

**Developing a Service for Patients with Very Severe Chronic Obstructive Pulmonary Disease (COPD) within resources.**

**Jason Boland**, Consultant in palliative medicine, Barnsley Hospice, Barnsley, UK  
Current address: Senior lecturer and honorary consultant in palliative medicine, Hull York Medical School, Hertford Building, University Of Hull, HU6 7RX, UK  
Email: [.boland@hyms.ac.uk](mailto:.boland@hyms.ac.uk); Tel: 01482 463482; Fax: 01482 464705

**Janet Owen**, End of life care clinical lead, South West Yorkshire Partnership Foundation Trust, Barnsley, UK

**Rachel Ainscough**, Programme Manager and Service Redesign Consultant Marie Curie Cancer Care

**Hazim Mahdi**, Consultant in Respiratory Medicine, Barnsley Hospital NHS Foundation Trust, Barnsley, UK

## **Abstract**

Chronic obstructive pulmonary disease (COPD) is a common life-limiting illness with significant burden for patient and carer. Despite this, access to supportive and specialist palliative care is inconsistent and implementation of published good practice recommendations may be challenging within current resources. The aim of this service development was to improve local service provision in Barnsley, within the currently available resources, for patients with very severe COPD, to improve patient identification and symptom management, increase advance care planning and the numbers of patients dying in their preferred place, and increase patient and carer support and satisfaction. To do this a working group was formed, the service problems identified and baseline data collected to identify the needs of people with very severe COPD. A multidisciplinary team (MDT) meeting was piloted and assessed by community matron feedback, patient case studies and an after death analysis (ADA). These indicated a high level of satisfaction, with improvements in advance care planning, co-ordination of management and support for patients' preferred place of care at the end of life. In conclusion this is the first reported very severe COPD service development established in this way and within current resources. Preliminary data indicates the development of the MDT meeting has been positive. The appointment of a coordinator will aid this development. Further evaluations particularly seeking patient views and estimations of cost savings will be performed.

## **Background**

Over 25,000 people die each year in the United Kingdom from chronic obstructive pulmonary disease (COPD). Patients with COPD often have limited access to palliative care including at the end of life despite having a similar prognosis and symptom burden to lung cancer.(1-4) Furthermore, both studies and guidelines have emphasised the need for collaborative working across primary and secondary care with multidisciplinary teams (MDTs) to provide improved access to services and support to patients with COPD at the end of their lives.(1, 2, 5, 6) However, there is a need for significant service improvement to improve Advance Care Planning (ACP) in patients with COPD before this goal of the End of Life Care Strategy can be achieved.(4, 7) However, service improvements can be challenging in the context of restricted budgets and historical patterns of practice.

In Barnsley, a former mining town in northern England, 16.4% of deaths in 2008-2010 were from respiratory disease(8) and a high percentage of these patients die in acute care, often with little or no palliative care input (Table 1). Patients in Barnsley with COPD have been shown to consider dyspnoea as a normal part of life and due to the way they view this, could be more effectively engaged by clinicians.(9) We therefore aimed to improve the quality of palliative care provided to patients with very severe COPD by introducing a MDT approach to improve their identification and management. This need for such an approach has been described and this is a report of how a service has implemented the recommendations in practice.(1, 2, 5, 6) This is, to our knowledge, the first report of such a service to have been developed in this way within current resources.

### **Box A: The key objectives of this service development were to:**

Improve identification of patients with very severe COPD with palliative care needs
Increase the number of ACP documents completed
Increase numbers of people dying in their preferred place
Reduce inappropriate hospital admissions and outpatient appointments
Ensure patients are able to access timely and effective symptom management
Share learning across MDT members and opportunities for professional development
Improve equity of access to services
Increase patient and carer support and satisfaction

## **Getting started**

### *Establishment of the working group*

A working group (WG) was established, consisting of a respiratory consultant, palliative medicine consultant, community matron, respiratory specialist nurse, general practitioner (GP), lead nurse, divisional service manager, business unit manager, team leader rapid response team, acute care case manager, occupational therapist, end of life care clinical lead, commissioners and Marie Curie Delivering Choice Programme advisor. The WG's remit was to assess the problems with the management of patients with very severe COPD and agree the management strategies to address them that could be immediately implemented (Box A). In view of the MDT model seen in other disease management strategies, the first agreed goal was to set up and evaluate the effect of a palliative care/respiratory MDT. The WG

- Defined the patient population and agreed eligibility criteria for referral to the proposed palliative care/respiratory MDT
- Defined the care pathway
- Developed the supporting documentation
- Defined the MDT members
- Mapped and identified baseline gaps in provision for patients with very severe COPD

As this was a service development and evaluation project, NHS research ethical committee approval was not required for this service development in accordance to NRES guidance.

### *Patient population and eligibility criteria*

A care pathway (appendix 1), referral criteria (Box B) and supporting documentation (appendix 2 and 3) for very severe COPD were developed by the WG, based upon the 2011 NICE quality standards and Gold Standard Framework prognostic indicator guidance.(10, 11)

**Box B:** Eligibility for referral to the very severe COPD MDT; at least two of the following were needed:(11)

Severe airflow obstruction (FEV1 <30%)
Respiratory failure
BMI <19
Housebound (MRC dyspnoea score 5)
History of 2 or more exacerbations during the previous year – either COPD or heart failure
Need for non-invasive ventilation
Eligibility for long term home oxygen

#### *Initiation of the MDT meeting*

A fortnightly MDT meeting was established to plan management for new referrals and monitor those known to the service. A pilot commenced in November 2011 for 6 months, with cases presented by the community matrons (key worker). A management plan, including palliative care, was formulated for the patient, documented in the patients' notes and sent to the GP. The MDT was chaired by the consultant respiratory physician, and attended by the palliative medicine consultant, consultant microbiologist, community matrons, respiratory nurse specialist, ward lead nurse, case manager and the community occupational therapist.

#### *Baseline data collection*

Baseline data included patient satisfaction questionnaires and after death analysis (ADA) of randomly chosen patients known to the community matron who had died within the previous 3 months [by JO and RA]. These fed into the WG discussions, to inform the development of the service. Patient satisfaction questionnaires asking about satisfaction and palliative care needs, designed by the Marie Curie Delivering Choice programme and adapted by the WG, were distributed by the community matron team to current patients on their caseloads who met the criteria for referral to the MDT. The Gold Standard Framework ADA audit,(12) adapted by Marie Curie Delivering Choice Programme, was used [by JO and RA] to evaluate the care of patients who had died from COPD from four of the community matron caseloads in the previous 6 months.

## *Evaluation*

At the end of the service development pilot, patient satisfaction questionnaires, and ADAs [by JO] were repeated and compared with baseline. The post-pilot patient satisfaction questionnaires were distributed by the community matron team to patients whose care had been influenced by the MDT and were still alive. ADAs were from patients who had died after MDT input. Case studies from patients who were still alive and discussed at the MDT, were presented by the community matrons. Community matron feedback consisting of questionnaires and a simple structured group feedback [facilitated by JO], explored the benefits and problems of the service development on themselves, patients and carers. The responses of these were recorded and key issues established.

Evaluation was planned and coordinated by the WG to identify key issues and further questions. The ADA, questionnaire, case history and feedback group data was collated, analysed and key issues and findings were identified. These were discussed with the WG to identify further questions and make recommendations for future service provision and planning, before re-evaluation. Progress was reported through the organisation's own governance structures and to the End of Life Care Operational and Strategy Group. As part of the monitoring and evaluation process, the MDT continuously explored improving the development and work to ensure that any unmet needs were identified and brought to the attention of the WG.

## **Results**

### **Pre-pilot baseline data**

The common issues seen from the patient satisfaction questionnaires and ADA and the key problems in service provision identified by the WG are summarised in Box C.

#### *Patient questionnaire data*

Anonymous data was collated from 16 returned patient satisfaction questionnaires (response rate = 80%). Care was generally rated as excellent/very good, however, 7/16 (44%) patients reported that they were not always involved in decisions about their care, 4/16 (25%) said they were not always able to talk to professionals about things that mattered to them, 3/16 (19%) reported family support as poor/fair and 2/16 (13%) were not satisfied with the emotional support. Just under half (7/16; 44%) reported that they did not feel the team caring for them always communicated appropriately about their care. In the previous year 7/16 (44%) had 2 or more admissions and 5/16 (31%) patients had seen their GP more than 3 times about their COPD. None of the returned questionnaires reported specialist palliative care involvement.

#### *ADA data*

The ADA was completed on 5 patient records and highlighted that 4/5 (80%) had a `do not attempt cardiopulmonary resuscitation` (DNACPR) and pre-emptive prescribing in place, 1/5 (20%) had documented evidence of ACP and holistic assessment. Patients had an average of five admissions in the previous year, 3/5 (60%) had had more than 10 crisis admissions and an average of 26 days was spent in hospital in the year before death. Documentation about a MDT plan was only present in one case, enabling team working and this patient to die at home, her preferred place. No patient had a referral to or involvement from specialist palliative care. There was no documentation around bereavement care in any of the cases.

**Box C:** Key issues highlighted from the WG, patient satisfaction questionnaires and ADA

Need for increased holistic individualised assessment
Need to decrease admissions in the end stages of disease
Need for a more coordinated approach with a clear management plan
Need for increased specialist palliative care involvement
Need for education and support for community matron team

**Post-pilot evaluation**

Twenty-one patients were referred for discussion at the MDT between 30 November and 9th May. The community matrons also contacted the respiratory and palliative medicine teams between MDTs to provide responsive management of patients. Following MDT discussions, palliative medicine consultations occurred in acute, hospice and domiciliary settings. The relatively small numbers of patients discussed allowed for in-depth discussion and teaching, which the community matrons reported improved their ability to care for other patients, decreasing the need for individual discussion at the MDT for some patients. This was in part responsible for the low referral rate to the MDT, despite the relatively broad referral criteria (Box B). The number of patients dying from COPD on the last days of life care pathway in the community increased from 1/49 (2%), in the corresponding 6 months in the previous year, to 4/53 (8%) in this 6 month pilot. Although small numbers it may reflect an increasing awareness, confidence and proactive care.

*Patient satisfaction questionnaires and case studies*

There was a poor response rate from the patient satisfaction questionnaires (4/20) so instead five case studies (a summarised example can be seen in Box D) and an ADA on eight patients were used. Most (8/10) professional questionnaires were returned and a structured group feedback session with seven community matrons was held. The main areas of reported improvement are summarised in Box E.



**Box D:** An illustrative case history.

Mr P is a 59 year old with COPD, alcohol dependence, malnutrition and weight loss. The community matron discussed this patient at the MDT as he was not included on the palliative care register as despite his advanced and life-limiting illnesses as his GP said “he didn’t have cancer”. The MDT agreed that he was likely in the last year of life and as a result he received appropriate clinical management and ACP, as well as increased social support and access to benefits.

Review of the case studies illustrated that improvements in quality of life and symptom control and a reduction in the number of hospital admissions can be made with simple measures: using a patient-centred approach, education and discussions around prognosis, and the optimisation of symptoms by both non-pharmacological and pharmacological means. For example, the use of relaxation techniques, a hand-held fan, and a trial of palliative oxygen, if hypoxaemic, provided symptom relief for some patients. Furthermore, by using careful titration of low dose opioids and appropriate use of benzodiazepines for dyspnoea and anxiety, activities of daily living and quality of life can be improved.

*Community matron questionnaire data and structured group feedback*

All preferred the new ways of working, felt they were supported better with improved access to the respiratory and palliative medicine consultants to manage symptoms and end of life care, and felt that the needs of the patient and family were met more fully. All were very satisfied/satisfied with the MDT, documentation and COPD pathway. All reported the input from the consultant in palliative medicine resulted in an improvement in patient experience and 6/8 (75%) reported better confidence in symptom management. They reported clear management plans following discussion at the MDT with patients subsequently being discussed at the GP led palliative care meetings with better coordination of care. They felt there was earlier recognition of end of life allowing holistic needs to be met and improving quality of life, although they said that patients and their families found ACP discussions difficult

and often did not want to complete a preferred priorities for care document. There was a perception that the MDT reduced admissions, highlighting a patient whose hospital admissions were reduced from up to 3 times per week to 3 times in 2 months and another who had 6 admissions in the year before MDT planning, in the 6 months after which she none.

*ADA data*

The ADA was completed on eight patient records. All demonstrated involvement from specialist palliative care. Of the 6/8 (75%) who specified a preferred place of death, five (83%) patients achieved this due to proactive planning. Bereavement follow-up occurred in 7/8 (88%) cases. There was documented evidence of a coordinated case management approach and/or discussion at the GP palliative care meetings in 7/8 (88%) cases. For the patients dying at home or care home 4/5 (80%) had a DNACPR, 2/5 (40%) were on a last days of life care pathway, 4/5 (80%) had anticipatory prescribing and 4/5 (80%) had evidence of communication with out of hours GPs. Although ACP was offered to 7/8 (88%) patients, only 2/7 (29%) wanted to complete a preferred priorities for care document. The ADA showed an average number of 13 bed days in the 6 months prior to death, with 1 patient accounting for over 50% of this. There was an average of 1.9 admissions per patient in these 6 months. Nearly two thirds (5/8; 63%) of patients died at home or in a care home.

**Box E:** Key benefits of the service development highlighted from the professional questionnaires and structured feedback sessions, case studies and ADA

Service development activity levels and associated outcomes
Improved access to specialist palliative care support
Recognition of end of life care needs
Improved coordination
Reduction in unnecessary hospital admissions
Support and shared learning

## **Discussion**

We report here our local initiative to put national guidelines(6, 11) into clinical practice within resources for patients with very severe COPD. Although service models have been previously described,(13) this is, to our knowledge, the first reported to have been developed in this way within current resources. It has promoted the combination of a palliative care approach to the traditional disease-directed therapy with the introduction of an MDT meeting. As community matrons deliver the majority of care to these patients, often without specialist input, the MDT offered a route of support, from both the respiratory and palliative medicine physicians. The accessibility of these physicians for support and advice has been one of the key benefits from this pilot. The outcomes so far have indicated benefits both to the community matrons and to patients, particularly in terms of symptom management and quality of life. End of life recognition and planning was more evident with more patients dying in their preferred place (at home/care home) with appropriate plans in place in contrast to published work indicating that recognising the transition to palliative care in COPD can be difficult. Bereavement support had also increased. During the pilot there was an increase in the number of patients who had specialist palliative care input. With the small numbers and limited time it is difficult to draw conclusions about admissions, but with the exception of 1 patient who accounted for over 50% of the bed days, admissions seemed to be fewer. This might be due to a combination of pharmacological optimisation (both disease and symptom directed), an action plan being devised, with consultant backup, resulting in increased confidence of the community matrons and patients, thereby potentially decreasing emergency, anxiety related, admissions. Although we did not get a large change in outcomes, which could be due to the small sample size and limited time-frame, those seen were not inconsiderable and were important to patients and the clinical staff, necessitating continuation of the service development and its further evaluation. Patients with very severe COPD have a large symptom burden and a limited prognosis, yet do not have consistent access to specialist palliative care or have their end of life care needs identified and addressed. By delivering palliative management alongside continuing optimally tolerated disease modifying therapy, symptom control and quality of life can be maximised. The same is also true of other non-malignant respiratory diseases, and patients with these

were also occasionally discussed at the MDT, thus a future option would be to include these illnesses and expand the meeting into a more encompassing chronic respiratory MDT. Although prognostication can be difficult in very severe COPD, there is a crucial need for good palliative care, communication including discussions around future care,(4, 14) as this group of patients want to more involved in decisions about their treatment, however they are more comfortable discussing their general views and probable preferences about future care, rather than forming a binding plan.(5)

Prior to the MDT, although there were many professionals involved, there was often no consistent management plan, poor communication and a lack of identification of palliative care need. The community matrons reported that some GPs remained reluctant to discuss patients with very severe COPD at their palliative care MDTs as there was not a clear prognosis, despite national guidance.(10, 11)

This service development incorporates all the components of the Chronic Care Model systems of care.(15) Patients are encouraged to self-manage as the health care professionals are formulating a clear plan and increasing the information and support given to patients. The delivery system is primarily non-physician based, with the community matrons being the key workers, delivering a responsive, variable intensity service depending on the patients' needs, to pre-empt problems and manage them proactively. This is supported by specialist physicians with clinical expertise and experience in the palliative and disease-directed management of COPD both within and between MDT meetings. Clinical information systems were utilised, both as monitoring of some of these patients used telehealth and if appropriate by their inclusion on the GP palliative care register and SystmOne End of Life Care template, to coordinate the delivery of planned care.

Given the high satisfaction and preliminary benefits for professionals across the district of Barnsley and ultimately patients and their families, the MDT meetings will continue, with the aim to identify a co-ordinator, with twice yearly re-evaluation of the benefits and savings

produced by this development. Future work will involve the identification of an MDT co-ordinator to facilitate the meetings and improve documentation and dissemination of outcomes; education sessions and workshops to enhance discussions and the skills of community matrons will also be provided. Further work is also needed to improve the measurement of patient relevant outcomes and discussion with patients in hospital/clinic regarding disease progression. The low rate of end of life discussions with patients by clinicians, in our service and elsewhere, remains a challenge in the provision of palliative care for those with non-malignant disease.(16) We hope to improve this by encouraging ACP to be initiated for patients by secondary care clinicians and then discussing the outcome of these with the primary care team. The primary care team are then well placed to continue the planning with the patients in the community as well as optimising the Gold Standards Framework approach for patients with COPD. Conversations about difficult issues are likely to be challenging, but this should not mean they should be avoided or that they are necessarily stressful for most, over and above the problems faced by the patient and carer at that stage of the illness, when conducted with sensitivity and a careful assessment made to ensure the patient is willing to participate.(17) Indeed, many find the opportunity to discuss hopes and concerns for future care helpful.(18) However, all too commonly, these discussions in people with advanced chronic conditions are avoided by clinicians who may be anxious about “taking away hope” and who remain unwilling to discuss future care plans when prognosis remains unclear.(4, 16)

### Limitations

As this project was an initial service development pilot funded from within current resources numbers of patients are small and the methodology used was simple. There was also poor questionnaire return from patients in the post-pilot data. No cost saving assessment was performed. However, we do have important positive preliminary data to support further development and evaluation of this service.

## Conclusion

The preliminary data from this service development pilot indicates that the development of an MDT meeting and pathway of care for patients with very severe COPD has benefited both patients and community matrons, with better recognition of end of life care needs and increased number of patient supported in their preference, if applicable, to die at home/care home. The matrons felt more supported in their case management with easier access to palliative and respiratory physicians, with a more coordinated approach to care across organisation boundaries. To further this work we plan to appoint a coordinator, deliver education and continue to monitor this development in a more robust way to confirm patient benefit and assess any cost savings. Although our preliminary findings need to be confirmed more systematically, we hope our initial experience will encourage other local providers to look at reconfiguring their services to encompass patients with very severe COPD.

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## References

1. Seamark DA, Seamark CJ, Halpin DM. Palliative care in chronic obstructive pulmonary disease: a review for clinicians. *J R Soc Med.* 2007;**100**:225-33.
2. Hardin KA, Meyers F, Louie S. Integrating palliative care in severe chronic obstructive lung disease. *Copd.* 2008;**5**:207-20.
3. Gore JM, Brophy CJ, Greenstone MA. 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.* 2000;**55**:1000-6.
4. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J.* 2008;**32**:796-803.
5. Macpherson A, Walshe C, O'Donnell V, et al. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study. *Palliat Med.* 2012.
6. Department of Health. Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England. 2010.
7. Gott M, Gardiner C, Small N, et al. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliat Med.* 2009;**23**:642-8.
8. National End of Life Care Intelligence Network. National End of Life Care Local Authority Profile for Barnsley, [endoflifecare-intelligence.org.uk/profiles.aspx](http://endoflifecare-intelligence.org.uk/profiles.aspx) (2012, accessed 10 September 2012).
9. Small N, Gardiner C, Barnes S, et al. "You get old, you get breathless, and you die": Chronic obstructive pulmonary disease in Barnsley, UK. *Health Place.* 2012.
10. The National Gold Standards Framework Centre. Prognostic Indicator Guidance, [://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20October%202011.pdf](http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20October%202011.pdf) (2011, accessed 7 September 2012).



11. National Institute for Health and Clinical Excellence. Chronic obstructive pulmonary disease quality standard, [://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/quality-statement-13-palliative-care#data-source-12](http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/quality-statement-13-palliative-care#data-source-12) (2011, accessed 8 October 2012).
12. The National Gold Standards Framework Centre. GSF After Death Analysis Audit Tool, [://www.goldstandardsframework.org.uk/GSFAuditTool](http://www.goldstandardsframework.org.uk/GSFAuditTool) (2012, accessed 12 September 2012).
13. Booth S, Bausewein C, Rucker G. New models of care for advanced lung disease. *Progress in Palliative Care*. 2011;**19**:254-63.
14. Pinnock H, Kendall M, Murray SA, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *Bmj*. 2011;**342**:d142.
15. Epping-Jordan JE, Pruitt SD, Bengoa R, et al. Improving the quality of health care for chronic conditions. *Qual Saf Health Care*. 2004;**13**:299-305.
16. Barclay S, Momen N, Case-Upton S, et al. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *Br J Gen Pract*. 2011;**61**:e49-62.
17. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med*. 2002;**16**:297-303.
18. Emanuel EJ, Fairclough DL, Wolfe P, et al. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? Is it helpful? *Arch Intern Med*. 2004;**164**:1999-2004.