li> <li>• Uncontrollable: Professionals struggled to manage it and brought for some fear of dying.</li> </ul>	Further research required to identify if descriptors differ in heart failure from cancer and if these are the same in other heart failure patients. This could form the basis for an assessment scale for better management
Comparative: COPD and cancer						

Booth et al.  
(2003) UK

Data collection by semistructured interviews.  
Data analysis using a coding framework from model of responses to illness by Hertzlich.  
Analysis assisted by QSR Nudist 4.0.

To investigate the experience of living with breathlessness in patients with cancer and COPD and their carers. To allow comparison of differing perspectives and provide insight for future development of clinical services and research.

Patients with coresidential carer and breathlessness at rest recruited. 10 COPD (6 male) patients and 10 cancer patients (6 male) with a variety of tumors.

Patients recruited from oncology and respiratory medicine clinics of a university teaching hospital.

Patients' concerns

- Experience of breathlessness and associated fears.
- Disability and dependence.
- Responses: fight versus give in, philosophical attitude, frustration.
- Limitations of treatments: clinicians have little understanding for the symptom, differently managed between specialities. Those feeling supported received help from specialist respiratory nurses, had easy access to GP.

Carers' concerns: caring is preoccupying, restricting, cause of anxiety.

Palliative care should be developed for this symptom.  
Greater crossover between respiratory, cardiac, and palliative care, community and hospital teams is needed.  
Prompt medical attention (day and night, every weekday, practical and emotional support for patients and families).

relationships and role restructuring. Support for the carer could be extended with experiences from carers with different relationships and roles toward the ill person.

Patients' experiences with care show a discrepancy between needs and services provided. Current health care delivery for patients with breathlessness is reactive and geared toward critical care in emergency situations (Elkington et al., 2004). The experiences of patients with COPD confirm the poor quality of life and considerable symptom burden from which this group suffers, which was shown by several other studies (Skilbeck et al., 1998) to be as severe as or worse than those with lung cancer. Despite this, patients with COPD do not have access to specialist support services in the same way as patients with lung cancer do. The evidence suggests that even when medical care is available, breathlessness is one of the symptoms that is often underestimated and therefore undertreated (Roberts et al., 1993). The difficulties that health professionals have managing the symptom may lead to the lack of attention to this problem and the underreporting of breathlessness by the patient (Roberts et al., 1993). Four studies also point toward the gaps that exist in primary care, where patients with COPD received only sporadic assistance from their GP (Oliver, 2001; Jones et al., 2003, 2004; Elkington et al., 2004). Communication conflicts and fleeting encounters with GPs were underlying most of the problems with care provided in the community.

The practice recommendations in the papers were twofold: the urgency for the extension of palliative care to noncancer conditions and the importance of the development of nursing care interventions (see Table 2). The nursing care was often suggested on the basis of evidence of the effectiveness of the respiratory nurse specialist (Elkington et al., 2004; Seemark et al., 2004) with a shift in emphasis of services from acute care to regular surveillance and long-term commitment.

## CONCLUSION

When collating the papers for this review on the experience of breathlessness it soon became clear that a meta-ethnography could not be undertaken, as the topics covering the experience were too diverse. The papers represented the views of different parties affected by breathlessness or those involved in their care. The purpose of this review was rather to serve as a guide to the qualitative literature that is available and as an appraisal of the evidence currently produced on the psycho-social aspects of breathlessness, 16 years on from the review by Williams (1989).

The evidence is still dominated by research conducted on COPD and therefore shapes our understanding of breathlessness from within this specific disease condition. However, studies have now started to appear that also represent the experience of breathlessness in the context of other conditions (Roberts et al., 1993; Booth et al., 2003; Edmonds et al., 2005) and consider the experience comparatively. These studies are the first steps to determining the specificity of experiences of breathlessness in the direct context of people's illness, but they also show that it is necessary to study the symptom in the broader context of the patient's life. The totality of the evidence now shows breathlessness as an intractable symptom in other advanced conditions.

An important area of research has opened that pays attention to the experience of the informal carer. The findings of the few studies focusing on their perspectives suggest that the burden of disease equally affects the carer, whose needs deserve to be addressed to enable them to continue in their role as caregivers.

These qualitative approaches confirmed the findings of other recent studies that reported the heavy level of suffering and disability for which chronic respiratory illness is responsible. The methods used in these studies enabled an understanding of the suffering of those affected. The studies concluded almost unanimously with suggestions for managing a complex symptom for which there are no easy solutions. They promote a holistic approach as part of palliative and nursing care as the most suitable strategy of dealing with breathlessness in advanced illness.

Future interventions could work along the palliative care model of "total pain" developed by Saunders (1967), which could also be appropriate for the management of breathlessness. Here psycho-social care is integrated with pharmacological management, taking account of both the physical and the emotional aspects of breathlessness.

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## Competing Interests

The authors declare that they have no competing interests.

## Authors' Contributions

M.G. conceived the systematic review, conducted all the procedures of the review (search, grading, data extraction, and synthesis) and drafted the

manuscript. C.B. graded the studies independently, critically assessed the methodological quality of the studies, and commented on several versions of the manuscript. I.J.H. participated in the overall design of the study and contributed to all the procedures of the review. All authors read and approved the final manuscript.

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