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Clinician perceived good practice in end-of-life care for patients with COPD

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Patients with chronic obstructive pulmonary disease (COPD) have significant end-of-life needs, but are much less likely than patients with cancer to access or receive appropriate palliative care. Little is known about the existing availability or quality of available services within the United Kingdom. We surveyed 100 NHS acute hospitals enquiring into the provision of care for patients with COPD and requesting examples of current good practice that might be used to set standards. Forty-two percent of hospitals had formal palliative care arrangements for patients with COPD, whereas 59% had plans to develop or further develop services. Analysis of qualitative data suggested four strands that highlighted good practice; teams, care pathways, service components and linkages. These data may help to inform the debate leading to the development of standards in end-of-life care for patients with COPD. *Palliative Medicine* (2008); **22**: 855–858

Key words: palliative care; pulmonary disease chronic obstructive

Background

There is evidence from recent studies that patients with chronic obstructive pulmonary disease (COPD) are less able to access or be offered appropriate palliative care at the end-of-life compared with patients suffering from cancer.[1,2] There is an implicit assumption in these data that palliative care services for patients with COPD are not well developed and of poor quality.[3] Little is, however, known of the true prevalence or nature of palliative care services currently offered to patients with COPD in the United Kingdom and even less of possible areas of good practice that exist.

The National Chronic Obstructive Pulmonary Disease Resources and Outcomes Project (NCROP) is a 4-year programme led by the Royal College of Physicians of London, The British Thoracic Society and The British Lung Foundation (BLF), which aims to assess the impact of peer review on the development of COPD services in UK acute hospital Trusts. As part of that programme, a baseline data collection survey of participating hospitals was carried out in 2007. Within that survey data were collected on the palliative care services offered to COPD patients with the specific identification of areas of good practice that might be disseminated to other units with the intention of raising standards. We report here the findings of that survey.

Methods

The NCROP project team enrolled 100 UK NHS acute hospital Trusts whose respiratory leads volunteered to participate in the programme in response to a written invitation sent to each of the 260 acute UK NHS Trusts in existence in 2006. Each participant was e-mailed a self-assessment survey of the COPD services offered by that unit. Included within the questionnaire were three questions regarding the palliative care services offered to patients with COPD at that institution and an opportunity to outline in free-text any areas of good practice in palliative care offered in the form of qualitative data. The three specific questions were formulated by the NCROP multidisciplinary steering group and were phrased as follows: Are there any formal arrangement for patients with COPD to receive palliative care in your area? Is there a policy for providing patient information about end-of-life care to severe patients with COPD whilst in a stable clinical state, for example, in outpatients or on discharge from hospital? Does the unit have plans to develop or further develop palliative care services for patients with COPD? (the second question was formulated after a theme of paucity of patient available information regarding other services for patients with COPD was identified from focus groups run by the BLF).

All data were entered into an SPSS (SPSS V15.0) database. Answers to these questions were analysed using simple descriptive statistics. The qualitative data were analysed independently by two experienced researchers (CMR and AS) using emergent grouped themes analysis.[4] Themes analysed independently were then

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compared and merged after consultation between researchers. Sub themes within the main themes were identified and recorded with examples taken from the text responses as illustrations.

This study was approved by the joint UCL/UCH MREC.

Results

All 100 units completed and returned the survey form. The responses to the three questions about palliative care services offered were:

1) Are there any formal arrangement for patients with COPD to receive palliative care in your area? 42/99 (42%) units responded yes.
2) Is there a policy for providing patient information about end-of-life care to severe patients with COPD whilst in a stable clinical state, for example, in outpatients or on discharge from hospital? 11/98 (11%) of units responded yes.
3) Does the unit have plans to develop or further develop palliative care services for patients with COPD? 59/98 (59%) of units responded yes.

The analysis of qualitative data of examples of good practice identified four main groupings. These were: i) Teams, ii) Care pathways, iii) Service components and iv) Linkages. Each theme could be further defined by sub themes. A summary and illustrations are provided in Table 1.

Discussion

There is evidence from previous studies that patients with severe COPD at the end-of-life are multi-symptomatic and suffer a poor quality of life.[1,3] It is also evident that such patients are less likely to access or be offered appropriate palliative care in comparison with patients with cancer at the end-of-life.[1,2] The corollary of these findings is that there must be an improvement in the services offered to such patients with COPD.

Currently there is no national service framework that includes end-of-life patients with COPD although one for COPD in general is due for publication in early 2009. On the contrary to the literature on end-of-life care in patients with cancer, there is relatively little that may be drawn from the research literature to inform standards of good practice for COPD. It is important that palliative care services for patients with COPD are designed for that purpose and do not simply transfer, without review, care pathways that are effective in malignant disease but unproven in COPD care. There is potentially much to gain in the palliative care community from drawing on the existing expertise and research experience of respiratory specialist teams[5] that have traditionally taken responsibility for patients with COPD at all stages of life. This survey has identified a number of specific exam-

Table 1 Grouped themes analysis of survey data of examples of palliative care good practice

Theme	Sub theme	Example
Teams	Members	Inclusion of a psychologist/a dietician, in a joint PC and COPD team/Macmillan nurse post covering COPD and interstitial lung disease patient care/British Lung Foundation funded palliative care COPD nurse/nurse consultant leads the COPD-palliative care team liaison
	Training	Respiratory nurse specialist trained in PC/Respiratory nurse taking MSc in PC/ palliative care team teach respiratory ward nurses
Care pathways	Formal	Implementation of the Liverpool care of the dying pathway on respiratory ward
	Policies	Assess all discharged patients who had type II failure/provision of patient information for end-of-life care to severe patients in outpatient setting/ written guidelines for referral to PC service
	Patient communication	Card system for those not wanting hospital admission during an exacerbation/ patient leaflets on end-of-life care options
Service components	Specialist services	A dyspnoea clinic for severe patients with COPD/Cognitive behavioural service/ establishing a research evaluation team for COPD palliation/Bay in respiratory ward set aside for palliative care COPD and other respiratory patients/Drop in centre for severe patients with COPD
	General services	Day care centre/respite care/offered to end-of-life patients with COPD/5% PC activity specifically funded for COPD/funding for administrative support to fund the palliative care COPD service/
Linkages	Acute sector	Formal MDT with PC team to discuss severe patients with COPD access to local hospice beds/ joint PC and COPD nurse team
	Acute/community	Joint respiratory nurse with palliative nurse home visits/ GP led cross sector palliative care COPD team/primary care awareness package for COPD end-of-life options delivered by 2ry care

COPD, chronic obstructive pulmonary disease; PC, palliative care; MDT, multi disciplinary team.

ples of perceived good practice in palliative care offered to end-of-life patients with COPD (Table 1).

The responses received to the three specific questions in the survey are illuminating and may help to explain why patients with COPD access palliative care services much less than their cancer patient counterparts. Less than a half of units currently have available within their area a palliative care service that includes patients with COPD. The implication is that nearly 60% end-of-life COPD sufferers will simply not have a local service provision to access. On the contrary, a survey of palliative care services for end-stage heart failure patients conducted in 2004 reported that 85% of services were able to accept cardiac patients although only 6% of units had formal referral criteria.[6] Others have described a dearth of formal service provision for those with severe long-term conditions.[7] It may be, however, that the absence of formal pathways and agreements severely limits patient access to services that in theory are open to patients with non-malignant disease. Any standard for service must, therefore, emphasise the urgent need for the introduction of agreed pathways that encourage access to palliative care for a wider range of patients and carers.

Of equal concern is the apparent lack of pro-active engagement with severe patients with COPD in discussing end-of-life issues that would in turn lead to access to palliative care. Only 11% of the units had such a policy that may increase patient led demand for better and more available services. It has previously been reported that both clinicians and patients with COPD themselves find initiating end-of-life discussions difficult, but there is some evidence that patients are more likely to want this and clinicians less likely to provide it.[8,9] Nevertheless, there are examples from our survey (Table 1) of good practice in this area, including the provision of written information about end-of-life care issues given to stable severe patients with COPD. Although some clinicians cite the difficulty in predicting end-of-life in COPD,[10] where prognosis is more variable compared with cancer care, there are markers that predict poor outcome; a policy of actively engaging patients who have been admitted to hospital with respiratory failure and treated with non-invasive ventilation (NIV) in end-of-life care choice discussions is one such example provided in this survey. Our own research[11] has shown that unwell patients with COPD when admitted acutely with an exacerbation are often unprepared to participate in critical decisions about medical management, including NIV, as such issues have not previously been raised. Policies that meet this need identified in this survey (Table 1) include joint home visiting of severe patients with COPD by a respiratory and palliative care nurse where such eventualities are discussed and recorded for the benefit of both patient and health carers. In some instances, this results in the issuing of a card that states the patient's preferences in the event of a sudden deterioration.

What is more hopeful in the survey returns is the response to the third question, where 59% of units had plans to develop or improve palliative care services for patients with COPD. Although this raises questions for the remaining 41% of units with no such plans, there are equally concerning issues for the proactive group. Without standards or an evidence base to draw from it is more difficult to know how to develop such a service. The free text examples of perceived good practice in this survey were drawn into four themed areas that may be helpful in providing a development framework. These were; Teams, Care Pathways, Service Components and Linkages. A summary of these components might be that the team is critical to success of the service and although its exact composition is as yet to be determined, there are a number of members who are key, including staff with both respiratory and palliative care experience. There are already accepted care pathways available to teams,[12] but formal policies are needed to introduce and apply these to relevant patients. Service components should be designed specifically to meet the needs of patients with COPD, for example, palliation of breathlessness that is so common yet poorly managed in end-of-life COPD.[13] Although much can be transferred from the experience of cancer patients, there are elements that require specific COPD-targeted services.

An excellent palliative care service that is stand-alone is less likely to succeed in providing comprehensive COPD care. Linkages across departments in secondary care and between the acute and community settings are cited as good practice. Within these broad statements are a number of interesting innovations described within the survey that bear further assessment, such as the British Lung Foundation support for specific COPD palliative nurses.

It is accepted that the examples provided here are only perceived to be of best practice, and evaluation of such models of care and prospective research in the area of COPD palliative care is much needed. In the absence of these more rigorous assessments, we must use what is available to us. The current study is, to our knowledge, the largest of its kind, although the 100 hospitals represent less than half of all UK acute Trusts. As Trusts are drawn from all four countries of the United Kingdom, there is no reason to suspect a systematic geographical bias, although it is possible that units enrolled in a study may have more enthusiastic teams with better-developed services. The data here, therefore, probably represent a best case scenario.

This survey has, however, identified areas of practice in end-of-life care for patients with COPD perceived by the 100 acute respiratory units involved in NCROP to be of high quality and innovative. To have identified such areas of perceived good practice offers a starting point from which a debate may begin to define better the core standards and specific service elements that may go some way to meet the needs of end-of-life patients with COPD.

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