

# BMJ Open Insights from Australians with respiratory disease living in the community with experience of self-managing through an emergency department 'near miss' for breathlessness: a strengths-based qualitative study

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## ABSTRACT

**Objectives** Breathlessness 'crises' in people with chronic respiratory conditions are a common precipitant for emergency department (ED) presentations, many of which might be avoided through improved self-management and support. This study sought insights from people with experience of ED 'near misses' where they considered going to the ED but successfully self-managed instead.

**Design and methods** A qualitative approach was used with a phenomenological orientation. Participants were eligible if they reported breathlessness on most days from a diagnosed respiratory condition and experience of  $\geq 1$  ED near miss. Recruitment was through respiratory support groups and pulmonary rehabilitation clinics. Semistructured interviews were conducted with each participant via telephone or face-to-face. Questions focused on ED-related decision-making, information finding, breathlessness management and support. This analysis used an integrative approach and independent coding by two researchers. Lazarus and Cohen's Transactional Model of Stress and Coping informed interpretive themes.

**Results** Interviews were conducted with 20 participants, 15 of whom had chronic obstructive pulmonary disease. Nineteen interviews were conducted via telephone. Analysis identified important factors in avoiding ED presentation to include perceived control over breathlessness, self-efficacy in coping with a crisis and desire not to be hospitalised. Effective coping strategies included: taking a project management approach that involved goal setting, monitoring and risk management; managing the affective dimension of breathlessness separately from the sensory perceptual and building three-way partnerships with primary care and respiratory services.

## Strengths and limitations of this study

- The study took a novel, strengths-based approach to understanding how people at risk of avoidable emergency department presentations for breathlessness can sometimes successfully self-manage a crisis at home.
- Analysis was informed by a theoretical framework ideally suited to distilling therapeutic targets for promoting self-management and coping.
- The sampling method means our results are unlikely to be representative of the whole population of people with chronic breathlessness due to respiratory conditions.

**Conclusions** In addition to teaching non-pharmacological and pharmacological management of breathlessness, interventions should aim to develop patients' generic self-management skills. Interventions to improve self-efficacy should ensure this is substantiated by transfer of skills and support, including knowledge about when ED presentation is necessary. Complementary initiatives are needed to improve coordinated, person-centred care. Future research should seek ways to break the cyclical relationship between affective and sensory-perceptual dimensions of breathlessness.

## BACKGROUND

Chronic breathlessness is a frequently encountered, burdensome and distressing symptom in people with advanced respiratory illness, which is defined as 'breathlessness that persists despite optimal treatment of the underlying pathophysiology and that results

in disability'.<sup>1</sup> The experience of chronic breathlessness varies between individuals and includes at least three dimensions: 'sensory perceptual' (severity and quality), 'affective' (unpleasantness and distress) and 'impact' (effects on everyday life).<sup>2</sup> While chronic breathlessness by definition cannot be resolved, it can be managed with psychological, physical and pharmacological therapies aimed at modulating the perception of breathlessness and the person's response.<sup>3</sup> These therapies are ideally delivered within a self-management framework in which people learn skills to reduce the impact on functioning and sustain emotional well-being.<sup>4 5</sup> Two systematic reviews have found that interventions aimed at improving self-management in people with chronic obstructive pulmonary disease (COPD) can reduce breathlessness and hospitalisation.<sup>6 7</sup> However, these reviews identified substantial heterogeneity among results and recommended further work to identify the most efficacious components.

Over and above breathlessness on a daily basis, people with chronic breathlessness periodically experience an acute worsening of symptoms that the American Thoracic Society (ATS) has termed a 'breathlessness crisis'.<sup>8</sup> Breathlessness crises commonly result in emergency department (ED) presentations, a substantial proportion of which might be avoided through improved self-management and support.<sup>9-12</sup> ED presentations and hospitalisations are associated with substantial personal and societal burden, making their prevention a priority.<sup>13</sup> But preventing avoidable ED presentations for breathlessness requires an in-depth understanding of help-seeking behaviours and the knowledge, beliefs and attitudes that drive them. Several studies have explored the experience of chronic breathlessness and its self-management,<sup>14 15</sup> but only a handful has examined experience during a crisis,<sup>16-18</sup> and none have focused on decisions about whether or not to present to the ED. The proposed study aimed to explore the 'natural history' of ED-related decision-making from the perspective of people with experience of successfully self-managing through a breathlessness crisis. A 'strengths-based' approach of this kind that leverages patient assets is increasingly recommended when developing chronic disease self-management interventions.<sup>19</sup>

## METHODS

The study was conducted from October 2015 to April 2016. Ethics approval was provided by the Human Research Ethics Committee at St Vincent's Hospital, Sydney, Australia.

The subjective, multidimensional nature of chronic breathlessness and ED-related decision-making required a qualitative approach to enquiry with a phenomenological orientation. Reporting of the study has been guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>20</sup>

## Sample

Eligible people were consenting adults (ie,  $\geq 18$  years) who spoke sufficient English and reported: (1) breathlessness most days in the last month from a diagnosed respiratory condition; and (2) one or more occasions where they considered going to the ED for breathlessness but decided to self-manage instead. People who believed their crisis was due to a cardiac event or an asthma attack were excluded because of the need to seek emergency assistance in these scenarios for definitive medical attention.

Participants were approached through: (1) the Australian Lung Foundation website and national e-mail lists, including support groups; and (2) oral invitations at pulmonary rehabilitation group sessions. Interested people were invited to contact the researchers, who then screened them against eligibility criteria and undertook an informed consent procedure culminating in written consent.

## Data collection

Cross-sectional, semistructured interviews were conducted face-to-face or by telephone with each participant according to preference and feasibility. Questions were developed specifically for this study and explored ED-related decision-making, breathlessness experience, self-management and support (see [box](#) for topic guide). Interviews were audiorecorded and transcribed for analysis. No field notes were made. Self-reported data were collected on demographics, number of near misses and presentations to the ED. Interviews were conducted by a male researcher/senior lecturer with a speech therapy background experienced in qualitative research (TL), with contributions in around half of interviews by a female Medical Science Honours student (MG), who had been trained in qualitative research methods specifically for this study. The interviewers had no previous or continuing relationships with participants. It was explained to participants that the research was being conducted to inform self-management interventions for other people with chronic breathlessness.

## Analysis

Analysis used an integrative method designed for informing the development of health interventions.<sup>21</sup> This method uses both inductive and deductive approaches to ensure themes both remain open to new insights from participants and also build on previous research. To minimise bias and enrich interpretation, initial analysis of each interview was conducted independently by two researchers (TL and PB or MG), who then met to agree on descriptive themes. Emergent themes were tested for authenticity in subsequent interviews. Established theoretical models of decision-making, self-management and coping were reviewed to assist with interpretive analysis. The Transactional Model of Stress and Coping developed by Lazarus and Cohen<sup>22</sup> was agreed to naturally accommodate emergent distinctions in the data (eg, between the severity of breathlessness compared with the capacity

### Box Guide for semistructured interviews with people about their experiences of emergency department 'near misses' for breathlessness

1. Please start by telling me, in your own words, about the time you nearly went to emergency because of feeling breathless but decided not to and, with the benefit of hindsight, are glad you didn't.
 

Prompts

  - What was it about your breathlessness that made you consider going to emergency?
  - Who (if anyone) made you consider going to emergency?
  - What else (if anything) made you consider going to emergency?
  - What (if anything) do you think helped you avoid going to emergency?
    - What (if any) information helped?
    - What (if any) training helped?
    - What (if any) support from a health professional helped? Were you able to contact a known healthcare professional for support? Were you advised there was no need to present by a known healthcare professional?
    - What (if any) support from family or friends helped?
    - Did you manage (or receive support from others) to employ strategies to calm your breathing and recover from the distressing episode?
2. Have there been other time(s) where you did go to emergency for breathlessness?
 

If 'yes'

  - a. What (if anything) was different about these time(s) compared with when you decided not to go and were glad you did not?
  - b. Can you give me a sequence of symptoms or sensations you feel that finally led you to go to the hospital?
  - c. In hindsight, were you glad you went to emergency? Why/why not?
  - d. What (if anything) did you learn from these experiences (or indeed going to emergency for any reason at all) about when to go to emergency in the future?
5. Now can you tell me about any times where you decided not to go to emergency but wished you had or did go but thought you should have gone earlier?
 

Prompts

  - As for question 2, with modification as necessary.
  - Are there any signs or other considerations that tell you that you MUST go to hospital?
6. What (if any) self-management strategies do you use for breathlessness more generally?
 

Prompts

  - Self-management strategies can include things like symptom monitoring, action plans, breathing techniques, exercises and cognitive-behavioural therapy. Do you use anything like that?
  - How useful do you find these strategies?
  - What (if anything) could be done to make the strategies more useful?
  - Where did you learn about the strategies you use (eg, pulmonary rehabilitation, internet)?
  - What (if anything) have health professionals given you in the way of training or resources for self-management of breathlessness?
  - What (if any) self-management strategies have you developed yourself?

to avoid the ED). The Model's emphasis on self-efficacy and feelings of control, as well as meaning-based coping (eg, through positive reappraisal and spiritual beliefs), was also amenable to a strengths-based perspective. In the absence of objective data to evaluate coping processes, assessment was based on self-report regarding emotional well-being and activities of daily living. Data were managed using NVivo V.11 software (QSR International, 2015). A summary of results (rather than individual transcripts) was e-mailed to participants with an invitation to comment on their veracity.

## RESULTS

Interviews were conducted with 20 participants (19 by telephone). Eighteen participants were recruited through support groups, with the remaining two recruited through pulmonary rehabilitation. A family member was present at the interview in two cases. The sample included people living in regional and metropolitan areas of New South Wales, Queensland, Victoria, South Australia or Tasmania (see [table 1](#) for a summary of participant characteristics). Interviews ranged in duration from 22 to 70 min. Some participants had a history of near misses and presentations to ED over many years whereas, for others, these had occurred only within the past year.

Participants demonstrated an impressive ability to reflect on and interpret factors they considered pertinent to self-managing through a breathlessness crisis. A summary of codes and their correspondence to elements of the Transactional Model of Stress and Coping is presented in [figure 1](#).

### Primary and secondary appraisals

Primary and secondary appraisals refer to an individual's assessment of the significance of a stressor and their capacity to cope with it, respectively.<sup>22</sup> Primary appraisal is a person's immediate appraisal of a stressor in terms of his/her susceptibility and the stressor's severity and cause. Secondary appraisal refers to a person's perceptions regarding the adequacy of the resources at his/her disposal to deal with the stressor.

Secondary appraisal played an essential role in determining whether or not a person attended the ED and explained variability in primary appraisal thresholds. Participants nearly always reported that the tipping point for going to the ED was when coping efforts at their disposal were ineffective; those who perceived greater control tended to have a higher threshold for seeking help from the ED.

Most of the things that we do seem to assist. It's when ... all these things don't work, the fallback position is to call the ambulance. (P10, woman with restrictive lung disease)

Primary appraisal of the sensory-perceptual dimension of breathlessness was concerned with both quality and severity, with both types of information helping people

**Table 1** Characteristics of 20 participants interviewed about their experiences of emergency department ‘near misses’ where they considered presenting for breathlessness but decided to self-manage instead

Characteristic	n (%)
Female	9 (45)
Living alone	8 (40)
Aged 65+ years	15 (75)
Primary diagnosis	
Chronic obstructive pulmonary disease	15 (75)
Restrictive lung disease	3 (15)
Bronchiectasis	1 (5)
Chronic thromboembolic pulmonary hypertension	1 (5)
Experience of breathlessness	
Lifelong	3 (15)
11–15 years	1 (5)
6–10 years	7 (35)
1–5 years	7 (35)
<1 year	1 (5)
Missing data	1 (5)
Frequency of emergency department near misses for breathlessness	
Weekly or more often	4 (20)
Monthly	1 (5)
11–15 times	3 (15)
5–10 times	2 (10)
<5 times	8 (40)
Missing data	2 (10)
Frequency of emergency department visits for breathlessness	
5 times or more	4 (20)
<5 times	14 (70)
Never	2 (10)

to decide whether ED presentations were warranted. Ten participants commented on how long the equivocal about whether or not to present typically lasted. Reports varied from 5 to 20 min, with most identifying 15–20 min.

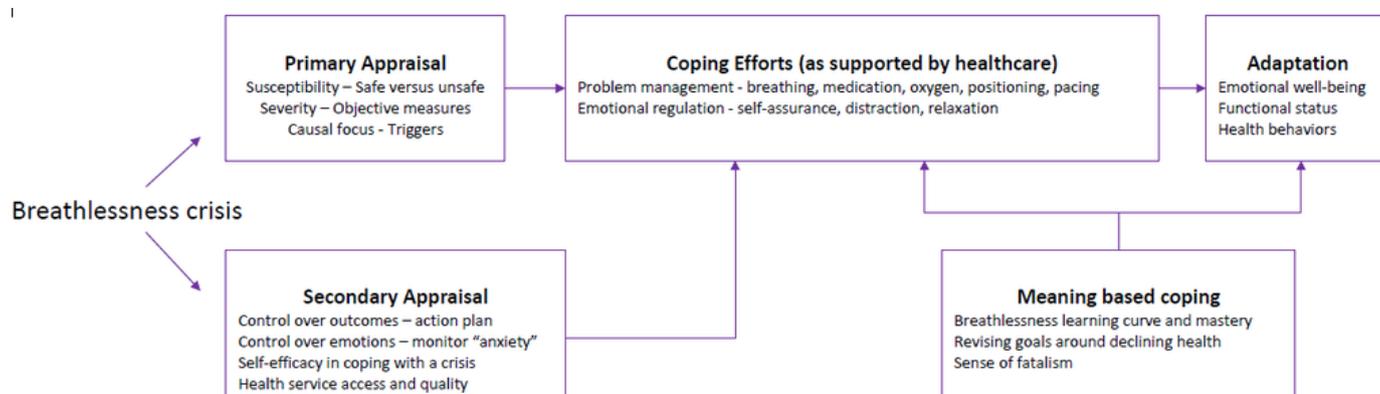
### Appraisal of breathlessness and anxiety

Changes in breathlessness were more likely to prompt an ED presentation if they occurred rapidly and unexpectedly in the absence of a known trigger. Changes in the quality of breathlessness especially likely to prompt help-seeking were described as feelings of chest tightening and other sensations associated with a chest infection (eg, ‘bubbling’).

When you get an infection of the lungs, your whole breathlessness just drops a whole massive level ... It’s completely different. (P04, man with COPD)

Oximetry was the most commonly used method for measuring severity both in a crisis situation and for daily monitoring, whereas capacity to engage in daily activities (a measure of both severity and impact) was used on a daily basis but ceased to be informative for monitoring during a crisis. Oximetry-measured oxygen saturation levels were used by some participants to guide whether they should use home oxygen and/or visit the ED, with individual thresholds varying from 80% to 90%. Participants appeared to have taught themselves oximetry and chosen thresholds on the basis of individual experience rather than professional advice. Some participants noted divergence between oximetry readings and their subjective experience.

And then with the oxygen, occasionally, my oximeter is showing me that my figures are 94, 95. I can still hardly breathe. So, I don’t know, I’m no expert, but to me it indicates that there’s something more than just your lungs. That there could be a blockage there stopping you to get your air... [even though] the oxygen in your blood could be okay. (P05, man with COPD)



**Figure 1** Participants’ descriptions of coping with a breathlessness crisis as they correspond to each element of the Transactional Model of Stress and Coping (adapted from Glanz and Schwartz, p216).<sup>48</sup>

Where oximetry conflicted with an experience of increasing breathlessness, participants tended to suspect their experience was related to ‘anxiety’ and did not warrant ED presentation.

In relation to why I don’t present to hospital, it’s simply me managing that myself, looking at what my saturation levels are at that time and understanding that it’s probably more anxiety than actual loss of breath, loss of oxygen. And if I determine that it’s more anxiety as opposed to lack of oxygen, well obviously, I just work my way through that via breathing techniques that they taught during the pulmonary rehab program, and just try and bring yourself down to a comfortable level. (P07, man with COPD)

At the same time, evidence of satisfactory saturation levels helped to reduce anxiety by countering the fear that the participant might die from suffocation.

You feel the panic, and I guess it’s just that fear of not getting the breath and then death... it’s just an awful feeling. (P03, woman with bronchiectasis)

Some participants tried to separately appraise anxiety by using different monitoring and/or management strategies. Participants used heart rate monitors to measure anxiety and techniques such as mindfulness to ‘rule it out’.

Your breathlessness doesn’t come right out as to how bad it is until your anxiety levels have gone down. Because while your anxiety levels are really high, you’re going to think the worst. (P09, woman with COPD)

When asked whether breathlessness or anxiety took the leading role, people typically referred to a cyclical relationship which needed to be broken to prevent mutual exacerbation.

I can get anxious, which causes me to become breathless ... which then feeds back and makes it [anxiety] worse ... If I don’t distract myself, and I think about my breathing, then the whole spiral just goes. (P03, man with COPD)

The anxiety kicks in and then it becomes a vicious circle. But what I do, is I refer then back to a statistic, which is my, ‘how much oxygen am I producing?’ And if I see that is around about the 95, well then I start to calm down and consciously try and relax, (P07, man with COPD)

Primary and secondary appraisal were, therefore, undertaken iteratively and in quick succession, with participants reappraising each dimension together with associated control and resources.

### Appraisal of control

For around half of the participants, daily appraisal involved careful monitoring of breathlessness triggers, which

contributed to feelings of control over their capacity to avoid future crises and emotional reassurance. Common triggers were reported to include physical activity, high or low temperature, high or low humidity, air born pollutants, medications and pollen. Participants distinguished between settings in which they felt safe and those in which they felt unsafe, with the former being absent from triggers and/or offering a high level of control by means of substantial management resources and support. Participants spoke of the risk that avoiding unsafe environments might restrict their lives and that conscious effort was needed to prevent this from happening.

I have become anti-social ... I like going out of the house, and I must go out of the house. I push myself to go out of the house. (P08, woman with restrictive lung disease)

Participants reported breathlessness crises to occur at various locations, including at home, at work and while engaged in recreational activities. However, some people identified night time as a period when breathlessness was most likely to feel out of control due to feelings that support and ability to control emotions were more limited. Participants acknowledged that their subjective appraisal of resources was a key factor in determining whether they sought help from the ED.

In the middle of the night, everything is deadly quiet, and you’re thinking, ‘Is there anyone out there that can help me?’ So that’s where the panic sets in. (P09, woman with COPD)

### Appraisal of support from health professionals

Appraisal of support from health professionals was concerned with accessibility, expertise and person-centredness. Several participants described themselves as working in partnership with health professionals and expected acknowledgement of their expertise as well as medical advice and support.

I think he (general practitioner) regards me as a person of average intelligence and he knows that I’m managing it with him, and he values what I tell him... I think, critically, if you can get that relationship with your GP, that’s important. (P07, man with COPD)

Participants who actively engaged with health professionals were aware of the different roles played by specialist and primary healthcare providers, and attributed importance to coordination and communication, in one case suggesting this was better in a regional than metropolitan setting. Participants tended to view their respiratory specialist as being responsible for treatment of the underlying disease and general practitioners (GPs) as offering support and monitoring for the impacts of breathlessness. While GPs were often perceived to be more person centred than respiratory specialists, they were also perceived to have less specific expertise.

Because your GP just doesn't have that knowledge, and they don't have the expertise. And they [respiratory specialists] are across new developments and treatment. (P07, man with COPD)

Participants rarely reported learning non-pharmacological management from a respiratory specialist, with most people citing a physiotherapist or nurse, sometimes during a pulmonary rehabilitation programme. Many participants reported negative encounters where they perceived that respiratory specialists or GPs had lacked person-centredness or expertise. People responded by seeking alternative health professionals or by disengaging from healthcare altogether.

So then I changed to him (GP) ... As far as I'm concerned, he [new GP] is a very good GP. He managed to monitor my health and also see what was wrong with me straight away. (P016, man with COPD)

Overall self-efficacy in breathlessness management varied between participants, with some participants reporting a high degree of confidence and others uncertainty about whether their management approach and decision-making were optimal. In most cases, self-efficacy seemed dependent on participants' appraisal of their own skills, rather than support from health professionals.

I've pretty much got it nailed for me. (P02, woman with COPD)

It's very difficult because, with breathlessness, everything is 'work to your limits, work to your limits', but where is that limit? (P08, woman with restrictive lung disease)

### Reluctance to be hospitalised

Secondary appraisal also often referenced perceptions on the advantages and disadvantages of attending the ED and the hospital admission that might follow. Hospital-related attitudes that made it less likely that people would present to ED included: previous experiences of poor care; concerns of making breathlessness worse through exposure to communicable diseases or triggers (eg, air-conditioning) or deconditioning due to inactivity; perceptions that repeated admissions might be interpreted by medical teams as a sign of declining health or make them take the problem less seriously; a worry that hospitalisation might negatively affect health insurance; not wanting to waste health professional time and healthcare resources and inconvenience or interference with other commitments. Participants sometimes reported a belief that hospitals had little to offer beyond the therapies they could administer themselves, especially where they had access to home oxygen, corticosteroids and antibiotics. For some participants, more than one of these beliefs were combined.

I believe that they count how many times you go in and that gives an indication of how they treat me, and

I don't think they could do anything for me because I can't do it for myself. (P15, woman with COPD)

Many patients cited experiences where ED staff lacked expertise in managing their breathlessness crises as well as showed a lack of person-centredness and disrespect for the patient's knowledge and skills in self-management.

I'm getting to the point now where I don't even want to go to X Hospital emergency department ... you go in there and the doctors just—they don't have the latest data, they go in on old stuff. Like last time I went in there – last time I left there, the doctors leave me to look after my fluid, this and that and everything else, and like, you say, 'I'm the expert, I'm living this', but they won't listen. And, 'oh no, we need to drain you'. They ignored everything that I said. I had a pulmonary embolism (PE. They ignored everything I said, and, 'oh, we've got to drain you'. So they gave me liquid Frusemide or whatever, pumped me full of that and it did nothing, which was just an absolutely joke and waste of time. But this is the thing—I've got to get past those to the doctors and behind they'd actually know all about me, if you know what I mean?. (P12, man with COPD)

### Coping efforts

Participants reported using a range of non-pharmacological and pharmacological strategies to manage breathlessness both in a crisis and on a daily basis. Certain strategies were differentially directed towards either the sensory perceptual (eg, reducing movement) or affective (eg, self-reassurance) dimensions of breathlessness. However, breathing techniques were perceived by different people to target either or both dimensions, with one person reporting being instructed in their use by a psychiatrist. Breathing techniques were perceived by many to include a mindfulness or relaxation component as well as a feeling of control over levels of oxygen and carbon dioxide.

The anxiety is increased by the breathlessness and the breathlessness increases anxiety... I purse my lips as if I'm blowing out candles. And I find that it does two things: it increases my O<sub>2</sub> saturation, and it also decreases my heart rate. (P16, man with COPD)

Nine participants reported using home oxygen, ranging from '24/7' to 'about an hour' daily. Several people relied on oxygen more than any other management strategy and regarded its failure to alleviate breathlessness as a decisive tipping point towards the ED. These included people who used oxygen only intermittently but still regarded it as their primary safety net to be kept close at hand.

If you're on oxygen and you wake up not being able to breathe, I'd probably say you need to come to hospital 'cause you're doing everything else that you should be doing. (P09, woman with COPD)

Pharmacological strategies for managing breathlessness most commonly included bronchodilators and corticosteroids. People who used opioids tended to perceive that these had been prescribed more for pain and/or anxiety than for breathlessness, though they acknowledged benefits to all these symptoms. Four people also used psychotropic medications; benzodiazepines during a crisis or antidepressants as a preventative. These included one person who reported self-medicating with lorazepam for breathlessness, which she believed was initially prescribed for postsurgical pain. Other medications that participants reported using against medical advice included daily administration of antibiotics to prevent chest infections. Having these medications at their disposal appeared to give participants a sense of control and preparedness for managing breathlessness crises.

You can't always get to your GP and sometimes you're too sick to go out anyway, so it's just as well to have it [supply of antibiotics] in your box and use them when you need to. (P18, woman with COPD)

People reported using non-pharmacological and pharmacological strategies in various combinations, with some using pharmacological strategies as the mainstay supplemented by non-pharmacological and some vice versa. Sometimes the choice was guided by breathlessness severity, with more severe breathlessness tending to prompt pharmacological strategies first and less severe, non-pharmacological.

If I feel like five or ten minutes after I've done that pursed lipped breathing and I'm not doing anything active and ... it [breathlessness] is still there then I go to the Ventolin ... it's not very scientific I know, but it's – my head tells me which way to go. (P22, man with COPD)

### Meaning-based coping

Meaning-based coping refers to a person's capacity to derive positive meaning from his or her experience of a stressor, even while accepting its negative impacts.<sup>22</sup> People who showed the most positive signs of adaptation tended to derive meaning from their breathlessness experience by focusing on their achievements and their learning journey over many years. While these people acknowledged the substantial impact that breathlessness had on their lives, they viewed this as a challenge they could rise to and overcome.

To learn from there to what I do now has been a phenomenal learning curve, and an effort to improve my quality of life, change my ways of thinking ... I look for every achievement I can find 'cause life is tough enough without finding something good in every day ... what's my role in my recovery? How am I going to help myself?' (P08, woman with restrictive lung disease)

These participants tended to take a project management approach that involved setting goals, analysing barriers (either breathlessness itself or gaps in resources and supports), finding appropriate solutions and iterative review and reflection. Even when breathlessness deteriorated over time, some people reported that they were able to revise their goals and restart the process after only a temporary emotional set back.

I don't want to sit back and let my body dominate me... I need to be control of my life. (P16, man with COPD)

As well as setting themselves breathlessness-related goals (eg, climbing stairs), these people also sought new meaning through sedentary activities that were less impeded by their breathlessness. These people considered their engagement with the process itself to be the major achievement rather than attainment of the goals.

You may see your path towards that goal but it doesn't always work that way, so sometimes you've got to go to plan B, plan C, or plan D, but as long as you keep the goal in mind you'll find a way around it. (P22, man with COPD)

By contrast, some others showed little reflection and commensurately less insight into gaps in their management skills or support. One person especially appeared to avoid thinking about her illness as a coping strategy.

I don't like to know too much ... it might make me think that I could get worse or something. I don't wanna know. (P20, woman with COPD)

Finally, several participants made reference to fatalistic beliefs as helping them to cope with the threat of breathlessness crises and a perceived possibility that they might die at any time.

I guess the truth is you can die from a [breathlessness] attack, but I've lived with that for long enough to know that that's where I'm gonna end up, and I'm not saying that I might get hit by a bus in the meantime—I don't know. Nobody's in charge of their destiny. (P09, woman with COPD)

## DISCUSSION

This study is unique in taking a strengths-based approach to understanding ED-related decision-making and self-management in relation to breathlessness crises. Findings suggest that the most influential factors determining decisions to self-manage rather than present to the ED may be a perception of control over breathlessness and self-efficacy in coping, as well as a disinclination to be hospitalised. Coping strategies that participants reported to be effective included: taking a project management approach that involved goal setting, monitoring and risk management; managing the affective dimension of breathlessness separately from the sensory perceptual

and building partnerships with health professionals who were perceived to respect the breathless person's expertise and provide coordinated care across community and hospital settings. Participants also provided insights into when they considered help-seeking for breathlessness to be necessary, especially changes in breathlessness quality perceived to be indicative of a chest infection.

Our study adds to previous research on the relationship between sensory perceptual and affective breathlessness experience, confirming that people not only readily distinguish these components<sup>23</sup> but also actively seek to do so to gauge the severity of threat. Our results are consistent with others in suggesting a reciprocal relationship between sensory perceptual and affective experiences<sup>18</sup> and finding symptom-related distress to be an important precipitant of ED presentation.<sup>24</sup> Our data also underscore the clinical importance of unpredictable (ie, non-triggered) breathlessness as a subcategory that may be most likely to cause alarm and prompt help-seeking.<sup>16</sup> A better understanding of the 'vicious circle' between affective and sensory perceptual dimensions of breathlessness might make an especially important contribution to reducing avoidable ED presentations. Real-time data on the temporal relationships between these dimensions, including physiological parameters, would be especially helpful for understanding typical patterns or differentiating subgroups for whom the dimensions are related in different ways.

Our results also further develop understanding of how perceived lack of support from health services can lead to avoidable ED presentations. Our findings support those of a previous qualitative study in suggesting that established partnerships with a GP who offers continuing, person-centred care may protect against avoidable ED presentations.<sup>25</sup> Participants in this study required not only medical expertise and a caring attitude but also respect for their status as expert patients developed over years of lived experience. Conversely, a perceived lack of person-centredness and disrespect for patient expertise in acute care served as a disincentive to attend the ED, even when participants thought that medical help was needed. As found in previous research, people with chronic breathlessness weighed up the benefits and burdens associated with healthcare interventions.<sup>26</sup> These findings confirm that a three-way partnership between the person with chronic breathlessness, GP and respiratory services may deliver optimal shared decision-making and management and highlights the need to support action planning and coordination around each person's needs.<sup>27</sup>

Self-efficacy has long been identified as important in self-management.<sup>28</sup> Our findings suggest that self-efficacy in coping with a crisis may be just as critical as breathlessness severity in determining whether people decide to attend the ED. This finding is encouraging given that self-efficacy may be more amenable to improvement than breathlessness itself. Previous interventions have improved self-efficacy by means of training people in a range of non-pharmacological management strategies, as

well as by support from multidisciplinary health professionals.<sup>29,30</sup> These interventions go beyond knowledge transfer, which alone is insufficient to reduce ED presentations.<sup>31</sup> Consistent with self-efficacy's original conceptualisation,<sup>32</sup> participants in our study derived motivation and resilience from viewing breathlessness as a challenge to be mastered. People with breathlessness who lack this perspective may benefit from coaching in goal setting, decision-making and problem solving to help them reframe.<sup>4</sup>

Participants in this study reported activities in each of the categories of daily self-management reported in previous qualitative research, namely those aimed at symptom management, pacing, environmental control, emotional adoption and maintaining a healthy lifestyle.<sup>33</sup> Management strategies reported by participants in our sample were generally similar to those recommended by the ATS Palliative Management of Dyspnea Crisis Project<sup>8</sup> and identified by previous research.<sup>14,17</sup> Oxygen therapy is recommended by the ATS as a strategy for managing breathlessness crises by people who are hypoxaemic. However, there is evidence that this is ineffective and burdensome for patients who do not meet this criterion.<sup>34</sup> In the absence of data on participants' oxygen saturation or home oxygen prescription, we are unable to comment further on whether oxygen was likely to give more benefit than airflow alone.

A surprising proportion of participants were also using oximetry to monitor their breathlessness and inform decisions about when to present to ED. Our findings results agree with those of a previous study, which found that people with COPD who were given oximeters to monitor their breathlessness found this to confer confidence in making self-management decisions.<sup>35</sup> However, the dependence on oxygen saturation levels some participants in our study displayed when making ED-related decisions may be a cause for concern given limited evidence for its sensitivity and specificity in distinguishing exacerbations from daily variability, especially in the absence of expert support or integration with other parameters such as heart and respiratory rates.<sup>36-44</sup> It is noteworthy that almost all participants in this study who used oxygen saturation levels as a guide for when to seek help set a threshold below the 88% lower end of levels recommended for people with COPD and other respiratory disorders.<sup>45</sup> There is evidence from a pilot randomised controlled trial that telemonitoring of oxygen saturation levels along with other measures can reduce COPD-related ED presentations.<sup>46</sup> However, there are also concerns that the high level of health professional support required to interpret telemonitoring data may increase patient dependency and undermine self-efficacy.<sup>47</sup> Taking all these considerations into account, it is difficult to provide evidence-based recommendations for the use of oximetry in monitoring and ED-related decision-making.

## Limitations

The main limitation of this study is that our sample was not intended to be representative of people at risk for avoidable ED presentations for breathlessness. The predominance of COPD in our sample also limited inference about how perspectives might differ between people with different diagnoses and comorbidities. While the self-reported and retrospective nature of data enabled reflection and interpretation, recall bias means that participant accounts were unlikely to fully and accurately represent events. Interviewing by telephone also limited potential for non-verbal communication and re-enactment of breathlessness crises that would have been available if participants had been interviewed at home. Neither of the researchers involved in interviewing or initial coding had clinical experience in working with this patient population, which may have led to them to miss patterns familiar to experienced clinicians. Medical and nursing personnel with substantial experience of managing breathlessness were involved in the later stages of analysis to ensure clinical experience contributed to interpretation without biasing the inductive phase. In transitioning from descriptive to interpretative phases of analysis, we used an established model that has been widely validated in a range of healthcare contexts.<sup>48</sup> However, the general applicability of the Transactional Model of Stress and Coping meant that some processes (eg, motivational relevance versus severity) were not as well delineated in this application as for less urgent health-related stressors. Also, the analysis reported here did not consider the role of moderators such as social support and dispositional coping style included in the model. Finally, while data were available with relevance to all components of the Model, we did not test saturation by iterative sampling or other methods.

## Conclusions

The perspectives of people with chronic breathlessness and respiratory disease gained through this study are instructive for developing interventions aimed at improving self-management skills and coping in people at risk of avoidable ED presentations for breathlessness. Future research is needed to better understand the relationships between affective and sensory-perceptual dimensions of breathlessness and the potential pulse oximetry may have for informing individualised decisions about when to present to ED. Interventions should aim to develop people's skills in goal setting, decision-making, problem solving and building partnerships with health professionals to increase their sense of control and self-efficacy. Complementary initiatives are needed to improve coordinated, person-centred care.

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