

# Breathlessness services as a new model of support for patients with respiratory disease

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## Abstract

The complexity of breathlessness in advanced disease requires a diversity of measures ideally tailored to the individual patient needs. ‘Breathlessness services’ have been systematically developed and tested to provide specific interventions and support for patients and their carers. The aim of this article is (1) to identify and describe components of breathlessness services and (2) to describe the clinical model of one specific service in more detail. This article is based on a systematic review evaluating randomized controlled trials (RCTs) and quasi-RCTs which examine the effectiveness of services aiming to improve breathlessness of patients with advanced disease. The Munich Breathlessness Service (MBS) is described in detail as an example of a recently set-up specialist service. Five service models were identified which were tested in six RCTs. Services varied regarding structure and composition with face-to-face meetings, some with additional telephone contacts. Service duration was median 6 weeks (range 2–12 weeks). Involved professions were nurses, various therapists and, in two models, also physicians. The breathing–thinking–functioning model was targeted by various service components. The MBS is run by a multi-professional team mainly with physicians and physiotherapists. Patients are seen weekly over 5–6 weeks with an individualized management plan. Breathlessness services are a new model for patients with advanced disease integrating symptom management and early access to palliative care.

## Keywords

Breathlessness service, dyspnoea, breathlessness, palliative care

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## Introduction

Breathlessness is one of the most distressing symptoms in advanced disease affecting patients with primary and secondary cancer, lung diseases (e.g. chronic obstructive pulmonary disease (COPD), pulmonary hypertension, cystic fibrosis, interstitial lung disease (ILD)), congestive heart failure (CHF) or motor neuron disease (MND)).<sup>1–3</sup> Breathlessness is a unique and subjective experience to the individual reflecting the patients’ perspective based on the daily experience, whereas the medical term ‘dyspnoea’ is focusing more on the clinical sign of an underlying condition.<sup>2,4</sup> Recently, it has been proposed to define breathlessness as a chronic syndrome that persists

despite optimal treatment of the underlying pathophysiology and that results in disability.<sup>5</sup>

As breathlessness affects individuals in different ways and in different dimensions, Booth and Spathis have proposed the *breathing–thinking–functioning*

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*model* as a clinical model to conceptualize the three predominant cognitive and behavioural reactions to breathlessness that, by causing vicious cycles, worsen and maintain the symptom.<sup>6,7</sup>

- Breathing domain: Breathlessness causes dysfunctional breathing patterns with an increased respiratory rate, the need for the use of accessory muscles and dynamic hyperinflation, leading to inefficient breathing and increased work of breathing.
- Thinking domain: Misconceptions and paying too much attention to the sensation of breathlessness such as memories of past or negative experiences lead to anxiety, distress, feelings of panic and thoughts about dying.
- Functioning domain: People suffering from breathlessness often reduce their physical activity, leading to self-isolation and the need for more help from others and also leading to deconditioning of limb, chest wall and accessory muscles.

Management of breathlessness is challenging and comprises various non-pharmacological and pharmacological measures. Optimal management of the underlying disease is always the first step. However, there is an inconsistent relationship between pathology and breathlessness perception, explaining why optimizing disease management alone does not guarantee good symptom control.<sup>6</sup>

There are a wide range of non-pharmacological interventions with various strengths of evidence. Pulmonary rehabilitation is supported by strong evidence and reduces breathlessness significantly.<sup>8</sup> Cognitive behavioural therapy also has an effect on breathlessness, anxiety and depression.<sup>9</sup> Handheld fans have been tested as well as rollators or various forms of breathing techniques such as ‘pursed lip breathing’ and ‘abdominal breathing.’<sup>10</sup> For pharmacological management, opioids are the drugs of choice for patients with severe breathlessness and breathlessness at rest with good evidence.<sup>11,12</sup> Although benzodiazepines are frequently used, the supporting evidence is very limited.<sup>13</sup>

Overall, one single intervention used alone is unlikely to palliate breathlessness effectively.<sup>14</sup> This complex symptom is more likely to require a complex intervention with a diversity of skills, personal attributes and strengths within team members.<sup>15</sup> A number of measures are necessary that are ideally tailored to the individual needs of the patient and provided

in one overarching concept. Over recent years, the so-called breathlessness services have been systematically developed and tested to provide specific interventions and support for patients, breathless from any advanced disease and their carers.<sup>16</sup>

The aim of this article is (1) to identify and describe components of services identified in the studies testing the effectiveness of breathlessness services which aim to improve the symptom in patients with advanced disease and (2) to describe the clinical model of one specific service in more detail.

## Methods

1. The description of service components is part of a wider systematic review currently being conducted focussing on non-pharmacological interventions in breathlessness. One part of the review is evaluating randomized controlled trials (RCTs) and quasi-RCTs which examine the effectiveness of services (as complex interventions) which aim to improve breathlessness of patients with advanced disease. We included studies with adults suffering from advanced disease of any aetiology associated with a high prevalence of breathlessness. These were
  - Advanced local or metastatic cancer
  - Severe COPD with a forced expiratory volume in one second predicted of <50%
  - Pulmonary hypertension with World Health Organization class  $\geq$  level III
  - Congestive heart failure (CHF) with the New York Heart Association stage III/IV
  - ILD
  - MND/Amyotrophic lateral sclerosis (ALS)

The outcome of interest was any measure of breathlessness assessed by specific validated breathlessness questionnaires or by other self-reported methods.

We searched the main electronic databases from the Cochrane Library (Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials), MEDLINE, EMBASE, PsycINFO and CINAHL using search terms relating to dyspnoea and breathlessness, underlying diseases and the Cochrane Highly Sensitive Search Strategy for identifying randomized trials. All titles and abstracts retrieved by the search were independently screened by two reviewers to identify all trials that may be eligible for the review.

2. The Munich Breathlessness Service (MBS) is described in detail as an example of a recently set-up specialist service targeting breathlessness in advanced disease. It was set up in 2014 building on the results of previous studies and the London Breathlessness Support Service (BSS).<sup>17</sup>

## Results

We identified five service models tested in six RCTs published in 10 papers.<sup>17–26</sup>

### Structure and composition of services

All services were delivered face-to-face at home or in the clinic in combination with intermittent telephone calls. Bredin and Higginson only used face-to-face meetings,<sup>17,19</sup> the other services also integrated one to six telephone contacts. The number of face-to-face meetings varied from one<sup>26</sup> to eight.<sup>19</sup> The contacts with the patients took place either in the clinic only<sup>19,24</sup> or in the patient's home<sup>20,22</sup> or both in the clinic and the patient's home. All but Yorke's intervention were delivered individually. Only the service described in Yorke's study integrated one group meeting as part of the intervention.<sup>26</sup>

The duration of the intervention delivered by the breathlessness services ranged from 2<sup>20</sup> to 12 weeks<sup>26</sup> with a median of 6 weeks. The Cambridge Breathlessness Intervention Service (CBIS; evaluated by Farquhar et al. in a pragmatic waiting list trial) provided the same service to patients with advanced malignant and non-malignant disease but varied the duration of the waiting time for the intervention in the study. People with advanced cancer were seen after 2 weeks and those with non-malignant disease waited 4 weeks.<sup>20–22</sup>

Services were provided by various professions either alone or most often in varying combinations. Bredin's clinic was run by specialist nurses alone<sup>19</sup>; in Johnson's study, the type of professional (e.g. nurse, physiotherapist, occupational therapist) providing the standardized intervention was not stipulated<sup>25</sup>; in Yorke's study, it was either nurses or physiotherapists or complementary therapists trained in the intervention.<sup>26</sup> In Higginson's BSS, consultants in palliative medicine jointly with consultants in respiratory medicine were the main service providers in close collaboration with physiotherapists or occupational therapists, and in CBIS, the service was mainly

provided by allied health professionals backed up by consultants in palliative medicine.<sup>17,20,22</sup> In CBIS, the lead for the intervention varied depending on the underlying condition with the palliative medicine consultant being the lead in cancer patients and the clinical specialist occupational therapist or the clinical specialist physiotherapist taking lead in non-cancer patients.<sup>21</sup>

Recipients of the services were patients with advanced malignant and non-malignant disease all suffering from breathlessness. Bredin's and Yorke's services were targeted at patients with primary lung cancer,<sup>19,26</sup> Johnson's intervention to patients with intrathoracic malignancy,<sup>25</sup> CBIS sees patients with any diagnosis – for the purpose of evaluating the service there were two protocols as previously discussed.<sup>20,22</sup> Higginson et al. evaluated the effectiveness of BSS based on the CBIS protocol offering the service to all patients with advanced disease irrespective of the underlying condition.<sup>17</sup> Details are shown in Table 1.

### Targeted domains in the breathlessness services

Many components of the interventions used in the services can be related to the *breathing–thinking–functioning model* (see Table 2).

The *breathing dimension* was targeted by breathing control exercises in all services. Patients were introduced to a handheld fan in the CBIS and BSS.<sup>17,20,22</sup> Airways clearance techniques were taught in Farquhar's and Higginson's studies,<sup>17,20,22</sup> and cough minimization techniques in Higginson's and Yorke's services.<sup>17,26</sup>

The *thinking dimension* was targeted by distraction techniques,<sup>19</sup> psychological support<sup>20,22</sup> and anxiety management.<sup>17,20,22,24–26</sup>

The *functioning dimension* was targeted by an individualized exercise plan,<sup>20,22</sup> a home programme of exercise delivered by a personalized sheet with a DVD<sup>17</sup> or advice on activity management and energy conservation strategies.

Initial assessment of the individual situation of the patient was part of the services evaluated by Bredin et al., Farquhar et al. and Higginson et al.<sup>17,19,20,22</sup> but not in the Breathing training described by Johnson and the Respiratory Distress Symptom Intervention developed by Yorke.<sup>24–26</sup>

Services also provided interventions that affect more than one dimension of the breathing–thinking–functioning model, for example, relaxation

**Table 1.** Composition of breathlessness services.

Study ID	Name of service	Delivery (frequency or amount)	Duration	Provider	Condition	Study design	Population: Intervention group/total	Effect
Bredin, 1999 (Bredin, 1998)	Nursing intervention for breathlessness	Face-to-face: clinic (once a week)	8 weeks	Specialist nurses	Small cell lung cancer, non-small cell lung cancer, or mesothelioma who had completed treatment and reported breathlessness Age: mean (range): intervention group: 68 (41–82) years; control group: 67 (41–83) years sex: intervention group: 80% men, control group 67% men	Multi-centre RCT	51/103	Primary outcome: distress caused by breathlessness (visual analogue scale): change from baseline, median (range): intervention group: 0 (–9 to 11); control group 10 (–7 to 11); $p = 0.09$ Primary outcome: distress due to breathlessness: NRS scale: change from baseline difference between groups: mean (95% CI): –1.29 (–2.57; –0.005); $p = 0.049$
Farquhar, 2014 (Farquhar, 2011)	CBIS	Telephone (2) face-to-face (1)	2 weeks	Clinical specialist occupational therapist; clinical specialist physiotherapist; medical consultant	Advanced cancer; appropriately treated cause of breathlessness; troubled by breathlessness in spite of optimization of underlying illness; might benefit from a self-management programme; age: mean (SD): intervention group: 70 (9.4) years; control group: 67 (13.3) years Sex: intervention group: 21 females; control group: 20 females	Single-centre phase III fast-track single-blind mixed-method RCT	35/67	
Farquhar, 2016	CBIS	Telephone (3) face-to-face (2–3)	4 weeks	Clinical specialist occupational therapist; clinical specialist physiotherapist; medical consultant	Non-malignant conditions; appropriately treated cause of breathlessness; troubled by breathlessness despite of optimization of underlying illness; might benefit from a self-management programme; age: mean (SD): intervention group: 72.3 (10.6) years; control group: 72.2 (9.4) years Sex: intervention group: 64% male; control group: 58% male	Single-centre phase III fast-track single-blind mixed method RCT	44/87	Qualitative analyses showed the positive impact of BIS on patients with non-malignant conditions and their carers; quantitative analyses showed a non-significant greater reduction in the primary outcome ('distress due to breathlessness'), when compared to standard care, of –0.24 (95% CI: –1.30, 0.82).

(continued)

Table 1. (continued)

Study ID	Name of service	Delivery (frequency or amount)	Duration	Provider	Condition	Study design	Population: Intervention group/total	Effect
Higginson, 2014 (Bausewein, 2012)	BSS	Face-to-face: clinic (2); face-to-face: home (1); letter (2)	6 weeks	Consultant palliative medicine; consultant respiratory medicine; clinical nurse specialist for lung cancer; physiotherapy/occupational therapy; social worker	Advanced disease such as cancer, COPD, chronic heart failure, interstitial lung disease and motor neuron disease Refractory breathlessness on exertion or rest (MRC dyspnoea scale score $\geq 2$ ), despite optimum treatment of the underlying disease Willing to engage with short-term home physiotherapy and occupational therapy; age: mean (SD): total: 67 (10) Sex: total: 61 males FEV <sub>1</sub> %: mean (SD): total: 46.2 (23.3)	Parallel group, pragmatic, single-blind fast track RCT	53/105	Primary outcome: CRQ mastery: difference between intervention and control ( $t = 6$ weeks): mean (95% CI): 0.58 (0.01; 1.15) $p = 0.048$
Johnson, 2015 (Johnson, 2014)	Breathing training	Telephone (1); face-to-face: clinic (3)	4 weeks	Either nurse or physiotherapist or occupational therapist or any other professional	Intrathoracic malignancy (primary or secondary tumours); refractory breathlessness with a self-reported intensity of $\geq 3/10$ on an NRS; clinician estimated prognosis of at least 3 months; participants with breathlessness intensity of $< 3/10$ ; refractory breathlessness defined as persistent breathlessness despite treatment of reversible causes; age: mean (SD): total: 69 (9) years Sex: total: 60 females	Multi-centre non-blinded parallel arm RCT	52/104/156 (three/ single session, total sample; 1:2 ratio)	Primary outcome: worst breathlessness over the past 24 hours: NRS scale: mean (SD): intervention group: reduction from 6.81 (1.89) to 5.84 (2.39). No between-arm difference: $p = 0.83$
Yorke, 2015	RDSI	Face-to-face: home or clinic (2); telephone (1); face-to-face group meeting: clinic (1)	12 weeks	Either specialist nurses or physiotherapists or complementary therapists specially trained in intervention	Primary lung cancer; expected prognosis of at least 3 months; WHO performance status 0–2; 'Bothered' from at least two of the cluster symptoms: breathlessness or cough or fatigue, in any combination; patients were screened for symptom eligibility by asking (i) Do you have breathlessness/cough/fatigue, and if 'yes', (ii) Are you bothered by breathlessness/cough/fatigue?; age: mean (SD): total: 67.7 (9.6) years Sex: total: 53% female	Non-blinded randomized feasibility trial	53/107	Primary outcome: dyspnoea-12 Group difference ( $t = 12$ weeks): mean (SD): 5.19 (2.33); $p = 0.026$

BIS: Breathlessness Intervention Service; RCT: randomized controlled trial; BSS: Breathlessness Support Service; COPD: chronic obstructive pulmonary disease; CI: confidence interval; RDSI: Respiratory Distress Symptom Intervention; WHO: World Health Organization; FEV<sub>1</sub>: forced expiratory volume in one second; SD: standard deviation; NRS: Numerical Rating Scale; CRQ: Chronic Respiratory Disease Questionnaire; MRC: Medical Research Council.

**Table 2.** Mechanisms of effect of service components.

Study-ID	Breathing	Thinking	Functioning	More than one underlying mechanism of effect	Education	Counselling and support	Other
Bredin, 1999 (Bredin, 1998)	Breathing control techniques	Distraction exercises	–	Relaxation techniques; progressive muscle relaxation	Exploration of the meaning of breathlessness, their disease and feelings about the future	Advice and support for patients and their families on ways of managing breathlessness	Detailed assessment of breathlessness and factors that ameliorate or exacerbate it; goal setting to complement breathing and relaxation techniques, to help in the management of functional and social activities, and to support the development and adoption of coping strategies; early recognition of problems warranting pharmacological or medical intervention
Farquhar, 2014 (Farquhar, 2011)	Handheld fan; breathing control; airway clearance techniques	Anxiety management; psychological support; brief cognitive therapy	Individualized exercise plan; activity pacing and exercise; positioning to reduce work of breathing (rest, recovery and activity)	Relaxation and visualization; mindfulness CD; formal relaxation therapy	Education to all participants (patients, carer, healthcare generalists); information fact sheets; explanation and reassurance; advice regarding nutrition and hydration; lifestyle adjustment; sleep hygiene	Emergency plan; support to family and patient to utilize education and self-support programmes	Medical review always; concurrent pharmacological intervention; hypnosis; wellbeing intervention; referrals to different specialists
Farquhar, 2016 (Farquhar, 2011)	Handheld fan; breathing control; airway clearance techniques	Anxiety management; psychological support; brief cognitive therapy	Individualized exercise plan; activity pacing and exercise; positioning to reduce work of breathing (rest, recovery and activity)	Relaxation and visualization; mindfulness CD; formal relaxation therapy	Education to all participants (patients, carer, health care generalists); information fact sheets; explanation and reassurance; advice regarding nutrition and hydration; lifestyle adjustment; sleep hygiene	Emergency plan; Support to family and patient to utilize education and self-support programmes	Medical review if needed; hypnosis; wellbeing intervention; referrals to different specialists

(continued)

Table 2. (continued)

Study ID	Breathing	Thinking	Functioning	More than one underlying mechanism of effect	Education	Counselling and support	Other
Higginson, 2014 (Bausewein, 2012)	Breathing control techniques; cough minimization techniques; sputum clearance techniques; Handheld fan; water spray	Anxiety-panic cycle control techniques	Home programme of exercise (DVD, personalized sheet); assessment for aids and minor adaptations and referral for provision of equipment (e.g. walking aid, rollator, wheel chair); assessment of ADL (mobility/transfers, self-care and domestic ADL); positioning	–	Education on planning; pacing, and energy conservation techniques to patients and carers; breathlessness pack to take away, with information leaflets on managing breathlessness; 'Poem' (a mantra, laminated, to put up in the house and to read and follow when in acute breathlessness, developed by Jenny Taylor at St. Christopher's Hospice); chart of positions	Management of exacerbations in COPD; pacing and fatigue management; development of crises plan; burden on patient & family; symptom burden (other than breathlessness), with recommendations to patients and GP of any appropriate treatments; psychosocial and spiritual issues	Ambulatory oxygen assessments; pulmonary rehabilitation; change of medications recommended if required; explore the symptom of breathlessness and its triggers; establish underlying cause of breathlessness; optimize disease-orientated management (check medications used correctly, appropriate treatments); review of previous investigations; experience of breathlessness; referral to pulmonary rehabilitation, community services, medical care services; assess the need for social support and liaison with the BSS social worker, as appropriate; liaison with the BSS team regarding interventions and feedback; carer assessment including understanding of disease and symptoms and information needs and coping strategies
Johnson, 2015 (Johnson, 2014)	Breathing control	Anxiety management	–	Relaxation	Written and DVD/video reinforcement material; pacing/prioritizing		–
Yorke, 2015	Controlled breathing techniques; cough easing technique	Anxiety management techniques	Activity management; energy conservation strategies	Acupressure	Information pack; sleep hygiene	Carer support; symptom experience and communication strategies	

COPD: chronic obstructive pulmonary disease; ADL: activities of daily living; GP: general practitioner; BSS: Breathlessness Support Service.

techniques<sup>20,22,24,25</sup> or acupuncture,<sup>26</sup> and recognized that although one ‘vicious circle’ may be dominant, all are likely to operate in one individual.

All services had additional educational and counselling elements. Educational elements included explanation and reassurance, advice on nutrition and hydration<sup>20,22</sup> or sleep hygiene.<sup>20,21,26</sup> Written information was provided in the form of breathlessness packs or information fact sheets.<sup>17,20,22,24,26</sup> CBIS also provided online educational films and relaxation tracks ([www.cuh.org.uk/breathlessness-intervention-service-bis/resources](http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources)).

Counselling included general advice to patients and families on breathlessness management, development of a crisis plan for management of exacerbations, other symptom burden, psychosocial and spiritual issues and carer support.

CBIS and BSS also included medical assessment with review of the underlying disease and change of medication, if necessary.<sup>17,20</sup> These services also referred patients to other services or medical specialties if further help or support was needed.

### *Munich Breathlessness Service*

The MBS started to operate in 2014 in the Munich University Hospital alongside a single-blinded fast-track RCT evaluating its effectiveness. The MBS aims to optimize management of breathlessness in patients with advanced malignant and non-malignant disease. The development of the breathlessness service was based on experiences of the London BSS<sup>17</sup> and a qualitative study of patients’, carers’ and clinicians’ experiences and needs (unpublished data).

Patients are included if they are affected by breathlessness on exertion or at rest due to any advanced life-limiting and progressive disease. Suitable patients are troubled by breathlessness despite optimally medical treatment of their underlying condition and must be able to engage in a multi-faceted intervention programme including physiotherapy and self-management (in a cognitive and functional manner). Carers are invited to join at all visits; active participation is encouraged.

The service is provided by a multi-professional team, comprising palliative care consultants, respiratory physicians, physiotherapists and an administrator.

If the patient has been referred by his/her practice-based respiratory physician, the last contact with this

clinician should have been within a few months of inclusion in the study and their disease should be stable. The referring respiratory physician will provide a referral letter and recent lung function tests and in this case the patient will not need to be seen by the respiratory physician of the MBS. The team also has access to psychologists, social workers and nurses if necessary.

The service is based within an outpatient clinic with patients attending twice within a 6-week period. In between these visits, patients have four weekly sessions with a community-based physiotherapist.

The service administrator arranges clinic visits making it as easy as possible for patients. Letters from treating physician(s) are reviewed before the visit. Patients provide a list of current medication, fill in a symptom-oriented assessment of palliative care needs and have a lung function test with a portable diagnostic spirometer shortly before the visit.

During their first visit, patients will receive detailed assessment of their breathlessness and the burden caused by breathlessness in the context of the underlying disease, relevant symptoms beyond breathlessness, psychosocial issues and carer burden. Palliative care specialists will optimize integrated management jointly with practice or hospital-based respiratory specialists comprising (i) non-pharmacological and pharmacological measures, (ii) help with day-to-day coping with breathlessness and acute crisis management and (iii) support for carers. An individual management plan is developed with the patient based on the ‘breathing–thinking–functioning model’. Written material, selected according to the individual’s needs, is given out to patients during the first visit. A written management plan including an information booklet, a handheld fan, a relaxation CD and a mantra printed on variable sized laminated paper is also provided. A range of additional service components are added if needed: at the first visit at the clinic, patients can be seen by a member of the respiratory medicine team in addition to palliative medicine, depending on the management of the underlying disease. Patients are offered the opportunity to see other professionals (psychologists, social workers) if needed in addition to physiotherapy. Written reports will be sent to patients and general practitioners. Physiotherapists and referrers are copied in.

The physiotherapist will focus on positioning, breathing techniques, exercise and pacing and fatigue management. Physiotherapists working with MBS patients have received a specialized training in



treating patients with breathlessness and those with lung disease. After the initial visit in the clinic, they are informed about the patient's goals by the MBS consultant. Physiotherapy sessions last for 60 minutes. Individual treatment goals are documented in an assessment sheet which is sent to the MBS consultant before the second clinic visit of the patient.

At the second clinic visit, patients and the palliative care consultant jointly review the management plan. This includes the use of the handheld fan and the physiotherapy sessions, reassessment of needs and information about advance care planning. Further steps may include additional physiotherapy, prescription of drugs and equipment or continued links to the regular palliative care outpatient clinic.

In summary, treatment at the MBS follows a structured approach and is short term. Within its standard elements, it is tailored to each individual patient, allowing for variation of the therapeutic approach, treatment elements and recommendations. Within the course of the treatment period, clinician contact is increased (by telephone) or other professionals join the team, if needed. Patients receive advance information about the aims of the treatment, care coordination during its course and written reviews.

For an overview of the intervention, please see the intervention plan as delineated in Table 3.

Since 2014, 120 patients have been treated in the MBS. As the accompanying study includes a fast-track design, all patients have access to the service (either immediately or after an 8-week waiting period). About two-thirds of the patients suffer from COPD, 10% have pulmonary hypertension, 7.5% have ILD and 6% have malignant disease or CHF, respectively. Referrals come via healthcare providers (15%), media (75%, via newspaper articles, adverts, leaflets) and social contacts (10%; e.g. self-help groups, family, friends).

Patients' feedback has identified the following as the most valuable aspects of the MBS approach to care:

- Communication with consultant 'heartening and reassuring'
- Honest talk, no euphemisms
- Plenty of time for 'finding out things you never come across otherwise'
- Taking away the fear (about living with the disease)
- Offering help with what matters most (emergency planning; palliative care services as new source of support)

- Practical exercises from physiotherapy, addressing individual restrictions such as climbing stairs
- Positive experience of self-efficiency and that daily training makes a difference
- Carer support: 'it's mainly psychological support to cope with the disease' – helped greatly

There are also several challenges in the service provision. Patients' trajectories are highly susceptible to adverse health events during the course of the treatment with just about half completing treatment within 6 weeks and about one-third needing more than 6 weeks. About 12% dropped out of the intervention. Also, patients find it difficult to manage weekly visits for several continuous weeks either because of health issues or because they are still very active. When patients rely on public transport, some find the travelling to/from the clinic burdensome.

Physiotherapy is delivered in the community by registered physiotherapists who specialize in the treatment of patients with lung disease and breathlessness, focusing on self-management strategies. Some patients have their own treating physiotherapist and do not want to change providers for the short-term intervention. This is challenging as they might not get the same specialist advice and support.

As the concept of a specialist breathlessness service is new in Germany, many physicians are quite sceptical about the concept fearing to lose 'their' patients or that they are providing this sort of care already. Some discourage the patients from accepting care, implying that the patients don't need palliative care (yet) or that they are taking the place from someone in more need.

## Discussion

Breathlessness services for patients with advanced disease are a rather new concept emerging over the last 10–15 years. Various service models have been developed, mainly in the United Kingdom, and evaluated in several studies. Overall, studies demonstrate positive results, indicating that these services have a positive impact on patients with breathlessness.

Breathlessness services combine two important aspects for patients with advanced disease. The services aim to improve the management of breathlessness and also provide early access to palliative care. Management of these patients is normally guided by treatment of the underlying disease with the

**Table 3.** The Munich Breathlessness Service.

Time	Type of contact	Professional	Action
Week 1	Clinic visit	Consultant palliative medicine; consultant respiratory medicine	Palliative medicine: –assessment of intensity and quality of shortness of breath, including emotional stress of patient and carer –review of symptom burden (IPOS) –information about non-pharmacological measures for symptom control –development of dyspnoea plan for emergency situations –if needed: referral to social worker or psychologist, increased clinician contact (by telephone) Respiratory medicine (either external or internal) –assessment of cause of shortness of breath –review of treatment plan –review of results from functional tests and physical examinations
	Letter	Consultant palliative medicine	Summary of assessment and recommendations, treatment plan; copy to GP/referrers
Weeks 2–5	Physiotherapy visits	Physiotherapy	–exercise and positions to facilitate breathing –breathing techniques –exercise plan –assessment of need for medical aids
Week 6	Clinic visit	Consultant palliative medicine	–assessment of intensity and quality of shortness of breath, including emotional stress of patient and carer –review of symptom burden (IPOS) –review of treatment plan (including medication) –if needed: referral to medical specialists
	Letter	Consultant palliative medicine	Summary of progress in shortness of breath management, further recommendations; copy to GP/ referrers

GP: general practitioner; IPOS: Integrated Palliative care Outcome Scale

assumption that symptoms such as breathlessness automatically improve. Specific knowledge about the management of breathlessness and especially the non-pharmacological options is rather scarce, and patients describe difficulty in accessing services and the helplessness of professionals in dealing with the symptom.<sup>27</sup> However, a number of treatment options for breathlessness have been evaluated and tested over recent years, and the overall understanding of the symptom has improved.<sup>28</sup> The breathlessness services focus on the symptom rather than the disease and provide expert knowledge and skills from a multi-professional team focusing mainly on non-pharmacological measures.<sup>15</sup> There seem to be two different models. First, those which are physician led, also including individual assessment, medical review and developing individualized management plans.<sup>17,20,22</sup> These physician-led models have mainly been developed by two groups in Cambridge and

London in the United Kingdom, working closely together. Physician-led models differ in respect to the intervention being interdisciplinary, that is, palliative and respiratory medicine consultants working closely together, such as in BSS, or palliative medicine only as in CBIS. Another difference between services is that some provide predefined sessions delivered by nurses or therapists to the patients either individually or in a group setting.<sup>24–26</sup> Bredin's model, one of the first in its kind, seems to combine parts of both.<sup>19</sup> It is nurse led but includes individual assessment and goal setting.

Early access to palliative care is meanwhile widely accepted in patients with cancer.<sup>29</sup> However, patients with non-malignant disease such as COPD or pulmonary hypertension or ILD, who have proven palliative care needs, find it hard to access palliative care at any stage but particularly early in the disease trajectory.

Breathlessness is a burdensome and distressing symptom predominantly in advanced respiratory

disease and occurs not only towards the end of life but early in the disease trajectory. It is frequently accompanied by other burdensome symptoms, and patients and families have other palliative care needs. Therefore, providing a service tailored to the needs of patients with breathlessness due to advanced disease by palliative care professionals not only relieves their symptom burden but also addresses other potential palliative care needs and allows early access to palliative care. Nevertheless, patients who are near death will be directly referred to palliative care services.

The services tested in RCTs are all based in the United Kingdom. The MBS builds on the United Kingdom experience and is a first attempt of such a service with adaptation to another healthcare system than the NHS. In the German healthcare system, combining a hospital-based outpatient clinic with community-based services is challenging as there is normally only little crossover between these settings. Also, in Germany, outpatient care is mainly provided by self-employed doctors, either family doctors or specialists. Thus, many respiratory physicians provide the main care for patients with lung disease from community-based practices. They have to get adapted to the idea that a palliative care service is offered as a short-term intervention to support them in the care of breathless patients. Some of the hesitance of respiratory physicians is reflected in the high self-referral rates to the service of patients who came across the service by adverts and leaflets. However, this is changing over time, and physician referral is increasing recently.

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