



Illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with advanced respiratory disease: an observational study

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Interventions that directly target illness perceptions, cognitive and behavioural responses to chronic breathlessness may improve symptom burden, self-efficacy and health-related quality of life <https://bit.ly/3l0aVp1>

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Abstract

Background Understanding the complexity and multidimensional nature of chronic breathlessness is key to its successful management. The aim of this study was to explore illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with advanced respiratory disease.

Methods This was a cross-sectional secondary analysis of data from a feasibility randomised control trial (SELF-BREATHE) for individuals living with chronic breathlessness due to advanced disease. All participants completed the following questionnaires: numerical rating scale (NRS) breathlessness severity, NRS distress due to breathlessness, NRS self-efficacy for managing breathlessness, Dyspnea-12 (D-12), Chronic Respiratory Disease Questionnaire (CRQ), Brief Illness Perception Questionnaire (Brief IPQ) and the Cognitive and Behavioural Responses Questionnaire, short version (CBRQ-S). The associations between the Brief IPQ and CBRQ-S with NRS breathlessness severity, distress and self-efficacy, D-12 and CRQ were examined using Spearman's rho correlation coefficient r_s . A Spearman's r_s of ≥ 0.50 was predefined as the threshold to denote important associations between variables. A p-value of < 0.008 was considered statistically significant, to account for the number of comparisons performed.

Results The illness perception items consequences, identity, concern and emotional response were associated with increased breathlessness severity, increased distress, reduced breathlessness self-management ability and lower health-related quality of life. Symptom focusing and embarrassment avoidance were identified as important cognitive responses to chronic breathlessness.

Conclusion Interventions that directly target illness perceptions, cognitive and behavioural responses to chronic breathlessness may improve symptom burden, self-efficacy and health-related quality of life.

Introduction

Breathlessness is a significant global transdiagnostic problem, with more than 75 million people living with breathlessness, including $>90\%$ of the 65 million people with severe lung disease [1], $>50\%$ of the 10 million with incurable cancer and 50% of the 23 million with heart failure [2, 3]. More than two-thirds of those living with breathlessness have multimorbidity [4].

The burden of breathlessness on individuals, family, society and health systems is increasing with population ageing and multimorbidity, further amplified by the coronavirus disease 2019 (COVID-19) pandemic [5, 6]. Proactive approaches to the management of breathlessness are required to build capacity and resilience within healthcare systems, especially given rising health and social care costs, and workforce challenges [7–10].



Understanding the complexity and multidimensional nature of chronic breathlessness is key to its successful management. The American Thoracic Society defines dyspnoea (breathlessness) as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” [11]. The mechanisms of breathlessness are complex and incompletely understood [11]. Breathlessness derives from interactions between multiple physiological, psychological, social and environmental factors that may induce secondary physiological and behavioural responses [11]. When considering factors that influence outcomes and symptom burden in individuals living with chronic breathlessness, illness perceptions, cognitive and behavioural responses may be important determinants, especially in the context of self-management [12]. Leventhal’s Common-Sense Model of Self-Regulation provides a framework to explore illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with chronic respiratory disease [13].

Leventhal’s common-sense model of illness self-regulation is a prominent social cognition approach to describing the processes by which patients form lay beliefs (positive and negative) about health threats (*e.g.* symptoms), how these health beliefs impact coping procedures, and how subsequent appraisals of these procedures, iteratively and dynamically, update beliefs and responses to managing the perceived threat, consequently resulting in positive or negative outcomes [13, 14]. The model takes an individual perspective, recognising that illness management is dependent on individuals’ motivation to respond to and manage threat(s). Lay beliefs and associated coping responses (positive and negative) make sense to the individual, even though they may be inconsistent or contradictory to expert health advice [14]. Therefore, understanding patients’ health beliefs, cognitive and behavioural responses to chronic breathlessness in advanced respiratory disease is key to the development of new potential treatments for chronic breathlessness. We hypothesised that more negative health beliefs, cognitive and behavioural factors contribute to chronic breathlessness severity in patients with advanced disease.

Cognitive factors include beliefs about the dangers of undertaking activity (fear avoidance beliefs) and beliefs about self-efficacy, while behavioural factors include avoidance of activity, prolonged bed rest and all-or-nothing behaviour (*i.e.* periods of high activity followed by periods of inactivity), also referred to as “booming-and-busting” [15].

To date, research on the relationship between illness perceptions and coping, self-efficacy and health-related quality of life has been respiratory disease specific, *e.g.* asthma [16] and COPD [12, 17]. No studies have taken a transdiagnostic approach to chronic breathlessness. The move away from the single-diagnosis approach towards a transdiagnostic conceptualisation and treatment of chronic breathlessness represents a significant paradigm shift [10, 18]. The transdiagnostic approach focuses on identifying the common and core maladaptive temperamental, psychological, cognitive, emotional interpersonal and behavioural processes that underpin a broad array of diagnostic presentations/symptoms and targeting these factors in treatment(s) [18, 19]. Transdiagnostic treatments apply the same underlying treatment principles across diagnoses, without tailoring the treatment(s) to a specific diagnosis, and as such operate outside the traditional diagnostic boundaries [10, 18].

The aim of this study was to explore the associations between illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with advanced malignant and non-malignant respiratory disease to inform future studies and intervention development.

Methods

Design

This was a cross-sectional secondary analysis of data from a randomised, controlled, feasibility trial of an online, self-guided breathlessness supportive intervention (SELF-BREATHE) for individuals with chronic breathlessness due to advanced disease [10]. Ethical and local research and development approval was obtained prior to commencing this research (Research Ethics Committee/Health Research Authority reference 20/LO/1108). SELF-BREATHE was registered at ClinicalTrials.gov with identifier number NCT04574050.

Population

Patients living with chronic breathlessness due to advanced malignant or non-malignant disease.

Inclusion criteria

- Adults aged ≥ 18 years.
- Chronic breathlessness defined as breathlessness that persisted (>3 months) despite optimal pharmacological treatment of the underlying lung disease, including COPD, asthma, interstitial lung

disease (ILD), chronic fibrotic lung disease following severe acute respiratory syndrome coronavirus 2 infection, bronchiectasis, cystic fibrosis and lung cancer.

- Medical Research Council (MRC) dyspnoea score ≥ 2 (short of breath when hurrying on the level or walking up a slight hill) [20].
- Access to a computer or tablet or smartphone with internet access.
- Able to provide informed consent.

Exclusion criteria

- Breathlessness of unknown cause.
- Primary diagnosis of chronic hyperventilation syndrome.
- Currently participating in a rehabilitation programme, *e.g.* pulmonary/cardiac rehabilitation.

Patient demographic and characterisation data

At baseline participants were asked to self-complete a demographic questionnaire which included the following: age, sex, ethnicity, educational level, employment status smoking status, MRC dyspnoea score and living status (alone *versus* living with others).

Patient-reported outcome measures

- Breathlessness severity: worst over the last 24 h was assessed on a 0–10 numerical rating scale (NRS) (0=no shortness of breath, 10=worse possible) [10].
- Dyspnoea 12 (D-12) quantifies breathlessness using 12 descriptors that tap the physical and affective aspects of dyspnoea [21].
- Distress due to breathlessness over the last 24 h was assessed on a 0–10 NRS (0=no distress, 10=worse possible distress).
- Self-efficacy for managing breathlessness was measured using the question “How confident are you that you can keep your shortness of breath from interfering with what you want to do?” scored on a 0–10 NRS (0=not at all confident, 10=totally confident) [10].
- The Chronic Respiratory Disease Questionnaire (CRQ) is a 20-item validated health-related quality of life questionnaire across four domains: dyspnoea, fatigue, emotion and mastery, which is applicable across respiratory diseases. Experiences are rated on 7-point scales ranging from 1 (maximum impairment) to 7 (no impairment) [22].

Patients’ illness perceptions, cognitive and behavioural responses to chronic breathlessness were assessed using the validated Brief Illness Perception Questionnaire (Brief IPQ) and Cognitive and Behavioural Responses Questionnaire, short version (CBRQ-S).

- The Brief IPQ is an eight-item questionnaire designed to rapidly assess cognitive and emotional representations of illness: consequences, timeline, personal control, treatment control, identity, concern, coherence and emotional response. Each item is rated on a 0–10 scale, with higher scores indicating a more threatening perception of the illness [23].
- The CBRQ-S explores patient’s cognitive and behavioural responses to their symptoms [24]. The CBRQ-S has four cognitive subscales (fear avoidance beliefs (*e.g.* “Physical activity makes my symptoms worse”), embarrassment avoidance beliefs (*e.g.* “I worry that people will think badly of me because of my symptoms”), symptom focusing (*e.g.* “My symptoms are always at the back of my mind”) and damage beliefs/catastrophising (*e.g.* “The severity of my symptoms must mean that there is something serious going on in my body”)) and two behavioural subscales (avoidance/resting behaviour (*e.g.* “I stay in bed to control my symptoms”) and all-or-nothing behaviour (*e.g.* “I find myself rushing to get things done before I crash”)). The cognitive subscales items are scored from 0 (strongly disagree) to 4 (strongly agree), while the behavioural subscales are scored from 0 (never) to 4 (all the time). Item scores are summed together to obtain a total score for each subscale. Higher scores indicate more negative cognitive responses to a symptom on the cognitive subscales. Higher scores on the behavioural subscales indicate greater use of avoidance and/or all-or-nothing behaviours in response to a symptom [25].

Data analysis

Patient demographics, characteristics and completed outcome measures were summarised using descriptive statistics. The associations between the Brief IPQ and CBRQ-S with NRS breathlessness severity, distress and self-efficacy, D-12, CRQ health-related quality of life and CRQ mastery were examined using Spearman’s rho correlation coefficient r_s . A Spearman’s r_s of ≥ 0.50 was predefined as the threshold to denote important associations between variables. A p-value of < 0.008 was considered statistically significant. A Bonferroni correction was applied to an α -level of < 0.05 ($0.05/6=0.008$) to allow for the

number of comparisons performed between individual items on the Brief IPQ and CBRQ-S with variables of interest. Statistical analysis of the data was performed using SPSS for Windows version 28 (IBM, Armonk, NY, USA).

Results

52 participants with chronic breathlessness, across a wide range of ages and disease severity, were recruited; mean±sd age 63±13 years, of which 31% were >71 years of age, and MRC dyspnoea score 2.4±1, of which 40.5% had an MRC ≥4 (table 1).

TABLE 1 Baseline demographics and characteristics of participants (n=52)

Age (years)	63±13
Age category	
<40 years	3 (5.8)
41–50 years	5 (9.6)
51–60 years	8 (15.4)
61–70 years	20 (38.5)
71–80 years	12 (23.1)
81–90 years	4 (7.7)
MRC dyspnoea score[#]	2.4±1
MRC dyspnoea score category[#]	
MRC 2	10 (19.2)
MRC 3	21 (40.4)
MRC 4	13 (25)
MRC 5	8 (15.5)
Sex	
Male	31
Female	21
Ethnicity[¶]	
White	42 (80.8)
Asian or Asian British	4 (7.7)
Black, African, Caribbean or Black British	1 (1.9)
Mixed	2 (3.8)
Other	3 (5.8)
Primary diagnosis	
COPD	31 (59.6)
Interstitial lung disease	5 (9.6)
Bronchiectasis	9 (17.3)
Cancer	2 (3.8)
Asthma	1 (1.9)
Cystic fibrosis	1 (1.9)
Long COVID	3 (5.8)
Smoking status	
Never-smoker	13 (25)
Ex-smoker	36 (69.2)
Current smoker	3 (5.8)
Living situation	
Living alone	25 (48.1)
Living with significant other/family	27 (51.9)
Support provided by a carer	
Yes	29 (55.8)
No	23 (44.2)
Breathlessness severity	
NRS worst breathlessness in last 24 h [#]	6.7±2.3
Dyspnea-12 total score [#]	18.4±8.8
NRS distress due to breathlessness [#]	5.3±2.8
Health-related quality of life	
CRQ ⁺	62±19
Breathlessness self-management	
NRS confidence in breathlessness self-management ⁺	4.3±2.7
CRQ mastery ⁺	3.8±1.4

Data are reported as mean±sd, n (%) or n. MRC: Medical Research Council; NRS: numerical rating scale (0–10); CRQ: Chronic Respiratory Disease Questionnaire. [#]: higher score worse; [¶]: self-reported; ⁺: higher score better.

TABLE 2 Illness perception in individuals living with chronic breathlessness due to advanced respiratory disease (n=52): Brief Illness Perception Questionnaire (Brief IPQ)

Brief IPQ item	Mean±sd	Median (range)
Consequences (0–10) How much does your illness affect your life?	8.02±2.04	8.5 (2–10)
Timeline (0–10) How long do you think your illness will continue?	9.41±1.25	10 (3–10)
Personal control (0–10) How much control do you feel you have over your illness?	3.87±2.67	3 (0–10)
Treatment control (0–10) How much do think your treatment can help your illness?	5.34±2.40	5 (0–10)
Identity (0–10) How much do you experience symptoms from your illness?	7.29±2.01	8 (3–10)
Concern (0–10) How concerned are you about your illness?	8.12±2.25	9 (0–10)
Coherence (0–10) How well do you feel you understand your illness?	7.48±2.41	8 (2–8)
Emotional response (0–10) How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed)	6.21±3.25	7 (0–10)
Higher scores reflect a more threatening view of illness.		

Illness perceptions

Descriptive information on illness perceptions in individuals living with chronic breathlessness due to advanced disease is summarised in table 2. High illness perception scores (reflecting a more threatening view of illness) were reported specifically for the items timeline, concern and consequences, and low scores for the items personal control and treatment control over their illness/breathlessness (table 2). Patients believed that their illness severely affected their life, that it was long lasting; they were very concerned about the illness and moderately affected emotionally.

The illness perception items consequences, identity, concern and emotional response were associated with increased breathlessness severity, increased distress, reduced breathlessness self-management ability and lower health-related quality of life (table 3).

Cognitive and behavioural responses

Cognitive and behavioural responses to chronic breathlessness in advanced disease are reported in table 4. Participants reported high scores for cognitive response and symptom focusing, and low scores for behavioural response avoidance/resting behaviour (table 4). Symptom focusing (attention) and embarrassment avoidance were associated with breathlessness severity (table 4). In addition, symptom focusing was associated with distress due to breathlessness, lower health-related quality of life and reduced breathlessness self-management (table 5 and figure 1).

Discussion

Key findings

This is the first study to explore illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with advanced malignant and non-malignant respiratory disease. Participant's illness perception scores showed a high level of understanding of their main condition (coherence) coupled with high scores (reflecting a more threatening view of illness) on the items timeline, concern and consequences. Personal control beliefs were low, indicating that most participants did not believe they had any influence on the course of their breathlessness.

In relation to illness perception items, more extreme scores on consequences, identity, concern and emotional response were associated with increased breathlessness severity, increased distress, reduced breathlessness self-management ability and lower health-related quality of life. Symptom focusing and embarrassment avoidance were identified as important cognitive responses to chronic breathlessness.

Relevance of findings

Comparing our findings with reference groups in the literature for patients with COPD and asthma [12], our cohort reported more strongly affected illness perceptions, they perceived more negative consequences,

TABLE 3 Spearman’s rho correlation coefficient r_s between the Brief Illness Perception Questionnaire (Brief IPQ) and selected measures (n=52)

Brief IPQ item	Consequences			Outcomes		
	Breathlessness severity		Distress	Health-related quality of life	Self-management	
	NRS worst breathlessness over 24 h	Dyspnea-12	NRS distress due to breathlessness	Health-related quality of life	NRS self-efficacy for managing breathlessness	CRQ mastery
Consequences	$r_s=0.57$, $p<0.001^*$	$r_s=0.57$, $p<0.001^*$	$r_s=0.47$, $p<0.001^*$	$r_s=-0.54$, $p<0.001^*$	$r_s=-0.53$, $p<0.001^*$	$r_s=-0.58$, $p<0.001^*$
Timeline	$r_s=-0.08$, $p=0.602$	$r_s=0.06$, $p=0.683$	$r_s=-0.16$, $p=0.249$	$r_s=0.06$, $p=0.682$	$r_s=-0.15$, $p=0.295$	$r_s=0.01$, $p=0.947$
Personal control	$r_s=-0.22$, $p=0.116$	$r_s=-0.16$, $p=0.285$	$r_s=-0.26$, $p=0.158$	$r_s=0.05$, $p=0.740$	$r_s=0.28$, $p=0.045$	$r_s=0.22$, $p=0.120$
Treatment control	$r_s=-0.12$, $p=0.416$	$r_s=0.00$, $p=0.994$	$r_s=0.04$, $p=0.962$	$r_s=-0.10$, $p=0.486$	$r_s=0.12$, $p=0.416$	$r_s=0.02$, $p=0.872$
Identity	$r_s=0.61$, $p<0.001^*$	$r_s=0.76$, $p<0.001^*$	$r_s=0.60$, $p<0.001^*$	$r_s=-0.65$, $p<0.001^*$	$r_s=-0.50$, $p<0.001^*$	$r_s=-0.65$, $p<0.001^*$
Concern	$r_s=0.41$, $p=0.002^*$	$r_s=0.61$, $p<0.001^*$	$r_s=0.41$, $p=0.003^*$	$r_s=-0.54$, $p<0.001^*$	$r_s=-0.59$, $p<0.001^*$	$r_s=-0.62$, $p<0.001^*$
Coherence	$r_s=0.03$, $p=0.817$	$r_s=0.04$, $p=0.772$	$r_s=-0.07$, $p=0.643$	$r_s=0.04$, $p=0.754$	$r_s=-0.04$, $p=0.783$	$r_s=-0.06$, $p=0.535$
Emotional response	$r_s=0.50$, $p<0.001^*$	$r_s=0.79$, $p<0.001^*$	$r_s=0.76$, $p<0.001^*$	$r_s=-0.81$, $p<0.001^*$	$r_s=-0.38$, $p<0.001^*$	$r_s=-0.78$, $p<0.001^*$

$r_s = \pm 1$: perfect correlation; $r_s = \pm 0.50-0.99$: strong correlation; $r_s = \pm 0.30-0.49$: medium correlation; $r_s < \pm 0.29$: small correlation; $r_s = 0$: no correlation. A Spearman’s r_s of ≥ 0.50 was predefined as the threshold to denote important associations between variables, highlighted in bold. *: correlation significant at $p < 0.008$ level (two-tailed). NRS: numerical rating scale (0–10); CRQ: Chronic Respiratory Disease Questionnaire.

less personal and treatment control, and increased identity, concern and emotional response [12]. Interestingly, the scores in our cohort and the COPD and asthma reference groups for timeline and coherence were similar [12].

Our findings are in keeping with other studies in chronic conditions where illness perceptions have been found to relate to patients’ quality of life and other clinical outcomes [16, 26, 27]. For example, patients who perceived high control of their illness were less likely to have unplanned hospital attendance [16, 26, 27]. This is of particular importance in the context of chronic breathlessness management, as data suggest that one-fifth of emergency department presentations by ambulance in the UK are due to acute-on-chronic breathlessness [8, 28]. Illness perceptions influence patients’ motivation to adopt specific strategies to manage their emotions and increase control over symptoms [13].

We found that symptom focusing was associated with increased breathlessness severity. Symptom focusing leads to enhanced attention to and/or hypervigilance of one’s breathing pattern and breathlessness. Consequently, individuals interpret any change in their breathing awareness and/or breathlessness as a signal of impending harm. This inadvertently creates a vicious cycle where the increased attention results in exaggerated or catastrophic perceptions of their breathing. Inefficient breathing adaptations are then adopted, which leads to a worsening of breathlessness [13, 29, 30]. A strength of this study was the

TABLE 4 Cognitive and behavioural responses to chronic breathlessness in advanced disease: Cognitive Behavioural Responses Questionnaire, short version (CBRQ-S)

CBRQ-S subscale	Mean±SD	Median (range)
Fear avoidance (0–12)	6.33±1.84	6 (3–11)
Embarrassment avoidance (0–12)	5.86±3.20	7 (0–12)
All-or-nothing behaviour (0–12)	5.48±3.2	5 (0–11)
Damage beliefs (0–12)	6.94±1.43	7 (3–9)
Symptom focusing (0–12)	8.07±3.08	8 (0–12)
Avoidance/resting behaviour (0–12)	3.53±3.14	3 (0–12)

TABLE 5 Spearman’s rho correlation coefficient r_s between the Cognitive Behavioural Responses Questionnaire, short version (CBRQ-S) and selected measures (n=52)

CBRQ-S subscale	Consequences			Outcomes		
	Breathlessness severity		Distress	Health-related quality of life	Self-management	
	NRS worst breathlessness over 24 h	Dyspnea-12	NRS distress due to breathlessness	Health-related quality of life	NRS self-efficacy for managing breathlessness	CRQ mastery
Fear avoidance	$r_s=0.06$, $p=0.673$	$r_s=0.27$, $p=0.067$	$r_s=0.25$, $p=0.080$	$r_s=-0.33$, $p=0.012$	$r_s=-0.10$, $p=0.472$	$r_s=-0.32$, $p=0.025$
Embarrassment avoidance	$r_s=0.26$, $p=0.064$	$r_s=0.50$, $p<0.001^*$	$r_s=0.19$, $p=0.198$	$r_s=-0.40$, $p=0.003^*$	$r_s=-0.36$, $p=0.010$	$r_s=-0.39$, $p=0.004^*$
All-or-nothing behaviour	$r_s=0.29$, $p=0.043$	$r_s=0.24$, $p=0.115$	$r_s=0.28$, $p=0.050$	$r_s=-0.41$, $p=0.003^*$	$r_s=-0.11$, $p=0.455$	$r_s=-0.134$, $p=0.357$
Damage beliefs	$r_s=0.20$, $p=0.146$	$r_s=0.13$, $p=0.385$	$r_s=0.00$, $p=0.997$	$r_s=-0.07$, $p=0.608$	$r_s=-0.08$, $p=0.567$	$r_s=-0.02$, $p=0.881$
Symptom focusing	$r_s=0.50$, $p<0.001^*$	$r_s=0.50$, $p<0.001^*$	$r_s=0.52$, $p<0.001^*$	$r_s=-0.60$, $p<0.001^*$	$r_s=-0.27$, $p<0.049$	$r_s=-0.54$, $p<0.001^*$
Avoidance/resting behaviour	$r_s=0.16$, $p=0.250$	$r_s=0.287$, $p=0.051$	$r_s=0.32$, $p=0.023$	$r_s=-0.22$, $p=0.116$	$r_s=-0.08$, $p=0.566$	$r_s=-0.22$, $p=0.120$

$r_s = \pm 1$: perfect correlation; $r_s = \pm 0.50-0.99$: strong correlation; $r_s = \pm 0.30-0.49$: medium correlation; $r_s < \pm 0.29$: small correlation; $r_s = 0$: no correlation. A Spearman’s r_s of ≥ 0.50 was predefined as the threshold to denote important associations between variables, highlighted in bold. *: correlation significant at $p < 0.008$ level (two-tailed). NRS: numerical rating scale (0–10); CRQ: Chronic Respiratory Disease Questionnaire.

multidimensional battery of outcome measures used, resulting in novel data on the potential importance of attention/hypervigilance in breathlessness severity.

Reflecting inclusion criteria of previously published clinical trials of breathlessness supportive services [31] and referral criteria to clinical services in the UK, such as pulmonary rehabilitation, we included patients

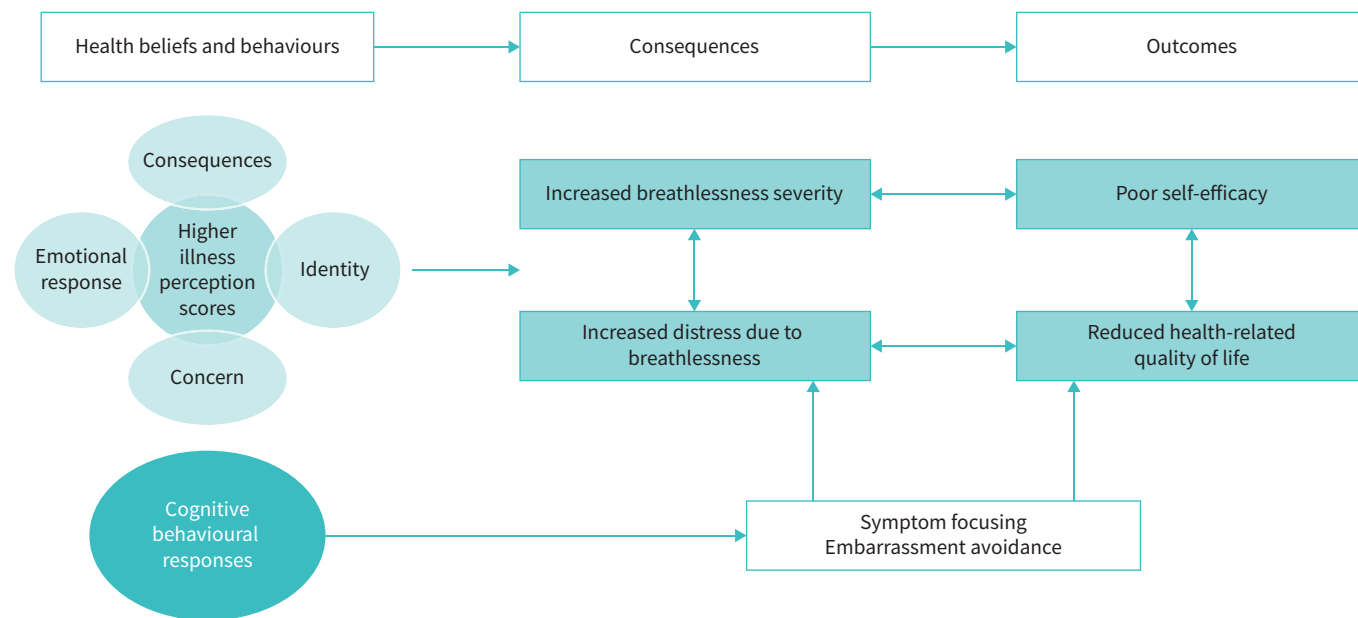


FIGURE 1 Illness perception, cognitive and behavioural responses, resultant consequences, and outcomes in patients living with chronic breathlessness due to advanced respiratory disease. Leventhal’s Common-Sense Model of Self-Regulation states that patient health beliefs (positive and negative) determine behavioural responses and coping strategies in response to illness, consequently resulting in positive or negative outcomes [13]. Interventions that target modifiable factors, *i.e.* patient health beliefs and behaviours, may improve patient outcomes. Bidirectional arrows highlight the interaction between consequences and outcomes.

with an MRC dyspnoea score of ≥ 2 . Individuals with an MRC dyspnoea score of 2 accounted for 19% of the cohort. Our findings highlight that even without severely disabling breathlessness these associations are important to consider, and therefore potentially applicable and transferable to patients earlier as well as later in the disease trajectory.

In understanding the complexity of living with chronic breathlessness it is vital to understand the importance of cognitive and behavioural factors associated with chronic breathlessness. While it is important to acknowledge the distressing nature of breathlessness in patients with serious disease, it is also important to understand the cognitive factors that are adding to distress, poor quality of life and low self-efficacy, because these factors are amenable to change. Evidence suggests that non-pharmacological treatments [31, 32] and self-management interventions improve health status and outcomes in patients with chronic breathlessness. Outcomes could be further enhanced by targeting symptom focusing specifically. Attentional training, a brief metacognitive treatment, is designed to re-orient patients' attention, reduce symptom focusing and produce a shift away from self-focus. This could lead to a reduction in breathlessness or at least pre-occupation with it [33, 34].

Given the high scores reported on the items timeline and concern on the Brief IPQ, in addition to the fact that patients' quality of life is adversely affected, a focus on values-based goals is warranted. Third-wave psychotherapies such as acceptance and commitment therapy (ACT) have been evaluated in the context of several long-term conditions and found to improve a range of outcomes [35]. ACT focuses on helping people to respond flexibly to symptoms, accept what cannot be changed, and focus on values and life goals.

Patients' willingness, motivation and ability to participate in these self-management interventions will vary, but discussing the role of perceptions and cognitive behavioural responses explicitly with patients may enhance motivation [13].

This study focuses on a transdiagnostic approach. Given the small sample size for conditions such as ILD (n=5), bronchiectasis (n=9) and cancer (n=2), we were unable to assess the potential influence of disease-specific diagnoses on illness perceptions, cognitive and behavioural responses to chronic breathlessness. A limitation of this study is that we do not have any data on illness and breathlessness symptom duration. Onset/duration of chronic breathlessness is not routinely documented in clinical notes. With hindsight we could have asked subjectively how long individuals had been living with/experiencing breathlessness. However, it must be acknowledged that there are challenges and limitations with this approach, especially regarding patient recall [36].

This is a cross-sectional secondary analysis of baseline data from a feasibility randomised controlled trial of an online breathlessness self-management intervention (SELF-BREATHE), the results of which have been published in *ERJ Open Research* [10]. As this was a feasibility study, it was not powered to conduct any pre- versus post-interventional analysis. We acknowledge that there are limitations with this cross-sectional secondary data analysis approach. Future prospective studies should seek to understand cause/effect relationships. However, it is important to highlight that mediation analysis will help discern mechanisms of change [37, 38]. Our data highlight the importance of including the illness perceptions and the cognitive and behavioural responses questionnaires repeatedly within clinical trials testing interventions for chronic breathlessness, so that mechanisms can be investigated [37, 38].

Both males and females were well represented in our study. However, our sample was predominantly White. Under-representation of minority ethnic groups in medical research is an ongoing issue in the UK and beyond [39, 40]. Ensuring equity, inclusion and diversity of participants must be a priority in planning subsequent studies.

We have developed a complex intervention for breathlessness: SELF-BREATHE. SELF-BREATHE is a complex, transdiagnostic, breathlessness, supportive digital intervention co-developed with patients [10, 41, 42], theoretically underpinned by Leventhal's common-sense model of illness self-regulation [10, 13, 43, 44]. It targets negative health beliefs and behavioural responses to chronic breathlessness *via* education and self-management non-pharmacological approaches, *e.g.* breathing exercises, pacing and goal setting [10]. The next step in our programme of research is to carry out a multicentre randomised controlled trial to test SELF-BREATHE.

Our findings provide a testable hypothesis that improving patient's illness perceptions, cognitive and behavioural responses *via* SELF-BREATHE will improve symptom burden, symptom control and health-related quality of life in adults living with chronic breathlessness due to advanced disease.

Conclusion

The illness perception items consequences, identity, concern and emotional response were associated with increased breathlessness severity, increased distress, reduced breathlessness self-management ability and lower health-related quality of life. Symptom focusing and embarrassment avoidance were identified as important cognitive responses to chronic breathlessness. These data provide a testable hypothesis that interventions targeting illness perceptions, cognitive and behavioural responses to chronic breathlessness will improve symptom burden, self-efficacy and health-related quality of life.

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Ethics statement: Ethical and local research and development approval was obtained prior to commencing this research (Research Ethics Committee/Health Research Authority reference 20/LO/1108).

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