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## Interdisciplinary management of chronic breathlessness

Charles C Reilly <sup>a,b</sup>, Lisa Jane Brighton <sup>a</sup>, Matthew Maddocks <sup>a</sup>

a. King's College London, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, Bessemer road, London, SE5 9PJ, UK

b. Department of Physiotherapy, King's College Hospital, Denmark Hill, London, SE5 9RS, UK

Correspondence to:

Dr Matthew Maddocks, Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, London, SE5 9PJ, United Kingdom.

Tel: +44 (0)202 7848 5252. E-mail: [matthew.maddocks@kcl.ac.uk](mailto:matthew.maddocks@kcl.ac.uk)

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### ABSTRACT

**Purpose of review:** Breathlessness is a common yet complex symptom of advanced disease. Effective management will most likely draw upon the skills of multiple disciplines and professions. This review considers recent advances in the management of chronic breathlessness with regards to interdisciplinary working.

**Recent findings:** There are growing data on: (i) interventions for chronic breathlessness that incorporate psychosocial mechanisms of action, e.g. active mind-body treatments; and (ii) holistic breathlessness services that exemplify interprofessional working with professionals sharing skills and practice for user benefit. Patients value the personalised, empathetic and understanding tenor of care provided by breathlessness services, above the profession that delivers any intervention. Workforce training, decision support tools, and self-management interventions may provide methods to scale-up these services and improve reach, though testing around the clinical effects of these approaches is required.

**Summary:** Chronic breathlessness provides an ideal context within which to realise the benefits of interdisciplinary working. Holistic breathlessness services can commit to a comprehensive approach to initial assessment, as they can subsequently deliver a wide range of interventions suited to needs as they are identified.

**Keywords:** breathlessness, chronic, interdisciplinary, multi-professional, palliative care

## **INTRODUCTION**

Breathlessness is a common and distressing symptom of advanced disease (1). It increases as disease progresses and often becomes chronic (i.e. it persists despite optimal treatment of the underlying disease(2)). Chronic Breathlessness results in fear, sleep disturbance, social isolation, and disability(3, 4). The Breathing Thinking Functioning model (5), describes the complex, multi-factorial nature of breathlessness, with cognitive and behavioural reactions to the symptom that maintain and can worsen it. The model portrays how effective management for breathlessness will draw on multiple interventions, drawing on expertise across multiple disciplines and professions. Breathlessness therefore provides a good context in which to mobilise interdisciplinary working; a purposeful endeavour that transcends professional boundaries with staff working towards a common goal (6). Palliative care teams are familiar with interprofessional working, as it is a core competency of the specialism(7). As highlighted eloquently by Hui et al(8), interdisciplinary working allows each patient's needs to be addressed in a holistic and timely manner, enhances patient-clinician communication and provides shared responsibility for work load, decision making and leadership.

This review will consider recent advances in the assessment and management of chronic breathlessness with an emphasis on interdisciplinary working. To identify literature we searched Medline for articles published January 1, 2015 to March 20, 2019, using the search term 'breathlessness' combined with 'services', 'disciplin\*' 'profession\*', 'therapy' or 'management'. Searches were restricted to adults and articles published in English language.

## **NON-PHARMACOLOGICAL TREATMENTS**

Several recent papers build on the evidence regarding non-pharmacological treatments to relieve chronic breathlessness, often with a focus on psychosocial mechanisms of action.

During the review period Swan and colleagues contributed a review around the effect of airflow(9) and a 2x2 factorial RCT examining the hand-held fan and a cognitive strategy the 'Calming Hand'(10). The review examined the effect of airflow for chronic breathlessness relief using 'before and after' measures from studies where airflow was used either as an intervention (e.g. fan) or comparator (e.g. in an oxygen trial). Across three meta-analyses drawing on 16 studies, fan at rest, medical airflow via nasal cannula at rest, and medical airflow during a constant load exercise test all led to reductions in breathlessness intensity. Point estimates of effect (-11.2mm on a visual analogue scale for fan at rest and -12.0mm for medical airflow at rest; -2.9 points on a 0-10 modified Borg scale for medical airflow during exercise) exceeded clinically important differences. Changes could reflect regression towards the mean, or change unrelated to the treatment given. Moreover, the small number of studies led to imprecision and wide confidence intervals. Overall, the authors concluded that fan therapy at rest or on exertion should be considered as an effective treatment for non-hypoxic breathless patients (9). In their factorial RCT participants were randomly allocated to exercise advice alone, plus fan, plus calming hand, or plus fan and calming hand. The primary objective was to test the feasibility of a Phase III trial. Feasibility was clearly demonstrated: 40 of 53 people screened were randomized and completed with few missing data. Within the clinical outcome measures at day 28, recovery time from exertion-induced breathlessness showed the most improvement for the fan. In qualitative interviews, participants said they valued faster recovery, and perceived the fan as a useful "medical" device(10).

In a Cochrane review Gendron et al(11) studied active mind-body movement therapies (e.g. yoga, tai chi, and qigong) as an adjunct to, or in comparison with, pulmonary rehabilitation for COPD. Ten studies (n=762) were included in their meta-analysis. All but one was conducted in China and provided tai chi and/or qigong. When compared to pulmonary rehabilitation, overall findings showed no between-group differences with regard to breathlessness measures, either by the modified Medical Research Council Scale (mean difference, MD 0.00 units, 95% CI -0.37 to 0.37), Borg Scale (MD 0.44 units, 95% CI -0.88 to 0.00) or Chronic Respiratory Questionnaire (CRQ) Dyspnoea Scale (MD -0.21, 95% CI -2.81 to 2.38). Some disease-specific quality of life outcomes did however favour active mind-body movement therapies. These observed improvements perhaps related to how the interventions were perceived as being socially and culturally appropriate. Comparisons of movement therapies added to pulmonary rehabilitation suggest modest incremental benefit on quality of life, with no improvement in breathlessness.

In a critical review, Yohannes et al(12) examined the efficacy of pulmonary rehabilitation as well as behavioural therapies (e.g. cognitive behavioural therapy and counselling) for the concurrent treatment of breathlessness and anxiety in COPD. The authors propose a “Dyspnea-Anxiety-Dyspnea Cycle” that unpicks the inter-relationship between breathlessness and anxiety with possible physical, physiological, and behavioural factors. The model has some COPD-specific features, e.g. lung hyperinflation, though probably can be generalised to chronic breathlessness more broadly. In the empirical review, 5 of 10 trials of pulmonary rehabilitation with measures of breathlessness and anxiety, found both improved following intervention. There was some evidence that cognitive behavioural therapy reduced breathlessness by challenging patients’ illness perception and health beliefs. However, these studies were small, mostly uncontrolled, and of short duration. The authors recommended controlled trials with long-term follow-up to test the efficacy of cognitive therapies(12).

### **BREATHLESSNESS-TRIGGERED SERVICES**

With the potential for people living with chronic breathlessness to benefit from a range of interventions, ‘holistic’ breathlessness services have emerged as one model of care that integrates delivery of these approaches(13). Rather than focusing on diagnosis or prognostic markers, access to these services is triggered by presence of breathlessness. Holistic breathlessness services share a philosophy of supporting the person to live as best as possible with their chronic breathlessness. They are typically delivered over 4-6 weeks using outpatient clinics, home visits and telephone support.

Holistic breathlessness services focus on the assessment of the individual’s physical, psychological, social, and spiritual concerns, in order to tailor subsequent interventions. This process can be aided by one or more structured tools that screen for the multidimensional impacts of breathlessness and support needs. Examples include the Integrated Palliative Care Outcome Scale(14), Sheffield Profile for Assessment and Referral to Care questionnaire (15) or London Chest Activity of Daily Living Scale (LCADL)(16). Such tools can help direct intervention and referral, e.g. using reports of ‘loss of appetite’ to prompt dietetic input or reported difficulties with ‘walking up stairs’ to prompt physiotherapy referral. This direct link to intervention is crucial considering evidence that holistic assessment without sufficient subsequent action can leave patients feeling worse off(17). In the

context of holistic breathlessness services, such assessment ensures targeted management strategies delivered by the most appropriate team member(s).

A systematic review of holistic breathlessness services demonstrates the clinical effectiveness of this approach(18). Meta-analyses showed reductions in distress due to breathlessness using a numerical rating scale (n=324; MD -2.30, 95%CI -4.43 to -0.16,  $p=0.03$ ) and depression scores on the Hospital Anxiety and Depression Scale (HADS; n=408, MD -1.67, 95%CI -2.52 to -0.81,  $p<0.001$ ) favouring breathlessness services. Statistically non-significant benefits were also observed for the mastery domain of the Chronic Respiratory Questionnaire (n=259, MD 0.23, 95%CI -0.10 to 0.55,  $p=0.17$ ) and HADS anxiety scores (n=552, MD -1.59, 95%CI -3.22 to 0.05,  $p=0.06$ ). Subsequent analysis individual patient data from three trials suggests that these benefits can occur regardless of the underlying disease or lung function(19). However, no consistent benefits were seen on measures of physical function or quality of life, and evidence around cost-effectiveness is currently very limited.

Qualitative data from patients show increased confidence and knowledge around their managing their illness and breathlessness. This translated in to patients feeling less anxiety during acute on chronic breathlessness crisis and improved participation e.g. returning to a singing club. Engagement with these services was not without challenges: some described initially low expectations that the service or component interventions could help them, and for some this led to reluctance to engage. However, for many patients and their families, they perceived benefits of these services and often attributed this to the teams' abilities to address the variety of concerns they were experiencing around and beyond their breathlessness. This included talking through the nature of their illness and breathlessness, developing crisis plans, and teaching variety of breathlessness management techniques including pacing and positioning and using handheld fans. Interdisciplinary working was likely a key contributing factor to successful service delivery.

A recent stakeholder consultation found that ensuring breathlessness services are cross-cutting and draw on relevant expertise from multiple disciplines, specialities and providers is strongly recommended by those with personal and professional experience of breathlessness care(20). Indeed, this approach has been core to the recent development of new breathlessness services internationally(21, 22). Figure 1 depicts the representation of disciplines described within 18 different holistic breathlessness services included in the review, with larger circles depicting a higher number of services reporting involving this discipline(18). Although the exact configuration of teams varies from service to service and reporting is not always comprehensive, this illustrates how services typically encompass input from two or more of medicine, nursing, occupational therapy, physiotherapy and psycho-social disciplines. In some instances, these disciplines are represented through direct membership of breathlessness service team, while others have close referral links to others with that expertise. Where fewer disciplines are directly represented (e.g. some of the nursing-led or physiotherapy-led services), this is usually in the context of close integration with specialist palliative care, where interdisciplinary approaches are more typically standard practice(23).

The result of this interdisciplinary approach is a toolkit of diverse approaches to management of chronic breathlessness, plus the skills required to deliver them. Services are therefore able to commit to a fully holistic approach to initial assessment, as they can subsequently deliver a wide range of interventions suited to the needs of the individual as they are identified. Figure 2

summarises the component interventions delivered within the same 18 holistic breathlessness services. Breathing techniques, psychological support, relaxation techniques and education are most common, but a variety of other interventions (e.g. spiritual support, sleep hygiene, transcutaneous electrical nerve stimulation) are also used. The accuracy of this data is limited by the level of detail in which service delivery is reported. However if anything this likely underestimates the variety of approaches holistic breathlessness services draw upon. As a result, perhaps, this multi-professional approach appears more effective than single-profession approaches to breathlessness care(24).

Alongside the diverse professional input into holistic breathlessness services, there is also evidence of an even wider network of interdisciplinary working: incorporating and building on expertise from family and patients themselves. Qualitative data from patients supported by breathlessness services comment on the benefits of involving their family carers(25-28), and learning new techniques to supplement their own(29-31). This approach is line with another recent recommendations from public and professional stakeholders, who recognise the importance of sharing breathlessness management skills with informal carers as non-professional partners chronic breathlessness management(20). Moreover, it reflects an increasing acknowledgement of the role of patients' expertise based on their lived experience breathlessness and self-management(32). Given that informal carers take on much of the care responsibilities for those living with chronic breathlessness(33), this should be considered a key part of interdisciplinary breathlessness management for this group.

## **WORKFORCE AND TRAINING**

In a survey study, Schunk et al(34) reported that both patients and caregivers felt stressed and frustrated due to a lack of awareness regarding the symptom burden of chronic breathlessness, which they believed to be a significant barrier to receiving the care and support that required. Interestingly, unmet clinical training needs was echoed by health care professionals. It was the common view point of patients, caregivers and caregivers that specialist breathlessness services would address important gaps in professional practice. However, the success of such services are dependent on increasing workforce knowledge about effective interventions and availability of skills-based training in breathlessness management(34). Recent reviews of palliative care training focus on developing communication skills to enhance clinicians' ability to show empathy and discuss emotions(35), and developing symptom assessment and management skills in generalist palliative care providers(36). Programmes for both domains are often built around good use of patient-reported outcomes to direct appropriate intervention. The use of simulated consultations and are valued by professionals(35, 36). Evidence-based Decision Support Tools (DSTs) focused on information needs, family anxiety, depression, and breathlessness have also been with professional consultation(37) and warrant testing.

## **FUTURE PERSPECTIVE**

The burden of chronic breathlessness is already significant and set-to increase with population ageing and multimorbidity. We need to think creatively around how patients with chronic breathlessness access interdisciplinary breathlessness care. The evidence demonstrates that both hospital and community based services are effective, yet replication of such services require significant resource allocation.

As described above, patients positively describe the attributes of staff working within these services and the interventions received rather than the discipline that delivered it. This suggests that patients value the individual's competence and expertise rather than their professional background. Drawing reference from the successful development of first contact practitioners to manage the complex needs of patients with both acute and chronic musculoskeletal conditions in primary and secondary care(38, 39), the development of advanced breathlessness practitioners could be an opportunity. The skill mix and clinical experience required integrate physical, psychological and pharmacological interventions within these roles could be met by one of many professional groups, for example a respiratory nurse or physiotherapist could develop their scope practice to deliver psychological interventions or prescribe pharmacological agents. Alternatively, there is increasing evidence supporting the use of the internet for self-management of long-term conditions(40), and emerging literature regarding internet-based interventions for breathlessness. For example, Nguyen et al. reported that an internet-based breathlessness self-management improved physical activity levels. This intervention was valued by patients with COPD(41). Most recently Burton et al(42), demonstrated that a self-guided online breathing retraining intervention improved health related quality of life in patients with chronic asthma. These data support the principle of delivering interdisciplinary self-management interventions for chronic breathlessness via the internet. Further studies are eagerly awaited.

## **CONCLUSION**

There is growing data on the effects of component interventions for chronic breathlessness. These can be combined in holistic breathlessness services, which provide a structure where interprofessional working can be realised, with multiple staff sharing skills, expertise and resource, working towards a common outcome. Recent meta-analysis demonstrates the clinical effectiveness of this approach. Qualitative evidence shows patients value the holistic and personalised tenor of care they provide. However, replication of such services will need significant resource (re)allocation. The continued growth/success of such services are dependent on development of clinical expertise in breathlessness management or finding models that provide a wider reach. Workforce training interventions, decision support tools, and self-management interventions may be appropriate tools with which to achieve growth, though through testing is required.

## **KEY POINTS**

- The complex and multifactorial nature of chronic breathlessness means the optimal management approach will draw on the skills and expertise of multiple disciplines and professional groups.
- Growing evidence highlights the role of cognitive behavioural interventions for chronic breathlessness, uncovering a role for staff with psychological expertise
- Holistic breathlessness services provide a structure within which interdisciplinary working and delivery of evidence-based interventions can be achieved with good evidence of effect on clinical outcome.
- Workforce training and/or approaches that centralise staff resource and promote self-management, e.g. internet-based models, may be useful to scale up holistic breathlessness services and improve their reach.

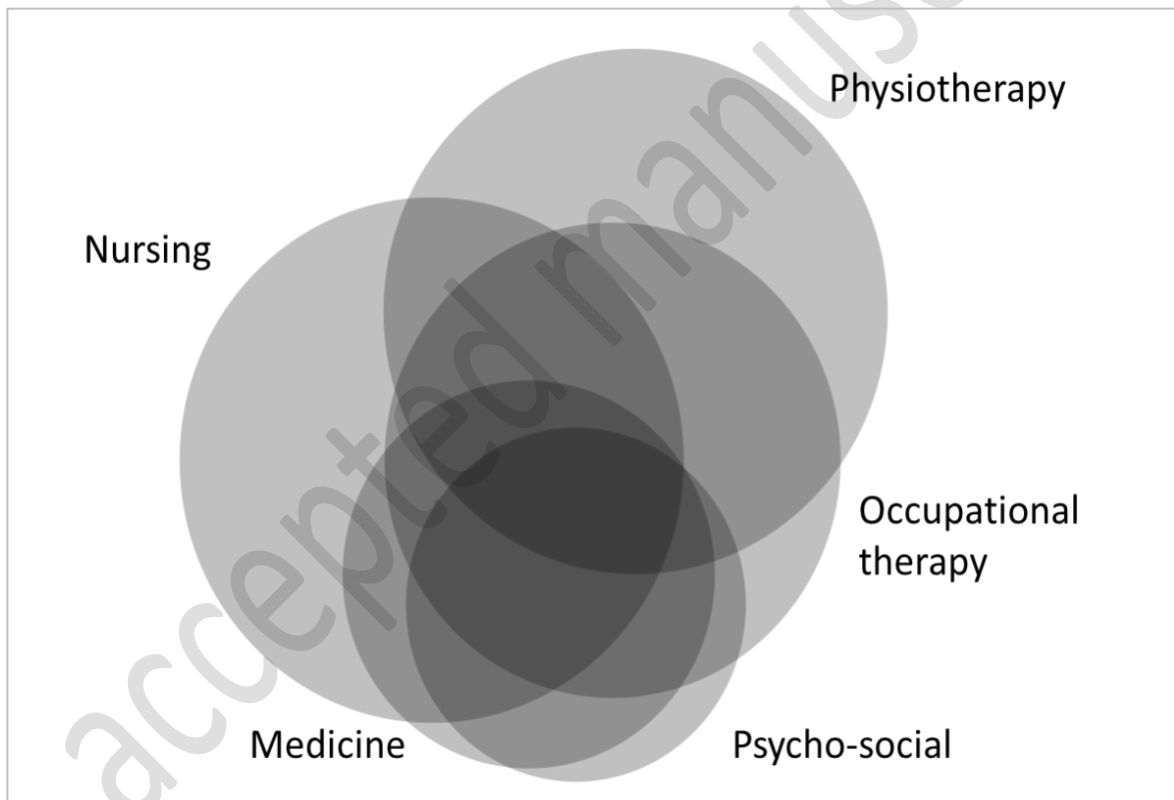
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## CONFLICTS OF INTEREST

None to declare.

## FIGURES



*Figure 1 - Interdisciplinary working across published holistic breathlessness services*



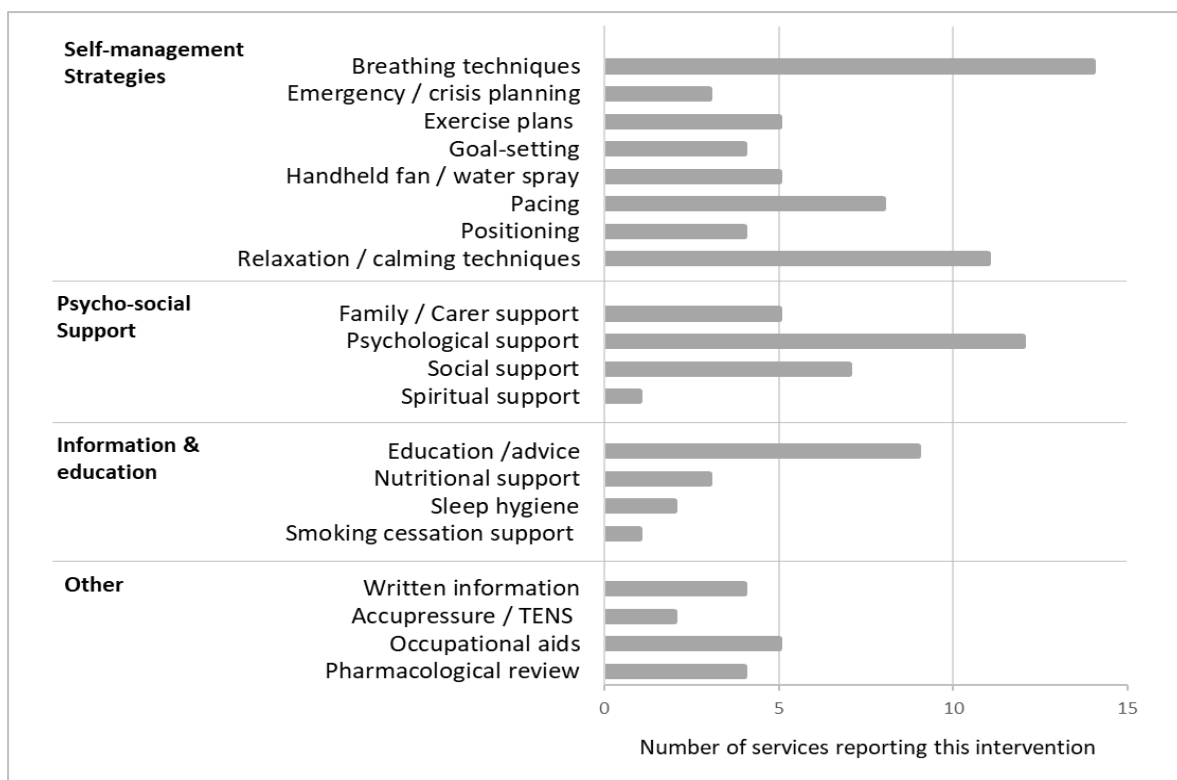


Figure 2 - Interventions reported across published holistic breathlessness services

## REFERENCES & RECOMMENDED READING

Papers of particular interest, published within the period of review (the last 2 years) have been highlighted as: \* of special interest, \*\* of outstanding interest.

5\* A detailed clinical model of breathlessness that helps understand different patient presentations and guides appropriate treatment.

8\*\* A comprehensive expert review related to integrated oncology and palliative care, which details the advantages, workings and evidence underpinning interdisciplinary working.

9\* A novel systematic review that explores the clinical effects of airflow in the context of clinical trials for breathlessness.

16\* A secondary analysis of a major breathlessness service trial, which portrays the impact of breathlessness on physical function and independence.

18\*\* A contemporary systematic review of holistic breathlessness services, combining quantitative and qualitative findings from all studies to date.

20\* Consensus-based recommendations for practice, policy and research, based on input from multiple stakeholders including patients, carers, professionals and policy makers.

38\*\* An excellent trial of a breathing self-management intervention for individuals with asthma, provides a strong methodological basis on which to model future trials for other conditions.

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