



Living with breathlessness: a systematic literature review and qualitative synthesis

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Breathing space: a conceptual framework for patients' coping, help-seeking and clinician response to breathlessness <http://ow.ly/Cqtp30hobHY>

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ABSTRACT What is the experience of people living with breathlessness due to medical conditions, those caring for them and those treating them, with regard to quality of life and the nature of clinical interactions?

Electronic databases (Ovid MEDLINE, Embase, CINAHL Plus and PsycINFO) were searched (January 1987 to October 2017; English language), for qualitative studies exploring the experience of chronic breathlessness (patients, carers and clinicians). Two independent reviewers screened titles, abstracts and papers retrieved against inclusion criteria. Disagreements were resolved with a third reviewer. Primary qualitative data were extracted and synthesised using thematic synthesis.

Inclusion and synthesis of 101 out of 2303 international papers produced four descriptive themes: 1) widespread effects of breathlessness; 2) coping; 3) help-seeking behaviour; and 4) clinicians' responsiveness to the symptom of breathlessness. The themes were combined to form the concept of "breathing space", to show how engaged coping and appropriate help-seeking (patient) and attention to symptom (clinician) helps maximise the patient's quality of living with breathlessness.

Breathlessness has widespread impact on both patient and carer and affects breathing space. The degree of breathing space is influenced by interaction between the patient's coping style, their help-seeking behaviour and their clinician's responsiveness to breathlessness itself, in addition to managing the underlying disease.

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Introduction

Breathlessness is a common and distressing symptom of many long-term cardiorespiratory conditions and cancers [1–3] prevalent globally [4]. A body of qualitative work describes its serious and widespread impact on the lives of patients and their families, and the challenges for their clinicians [5–11]. Despite optimal treatment for the underlying condition, breathlessness often persists and results in disability, recently described as chronic breathlessness syndrome [12]. Such breathlessness requires management, yet remains largely invisible to both the public and clinicians who may feel that nothing further can be done. This is partly due to its slow onset in many conditions, so breathlessness is seen as “normal”, intentional “hiding” of the symptom, a stoical response to breathlessness by patients and a lack of attention to the symptom from clinicians [13].

An understanding of patient and family experience, and clinicians’ response to this symptom, is important to inform relevant clinical practice. Although qualitative studies are by nature small and not intended to be generalisable, a systematic review and synthesis of primary qualitative studies can create a body of evidence helpful to develop theory and inform practice [14].

Other than one published in 2007 [8] which included 22 studies, qualitative systematic reviews [5–7, 9–11] focus on a single medical condition and are primarily from the patient’s perspective. The aim of this systematic review and qualitative synthesis is to explore the now large body of qualitative research on the experience of and response to breathlessness due to a variety of medical conditions, by those living with it, those who care for them and clinicians who treat them, with regard to informing directions for practice for maximising quality of life and optimising clinical interactions.

Methods

Design

A systematic search of qualitative studies was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles [15].

Search strategy

The search strategy (table 1) was guided by search terms, derivatives and related Medical Subject Headings (MeSH) terms for breathlessness (exposure); patient, carer and clinician (population); and experience,

TABLE 1 Search strategy (MEDLINE example)

	Search terms
Design	
1	interview*
2	Qualitative
3	finding*
Exposure	
4	breathless*
5	dyspn* MeSH Dyspnea exp
6	(short* adj 3 breath)
Population	
7	patient* MeSH patient-physician relations
8	carer* MeSH caregivers
9	health* adj2 profession*
10	health personnel MeSH exp.health personnel
Outcome	
11	experience
12	interaction*
13	help seeking MeSH Primary Health Care
14	coping MeSH Adaptation, Psychological
15	belief* MeSH attitude
16	psychosocial
17	psycho-social
18	1 OR 2 OR 3
19	4 OR 5 OR 6
20	7 OR 8 OR 9 OR 10
21	11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17
22	18 AND 19 AND 20 AND 21

MeSH: Medical Subject Headings.

interaction, help-seeking, coping and beliefs (outcomes), combined with a validated filter for qualitative research (design) [16].

MEDLINE, PsycINFO, Embase and CINAHL databases were searched between January 1987 and October 2017 (English language). Reference lists of reviews were hand searched and experts contacted. Titles, abstracts and retrieved papers were independently reviewed by AH and NBK against stated eligibility criteria. Any disagreements were resolved in discussion with MJ.

Studies were included if they reported on the experience of breathlessness due to an underlying medical condition from the perspective of patients, carers or clinicians and presented primary empirical qualitative data. Studies were excluded if the breathlessness was due to asthma, obesity or in a restricted population, e.g. post-transplant.

Quality appraisal

The quality of included studies was assessed using the Qualitative Assessment and Review Instrument critical appraisal checklist for interpretive and critical research; all were assessed by AH and a random five-article sample by NBK [17].

Data extraction

A data extraction tool was developed to extract contextual information about each study and all primary data (direct participants' quotations). Data were extracted from all papers by AH, with independent data extraction from a random five-article sample by NBK.

Analysis

The synthesis was reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidance [18].

Data were synthesised using thematic synthesis [19] and the principles of thematic analysis [20], whereby the context of each study is taken into account, while aiming to produce a generalisable synthesis [21]. The included studies were heterogeneous in terms of their research aims and populations studied, so only primary quotes from participants were extracted and coded.

The synthesis was performed in three stages: the first stage was line-by-line coding of the primary research findings of each study on the experience of breathlessness by AH. These codes were then refined, and through an inductive reasoning process organised into themes that described experience (descriptive themes) [19]. The analytical theme that describes the concept of "breathing space" emerged following a process of phenomenologically orientated reflection on the descriptive themes [22] involving discussion and interpretation between AH, MJ and KG to provide a broad understanding of the experience of breathlessness and interaction with clinicians. AH has a non-clinical psychology background, NBK is a medical student, MJ is a professor of palliative care and KG is a nursing academic and qualitative researcher. Each will have brought their previous experiences to bear in interpretation, but transparency of the method, independent selection of and extraction from primary studies and group discussion provides rigour to the review and synthesis process. The data were managed using NVivo 10 (QSR International, Doncaster, Australia).

Results

Selected studies

The database searches identified 2303 articles, with an additional 50 articles identified through other sources (figure 1). These articles were independently screened and after discussion between AH, NBK and MJ, 101 full papers were included (table 2).

Participants were patients in 68 studies, clinicians in five studies and family carers in 10 studies. Additionally, there were 18 studies with a mix of patients, carers and clinicians. The conditions explored in the 101 studies were as follows: chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (n=3), heart failure (n=5), cancer (n=7), chronic bronchitis and mixed causes (n=9). In keeping with the qualitative methods used, the average sample size was 20 (range 4–60). Included studies were from a variety of cultural settings, spread across four continents, including both low- and high-income countries.

Data extraction

No differences were found between the data extracted from the five articles by the two authors.

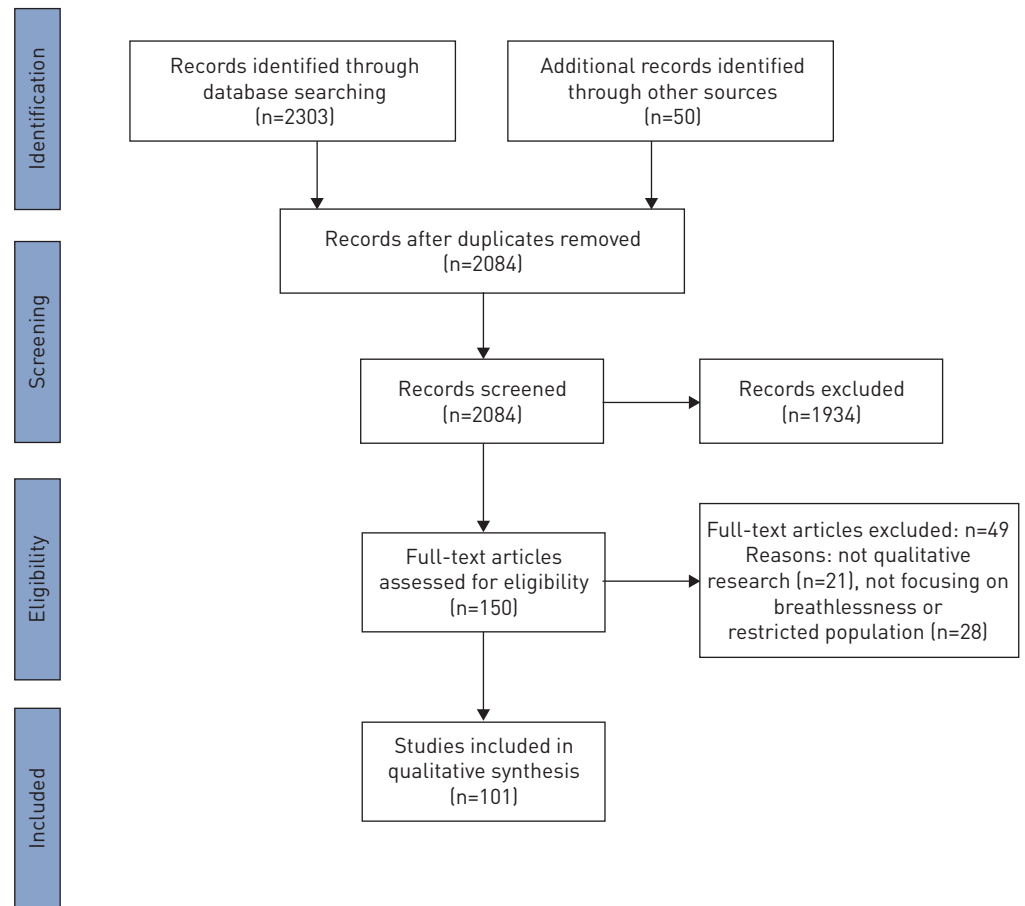


FIGURE 1 PRISMA 2009 flow diagram for the database searches. Reproduced and modified from [145].

Quality analysis

All selected articles were judged to be of sufficient quality to be included in the review.

Thematic synthesis

Coding of the 101 studies elicited 98 codes, which were condensed into four descriptive themes: 1) widespread effects of breathlessness; 2) coping; 3) help-seeking behaviour; and 4) clinician responsiveness to breathlessness (table 3). The overarching analytical theme of breathing space emerged from reflection and discussion of these four descriptive themes to describe coherent characteristics and features of the experience of living with breathlessness and to draw out implicit meanings.

The theme “widespread effects of breathlessness” has been described in other work [124, 125] and is presented in the online supplementary material; themes 2–4 are presented here. A brief summary of theme 1 is presented.

Widespread effects of breathlessness

The concept of “total dyspnoea” [126] was used as a theoretical framework for data analysis with respect to the widespread effects of breathlessness: physical, psychological, social and existential. This concept enables patients to be seen as complex, whole people in need of a holistic understanding of the many ways breathlessness affects their lives, on which effective management can be based.

Coping

The long-term consequences on an individual’s health and that of their carer are influenced by how well they cope with the stress caused by living with breathlessness. TOBIN *et al.*’s [127] categorisation of engaged and disengaged coping was used as a framework to analyse the findings with respect to coping.

TABLE 2 Characteristics of included studies

First author, year [reference]	Setting	Participants	Theoretical approach
AASBØ, 2016 [23]	Norway	Carers of patients with COPD (4 M, 6 F)	Thematic analysis
AASBØ, 2017 [24]	Norway	Carers of patients with COPD (4 M, 6 F)	Thematic analysis
ADAMS, 2006 [25]	Denmark, the Netherlands and UK	COPD patients (16 M, 7 F)	Grounded theory
AHMADI, 2014 [26]	Sweden	COPD, CHF, aortic stenosis, anxiety and asthma patients (7 M, 9 F, disease split unspecified)	Unspecified
APPS, 2014 [27]	UK	COPD patients (6 M, 9 F)	Unspecified
ARNOLD, 2006 [28]	UK	COPD patients (9 M, 11 F)	Unspecified
AVŞAR, 2010 [29]	Turkey	COPD patients (11 M, 3 F)	Phenomenological
BAILEY, 2001 [30]	Canada	COPD “family nurse units” (patient, 2 family members, 1 nurse)	Narrative analysis
BAILEY, 2004 [31]	Canada	10 family nurse units Clinicians (n=10, sex unspecified)	Ethnographic narrative
BAILEY, 2004 [32]	Canada	COPD “family nurse units” (patient, 2 family members, 1 nurse)	Narrative analysis
BAJWAH, 2013 [33]	UK	10 family nurse units Progressive idiopathic fibrotic ILD patients (5 M, 3 F) and 4 spouses (3 F, 1 M)	Unspecified
BARNETT, 2005 [34]	UK	COPD patients (n=10, sex unspecified)	Phenomenological
BERGS, 2002 [35]	Iceland	Carers of patients with COPD (0 M, 6 F)	Phenomenological
BOOTH, 2003 [36]	UK	COPD patients (6 M, 4 F) and cancer patients (6 M, 4 F) Cancers: respiratory system (n=6), breast (n=1), non-Hodgkin’s lymphoma (n=2), renal cell carcinoma (n=1)	Unspecified
BOOTH, 2006 [37]	UK	COPD, heart failure, cancer (colon n=1, myelofibrosis n=1) and other (ILD) 10 patients (4 M, 6 F) and 10 carers (sex unspecified)	Unspecified
BOVE, 2016 [38]	Denmark	Carers of patients with COPD (9 M, 13 F)	Framework method
BOYLE, 2009 [39]	USA	Carers of patients with COPD (0 M, 10 F)	Phenomenological–hermeneutic
BRANDT, 2013 [40]	USA	COPD patients (19 M, 9 F)	Naturalistic method
CARESS, 2010 [41]	UK	COPD patients (8 M, 6 F) and carers (3 M, 9 F)	Unspecified
CHANG, 2016 [42]	Taiwan	COPD patients (12 M, 2 F)	Phenomenological
CICUTTO, 2004 [43]	Canada	COPD patients (23 M, 19 F)	Unspecified
CLANCY, 2009 [44]	UK	COPD patients (6 M, 4 F) and carers (2 M, 5 F)	Longitudinal Heideggerian
COONEY, 2013 [45]	Ireland	COPD patients (15 M, 11 F)	Straussian grounded theory
DICKINSON, 2009 [46]	UK	COPD patients (n=12, sex unspecified)	Framework approach
DUCK, 2015 [47]	UK	IPF patients (7 M, 10 F) and their carers (2 M, 4 F)	Framework analysis
DUNGER, 2015 [48]	Germany	COPD patients (4 M, 6 F) and lung cancer patients (5 M, 3 F)	Framework analysis
EDMONDS, 2005 [49]	UK	Heart failure patients (20 M, 7 F)	Unspecified
EK, 2008 [50]	Sweden	COPD patients (3 M, 5 F)	Phenomenological
EK, 2011 [51]	Sweden	COPD patients (1 M, 3 F)	Phenomenological–hermeneutic
EK, 2011 [52]	Sweden	COPD patients and carers (4 couples)	Phenomenological–hermeneutic
ELKINGTON, 2004 [53]	UK	Carers of patients with COPD (7 M, 18 F)	Unspecified
ELOFSSON, 2004 [54]	Sweden	COPD patients (4 M, 2 F)	Phenomenological–hermeneutic
FIGUEIREDO, 2016 [55]	Portugal	Carers of patients with COPD (12 M)	Thematic analysis
FOTOKIAN, 2017 [56]	Iran	COPD patients (n=15), their carers (n=4) and clinicians (n=5) (sex unspecified)	Grounded theory
FRASER, 2006 [57]	USA	COPD patients (5 M, 5 F)	Phenomenological–hermeneutic
GABRIEL, 2014 [58]	Portugal	COPD patients (16 M, 4 F) and their carers (2 M, 18 F)	Thematic analysis
GARDINER, 2009 [59]	UK	COPD patients (13 M, 8 F)	Thematic analysis
GENOE, 2017 [60]	Canada	COPD patients (6 M, 2 F)	Interpretive phenomenological analysis
GOLDMAN, 2017 [61]	USA	COPD patients (16 M, 23 F)	Iterative immersion/crystallisation qualitative analysis process
GOTT, 2009 [62]	UK	39 clinicians working with COPD patients	Unspecified
GUTHRIE, 2001 [63]	UK	COPD patients (8 M, 12 F)	Unspecified
GYSELS, 2008 [64]	UK	COPD patients (7 M, 11 F)	Grounded theory

Continued

TABLE 2 Continued

First author, year [reference]	Setting	Participants	Theoretical approach
GYSELS, 2009 [65]	UK	Carers (all female n=15) Various conditions: lung cancer (n=1), COPD (n=2), heart failure (n=3), MND (n=8), palliative care (unspecified; n=1)	Grounded theory
GYSELS, 2009 [66]	UK	COPD patients (7 M, 11 F)	Grounded theory
GYSELS, 2010 [67]	UK	COPD patients (7 M, 11 F)	Unspecified
GYSELS, 2011 [68]	UK	Patients Various conditions: cancer (unspecified; 5 M, 5 F), COPD (5 M, 9 F), heart failure (7 M, 3 F), MND (9 M, 1 F)	Unspecified
HABRAKEN, 2008 [69]	The Netherlands	COPD patients (8 M, 3 F)	Unspecified
HALLAS, 2012 [70]	UK	Patients with various conditions (5 M, 7 F) Respiratory conditions: IPF (n=5), cystic fibrosis (n=1), bronchiectasis (n=2), COPD (n=1), primary pulmonary hypertension (n=1), recurrent pneumothoraces (n=1); Heart problems: Eisenmenger's syndrome (n=1)	Phenomenological
HARRIS, 2008 [71]	UK	COPD patients (12 M, 4 F)	Interpretive phenomenological
HASSON, 2008 [72]	Northern Ireland	COPD patients (10 M, 3 F)	Unspecified
HENOCH, 2008 [73]	Sweden	Lung cancer patients (11 M, 9 F)	Unspecified
JENG, 2002 [74]	Taiwan	COPD patients (7 M, 2 F)	Constant comparison and content analysis
JONES, 2004 [75]	UK	COPD patients (8 M, 8 F)	Unspecified
KANERVISTO, 2007 [76]	Finland	COPD patients (n=5, sex unspecified) and spouses (n=4, sex unspecified)	Content analysis
KERR, 2010 [77]	UK	COPD patients (6 M, 3 F)	Grounded theory
KORPERSHOEK, 2016 [78]	The Netherlands	COPD patients (8 M, 7 F)	Grounded theory
LAI, 2007 [79]	China	Lung cancer patients (n=11, sex unspecified)	Content analysis
LEIDY, 1999 [80]	USA	COPD patients (6 M, 6 F)	Phenomenological
LEWIS, 2014 [81]	UK	COPD patients (n=25, sex unspecified)	Phenomenological
LOWEY, 2013 [82]	USA	COPD and heart failure patients (proportion unspecified; 9 M, 11 F)	Unspecified
MAGUIRE, 2014 [83]	UK	Lung cancer patients (4 M, 6 F)	Interpretive phenomenological analysis
MARX, 2016 [84]	Germany	COPD patients (10 M, 7 F)	Grounded theory
MOSHER, 2015 [85]	USA	Lung cancer patients (n=21: 10 M, 11 F) and carers (n=21: 6 M, 15 F)	Thematic analysis
NICHOLLS, 2003 [86]	New Zealand	COPD patients (5 M, 5 F)	Phenomenological
NICOLSON, 2000 [87]	UK	Chronic bronchitis patients (10 M, 10 F)	Unspecified
NICOLSON, 2003 [88]	UK	COPD patients (10 M, 10 F)	Symbolic interactionist theoretical framework
O'DRISCOLL, 1999 [89]	UK	Lung cancer patients (30 M, 22 F) Nonsmall cell (n=32), small cell (n=13), mesothelioma (n=4), suspected (n=3)	Content analysis
OLIVER, 2001 [90]	UK	COPD patients (n=16, sex unspecified)	Phenomenological
O'NEILL, 2002 [91]	USA	COPD patients (0 M, 21 F)	Common sense concept
OVERGAARD, 2016 [92]	Denmark	IPF patients (15 M, 10 F) and their carers (n=24)	Framework method
PAAP, 2014 [93]	The Netherlands	COPD patients (13 M, 8 F)	Grounded theory
PINNOCK, 2011 [94]	UK	COPD patients (14 M, 7 F) Carers (13 informal, 18 professional)	Unspecified
ROBERTS, 1993 [95]	Canada	Cancer patients (4 M, 6 F), clinicians (all nurses; n=12, sex unspecified) Cancers: lung (n=4), breast (n=2), throat (n=1), stomach (n=1), prostate (n=1), kidney (n=1)	Unspecified
ROBINSON, 2005 [96]	UK	COPD patients (6 M, 4 F)	Qualitative phenomenological
RYAN, 2009 [97]	Ireland	Heart failure patients (6 M, 3 F)	Phenomenological
SEAMARK, 2004 [98]	UK	COPD patients (9 M, 1 F) and carers (n=8)	Interpretative phenomenological
SHIPMAN, 2009 [99]	UK	COPD patients (9 M, 7 F)	Unspecified

Continued

TABLE 2 Continued

First author, year [reference]	Setting	Participants	Theoretical approach
SIMON, 2016 [100]	Germany	CHF patients, COPD patients, lung cancer patients and MND patients (n=51: 30 M, 21 F)	Framework analysis
SIMPSON, 2010 [101]	Canada	Carers of patients with COPD (3 M, 11 F)	Attride-Stirling thematic network
SMALL, 2012 [102]	UK	COPD patients (8 Devon, 13 Barnsley, sex unspecified) Clinicians (19 Devon, 20 Barnsley, sex unspecified)	Unspecified
SPENCE, 2009 [103]	Ireland	Clinicians (7 M, 16 F)	Unspecified
SPENCE, 2008 [104]	Ireland	Carers of patients with COPD (1 M, 6 F)	Thematic analysis
STRANG, 2014 [105]	Sweden	COPD patients (15 M, 16 F)	Manifest and latent content analysis
STRIDSMAN, 2015 [106]	Sweden	COPD patients (5 M, 5 F)	Latent qualitative content analysis
STULL, 1999 [107]	USA	Heart failure patients (17 M, 4 F)	Grounded theory
TAYLOR, 2017 [108]	UK	Heart failure patients (11 M, 5 F)	Framework method
WAINWRIGHT, 2017 [109]	Uruguay	COPD patients (23 M, 14 F)	Sensorial medical anthropology
WALTHALL, 2017 [110]	UK	Heart failure patients (15 M, 10 F)	Thematic analysis
WALTERS, 2008 [111]	Australia	COPD patients (5 M, 9 F) Clinicians (GPs; n=19, sex unspecified)	Unspecified
WILLGOSS, 2012 [112]	UK	COPD patients (5 M, 9 F)	Thematic network analysis
WILLIAMS, 1993 [113]	UK	COPD patients (n=24, sex unspecified) and their families	Sociological approach
WILLIAMS, 2007 [114]	UK	COPD patients (4 M, 2 F)	Unspecified
WILLIAMS, 2010 [115]	UK	COPD patients (6 M, 3 F)	Grounded theory
WILLIAMS, 2011 [116]	UK	COPD patients (12 M, 6 F)	Grounded theory
WILSON, 2007 [117]	Ireland	COPD patients (25 M, 7 F) Clinicians (n=8, sex unspecified)	Unspecified
WONG, 2014 [118]	Malaysia	COPD patients (18 M) and their doctors (5 M, 13 F)	Thematic analysis
WOOD, 2013 [119]	UK	Lung cancer patients (7 M, 2 F)	Unspecified
WORTZ, 2012 [120]	USA	COPD patients (25 M, 22 F)	Unspecified
YOUNG, 2012 [121]	Canada	Clinicians, caring for patients with COPD (10 family physicians, 8 respiratory specialists, sex unspecified)	Unspecified
YU, 2007 [122]	China	COPD patients (5 M, 0 F)	Thematic network analysis
ZAKRISSON, 2010 [123]	Sweden	Clinicians, caring for patients with COPD (n=12, sex and speciality unspecified)	Unspecified

COPD: chronic obstructive pulmonary disease; M: male; F: female; CHF: congestive heart failure; ILD: interstitial lung disease; IPF: idiopathic pulmonary fibrosis; MND: motor neurone disease; GP: general practitioner.

There were examples of disengaged coping strategies in the face of the stress caused by breathlessness; “problem avoidance”, “wishful thinking”, “self-criticism” and “social withdrawal”.

“Problem avoidance” and “wishful thinking” risk delayed presentation, either through denying a problem, or hoping that it will just go away:

About 30 years ago, I was first told that I had the beginnings of emphysema ... So, what's that mean? I mean, how bad can that be? I didn't have time to be sick. So I didn't let it bother me ... I just continued to let it get worse, and ignored it. (Patient) [57]

“Self-criticism” and self-blame led some to hide their breathlessness to avoid embarrassment. Others hid their breathlessness from others, feeling that their difficulties due to breathlessness were poorly understood and unrecognised by others:

TABLE 3 Codes and themes from the synthesis

Themes	Subthemes	Codes
Widespread effects of breathlessness	Physical effects Psychological effects Social effects Existential effects	Bereavement, change in relationships, change in roles or identity, impact on carer, isolation, manner of death, restricted freedom, physical limitations, psychological effects, shrinking lifeworld, social limitations, stress of breathlessness, carers' needs, hopelessness, loss, self-esteem, social embarrassment, spiritual or existential aspect
Coping	Disengaged coping Engaged coping	Acceptance, adaptation, communication, cooperation with patient needed, helplessness, importance of mobility, lack of understanding, comorbidities, breathing techniques, attitude to support groups, 1 day at a time, carer's own health, palliative care, sense of duty, smoking cessation, stagnation, stoicism, carer support needed, community support, pulmonary rehabilitation, self-management, autonomy, avoidance, being cared for, benefit of air movement, benefit of being outside, benefit of fan, benefit of fresh air, breathlessness as a way of life, connectedness, health within illness, hope, hopelessness, importance of mobility, increased activity post-pulmonary rehabilitation, increased self-efficacy, injustice, innovation, lack of knowledge, motivation to keep going, need for activity, own pace, perseverance, resignation, self-monitoring, breathlessness is normal, struggling, suicide, support from others, taking 1 day at a time, stigma, hiding
Help-seeking behaviour	Recognising breathlessness as a problem to be solved Deciding to take action Selecting a potential helper Disclosing the problem Consequences of help-seeking	Help-seeking, reluctance to present to healthcare professional, pride not asking for help, need for information, information seeking for self, lack of information, explaining it away, access to healthcare professional, lack of acknowledgement, consultation constraints
Healthcare professional responsiveness to breathlessness	Testimonial injustice Hermeneutical injustice Responses to breathlessness	Epistemic injustice, lack of understanding, nothing more can be done, palliative care, clinician distress, diagnosis, prognosis, holistic approach, management of breathlessness, future care, invisibility, continuity of care, where to present, waiting

Even if it's going next door, you can see the anxiety building up because he will never ever show anybody what he's like. He won't show it. It's only me knows in the family. (Carer) [41]

The result was reduced access to social support from friends, family or other sources:

... she wouldn't go to a community group, she is not into that. (Carer) [41]

Conversely, others employed engaged coping strategies such as "problem solving", "cognitive restructuring", "expressing emotion" and "seeking social support" in order to manage their stress effectively.

Instead of avoiding activities causing breathlessness, engaged copers used "problem solving" to find new ways of managing their daily lives by adapting their activities or pacing themselves:

Yesterday, I left my shower until the afternoon and I found that I was much better. I had the water just above body heat – so as not to have too much steam, and I had a draught blowing through. (Patient) [86]

Ways to keep in social contact and deal with problems were found. This included the use of various aids (e.g. ambulatory oxygen, nebulisers or mobility aids, phones and the internet), or choosing alternative activities which they found rewarding:

I go to friends sometimes and take my nebuliser with me. She understands and does not mind. Otherwise you could be tied in forever. (Patient) [34]

The relationship (with family) hasn't suffered, but it's a different kind of relationship. It's a "telephone relationship". (Patient) [98]

"Cognitive restructuring" and having a "can-do" attitude helped some to have a less bleak outlook and to be more accepting of their limitations and prognosis:

I am not going to live forever, but I am going to live the best I can for as long as I can. (Patient) [91]

Active seeking of information from others helped develop an informed understanding of their situation and "expressing emotions" was helpful to some:

One thing I found useful was the literature and advice ... from the right source on the subject. (Patient) [70]

Well you have to talk with people who know what you're talking about and unless you've really walked this trip, you really don't know what it's about and that's why I like RAPS [support group]. (Patient) [43]

Self-compassion instead of self-blame enabled smokers to show their younger selves compassion and recognise that at the time they started smoking the harm wasn't well understood:

I know it's self-inflicted. I'm not very happy about it, but you have to accept it. My mother and father smoked, it was a way of life, smoking. We were not aware then of the health damage it could do. (Patient) [34]

Furthermore, engaged copers may "seek social support" from both family and friends and from others who have learnt to deal with breathlessness:

I felt comfortable ... all the other people here with the same problems and you find out you're not alone. You get an incentive to try and help yourself more when you see what other people have done, you say okay, maybe I should try this, maybe I should try that. (Patient) [43]

Help-seeking behaviour

According to the concept analysis of help-seeking by CORNALLY and MCCARTHY [128], for a patient to seek help, they need to: 1) recognise breathlessness as a problem that could be solved; 2) decide to take action; 3) select who can be asked to help; and 4) disclose the problem to the helper. In this paper the term "helped" is used rather than "solved", as breathlessness can be managed but rarely solved.

Recognising breathlessness as a problem to be helped

Breathlessness often develops slowly and many patients find alternative explanations for it, such as ageing or smoking, and thus take a long time to realise that their breathlessness is a problem to be addressed:

There were times when I struggled but I just thought it was because of old age and just let it go. (Patient) [44]

I didn't go to the GP, only if I'd got something, you know, wrong with me. But I'd get a bit out of breath and as I say I just put it down to smoking like. (Patient) [113]

Deciding to take action

Once breathlessness was recognised as a problem some found it difficult to act, with many remaining passive until forced by crisis and often with action taken by family:

My daughter asked for him. I didn't ask for him, she sent for him. (Patient) [90]

It has to be really bad for me to ... see the doctor (Patient) [25]

Patients may feel unworthy of support for a symptom they perceived to have brought on themselves:

I resent myself for letting it get to this, for smoking. When I did know better I did nothing about it. (Patient) [86]

Are we wasting valuable time for someone else or ... or are we a lost cause – I mean you obviously think that way, don't you? (Patient) [98]

Selecting a potential helper

In the UK a patient who sees breathlessness as a problem which can be helped and who decides to act would usually contact their general practitioner (GP):

I see my own doctor who understands how I feel and I get on very well with him. (Patient) [98]

However, some patients, once diagnosed, feel that they cannot discuss their breathlessness with their GP, but instead feel they should discuss it only with their specialist:

Interviewer: "Is your GP involved in the care for your lungs?"

Patient: "No. I'm seeing a respiratory physician ..." "I visit the respiratory physician once a year, and when I'm really ill I go and see my GP. But that can be about something completely different. We don't discuss my emphysema then. It's registered somewhere, emphysema, but we don't talk about it." (Patient) [69]

In crisis the patient may not feel able to access their GP and instead seek help from the emergency department:

I was working and my breathing all that week had been rather haywire ... I do maintenance and we were steam cleaning a patio garden – and I am afraid the steam really wound me up ... So ... I sat on the bed for about an hour. I couldn't breathe and I thought Jesus I've got to get to hospital! (Patient) [49]

Disclosing the problem

Finally, when the patient meets the potential helper they need to disclose the problem. However, time constraints and the need to repeat information influence the detail provided:

For the first two or three years I was seeing Dr G all the time and then, all of a sudden, I found that I'd seen about four or five different doctors. And I found that a bit of a problem really, 'cause you've got no continuity at all. You've got to explain it all again, start from scratch each time, and that can be very wearing. 'Cause you're out of breath to start with, and you get more and more out of breath trying to explain why you're out of breath! (Patient) [113]

The characteristics and manner of the listener also affect disclosure and judgements as to what is medically relevant information and therefore not mention breathlessness, or its impact:

You can't go to the doctor and say "I can't dance". It's a strange thing to say to the doctor. (Patient) [64]

Furthermore, if a patient discloses information about breathlessness, the listener may not respond in a helpful way and then the patient makes no further disclosure:

I wanted people to take notice ... I used to offer this information ... I'm really quite breathless ... they were probably more interested in the pain ... (Patient) [36]

Consequences of help-seeking

For some, help-seeking led to problem resolution and increased wellbeing:

It's fantastic because you have the practical exercise and then you have the education, and that is as important because I knew nothing about it [COPD] until then and I learned so much and how to cope. (Patient) [66]

For others the problem remained unresolved with subsequent dissatisfaction, resentment and increased helplessness. The patient may then use health services inappropriately or may give up, assuming their problem is not valid and/or that there is nothing that can be done to solve it:

They have given me about all the drugs they can to cope with it. I don't think they can do anything more. (Patient) [72]

Clinician responsiveness to breathlessness

The concept of epistemic injustice [129] was used as the theoretical framework for analysis of this theme. Epistemic injustice can be subdivided into testimonial injustice (a person's testimony is not taken into account when a decision is made by another) and hermeneutical injustice (there is no shared understanding of a phenomenon to enable full interpretation of an experience) and each can shape patient/clinician interactions.

Testimonial injustice

The theme "help-seeking" illustrates that patients may select which information is included in their testimony. Additionally, reliance on medical knowledge, observable signs and symptoms, and objective performance tests by clinicians may lead them to disregard the patient's experience of breathlessness and overall functioning:

It started about 4 years ago, I was visiting next door's new baby ... when I tried to lift him up I couldn't breathe. I went to the doctors and had all the tests and when they came back normal I just carried on. (Patient) [44]

Patients and carers are aware of time pressures for consultations, which may not allow full disclosure. This may be conveyed overtly by the clinician by hurrying the patient, or directing the consultation to contain the content. The result is a reticence in disclosing their concerns:

All he is interested in is give me a prescription, how do you feel, yep ... you have had your 10 minutes ... on your way. (Patient) [90]

... but I could never go to the doctor and just say, I can't do this anymore. No, I have not noticed any open door offering help for myself. (Carer) [35]

Clinicians were dissatisfied with service configuration constraints and understood the importance of offering patients the opportunity to discuss what was important to them:

I think time's a massive issue. In your ten-minute consultation when they've come with a fungal toenail infection and this, that and the other, to actually say "and we also need to talk about your COPD, and you do realise that eventually you could possibly die from this illness" it just opens a massive can of worms and so you don't really want to go there. (Doctor) [62]

Hermeneutical injustice

Patients found it difficult to explain their symptoms to clinicians, who, in turn, appeared not to fully appreciate the effects of breathlessness on their patient:

And he said to me: "Where do you work?" I said "Work?" He said: "What do you do for a job?" I said: "Well, nothing doctor". And then I left. I thought what a silly question to ask me. "What do you do for a living?" And then afterwards I thought, he's seen emphysema on the screen but didn't realize the full extent of it. I mean, there's no way I could get a job or could go to work. (Patient) [64]

This may be compounded by the patient often appearing comfortable when at rest in the consultation, or only contacting the clinician during an exacerbation. Patients described unpredictable symptoms, poorly understood by clinicians, which resulted in a lack of support and limited offers of medical help:

People like Mr X who doesn't really bother us that much, we really only see him when he's not well. (Doctor) [94]

And they must say "Oh there's THAT one again" and sometimes I had to stay on the trolley all night and like they'd be looking at me like "What's wrong with HER?" because by the time they see me I'd be alright maybe? (Patient) [97]

Responses to breathlessness

A response that "nothing more that could be done" left both patients and carers feeling abandoned and that breathlessness was now a normal part of life:

But then when you leave hospital he knew that there was nothing after that. Nothing there was just me and him. (Carer) [53]

Getting breathless has become normal for me, I don't even notice it. (Patient) [71]

Poor communication and a lack of information contributed to limited access to breathlessness-specific interventions or other services such as palliative care:

I've heard of it [palliative care] but to be honest I never understood what the word meant. (Patient) [104]

We've never been given any information about that [exercise]. We just thought that it was... something he had to put up with. So, no, we've never been aware that there were things that he could have done to help him. (Carer) [41]

Some clinicians recognised the impact of breathlessness, but felt ill-equipped and under-resourced to manage it:

... so that can weigh you down emotionally because sometimes you can feel helpless that you're going in and you're doing the best that you can, but you don't have the resources available to help them ... (Doctor) [121]

A lack of explicit discussion of breathlessness and its management left patients unsure what to do if it worsened. Some coped alone as best they could, while others felt that hospital presentation was their only route to rescue:

They're all terrifying at night – I go “Uh oh here we go again” you just have to get out – put your feet on the floor, and you think “Will I ring the ambulance or not?” or “Am I going to die under this one?” But most times I don't ring anybody, I just sit up all night waiting for it to pass and there's nobody in the house so that's really frightening. (Patient) [97]

Sometimes you can think, when you're too sick, that they [medical staff] can tell me what to do, so I don't have to make all the decisions. I trust myself, but it would be nice if someone just took care of me like that. (Patient) [51]

Conversely, knowing that a clinician was available and responsive to breathlessness provided great peace of mind to both patients and their carers:

They are very good and I know I can ring them up. The doctors are great, they are marvellous; you can ring or he'll even ring to see if you are alright. That means an awful lot. (Carer) [104]

When the impact of breathlessness was recognised by the clinician, patients had it managed alongside disease-directed treatments, using a palliative approach even if they were not deemed to be at the “end-of-life”. This often allowed the opportunity to talk about future care and enabled better coping:

I don't think people [with COPD] realise you can do this, can make wishes or choices of what happens, to say “I don't want to go into hospital, it doesn't matter what”, things like that, so that in a way they're prepared for it. (Doctor) [62]

She has got me organised and now I understand how the disease works. As a result I have had a good summer. It makes me feel more resilient. (Patient) [96]

In addition, clinicians seemed to find satisfaction and a less nihilistic attitude to management:

I still think we can make a major difference to their quality of life through various interventions aimed at symptoms, so certainly the feedback that one gets from patients is that they feel they've gone from being hopeless and just through the implementation of some very simple symptom based remedies one can make a big difference to how they feel. (Doctor) [33]

Breathing space: a concept to describe living with breathlessness

The overarching analytical theme, breathing space, represents the integration of the four descriptive themes. The phrase breathing space dates back to the 1600s [130, 131] and includes the meaning of a “period of rest that allows you to get your energy back or try a different solution” [132], “sufficient space in which to move and work” [133] and an opportunity to find out what is important and to express oneself [134]. The concept of breathing space draws on previous work relating to quality of life defined as

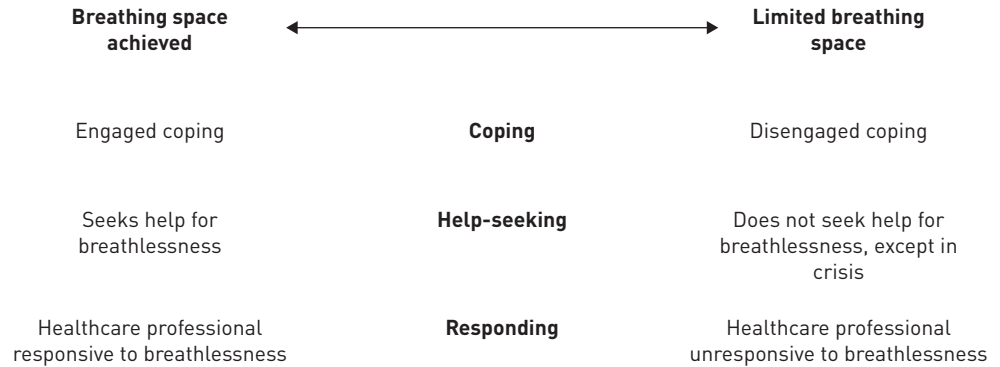


FIGURE 2 Breathing space.

“the degree to which a person enjoys the important possibilities of his or her life” [135] and on the work of the phenomenological philosophers Heidegger and Merleau-Ponty applied by CAREL [136] to the experience of illness. CAREL argues that as our body is the basis of our interaction with the world, being able to or being unable to carry out our activities affects both our view of ourselves and our quality of life greatly.

Here we use breathing space as a metaphor for the experience of living with breathlessness: rest from the constraints imposed by breathlessness; space and time to recoup strength and then plan further action; and the circumstances under which one can find one’s priorities and then fulfil them (figure 2).

The degree of breathing space achieved results from a complex interaction between the patient’s coping style, their help-seeking behaviour and their clinician’s responsiveness to breathlessness. It is a continuum with some patients having restricted breathing space, while others are able to achieve more breathing space. restricted breathing space is characterised by avoidance, resignation and stagnation; summarised by the phrase “life stops”:

It just stops your life, stops you from living. (Patient) [41]

You fall into a huge hole, then the world gets so tiny, it all gets so narrow that it is almost unbearable. (Carer) [38]

I tell you, my house is my prison. (Carer) [58]

In this case patients and carers may feel they have no control:

I have no activities, it controls me ... it controls my life. (Patient) [79]

I feel like Sleeping Beauty. The hawthorn hedge has closed around me and I cannot do anything about it. (Carer) [38]

Restricted breathing space may result from a combination of a disengaged coping style, delayed or crisis help-seeking behaviour and a lack of responsiveness to breathlessness by the patient’s clinicians.

Conversely, greater breathing space may result from a combination of engaged coping strategies, timely help-seeking and responsiveness to breathlessness by their clinician. A greater degree of breathing space is characterised by acceptance, adaptation and participation and can be summarised by the phrase “life changes”:

I’ve sort of changed my life. You can’t do the things you used to do, so you’ve got to say “well, okay, what can I do?” and do it. (Patient) [86]

I changed as a person. The disease makes me feel more mature, more prepared and responsible for other people. (Carer) [58]

Discussion

The concept of breathing space describes the whole experience of living with breathlessness, going beyond its widespread effects to encompass how the patient (and family) copes with breathlessness, how they seek help for it and how their clinicians respond to it. This interaction influences whether a patient achieves maximum breathing space within the limitations of their disease, or whether their life becomes increasingly restrictive.

Family carers also experience the widespread effects of breathlessness on their physical and mental health, as well as social and existential effects on their lives. The way that the person they care for copes and seeks help can put extra burden onto the carer. Additionally, carers experience the responsiveness, or lack thereof, of clinicians and may feel isolated and helpless.

In addition, this review draws on the perspectives of clinicians who care for breathless patients, showing how their response to breathlessness shapes patients' help-seeking and coping strategies. Clinicians may be unaware of breathlessness-directed treatments, but those that are aware find satisfaction when their management has helped patients to have better quality of life.

This theoretical analysis provides significant new insights from patient, carer and clinician perspectives, which have been systematically drawn into a collective whole to provide direction for clinical practice.

The widespread effects of breathlessness are consistent with previous reports [5–11]; illustrating the common experience of breathlessness irrespective of medical condition. The physical, psychological, social and existential effects of breathlessness are characteristic of the effects of chronic illness in general as described by CHARMAZ [137]. The burden on family and friends and their need for information and support is also observed in other work [125, 138, 139]. The concept of breathing space extends and adds to “total dyspnoea” [126], by describing how the interaction between the patient's coping and help-seeking behaviour and clinicians' responsiveness to breathlessness determine the overall experience of both patients and carers living with breathlessness. There is overlap between the breathing space concept and that of the “shifting perspectives model of chronic illness” [140]. The opposite ends of the continuum of breathing space are illustrated in recent articles; however, each of these papers tend to focus only on one [56, 60, 106] or other [42, 84] end of the continuum, rather than bringing them together as a more integrative concept.

New existential perspectives of wellbeing within illness support these ideas [141]. Wellbeing is usually described in relation to its absence and as a resource within the experience of breathlessness, rather than relying on the complete eradication of the breathlessness. Breathing space opens up the possibility of being able to carry on with this breathlessness and a settling or “letting be” that can potentially offer pathways to coping.

Breathing space resonates with the breathing, thinking, functioning clinical model [142]; a framework to help clinicians support patients with breathlessness to break the vicious cycles of physical, cognitive/emotional and functional deterioration experienced by many.

Breathing space may be a useful concept with which to understand other work. The HELP-COPD study [143] found that patients had very few felt needs and did not take up offers of help. Disengaged coping behaviour developing over time coupled with a lack of responsiveness to breathlessness by their clinicians might lead to restricted breathing space and lowered expectations with consequent unrecognised need.

Clinicians could use the breathing space concept to explore how the patient is coping and seeking help as well as previous experience of clinical attention to breathlessness. This approach is seen in the London Respiratory Network's Breathing SPACE framework [144] which encourages engaged coping strategies such as exercising, smoking cessation and seeking peer support and addresses mental health issues demonstrating responsiveness to symptoms in addition to disease processes.

Strengths and limitations of this study

This large systematic literature review and synthesis followed the PRISMA process [15] to ensure rigour and minimise selection and reporting bias. The qualitative synthesis was conducted using recognised methodology [19]. Synthesis used direct quotes to keep close to the primary data.

Limitations include language restrictions; only articles in English were included. However, the selected studies are drawn from a wide range of countries, each with their different cultural contexts. Only published primary quotes were extracted and it is acknowledged that there would have been more primary data than were published to which we have no access. However, qualitative methods mandate that representative quotes are used, and thus we believe, given the number of papers in this synthesis, that our findings are representative.

Implications for society, clinical practice, service providers and policy makers

Society

Greater understanding of the widespread effects of breathlessness is needed in order to overcome any epistemic injustice [129]. Public recognition of chronic breathlessness may help patients bring their symptom into the “open” and legitimise requests for clinical help before a crisis, rather than assuming this is something they and their carer have to live with.

Clinicians

The breathing space concept could be used by clinicians as a way to systematically assess breathlessness and its impact on the patient and carer, their current access to and uptake of evidence-based management strategies and support from other relevant clinicians and their pattern of emergency services use. This would allow the clinician to give advice on how to cope in a more engaged style, how and when to seek help appropriately and to decide what further evidence-based breathlessness management to offer. Additionally, the knowledge and information needs of patients and carers should be explored and met, especially with respect to diagnosis and prognosis.

Education and training for clinicians in primary and secondary care in the assessment of breathing space and the management of breathlessness, such as that provided around the breathing, thinking, functioning model [142], could improve patients’ access to breathlessness-targeted treatments delivered by the multidisciplinary team, including support for carers. Inclusion of qualitative research as part of critical appraisal in the education of medical trainees would enable them to develop an appreciation of patient and carer voice.

This review suggests that clinicians who are responsive to breathlessness and offer evidence-based breathlessness management find satisfaction in their work and have an improved sense of achievement rather than the sense of therapeutic nihilism experienced by others.

Service providers and policy makers

Adequate provision of services which support patients and carers to achieve a greater degree of breathing space is called for.

Future research

Future work should include ways to address the lack of public understanding of chronic breathlessness.

The usefulness of the breathing space concept in assessment by clinicians should be evaluated.

The degree to which breathing space can be achieved by the use of engaged coping strategies, appropriate help-seeking behaviour and responsiveness to breathlessness by clinicians should be tested.

The effectiveness of education programmes for clinicians should be evaluated with regard to interactions with patients and families and the use of tailored approaches to breathlessness management.

The extent to which the breathing space concept could be used as an explanatory concept in other chronic conditions should be investigated.

While most included studies discussed people with COPD, people with a wide range of other causes for their breathlessness are represented in this qualitative synthesis. However, other research questions may arise in relation to less studied disease groups for which a qualitative approach would be the appropriate study design.

Conclusion

The breathing space concept could help clinicians understand how patients and their families experience, and respond to, the widespread effects of breathlessness and thereby increase or reduce their limitations. The degree of breathing space achieved is influenced by interaction between the patient’s coping style, their help-seeking behaviour and the responsiveness of their clinician to breathlessness itself, in addition to managing the underlying disease.

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