Extending palliative care to patients with respiratory disease

This article describes the importance of improving access to palliative care services of patients with advanced chronic respiratory disease. It outlines their needs, the challenges involved in meeting them and ways in which current models of care may need to be modified to increase access.

The founders of palliative medicine always intended that their knowledge, skills and resources would be made available to all those who needed them regardless of diagnosis. As Sykes et al (2004) describe, palliative care started outside the NHS but it was always hoped that once established the science, practice and philosophy of the speciality would improve the care of patients in hospitals, residential and nursing care and those at home.

Despite this, palliative care services have been designed around the needs of people living with cancer who, Eve et al (1997) report, have formed 95% of patients receiving the care from community specialist palliative care nurses and hospices. The growing recognition within palliative care, from clinicians caring for patients with non-malignant disease and the general public, that patients and families were not receiving an equitable service has increased interest in investigating the needs of patients with respiratory disease.

Patients with respiratory disease form a large component of the general medical case load and emergency take. Gore et al (2000) and Shee and Green (2003) studied patients with chronic obstructive pulmonary disease and found that people with chronic respiratory disease are perceived to have lengthy admissions, inappropriate readmissions without objective evidence of deterioration and to have hasty decisions made about their care when they themselves are in extremis. Fitzsimons et al (2007) report clinicians' concerns about the disparity of services available to their patients with chronic respiratory disease compared with those for patients with lung cancer: patients have also noted the inequity of treatment.

What needs do respiratory patients have?

Respiratory patients have the same needs as any patient facing a life-limiting condition, including accurate information about their condition, psychological support to cope with declining health and increasing dependence on others, and the chance to express their preferences for the sort of care they would choose. As Addington-Hall et al (1998) and Edmonds et al (2001) describe, respiratory patients experience a symptom burden of equal severity and longer duration to comparable groups with lung cancer in terms of both pain and breathlessness. Gore et al (2000) report a high incidence of anxiety and depression which is less likely to be assessed or treated than in a cancer population.

Elkington et al (2005) focussed on the experience of carers who reported pain and breathlessness to be common and infrequently treated at the end of life and who felt isolated and uninformed as they cared for their relative. Patients with chronic respiratory disease are less likely to be told that they are dying or to have the opportunity to assert the place and manner of the end-of-life care they would choose. When this group have expressed a desire for a home death, both Addington-Hall et al (1998) and Edmonds et al (2001) found that these patients were more likely to have died alone or in hospital. In a nationwide survey of respiratory physicians carried out by the National Council for Palliative Care (2008) over half of all respondents reported that there was no access to bereavement counselling for carers of patients with chronic respiratory disease.

In summary patients with chronic respiratory disease and their families require:

- Information about their illness and its prognosis
- Symptom control including comprehensive assessment of their needs and specialist palliative care where needed
- Psychological support to address the high incidence of anxiety and depression
- The opportunity to undertake advance care planning and to discuss fears about dying
- Support for carers, to prevent exhaustion and psychological morbidity.

Breathlessness

Breathlessness is the most widely experienced and distressing symptom of chronic respiratory disease. The complexity of dyspnoea is attested to by the variety of definitions – the most widely used at present is that given by the American Thoracic Society (1999) as:

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> **'…a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interaction among multiple physiological, psychological, social and environmental factors and may induce secondary physiological and behavioural responses.'**

This encompasses the multidimensional nature of breathlessness and refers to its social consequences as described by Seamark et al (2004) – often impoverishment (work often becomes impossible for both patient and carer) and social isolation (the practical difficulties of maintaining relationships and the social stigma of disability, chronic illness and visible use of oxygen) culminating in depression and even despair.

A nihilistic approach to dyspnoea is no longer justified. As the options for disease-modifying treatment decrease refocusing therapeutic attention on the symptom may yield beneficial results. Clinicians and scientists from neurophysiology, respiratory medicine and palliative medicine are concentrating research efforts on increasing understanding of the pathophysiological basis for breathlessness in the hope that this will yield new treatment strategies. All attempts to define dyspnoea affirm it as a subjective experience and hence not easily evaluated by pulmonary function tests, imaging or other objective measures. Banzett and Moosavi (2001) described breathlessness as a somatopsychic phenomenon where the sensation itself and the individual's reaction to it are combined to affect the individual.

Figure 1 represents the complex neurophysiology of breathlessness. Multiple sensory structures respond to and integrate chemical and physical stimuli which are then modified by input from higher centres including cognition, memory and emotions resulting in the somatopsychic experience of breathlessness. Although it has been superseded in some ways (the putative connections are now confirmed) the diagram suggests a rationale for the success of psychological interventions which alter the central perception of breathlessness and one of the authors (SB) finds it very useful in explaining breathlessness to patients and families.

The foundations of managing breathlessness as detailed by Booth et al (2008) are a multidisciplinary approach combining non-pharmacological (principally exercise, facial cooling with a hand-held fan, and psychosocial interventions) and pharmacological strategies both separately and together. Palliative pharmacological treatments include opioids, as described by Jennings et al (2002), and benzodiazepines for which there is very little evidence. For most people, oxygen has been shown by Booth et al (2004) and Cranston et al (2008) to have no benefit over air in the palliation of breathlessness and, as suggested by Schwartzstein et al (1987), the use of a hand-held fan should be tried first.

The place of inhaled furosemide, antidepressants, buspirone, cannabinoids and non-invasive ventilation needs further research as outlined by Shee and Green (2003) and Booth et al (2008, 2009). Brenes (2003) outlines the importance of screening for depression and providing 'training' in anxiety reduction strategies.

What are the barriers to these patients receiving palliative care?

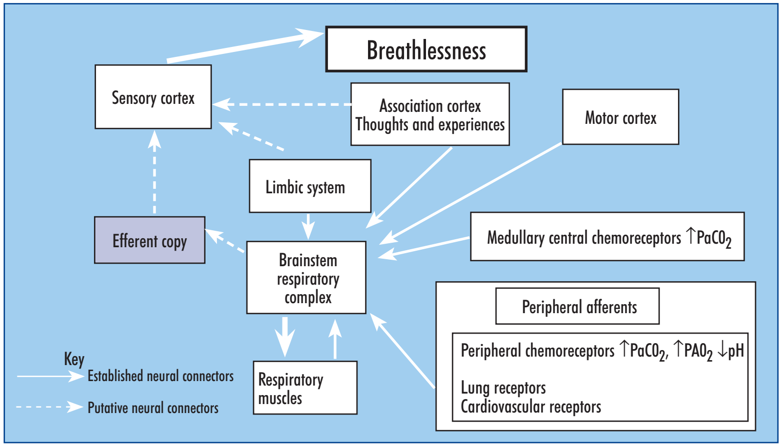
The inadequate information available to respiratory patients may mean that they do not realize that palliative care may be appropriate for them. Commonly held misperceptions about the roles of community specialist palliative care nurses and hospices may deter them. Booth et al (2006) reported that patients perceived that clinicians had little idea of the impact of breathlessness and were uncertain how to help the symptom, consequently patients did not report it.

A community-based study by McKinley et al (2004) suggested that the difficulty in identifying a terminal phase in patients with chronic respiratory disease results in patients being less likely to have medications prescribed for symptom control at the time of death, although these patients were as likely to die at home (if that had been their preference) as cancer patients.

Fitzsimons et al (2007) reported that even when teams have assessed the palliative care needs of their patients accurately, they feel ill-equipped to provide the psychosocial and emotional support they perceive to be required and feel they lack the skills to discuss end-of-life issues.

Hospital specialists (Dharmasena and Forbes, 2001; Ewing et al, 2009) do not refer to specialist palliative care because they overestimate the degree of symptom control achieved and still perceive that palliative care is only concerned with cancer. They are open, however, to the idea of referring patients with non-malignant conditions for symptom control. Other reasons for referral included psychological support for relatives, terminal care and the need to 'share the load' of a complicated patient. Ewing et al (2009) noted that physicians were less likely to refer

Figure 1. A proposed conceptual model for the genesis of dyspnoea and its relationship to respiratory control. From Stulbarg and Adams (1994).



for social and spiritual needs, often delegating assessment and referral to nursing colleagues. Dharmasena and Forbes (2001) found that barriers to referral included high levels of concern that palliative medicine specialists lacked disease-specific experience, that their patients would feel abandoned by their original hospital team, that patients would infer information about the nature of their disease from the referral, that they might have misdiagnosed end-stage disease and that the referral would lead to the deskilling of generalists to provide general palliative care. Formal shared-care arrangements were seen as a solution to many of these difficulties.

Proposed referral criteria for people with chronic obstructive pulmonary disease to specialist palliative care were set out in the National Council document *A Fresh Approach: Palliative and end of life care for people with Chronic Respiratory Disease* (Sutton et al, 2008). The criteria included the referral of any patient with chronic obstructive pulmonary disease who has:

1. Uncontrolled physical symptoms either related to chronic obstructive pulmonary disease or any co-morbidity that are having a significant impact on his/her quality of life despite optimal medical management
2. Psychological, social or spiritual issues requiring multidisciplinary intervention
3. Been admitted to hospital acutely three or more times in the preceding 12 months
4. Ongoing loss of function where advance care planning needs to be addressed
5. A prognosis of days to weeks.

Challenges facing palliative care clinicians working with respiratory patients

Addington-Hall (2004) voiced the concerns of many palliative care clinicians when she postulated that attempting to meet the needs of all patients with non-malignant disease would overwhelm the specialty and lead to a deskilling of generalists, citing data suggesting that one in six of non-cancer patients had similar levels of need as the most severely affected one-third of cancer patients who receive specialist palliative care. Many specialists in palliative care have only been involved in the care of oncology patients (specialist training has now changed) and they may have little experience in managing non-malignant conditions. Palliative medicine specialists may be daunted by the smaller evidence base available to guide the management of breathlessness as compared with that available for pain. Murtagh et al (2004) describe recognized difficulties in terms of understanding the functional trajectory of non-malignant disease compared with cancer, a larger overlap between periods of active and palliative treatment, and difficulties in recognizing the dying process and in the handing of uncertainty. These difficulties compound the issues of timing of discussions regarding end-of-life care and concerns with patients with respiratory disease – an absence of this may reduce the chances of their preference being met.

Models of care for patients with respiratory disease and palliative care needs

As the needs of patients with non-malignant disease become clearer it is important that services are tailored to meet their requirements rather than the model simply being transferred from a cancer setting.

A survey of clinician-perceived good practice in end-of-life care for patients with chronic obstructive pulmonary disease by Roberts et al (2008) encouragingly found that there were formal arrangements to provide palliative care for patients in 42% of clinical teams surveyed and plans to develop services in 59%. Of concern only 11% had formal arrangements to provide information about end-of-life care. Sutton et al (2008) outlined a national survey of respiratory physicians working in England, Wales and Northern Ireland in which 21.7% reported having easy access to a hospice inpatient unit, 66% having easy access to a palliative medicine consult for an inpatient and 40% having easy access to a palliative medicine outpatient appointment. Innovations were present at many levels with multidisciplinary teams involving members from palliative medicine teams, respiratory–palliative care special interest groups, joint working to produce symptom control and referral guidelines, joint palliative care and chronic obstructive pulmonary disease nursing posts and chronic obstructive pulmonary disease nurses attaining high-level qualifications in palliative care such as an MSc. This survey outlined a card system to identify those not wanting an admission in the case of an exacerbation and the use of the Liverpool Care Pathway to increase skills of staff providing end-of-life care on hospital wards.

There is an enlarging evidence base investigating the optimum service model to help breathless patients. *Table 1* outlines information from trials based in nurse-led hospital outpatient clinics, hospice-based physiotherapy clinics and a physiotherapist-led programme seeing patients in inpatient, outpatient and community settings. All studies reported sustained reduction in the distress associated with breathlessness and levels of breathlessness ‘at best’ and ‘worst’ using visual analogue scales. High attrition rates (ranging from 43–82%) demonstrate the importance of breathlessness in cancer patients as a prognostic factor and are concerning when considering the feasibility of implementing intervention strategies more widely as described by Zhao and Yates (2008). In addition all the teams used ‘complex interventions’, making it difficult to confirm whether all components are equally effective.

One community-based model, integrated with the hospital palliative care service at Cambridge University Hospitals NHS Foundation Trust, the Breathlessness Intervention Service comprises a band 8 allied health professional, a band 7 physiotherapist and a Macmillan consultant in palliative medicine. The Breathlessness Intervention Service sees any patient with intractable breathlessness regardless of diagnosis, offering education and training to the patient and carer including anxiety reduction, wellbeing interventions and bespoke exercise programmes. Patients are seen wherever is most appropriate, either in outpatient clinics but mostly in their own home. The service undertakes end-of-life care planning where appropriate. It works very closely with primary and secondary care specialist teams, particularly with respiratory nurses, pulmonary rehabilitation and the hospice day centre. An advanced respiratory disease multidisciplinary team is developing at which all services caring for such patients liaise. The service is currently being evaluated as a phase III MRC evaluation of complex intervention.

As many patients with chronic respiratory disease spend large amounts of time in hospital, interventions aimed at improving access for these patients to palliative care need to be based in this environment. One such development is the hospital specialist team which should be available in each district general and tertiary referral hospital. As Dharmasena and Forbes (2001) and Ewing et al (2009) state hospital specialists have a high level of preparedness to refer to these teams. There is also a perception that palliative care participation in the multidisciplinary team improves the palliative management for the group of patients represented. Kite et al (1999) describe hospital specialist teams as able to provide a flexible service with the provision of both one-off, short-term and long-term input to provide advice on symptom control, discharge provision, future care planning, terminal care and managing opioids.

Educating other specialists to provide palliative care for their patients is seen as an important part of the role of the hospital support team. Bailey et al (2005) describe an education programme rolled out to physician, nursing and ancillary staff focussing on the identification of actively dying patients and a guided care plan which led to fewer deaths on intensive treatment unit, reduced symptom burden, and increased opioid availability and do-not-resuscitate orders being completed.

Needs for the future

Palliative care research has concentrated on the lived experience of illness and there has been a lack of transla-

Table 1. Studies evaluating the outcomes of breathlessness clinics* in the UK

Reference	Setting	No. completing intervention	Outcome measures	Components of intervention	Length of intervention	Method of evaluation	Outcome of intervention
Corner et al (1996)	Specialist oncology hospital, nurse led	20/34	VAS ratings of breathlessness and distress caused by it. Functional Capacity Scale, and the HADS and qualitative interviews	Counselling, breathing retraining, relaxation, coping and adaptation strategies and goal setting. Opportunity to discuss end-of-life care	Weekly sessions of 1 hour for 3–6 weeks	Randomized controlled feasibility study	Significant improvements in worst SOB ($P=0.02$), distress caused by SOB ($P=0.02$), functional capacity ($P=0.03$) in intervention group
Bredin et al (1999)	Six oncology centres, nurse led	103/119	1-year outcome measure distress caused by breathlessness on VAS, HADS, RSI	As above	As above	Randomized controlled trial	As above
Hately et al (2003)	Hospice outpatient clinic, referrals from all settings, physio led	30/45	Frequency of breathlessness and VAS of breathlessness at best, worst, and distress caused by breathlessness and reported physical capacity. 'Quality of life at End of Life' assessment tool. RSI. Free text reports from physiotherapist	Not fully described but based on Corner model of counselling, pacing and breathing retraining	Three sessions over 4–6 weeks	Non-randomized evaluation of breathlessness clinic using before and after scores of outcome measures by specialist nurse of hospice	Significant improvements SOB at best ($P=0.0001$), at worst ($P<0.0001$) and distress caused by SOB ($P<0.0001$)
Connors et al (2007)	Outpatients, community, inpatient, physio led	14/169	Chronic Respiratory Questionnaire, VAS of breathlessness at worst, best and distress caused by breathlessness	Wk 1: assessment, breathing control Wk 2: review, relaxation, anxiety management Wk 3: review, energy conservation, goal setting, lifestyle adaptation Wk 4: review, assessment Wk 8: reassessment and review	4 weeks with review at 8 weeks if desired	Audit	Those that completed improvements in Chronic Respiratory Questionnaire and VAS scores of breathlessness (worst and distress because of SOB)

* All studies were in patients with lung cancer, except Connors et al (2007) which was in patients with intrathoracic malignancy. HADS = Hospital Anxiety and Depression Scale; RSI = Respiratory Symptom Index; SOB = shortness of breath; VAS = visual analogue scale. From Booth (2009)

tional research taking information from basic science into clinical practice. There needs to be a similar evidence base available for those attempting to treat breathlessness as those trying to treat pain. Palliative care was the first specialty to look at the management of symptoms as a clinical science in its own right and this work needs to be expanded. There will need to be cooperation across the disciplines with palliative care contributing experience in qualitative research, respiratory medicine contributing familiarity with scientific research techniques and for full use to be made of functional imaging techniques such as functional magnetic resonance imaging.

Extending palliative care appropriately and successfully for respiratory patients has the potential to relieve suffering and promote comfort and choice for a large and disadvantaged patient group. It is imperative that we achieve this. **BJHM**

Figure 1 *is reproduced from Stulbarg and Adams (1994) by kind permission.*

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Addington-Hall J (2004) Clinical challenges in non-malignant disease. In: Sykes N, Edmonds P, Wiles J, eds. *Management of Advanced Disease*. Arnold, London: 319–26

Addington-Hall J, Fakhoury W, McCarthy M (1998) Specialist palliative care in non-malignant disease. *Palliat Med* **12:** 417–27

American Thoracic Society (1999) Dyspnea- mechanisms, assessment and management: a consensus statement. *Am J Respir Crit Care Med* **159:** 321–40

Bailey FA, Burgio KL, Woodby LL et al (2005) Improving processes of hospital care during the last hours of life. *Arch Intern Med* **165**(15): 1722–7

Banzett RB, Moosavi SH (2001) Dyspnoea and pain: similarities and contrasts between two very unpleasant sensations. *American Pain Society Bulletin II* **2:** 1–6

Booth S (2009) Improving the Palliative Care of Breathlessness. MD thesis. University of London, London

Booth S, Wade R, Anderson H, Swannick M, Kite S, Johnson M (2004) The use of oxygen in the palliation of breathlessness: a report of the Expert Working Group of the Scientific Committee of the Association of Palliative Medicine. *Respir Med* **98:** 66–77

Booth S, Farquhar M, Gysels M, Bausewein C, Higginson IJ (2006) The impact of a breathlessness intervention service (BIS) on the lives of patients with intractable dyspnoea: a qualitative phase I study. *Palliat Support Care* **4**(3): 287–93

Booth S, Moosavi SH, Higginson IH (2008) The aetiology and management of intractable breathlessness in patients with advanced cancer with a systematic review of pharmacological and inhaled therapy. *Nat Clin Pract Oncol* **5:** 90–100

Booth S, Bausewein C, Higginson I, Moosavi SH (2009) Pharmacological treatment of refractory breathlessness. *Expert Rev Respir Med* **3**(1): 1–16

Bredin M, Corner J, Krishnalamy M, Plant H, Bailey C, A'Hern R (1999) Non pharmacological intervention for breathlessness in lung cancer. *Palliat Med* **10**(4): 299–305

Brenes GA (2003) Anxiety and chronic obstructive pulmonary disease: prevalence, impact and treatment. *Psychosom Med* **65**(6): 963–70

Connors S, Graham S, Peel T (2007) An evaluation of a physiotherapy led non-pharmacological breathlessness programme for patients with intrathoracic malignancy. *Palliat Med* **21:** 285–7

Corner J, Plant H, A'Hern R (1996) Non pharmacological intervention for breathlessness in lung cancer. *Palliat Med* **10**(4): 299–305

Cranston JM, Crockett A, Currow D (2008) Oxygen therapy for dyspnoea in adults. *Cochrane Database Syst Rev* (3): CD004769

Dharmasena H, Forbes K (2001) Palliative care for patients with non-malignant disease: will hospital physicians refer? *Palliat Med* **15:** 299–305

Edmonds P, Karlsen S, Khan S, Addington-Hall J (2001) A Comparison of the palliative care needs of patients dying from chronic respiratory disease and lung cancer. *Palliat Med* **15:** 287–95

Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P (2005) The healthcare needs of chronic obstructive pulmonary disease in the last year of life. *Palliat Med* **15:** 299–305

Eve A, Smith AM, Tebbit P (1997) Hospice and palliative care in the UK 1994-5, including a summary of trends 1990-5. *Palliat Med* **11:** 31–43

Ewing G, Farquhar M, Booth S (2009) Delivering palliative care in an acute hospital setting: views of referrers and specialist providers. *J Pain Symptom Manage* **38**(3): 327–40

Fitzsimons D, Mullan D, Wilson JS et al (2007) The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliat Med* **21:** 313–22

Gore JM, Brophy CJ, Greenstone MA (2000) How well do we care for patients with end-stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and Lung Cancer. *Thorax* **55:** 1000–6

Hately J, Lawrence V, Scott A, Baker R, Thomas P (2003) Breathlessness clinics within specialist palliative care settings can improve the quality of life and functional capacity of patients with lung cancer. *Palliat Med* **17**(5): 410–17

Jennings AL, Davies AN, Higgins JP, Gibbs JS, Broadley KE (2002) A systematic review of the use of opioids in the management of dyspnoea. *Thorax* **57:** 939–44

Kite S, Jones K, Tookman A (1999) Specialist palliative care and patients with noncancer diagnoses: the experience of a service. *Palliat Med* **13:** 477–84

McKinley R, Stokes T, Exley C, Field D (2004) Care of people dying with malignant and cardio-respiratory disease in general practice. *Br J Gen Pract* **54:** 909–13

Murtagh F, Preston M, Higginson I (2004) Patterns of dying: palliative care for non-malignant disease. *Clin Med* **4**(1): 39–44

Sutton L, Sam E, Partridge M et al (2008) *A Fresh Approach: Palliative and end of life care for people with chronic respiratory disease.* National Council for Palliative Care, London

Roberts CM, Sugar A, Buckingham RJ, Stone RA (2008) Clinician perceived good practice in end-of-life care for patients with COPD. *Palliat Med* **22:** 855–8

Schwartzstein RM, Lahive K, Pope A, Weinberger SE, Weiss JW (1987) Cold facial stimulation reduces breathlessness induced in normal subjects. *Am Rev Respir Dis* **136**(1): 58–61

Seamark DA, Blake SD, Seamark CJ (2004) Living with severe chronic obstructive pulmonary disease (COPD) perceptions of patients and their carers. *Palliat Med* **18:** 619–25

Shee CD, Green M (2003) Non-invasive ventilation and palliation: experience in a district general hospital and a review. *Palliat Med* **17:** 21–6

Stulbarg MS, Adams L (1994) Dyspnea. In: Murray JF, Nadel JA, eds. *Textbook of Respiratory Medicine.* 2nd edn. WB Saunders, Pennsylvania: 513–14

Sykes N, Edmonds, Wiles J (2004) *Management of Advanced Disease.* 4th edn. Arnold, London

Zhao I, Yates P (2008) Non-pharmacological interventions for breathlessness management in patients with lung cancer a systematic review. *Palliat Med* **22**(6): 693–701

KEY POINTS

- Advanced chronic lung disease is among the most common diseases in the world.
- Patients with end-stage chronic respiratory disease have a symptom burden equal to and of longer duration than comparable groups with lung cancer.
- Breathlessness is the most widely experienced and distressing symptom and needs further research to guide its management.
- Existing service models need their transferability to non-malignant settings or patients evaluated and modified where necessary.
- Interdisciplinary working has the potential to vastly improve the quality of life of this group of patients.