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Individualized breathlessness interventions may improve outcomes in patients with advanced COPD

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SUMMARY AT A GLANCE

Refractory breathlessness in patients with advanced COPD is a complex and difficult symptom to manage. In this feasibility study, we demonstrate that implementation of an individualized breathlessness intervention, involving a written plan, information leaflets and breathlessness education, is associated with an improvement in breathlessness scores and high patient acceptability.

ABSTRACT

Background and objective

Many patients with advanced chronic obstructive pulmonary disease (COPD) experience refractory breathlessness, and individualized breathlessness interventions may improve management of this complex symptom. The aims of this study were to develop, implement, and assess the efficacy of a breathlessness intervention for patients with COPD and refractory breathlessness, and to evaluate patient acceptability.

Methods

An individualized breathlessness plan, information leaflets, breathlessness education, and a hand-held fan were offered to consecutive patients with severe COPD and refractory breathlessness attending a tertiary integrated respiratory and palliative care service. Validated dyspnoea, quality-of-life, and anxiety/depression questionnaires were administered at baseline and after 6 weeks, with change in dyspnoea scores being the primary outcome measure. A subset of patients participated in a structured telephone interview to qualitatively assess the intervention.

Results

Twenty-six patients with severe COPD (mean FEV_1 38%) were included, with a mean age of 74 years. Mean MMRC breathlessness score was 3.5. Anxiety and depression were common, being present in 38% and 35% of participants. At six weeks, there was a clinically significant improvement in breathlessness severity as measured by the Numerical Rating Scale. The subset of patients with anxiety/depression also saw significant improvement in all domains

of the CRQ-SAS. Patients reported that the intervention was highly useful and acceptable.

Conclusion

This feasibility study of individualized breathlessness interventions in patients with severe COPD and refractory breathlessness is the first to demonstrate a clinically significant reduction in dyspnoea scores, with high levels of patient acceptability.

Keywords: Clinical respiratory medicine; COPD; emphysema; quality of life

Short title: Individualized dyspnoea plans in COPD

Introduction

Chronic obstructive pulmonary disease (COPD) is a common, progressive respiratory illness, characterised by persistent symptoms, airflow obstruction and respiratory failure.[1] In the advanced stages, patients may develop refractory breathlessness, defined as breathlessness persisting at rest or on minimal exertion despite optimal medical management.[2] Importantly, approximately 20% of patients presenting by ambulance to hospital emergency departments report acute-on-chronic breathlessness.[3]

Refractory breathlessness is difficult to manage, requiring a holistic approach including both non-pharmacological and pharmacological strategies, in addition to optimal disease-directed management. Pulmonary rehabilitation, physical activity, breathing exercises, the use of a hand-held fan to move air on the face, and walking aids are non-pharmacological strategies that have demonstrated efficacy in managing refractory breathlessness.[4,5] When these strategies are insufficient to provide symptom relief, low-dose opioids may safely and effectively reduce breathlessness in some patients.[6–10]

A dyspnoeic crisis is defined as "sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers' ability to achieve symptom relief."[11] Self-management plans are recommended for management of dyspnoeic crises, and such interventions have been shown to improve health outcomes and reduce respiratory-related hospitalisations.[12] However, as the

management of chronic breathlessness is complex, and many patients also experience anxiety and/or depression,[13] even simple strategies may be difficult for patients and carers to recall and implement during a dyspnoeic crisis, or when managing long-term, refractory breathlessness.

Pulmonary rehabilitation and hospital admissions are key opportunities to provide patient education, however, short- and long-term recall of information is often impaired in patients with end-stage COPD.[14] Therefore, breathlessness management education to address this distressing symptom should involve a multi-disciplinary team approach, be iterative over several patient encounters, and provide supporting written information and self-management action plans.

The aim of this feasibility, mixed methods study was to develop and evaluate the efficacy and acceptability of individualized breathlessness interventions in patients with advanced COPD and refractory breathlessness.

Methods

Development of Breathlessness Plan and Information Leaflets

The Advanced Lung Disease Service (ALDS) is an integrated respiratory and palliative care service at The Royal Melbourne Hospital, which offers holistic care to patients with advanced lung disease, including a focus on symptom management.[15] A written breathlessness plan template was developed for ALDS patients following a comprehensive literature review, and in liaison with other service providers.

Additional supporting documents were created, including information leaflets regarding management of refractory breathlessness for health professionals and also for patients and carers, and an illustrated leaflet for patients and carers describing the use of non-pharmacological strategies to manage breathlessness. All documents were further refined following stakeholder feedback from patients and carers, emergency department staff and general practitioners.

Interventional Study Design

All patients provided written consent to participate and ethics approval was granted by the Melbourne Health Human Research Ethics Committee. A prospective, cohort study was undertaken, with consecutive ALDS patients with COPD invited to participate if they met the following inclusion criteria:

- Refractory breathlessness despite optimal disease-directed care, with a breathlessness score of 3-4 on the Modified Medical Research Council Breathlessness Scale (MMRC);[16] and

- ≥1 presentation(s) to the emergency department; or ≥1 hospital admission(s) with worsening breathlessness within the last 24 months; and
- Medically stable with no exacerbations or change in treatment for at least 6 weeks prior to study enrolment.

Participating patients received a breathlessness pack (Figure 1), which included a hand-held fan, information leaflets, and an individualized breathlessness plan (Supplementary Appendix S1). Where applicable, this plan included details regarding the correct use of domiciliary oxygen therapy and/or opioids for breathlessness. These instruments were then used to facilitate a structured patient education session regarding breathlessness management, including breathing techniques, rescue positions, use of the hand-held fan, and opioid/oxygen education. This process was completed by the respiratory physician and respiratory nurse specialist in the ALDS clinic, with each discussion taking approximately 30-45 minutes.

Study outcomes

The primary outcome was the change in validated dyspnoea scores between baseline and six weeks after delivery of the breathlessness intervention. Secondary outcomes were the change in validated anxiety, depression, and quality of life scores, and overall acceptability of the intervention via qualitative interviews.

Baseline data collected at study enrolment included measures of breathlessness, quality of life, and mood using the Chronic Respiratory Questionnaire (CRQ-SAS), Hospital Anxiety and Depression Scale (HADS), Modified Medical Research Council Breathlessness Scale (MMRC) and Numerical Rating Scale (NRS). The CRQ-SAS is comprised of four domains (dyspnoea, fatigue, emotional function and disease mastery), each scaled from 1-7. The HADS questionnaire has depression and anxiety subscales, each scaled from 0-21. A cut-off of 8 for each subscale was used to identify patients who were either likely or unlikely to have depression and/or anxiety.[17,18] The MMRC breathlessness score is scaled from 0-4.[16] Finally, patients were asked to rate three different aspects of their breathlessness severity (on average; on exertion; at worst) over the preceding 24-hours using a horizontal NRS measuring from 0-10. An increase in scores on the CRQ indicates improvement, whilst a decrease in scores on the HADS, MMRC and NRS indicate improvement. The minimum clinically important difference is 0.5 for the CRQ domains, 1 for the NRS, and 1.5 for the HADS.[18–20]

Patient demographics, disease severity, and health care utilisation were extracted from hospital medical records. The breathlessness plan and information leaflets were also sent to each patient's usual GP at study enrolment. Six weeks after study enrolment, patients were invited to complete the CRQ-SAS and HADS questionnaires, and to report their NRS and MMRC breathlessness scores again.

Qualitative feedback was sought from the final eleven consecutive patients enrolled in the study through a semi-structured interview. Patients were asked to consider the utility and their overall satisfaction with each component of the breathlessness intervention. Data collection at six weeks and the qualitative interviews were undertaken by a researcher (JP) who was independent from the clinical team. Interviews were audio recorded and transcribed verbatim, then examined using thematic analysis.

Data Analysis

Data were analysed by researchers (MQ/DW) who were independent from the clinical team. Categorical data are presented as counts and frequencies, and continuous variables reported as means (standard deviation) or medians (interquartile range), where appropriate. Analysis was performed for patients who completed the study, and also by an "intention-to-treat" approach, including the 6 patients who started but did not complete the study. Results were considered significant if the change from baseline met the minimum clinically important difference.

Results

Participant demographics and management

Thirty-two participants were enrolled, however, 3 died during the study period and 3 were lost to follow-up. Of the remaining 26 participants, 17 (65%) were female, with mean age 74 years (SD 8.1) (Table 1). Participants had severe COPD, with mean FEV_1 0.7L (SD 0.2L) and DLco 33% (SD 10%). Twenty (77%) participants used home oxygen therapy, of whom 12 (60%) were on long-term oxygen therapy. Five participants (19%) had been referred to community palliative care services prior to study enrolment. None of the participants had previously been given a breathlessness management plan. There was no statistically significant difference in baseline characteristics between participants who did and did not complete the study (Supplementary Table S1).

All participants were on optimal pharmacological treatment for COPD and 21 (81%) had previously completed pulmonary rehabilitation. Two (8%) participants had declined pulmonary rehabilitation referral, and 2 (8%) undertook a basic home exercise program. Smoking cessation strategies, including the opportunity to attend a smoking cessation clinic, were discussed with all five smoking participants, however, there was no change in smoking status during the study period.

Opioids had previously been prescribed for refractory breathlessness to 13 (50%)

participants, at a median dose of 16mg (IQR: 10-36mg) oral morphine equivalent per 24 hours. Thirteen (50%) patients also used benzodiazepines for management of anxiety. There were no changes in opioid or benzodiazepine doses during the study period.

Effect on breathlessness

There was no significant difference in primary or secondary outcome measures when analysed using only participants who completed the study or by an "intention-to-treat" approach. At six weeks, a clinically significant improvement in breathlessness was seen in the "on average" and "at worst" domains of breathlessness severity measured with the NRS (Table 2). The "at worst" domain improved the most significantly, with a 1.5-point reduction from baseline.

Effect on depression and anxiety

Overall, depression and anxiety scores in study participants averaged 7.0 and 7.5 on each of the subscales, respectively.[21] However, variance was high, with depression scores ranging from 2 to 20 and anxiety scores ranging from 3 to 18. After the breathlessness intervention, a reduction in both subscale scores was seen, particularly with anxiety, although this did not meet the minimum clinically significant difference (Table 2).

Effect on quality of life

Ten (38%) participants were identified as likely having anxiety at baseline, with a mean

HADS anxiety subscale score of 12.0 (SD 3.5). Baseline CRQ-SAS scores in the dyspnoea, emotional function and disease mastery domains were significantly worse in this cohort. At the conclusion of the study, however, there was a clinically significant improvement across all four CRQ-SAS domains, including fatigue (Table 3). Similarly, 9 (35%) participants were identified as likely having depression at baseline, with an average HADS depression subscale score of 11.7 (SD 3.9). This cohort scored significantly worse on all four domains of the CRQ-SAS at baseline, with clinically significant improvements also seen in all domains at the conclusion of the study. These changes were not seen in the patients who did not meet the criteria for anxiety or depression on the HADS.

Qualitative interviews

Nine of 11 participants consented to completing qualitative interviews. All participants reported finding the initial clinical contact and written resources useful, and valued the intervention. However, differing patterns of written resource utilisation were evident. A subgroup of participants felt they knew most of the information already, and therefore did not feel that they needed to refer to the written documents. Another group found the written information very useful, and had referred to the plan and leaflets multiple times. Many found use of the hand-held fan to be of great benefit (Table 4).

A significant theme raised by most participants was the importance of reassurance that the episode of breathlessness would pass. This message was emphasised during the

breathlessness education discussion, and on both the written plan and the information leaflets. Specific instructions for breathing exercises were also found to be useful, particularly the controlled breathing exercises and pursed lip breathing. This helped participants to change their daily routines and to adopt new practices.

None of the participants shared their written documents with their general practitioners, who were perceived to be too busy. Relatives of five participants were aware of the plan, as they had accompanied the participant to their clinic appointment. Furthermore, one participant stated their family member actively used the plan "a couple of times. He found the information useful" (P6). One participant identified that having a follow-up session at home would be beneficial and felt this could be delivered by a respiratory nurse.

Discussion

To our knowledge, this is the first study in the Asia-Pacific region to identify that individualized breathlessness plans and specific breathlessness education are associated with a significant reduction in breathlessness, and that this simple intervention was considered acceptable and highly beneficial by patients with advanced COPD and refractory breathlessness. Clinically significant improvements in multiple quality-of-life domains were seen in patients with probable underlying anxiety and/or depression at baseline.

Our study adds to the available literature suggesting that breathlessness interventions are useful. A randomised controlled trial of the breathlessness support service at King's College London demonstrated significantly improved disease mastery on the CRQ in the intervention group after 6 weeks.[22] Despite this, there was no significant improvement in breathlessness scores. Similarly, the Cambridge Breathlessness Intervention Service study showed only a non-significant trend towards improvement in the primary outcome of breathlessness-related patient distress on the NRS in the intervention group.[23] Therefore, our results are the first to suggest an improvement in actual breathlessness associated with this form of intervention. Whilst this could be due to different study methodologies, with ours being an uncontrolled feasibility study, an alternative explanation is the different patient populations. Our study focused on COPD patients, whereas the King's and Cambridge studies also included other respiratory diseases. Given the high prevalence of psychological comorbidity in COPD,[13] perhaps these patients are more receptive to breathlessness education.

Qualitative data from the breathlessness services at both King's and Cambridge demonstrated high patient satisfaction.[23,24] Similarly, in our study, patients placed particular value upon the education and reassurance that an episode of breathlessness would resolve, thereby limiting associated feelings of panic. Interestingly, all the patients who raised this theme had previously undertaken a pulmonary rehabilitation program, which also included

education on breathlessness and self-management. A Cochrane analysis comparing pulmonary rehabilitation trials which included exercise alone versus those that included exercise plus other components such as education, did not demonstrate a significant treatment effect between subgroups for any of the CRQ or St George's Respiratory Questionnaire domains.[25] These data, together with our qualitative analysis, suggests two possibilities – that the type of breathlessness education provided within a general pulmonary rehabilitation setting is different to what is needed by patients with advanced COPD and refractory breathlessness, and/or that learnt knowledge may be forgotten over time. These findings highlight the importance of iterative education tailored to each patient's disease, understanding and changing needs.

Furthermore, these findings have implications for models of care, and suggest that in addition to pulmonary rehabilitation programs, patients need clinical services that offer longer-term, multi-disciplinary, individualized breathlessness management support, ideally with continuity of care. Any new service should effectively utilise existing local health professional expertise and resources, whilst aiming to be cost-effective, sustainable and scalable. Targeting patients with significant levels of anxiety and/or depression may be a useful approach to maximise the benefit derived from such an intervention.

This was a small feasibility study without a control arm and a causal relationship between the intervention and breathlessness improvement cannot be inferred. With no separate

control group, a “before and after” comparison was chosen, which does not allow for temporal confounding, particularly in relation to exacerbations or disease progression. Similarly, the reduction in breathlessness may have occurred by chance due to the regression to the mean phenomenon. Therefore, while our findings are novel and exciting, a randomised study is required to further examine the effects of this intervention, including any effects on unscheduled healthcare utilisation. Identifying the number and format of iterative intervention required to achieve optimal benefit will also be important, which may include home visits, telephone contact, group sessions and use of smartphone applications.

In conclusion, individualized written breathlessness plans and focused breathlessness self-management education are highly acceptable to patients with advanced COPD, and are associated with improvements in breathlessness, as well as multiple quality of life domains in patients with co-existent anxiety and/or depression. Further research is required to explore this preliminary finding and also to identity whether this simple and inexpensive intervention could be used for patients with other causes of refractory breathlessness.

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Table 1: Baseline demographics (n=26)

Characteristic	**N or Mean (% or SD)**
Age (years)	74.0 (8.1)
Female	17 (65%)
Ex-smoker	20 (77%)
Current smoker	5 (19%)
Lives alone	14 (54%)
FEV_1 (L)	0.7 (0.2)
FEV_1 (% predicted)	38 (17)
DLco (% predicted)	33 (10)
PaO_2 on room air (mmHg)	60.2 (10.4)
6MWT distance on room air (metres)	104.4 (121.5)
Domiciliary oxygen therapy	20 (77%)
Opioid use	13 (50%)
No of hospital admissions in past 12 months	2.2 (2.6)
No of hospital admissions in past 24 months	3.2 (3.2)

Table 2: Dyspnoea, quality of life and anxiety/depression scores at baseline and after 6 weeks (n=26). Scores are reported as mean (standard deviation).

	Baseline	Week 6
Modified Medical Research Council	3.5 (0.5)	3.4 (0.6)
Numerical Rating Scale		
Average Breathlessness	5.6 (1.6)	4.6 (2.2)*
Worst Breathlessness	7.6 (1.5)	6.1 (2.6)*
Breathlessness on Exertion	7.2 (1.7)	6.4 (2.7)
Chronic Respiratory Questionnaire-SAS		
Dyspnoea	3.2 (1.2)	3.5 (1.2)
Fatigue	3.2 (1.3)	3.3 (1.1)
Emotional Function	4.4 (1.4)	4.6 (1.1)
Disease Mastery	4.1 (1.4)	4.5 (1.3)
Hospital Anxiety and Depression Scale		
Anxiety	7.5 (4.4)	7.0 (3.5)
Depression	7.0 (4.4)	6.8 (3.6)

*Indicates a change from baseline which meets the minimum clinically important difference.

Table 3: CRQ-SAS scores at baseline and at week 6, when stratified according to anxiety and depression scores on HADS (n=26). Scores are reported as mean (standard deviation).

	CRQ Domain	Baseline	Week 6
Anxiety Likely (HADS subscore ≥8) n=10	Dyspnoea	2.6 (1.0)	3.4 (1.3)*
	Fatigue	3.3 (1.8)	3.9 (1.2)*
	Emotional Function	3.5 (1.5)	4.5 (1.1)*
	Disease Mastery	3.2 (1.4)	4.2 (1.3)*
Anxiety Unlikely (HADS subscore <8) n=16	Dyspnoea	3.6 (1.1)	3.6 (1.2)
	Fatigue	3.2 (0.9)	3.0 (0.9)
	Emotional Function	4.9 (0.9)	4.6 (1.1)
	Disease Mastery	4.6 (1.2)	4.7 (1.3)
Depression Likely (HADS subscore ≥8) n=9	Dyspnoea	2.7 (1.0)	3.5 (1.3)*
	Fatigue	2.3 (0.6)	3.1 (0.9)*
	Emotional Function	3.2 (0.9)	4.1 (0.8)*
	Disease Mastery	2.8 (1.0)	4.0 (1.2)*
Depression Unlikely (HADS subscore <8) n=17	Dyspnoea	3.5 (1.2)	3.5 (1.1)
	Fatigue	3.7 (1.3)	3.5 (1.2)
	Emotional Function	5.0 (1.1)	4.8 (1.1)
	Disease Mastery	4.8 (1.1)	4.8 (1.3)

*Indicates a change from baseline which meets the minimum clinically important difference.

Table 4: Thematic analyses of participant interviews

Themes	**Quotations**
Hand-held fan	"I was amazed at how well that worked … I was pleasantly surprised" (P9).
Reassurance	"Just reinforcing that you know it's going to pass … and not to panic that's the main thing" (P2). "It's good to have it there and you don't feel alone" (P3). "… it's always nice to have something you know is a backup if you need it" (P4). "… I have to not panic. That's been the biggest message … it has given me something to hang on to" (P8).
Breathing exercises	"I've got myself into the habit of the breathing and the counting which has been a help" (P2).
Health professional support	GP – "The last time I saw him (my GP) he had 5 minutes … and that was it you know. I haven't got much of a rapport there." (P2).
	Specialist nurse – "… so it's not so much patient clinician you know, it's just somebody on the team with you" (P2).
	Physician – "Anyone could have done it with me … but because it came from the specialist I think I put more weight to it" (P8).

*Px = participant number

Figure legend

Figure 1: Components of the breathlessness intervention, delivered during a dedicated breathlessness information session with respiratory physician and respiratory nurse

a. *Explanation* of:
   - Underlying disease
   - Mechanics of breathing and mechanisms of breathlessness
   - Contribution of medical comorbidities, including anxiety/depression
b. *Reassurance* that:
   - Breathlessness is not intrinsically harmful
   - Even though distressing, episodes will almost always settle
c. *Education* regarding:
   - Non-pharmacological self-management techniques:
     - Posturing and bracing
     - Breathing techniques (controlled breathing, pursed lip breathing, optimisation of diaphragm use)
     - Relaxation and distraction techniques
     - Pacing
     - Hand-held fan, emphasising air movement across the face
   - Patient-specific prescription management, which may include:
     - Respiratory medications (eg. inhalers)
     - Oxygen
     - Opioids
     - Anxiolytics
   - Emergency contact details if symptoms remain distressing
d. *Provision* of:
   - Written individualised breathlessness plan (Supplementary Figure S1)
   - Two information leaflets
     i. General information regarding breathlessness
     ii. Non-pharmacological management of breathlessness, with illustrations
   - Hand-held fan

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