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Accepted Manuscript

“I Can Breathe Again!” Patients’ Self-Management Strategies for Episodic Breathlessness in Advanced Disease, Derived from Qualitative Interviews

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Original Article

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**“I Can Breathe Again!” Patients’ Self-Management Strategies for Episodic Breathlessness
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Abstract

Context. Episodic breathlessness causes additional distress to breathless patients with advanced disease but management is still insufficient and there is a lack of knowledge on effective coping strategies.

Objectives. The aim was to explore patients' self-management strategies for episodic breathlessness.

Methods. In-depth interviews with patients suffering from episodic breathlessness as a result of chronic heart failure (CHF), chronic obstructive pulmonary disease (COPD), lung cancer (LC), or motor neuron disease (MND) were conducted. Interviews were transcribed verbatim and analyzed guided by the analytic hierarchy of Framework analysis.

Results. A total of 51 participants were interviewed (15 CHF, 14 COPD, 13 LC, nine MND; mean (standard deviation [SD]) age 68 (12), 41% female, median Karnofsky index 60%). They described six main strategies for coping with episodes of breathlessness: reduction of physical exertion, cognitive and psychological strategies, breathing techniques and positions, air and oxygen, drugs and medical devices, and environmental and other strategies. Some strategies were used in an opposing way, e.g., concentrating on the breathing vs. distraction from any thoughts of breathlessness or laying down flat vs. standing up and raising hands.

Conclusion. Patients used a number of different strategies to cope with episodic breathlessness, adding more detailed understanding of existing strategies for breathlessness. The findings, therefore, may provide a valuable aid for health care providers, affected patients and their relatives.

Key Words: coping, dyspnea, episodic breathlessness, palliative care, respiratory symptoms, self-management

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ACCEPTED MANUSCRIPT

Introduction

Episodic breathlessness causes additional distress to breathless patients with advanced, life-limiting disease such as chronic obstructive pulmonary disease (COPD) or cancer.(1-3) Prevalence has been reported to be up to 81% in advanced cancer patients.(2) In 2014, an international consensus definition and categorization have been established for episodic breathlessness as “one form of breathlessness characterised by a severe worsening of breathlessness intensity or unpleasantness beyond usual fluctuations in the patient's perception. Episodes are time-limited (seconds to hours) and occur intermittently, with or without underlying continuous breathlessness. Episodes may be predictable or unpredictable, depending on whether any trigger(s) can be identified (...)” (4).

Although research on episodic breathlessness has increased over recent years and experiences and characteristics have been described, there is a lack of knowledge on specific management strategies to relieve the symptom effectively (2, 3, 5-7). Previous studies have investigated self-management and coping strategies for breathlessness in general in patients with COPD, asthma or lung cancer (LC) (8-12). However, as we now have a clearer understanding of different features of breathlessness, e.g., continuous and episodic breathlessness, more specific management strategies should be developed for episodic breathlessness.

Therefore, we aimed to explore patients' experience of breathlessness episodes, their impact on patients' lives and their individual coping strategies. The data on the experience, types, patterns and characteristics of episodic breathlessness have been reported elsewhere.(5, 6, 13) This article reports on self-management and coping strategies that are used by patients to relieve episodic breathlessness.

Methods

Study details have been reported previously (5, 13). This section provides a concise summary of the methods applied. Since the consensus definition of episodic breathlessness was not available at the time of this study, a working definition suggested by Reddy was applied: Episodic breathlessness is a “clinically significant aggravation of dyspnea in patients with continuous dyspnea or occurring intermittently” (2).

Study Design and Ethics

We conducted a qualitative study using in-depth face-to-face interviews. The study followed the consolidated criteria for reporting qualitative research (COREQ) guideline for reporting qualitative research (14). Ethics board approval has been obtained from the Joint University College London/University College London Hospitals Committees on the Ethics of Human Research Alpha (09/H0715/81).

Participants and Setting

A purposive sample was recruited in five outpatient clinics of two university hospitals in south London from January to May 2010 (5, 13). Patients suffering from breathlessness resulting from one of the following diseases were eligible: COPD (Global initiative for Obstructive Lung Disease classification [GOLD] Stages III-IV), chronic heart failure (CHF) (New York Heart Association classification (NYHA) stages II-IV), primary or secondary LC (all stages), or motor neuron disease (MND) (all stages). Participants could be on any treatment for the underlying disease or for breathlessness.

Data Collection

Before the interview started, consent was obtained and demographic and clinical data were documented. The semi-structured, in-depth, face-to-face interviews were conducted with an exploratory approach by two trained interviewers (S.T.S. and H.B.), usually at participants’

homes. The topic guide focused on experiences with episodic breathlessness, characteristics and triggers for such episodes, impact on daily living and management strategies for episodic breathlessness. Patients were asked to specifically describe their experiences with coping strategies of episodic breathlessness in detail with regard to strategies used, how these strategies worked, how effective they were and which dimension of breathlessness were changed (e.g., sensory sensation, emotion or impact). The interviews were tape-recorded and transcribed verbatim.

Data Analysis

Themes were derived from the data. The interview transcripts were read twice to familiarize with the content. We used the matrix-based Framework analysis method, guided by the analytic hierarchy of data management (identifying initial themes, coding), descriptive accounts (sorting, summarizing, identifying dimensions and categories) and explanatory accounts (detecting patterns, identifying clusters, developing explanations and a theory) (15), using the computer program NVivo 8 (devised by QSR International in 2008).

Results

Participants

Fifty-one participants were interviewed and provided data on self-management or coping strategies for episodic breathlessness (Table 1). The median duration of the interviews was 55 minutes (range 17-89 minutes) and 45/51 interviews were conducted in the participants' home. During 18 interviews, other (non-participating) people were present (e.g., wife, granddaughter).

All but two patients suffered from episodic breathlessness due to physical exertion. In addition, most patients experienced episodic breathlessness as a result of other triggers such as

emotions or environmental factors. About half of participants suffered from unpredictable episodic breathlessness “out of the blue.”

Self-Management Strategies

All participants described at least one “strategy” to manage episodes of breathlessness. While some could only provide one or a few facts, others provided rich descriptions about their experiences with several strategies. Six main themes emerged from the data (Fig. 1).

Reduction of Physical Exertion. All but two participants described that they reduced or even avoided exercise to relieve episodic breathlessness, i.e., most participants stop and rest, stand still, sit down or lie down in acute situations of breathlessness. For some patients this was the only effective strategy.

Sit down and relax, that’s all you can do.... (COPD-6)

(...) erm, sitting down seems to be the, the easiest...and most (...) most effective, yeah. (LC-2).

And so normally (...) I’ll either go and lay down in bed until it passes over or I’ll just sit here and wait for it to die down (...) to the normal. (CHF-13)

Some patients emphasized that they learned to “listen to their body,” paced oneself, avoid rushing and adapt any activity according to their capabilities.

I just ride it and I say, “Right, okay, [name of patient], slow down, sit down, shut up, or whatever until you feel a bit... your, your levels are balanced out, you’re balanced out again.” (...) I have to let it rule what I am capable of doing (...) So you’ve got to accept it if you want any kind of quality of life (...) You’ve got to adapt your life to whatever the symptom

is, and that's what I do. And I... I just stop, I just rest back, I put the phone down.... (LC-5)

I need to completely stop and that, and that's, erm, er, quite difficult when you're with a group of people, because it was like I was saying about talking, it's very difficult not to talk or to laugh or to, erm, engage. (LC-13).

Cognitive and Psychological Strategies. Thirty-one participants mentioned that they used cognitive strategies for the control and relief of episodic breathlessness, i.e., relaxation and panic reduction techniques, but also to “fight” episodic breathlessness. Patients in all disease groups (nine CHF, three LC, four COPD, two MND) described that calming down mentally or relaxing is helpful. Many achieved relief through concentrating on their breathing.

I really have to sort of concentrate (...) on breathing properly because it's, it's hard. (CHF-4)

I know full well that if I get panicky... it'll only get worse (...) I concentrate, I shut my eyes and I breathe slowly (...) and then I can usually bring it back down, it's never going to be better but it comes from a bad one down to a manageable one. (LC-9)

(...) but if I can physically also try and mentally, I think, okay just drop your shoulders, mentally relax, calm everything down (...) Yeah I think it's just getting to a place of complete calm (...). (LC-13)

Some patients described a positive attitude and others described how they actively confronted upcoming episodes of breathlessness.

You've got to think positive you've got to think I can do this (...) you've got to push yourself a bit. Because if you don't and you give into it you've had it, you know what I mean? And while you're on the go, while you're keeping yourself going it's all loosening your chest, it's giving you that bit of exercise (...). (COPD-9)

Because it's a mental thing too (...) I have to kind of steady up like and say to myself, you know, I'll be positive now. And I, I'll kind of defy it like (...) You're fighting, you're fighting off the, the tightening up of your chest. (COPD-14).

In contrast, a number of patients needed to distract themselves from their breathlessness to avoid panicking. Distraction was particularly used by CHF and COPD patients by strongly trying to think of something else or watch TV.

(...) means that I've got something to watch (...) it takes my mind off what I'm suffering. (COPD-6).

I, I find it better for me just sitting down (...) And not thinking about it (...) and if it's really one of my really bad breathing things I just sit down and I think what are they [grandchildren] doing now, are they all right,. And then I gradually sort of come down and then I realise that I'm breathing properly. (CHF-4)

Notably, some participants mentioned that “Knowing what to do... is a great help” (COPD-6).

Similarly, knowing that breathlessness will stop again was important and helpful for some.

...it's just the resting and thinking well it's going to go, it's going to stop (...) that again is a psychological thing. It's going to stop (...) So basically

then you calm down and you think yeah it's going to stop eventually (...)

Because in my normal situation I don't breathe like this you know. (CHF-15)

Breathing Techniques and Positions. Thirty-five participants reported specific 'breathing techniques', positions and devices such as rollators that they use while being acutely breathless. Some used breathing techniques they had been taught by a physiotherapist or breathing therapist or read in information leaflets in the hospital or during pulmonary rehabilitation: lip breathing, abdominal breathing, leaning forward or putting the arms up. Some patients even developed their own breathing techniques.

I go ((breaths in)) you know, and ((exhales)) like that (...) for a while. You know like erm, you know, the thing what you, you tell pregnant women to do (laughs) when they feel pain! (CHF-10)

Many patients from all disease groups but LC emphasized specific positions that helped them to relieve episodic breathlessness. Interestingly, the positions differed fundamentally between individual patients. While some patients described the need to lie down, others rejected this categorically and described the need to stand up.

No, I just lay down and I try (...) ... to breathe (...) In and out so... (...).
(LC-1)

I would stand, erm, if I'm walking, for example, to help me I, I walk like this [demonstrating] (...) With the hand on my back yeah. So I can walk along like that. And it expands my chest (...) If I laid down it wouldn't be any good. Because I can't breathe when I'm laying down. (MND-7).

Many patients use several pillows to raise their upper part of the body and to sleep in an upright position (CHF 4, COPD 4, LC 1, MND 5) whereas two patients emphasized “where it comes on if I'm laying down I just like try and lay as flat as possible” (MND-3) or “When I try to breathe it's best that I lay down” (LC-1).

Air and Oxygen. Twenty-eight participants mentioned positive effects of fresh air, cool air, or movement of air on the face for relieve of episodic breathlessness: “... when you're out of breath or, you know, when you're out of breath all you need is air” (MND-8).

COPD patients found oxygen to be effective in relieving severe episodes of breathlessness; however, seven of these nine patients were on long-term oxygen.

When it gets worse I just come straight to the oxygen. (...) So you can't stop it's going to be you can't stop it. But you can help yourself like taking oxygen. (COPD-12).

Eight participants have tried or used a fan, but only five of them found it helpful and one patient said “I wouldn't use a fan” (LC-7).

Relax and, erm, how do I explain. Erm, sit in front of the fan. (CHF-1)

So... the only thing I try to do is, erm, be somewhere where there's fresh air (...) If I might probably go outside and sit down or ... or turn the fan on in front of me. (CHF-15)

Oh no it come on quickly otherwise you'd just... sometimes you could control it I think if it was coming on... you could get the fans on, get the doors open. (MND-8)

Drugs and Medical Devices. Participants used a variety of different drugs for episodic breathlessness. Only 1/51 patients used morphine for breathless episodes. Inhalers which

adrenergic agonists or anticholinergics were used most often by COPD and lung cancer patients with conflicting effects. Three patients with CHF used sublingual nitroglycerine spray in episodic breathlessness. One CHF patient who suffered from additional asthma, had a prepared emergency list how to proceed in a case of episodic breathlessness: 1) inhaler (salbutamol), 2) nitro spray, 3) nebulizer, 4) call the ambulance for the emergency department. Some patients explicitly stated that they do not use any medication as it does not help or that the episode is not long enough for drugs to use.

The first thing I do is use up my inhalers and if that doesn't work I use the, erm, GTN spray and just wait. (CHF-15)

And so it's probably the steroids that are most effective (...) erm, with helping me with my breathing. (LC-13)

Environmental and Other Strategies. Similar to the many participants emphasizing that fresh air helps them with managing episodes of breathlessness (see above), some patients perceived cold temperature as helpful. Cold air, however, should not be too cold and it depended on the weather outside.

I was waking up, erm, really breathless in the night when I used to go to the (...) open a window...and get some cooler air, of course it wasn't cold then, not like it is now [cold winter day] (...) Get some cooler air, because if you, if you, you know, if it cools you down a touch it sort of helps. (CHF-2)

In contrast, some patients told that they needed to be warm to relieve or prevent episodic breathlessness:

As soon as I get cold I lose my breath. (COPD-6)

... the warmer the, the air is the better... it is for me. (LC-7)

A number of patients perceived drinking and keeping the mouth moist as helpful to relieve episodic breathlessness, i.e., drinking a glass of water or hot lemon or a beer. Similarly, some patients perceived a chewing gum or other foodstuff with ‘refreshing’ tastes and effects as helpful during a breathlessness episode.

Well chewing gum helps. (...) And, er, I find a drink of water can help.

(...) This keeps the mouth moist, yeah. (...) Chewing gum does, keeps it...

and also, er, I've found drink can help, alcohol, like beer (...) it's

probably relaxes, you see. (COPD-2)

Water helps me. (...) And sometimes an extra strong mint help me. (CHF-

5)

I've been drinking hot lemon with, er, honey in and I find that, er, the

honey the lemon together often eases the throat... (...) which in turn makes

it easier to breathe. (LC-9)

Discussion

Breathless patients described several effective and helpful strategies to manage acute episodes of breathlessness. The most common strategies were reduction of physical activity and exertion, and panic control through relaxation and breathing techniques. Strategies did not differ between disease groups but between individual patients and were related to the trigger of the breathless episode. The identified strategies were largely easy to apply and can be practical aids in the daily care of patients suffering from episodic breathlessness. The results of this study may be beneficial in the discussion between patients and health care providers about the individual

management options and preferences for episodic breathlessness and may moreover be helpful for the development and evaluation of future management strategies.

Interpretation of Findings in Relation to Previously Published Work

Some of the described strategies have partly been reported before in research on breathlessness in general including continuous and episodic breathlessness (8-12). Booth et al. recommended and described a variety of self-management strategies within their book on management of breathlessness for clinical practice, including techniques to cope with episodic breathlessness (e.g., breathing techniques and anxiety management) (16). Christenbery et al. investigated the frequency of usage and perceived worth of breathlessness self-management strategies by COPD patients using the Dyspnea Intervention Scale (DIS) (8, 9). Similar to our findings, moving slower, keeping still, using oxygen, performing breathing exercises, decreasing activities, and using cool air were among the most frequently used techniques to relieve breathlessness; however, although mentioned by most patients, “moving slower” ($n=72/79$) and “keeping still” ($n=68/79$) were used only occasionally, which might indicate a response to exertion-induced episodes of breathlessness rather than continuous breathlessness (9). Park et al. used a checklist and open-ended questions to explore the types and effectiveness of strategies that Korean immigrants with COPD or asthma use to manage breathlessness (12). Similar to our findings, most frequently and effectively used strategies were problem-focused: “to keep still or rest,” “move slower,” “get some fresh air,” “avoid strenuous activities,” and “take bronchodilator” among other things (12). Moreover, 60% of participants “calmed themselves down.” Furthermore, no patient in the Park et al. study used distraction, which has been identified as a successful strategy in our study and another study in LC patients (10, 12). Finally, in the Park et al. study, most participants from both disease groups rated emotion-focused

strategies to be less effective than problem-focused strategies, which is in contrast to the findings of our study, which identified psychological strategies and relaxation as quite helpful for the relief of episodic breathlessness (9). In summary, reduction of physical exertion, oxygen and pharmacological interventions focus more on the relief of continuous breathlessness whereas cognitive and psychological strategies and breathing techniques have more of an effect on episodic breathlessness.

Implications for Clinical Practice and Research

Self-management programs are increasingly recognized in chronic diseases such as COPD and especially breathlessness. A current Cochrane review based on 23 randomized controlled trials (RCTs) concludes that self-management interventions in patients with COPD are associated with improvement in breathlessness, improved health-related quality of life and a reduction in respiratory-related and all-cause hospital admissions (17). There is high quality and well-based evidence for the effectiveness of pulmonary rehabilitation in COPD and interstitial lung disease (18, 19). However, programs still do not acknowledge episodic breathlessness as a specific form of breathlessness, which hinders an even more effective management of episodes of breathlessness. Although COPD patients reported panic as a trigger more often than others, we found that COPD patients did cope comparably well by learning how to control the panic through their illness trajectory over years, particularly those who attended pulmonary rehabilitation.

Breathlessness services that incorporate management strategies with pharmacological and non-pharmacological interventions and use a multidisciplinary approach have proved to be beneficial for patient with breathlessness (improving mastery and reducing distress due to breathlessness) (20, 21). A recent published pilot study described improvements in

breathlessness after a set of behavioral interventions (22). These services include a variety of strategies to relieve episodic breathlessness although they have been evaluated for breathlessness in general and not specifically for episodic breathlessness.

Patients reported repeatedly that information about episodic breathlessness and effective management strategies helped them to better cope with their situation. Therefore, providing this information is a first step of successful management. Strategies such as pacing, exercise to an acceptable level, to avoid rushing and to take rests, having a drink, panic control and relaxation strategies are essential methods that should be discussed with patients suffering from episodic breathlessness. Furthermore, guidelines and information leaflets exist for breathlessness in general but should throw light on episodic breathlessness and its specific management options.

The results of this study show the way that coping with episodic breathlessness differed in two essential aspects between individual patients. First, relaxation and control were used by some patients by concentrating on breathing; for others the primary coping strategy was distraction from any thought or feeling of breathlessness, e.g., by thinking about and focusing on something else. Second, positions that have been helpful for patients varied from laying flat to standing up or resting the upper part of the body or arms. This demonstrates that effective strategies to control episodic breathlessness need to be individualized.

Strengths and Limitations

This study has some strengths and limitations. We explored the coping strategies of patients suffering from episodic breathlessness in several disease groups and not only one underlying disease, allowing for more generalizability of the results. Also, for a qualitative design, we included quite a large sample. However, the number of included patients in the four disease groups differed and patients with MND might be considered as underrepresented. This is

related to the fact that recruitment took place in outpatient clinics, which MND patients often cannot attend because of more disability due to progressive disease. A limitation could be that patients in outpatient clinics of a tertiary center are biased as many might have attended pulmonary rehabilitation and specialist physiotherapy. Therefore, their coping strategies could be potentially taught by professionals rather than having evolved from the patients themselves.

Conclusion

Patients reported a number of different strategies to cope with episodic breathlessness which are suitable for daily use. Some are taught in pulmonary rehabilitation programs or physiotherapy sessions, others have been developed by patients themselves. Not all recommended strategies (such as leaning forward, breathing techniques or a draft of cold air) are helpful for all patients demonstrating that any support for patients should be individualized and tailored by the patient's own experiences.

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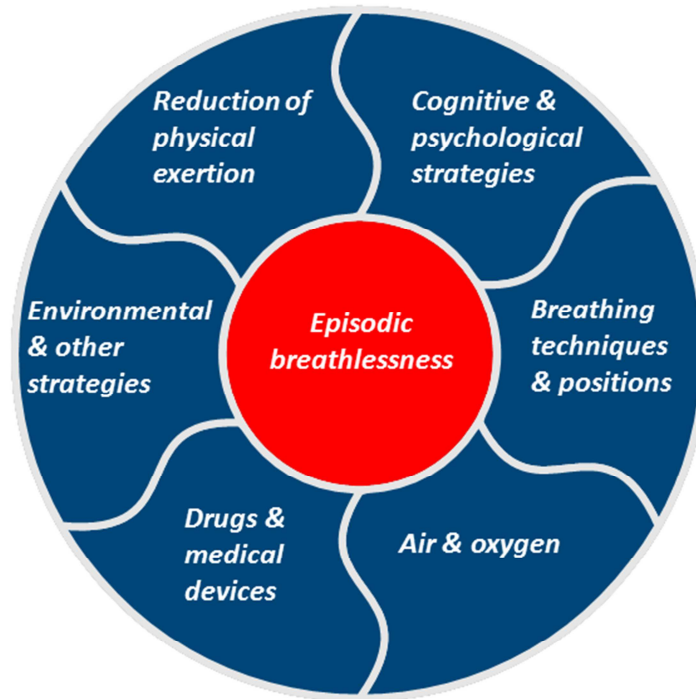
Fig. Legend

Fig. 1. Overview of management strategies described by patients.

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Table 1: Demographic and clinical characteristics of participants

Characteristic	n=51 (100%)
Age - mean (SD; range)	68.2 (11.6; 39-92)
Female	21 (41%)
Ethnicity	
Caucasian	39 (77%)
Caribbean	5 (10%)
Indian	4 (8%)
African	3 (6%)
Living alone	19 (37%)
Primary disease	
CHF	15 (29%; 2/10/3 NYHA II/III/IV)
COPD	14 (28%; 7/7 GOLD stage III/IV)
LCr	13 (26%; 7/4/2 primary/secondary LC (breast)/mesothelioma)
MND	9 (18%)
Karnofsky Index -	
median (range)	60 (30-90)
Non-smoker	17 (33%)
Oxygen supply	14 (28%)
Numbers and percentages are presented unless otherwise stated.	
CHF chronic heart failure, COPD chronic obstructive pulmonary disease, GOLD Global initiative for chronic Obstructive Lung Disease, LC lung cancer, MND Motor Neuron Disease, NYHA New York Heart Association, SD standard deviation	



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