

Palliative care service provision for Chronic Obstructive Pulmonary Disease (COPD) patients – mapping current and proposed service development against palliative care gold standards

Buxton KL*, Roberts CM, Buckingham RJ, Pursey NA, Stone RA.

*University College Hospital, London, UK.

Clinical Standards Department, Royal College of Physicians, London, UK.

CLINICAL STANDARDS



Introduction

- Chronic Obstructive Pulmonary Disease (COPD) is a progressive and life limiting condition associated with a significant symptomatic burden particularly in the end stages. Symptoms can be physical, psychological, social and spiritual and can reach a severity often reported by those with a terminal malignant illness.¹⁻³
- COPD patients are less likely to access palliative care services at the end of life due to the poor provision of information about end-of-life options available¹⁻³ and the variable levels of services provided.⁴⁻⁵
- This disparity in service provision and access between patients with malignant and non-malignant end stage disease has led to the development of the Gold Standards Framework (GSF) that defines standards for the provision/cohesion of end-of-life care.⁶
- The data presented here maps the current and proposed future areas of service development for COPD patients against the GSF.

Methods

- The 2008 national audit of COPD care included a survey of resources and organisation of care within which was a free text box to describe current examples of good practice in palliative care and proposed service developments.
- These examples were analysed using emergent grouped themes analysis and then mapped against the seven key standards defined by the GSF.
- All 184 acute trusts admitting COPD exacerbations from the 4 countries of the UK and offshore islands were invited to participate in the electronic web based survey between March & May 2008. Trusts responded as respiratory service units which in some cases meant a Trust may have more than one acute unit and made more than one return.

Results

- 180/184 (98%) eligible trusts responded to the survey providing 239 respiratory units in total.
- The emergent grouped themes analysis of free text box answers regarding good practice identified four key areas. These were: 1) Service Components, 2) Education, 3) Management Tools and 4) Linkages. Each key area was further categorised into sub themes. (Table 1)
- To put the themes identified into context considering proposed best practice from the palliative field, table 2 matches the key standards from the GSF against the identified themes. The control of symptoms standard matches to two themes because it incorporates both advance care planning and symptom management. This data demonstrates the emergent themes meet only some of the proposed structure for holistic service development.
- Further analysis allowed distinction between services already in place and those in the planning stages. This analysis is given in table 3 mapped alongside the GSF key standards.

Tables

Table 1: Emerging group themes analysis of examples of good practice

Theme	Sub themes	Examples of good practice
Service Components	<i>Generic Palliative Care Services</i>	Availability of hospice inpatient beds, outpatient clinics, community specialist nursing teams, day hospice, hospice @ home teams, complementary therapies, palliative social worker, dietician with special interest in palliative care, bereavement support, telephone advice and support 24/7
	<i>Specific Palliative Services related to COPD</i>	Breathlessness clinic provided by COPD, PC or jointly/chronic disease management clinic with clinical psychologist/MDT working to teach relaxation techniques and management of panic episodes
Education	<i>Professionals</i>	Teams - Joint workshops between specialties/training for COPD nurse in non malignant PC
	<i>Patients</i>	Individuals - Extended role of COPD nurse to include EOL skills/secondment of COPD nurses to PC and vice versa/COPD nurse completing MSc in PC Face to Face - Advance care planning in last 12 months of life/EOL discussions in outpatients or pulmonary rehab programme/COPD physiotherapist demonstrating NIV to patients Written Information - Provision of leaflets regarding EOL decisions, PC options for management, NIV, resuscitation
Management Tools	<i>Pathways/Frameworks</i>	LCP in use on respiratory wards/use of GSF to address EOL care and preferred place of care/use of EOL care strategy to guide service development/use of advanced decisions & preferred priorities of care document to initiate EOL discussions and document decisions
	<i>Guidelines</i>	Symptom control guidelines jointly developed between PC and respiratory team/Identification of prognostic indicators to help highlight patients with PC needs
Linkages	<i>Within a Setting</i>	Joint hospital visits, home visits and clinics between COPD and PC workers/link GSF nurse co-ordinating community care/joint monthly MDT to discuss end stage COPD patients
	<i>Across Settings</i>	Joint home visits between COPD physicians and PC workers/COPD hospital database used to flag those with deteriorating prognostic indicators so the GP can be alerted to include them in GSF/joint hospital and community MDT
	<i>Information Distribution</i>	EOL discussions taking place in clinic are documented and forwarded to GP, patient, local A&E department/out of hours forms used to communicate with GP's and ambulance service about terminally ill patients for whom hospital transfer and resuscitation are inappropriate

COPD – chronic obstructive pulmonary disease, PC – palliative care, MDT – multidisciplinary team, EOL – end of life, NIV – non invasive ventilation, LCP – Liverpool care pathway, GSF – gold standards framework, GP – general practitioner

Table 2: Mapping of emerging themes to GSF key standards

Themes	GSF key standards
Service Components	Carer support
Education	Continued Learning Control of symptoms
Management Tools	Care in dying phase Control of symptoms
Linkages	Communication Continuity out of hours Co-ordination

Table 3: Analysis of service development mapped to levels recommended in the GSF

GSF key standard	Selected examples of good practice	Number of units giving an example to demonstrate part/all of the key standard:	
		In place	Planned
Communication	COPD patients placed on GSF register and discussed with whole primary care team and secondary care based respiratory nurse Palliative care in respiratory disease group involving both hospital & community teams meets 6 monthly to discuss patient care	5 (2.1%)	9 (3.8%)
Co-ordination	Local GSF link nurse co-ordinates community care Community matrons providing support at home and organising care as needs change	2 (0.8%)	2 (0.8%)
Control of symptoms	Symptom control guidelines developed jointly between COPD/PC teams GSF/Preferred priorities of care/advance decisions documents used to initiate advance care planning and record decisions made	17 (7.1%)	23 (9.6%)
Continuity out of hours	EOL discussions held in outpatient clinic are recorded and distributed to other lead professionals i.e. GP EOL decisions, including copy of resuscitation status are recorded and distributed to out of hours professionals e.g. GP 24/7 cover, ambulance service, local A&E	3 (1.3%)	0
Continued learning	Training sessions for COPD team on PC skills Secondment of COPD nurse to PC team for 1 day per week/COPD nurses completing MSc in PC	15 (6.3%)	8 (3.3%)
Carer support	Hands on carer support via hospice @ home/night sitting service Complementary therapies/psychological & bereavement support	6 (2.5%)	2 (0.8%)
Care in dying phase	Routine use of LCP	38 (15.9%)	6 (2.5%)

Conclusions

- These national data suggest only limited areas of current good practice for palliative care services orientated to COPD patients.
- Planned service developments map predominantly to only three of the recommended key standards namely control of symptoms, continued learning and care in the dying phase.
- Future service developments should take into account the GSF key standards with particular development of services addressing communication, co-ordination, carer support and continuity out of hours.

References

- 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; 55:1000-1006.
- Elkington H, White P, Addington-Hall J, Higgs R, Pettinari C. The last year of life of COPD: a qualitative study of symptoms and services. *Respiratory Medicine*. 2004; 98:439-445.
- Elkington H, White P, Addington-Hall J, Higgs R, Edmonds P. The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine*. 2005; 19:485-491.
- Partridge MR, Khatri A, Sutton L, Welham S, Ahmedzai SH. Palliative care services for those with chronic lung disease. *Chronic Respiratory Disease*. 2009; 6:13-17.
- Roberts CM, Seiger A, Buckingham RJ, Stone RA. Clinician perceived good practice in end-of-life care for patients with COPD. *Palliative Medicine*. 2008; 22:855-858.
- Thomas K & Department of Health. Gold Standards Framework: A programme for community palliative care. www.goldstandardsframework.nhs.uk 2005.

This work was carried out under the auspices of the National COPD Resources and Outcomes Project (NCROP) – a partnership between the Clinical Effectiveness and Evaluation unit at the Royal College of Physicians of London, The British Thoracic Society and the British Lung Foundation, and was fully funded by The Health Foundation

