

Acute to palliative care management of COPD: Exploring the older patient, carer and health professionals' treatment decisions

Karen Iley, School of Nursing Midwifery & Social Work
Professor Ann Caress, School of Nursing, Midwifery & Social Work
Dr Catherine Walsh, School of Nursing, Midwifery & Social Work
Dr Jonathon Simpson, Respiratory medicine, Central Manchester Foundation Hospital Trust
Burnage Breathe Easy Group

Purpose

This proposed pilot study will focus on older people with Chronic Obstructive Pulmonary Disease (COPD) and associated co-morbidities such as heart failure. The decisions they and their clinicians make in the context of ageing and it's relationship with moving from acute medical management towards palliative care management in readiness for end of life care will be explored.

Background

The core population of patients requiring palliative care is increasing due to the ageing population in the UK and a difficulty faced is that most services are focussed on meeting the needs of younger patients typically those with cancer (Gardiner et al 2011). A particular challenge is to meet the needs of older people with advanced progressive and incurable diseases by ensuring access to appropriate services (WHO 2004). COPD is the fifth largest cause of death in the UK and rates are predicted to increase (DOH 2011). It is known that the prevalence of COPD increases with age, with the peak age range being 70 to 80 years. The disease is one of the most common causes of admission to hospital and rates have increased by fifty percent in the last ten years (Price et al 2006). However, healthcare services provided across the UK for patients with COPD vary widely, firstly, by length of hospital stays, secondly, by mortality rates and thirdly, the type of services and by support offered to patients (Jarvis et al 2007). How and why services influences these outcomes in patients with COPD is not clear as the role of the healthcare team and the organisation of care within respiratory services and for older people have not been effectively evaluated (Price et al 2006)

Patients with COPD are less able or likely to be offered appropriate palliative care at the end of life compared to patients with cancer despite having comparable levels of symptom severity and psychosocial needs (Spathis & Booth 2008). The reasons for this are not fully known but may be due to less involvement of specialist palliative care (Gardiner et al 2011). There is limited evidence that health professionals enable informed patient and carer decision making despite patients needing this information. There is some evidence to show that specialists in care of the older person may assume they are able to provide appropriate care themselves (Gardiner et al 2011). However, there has been limited exploration of how older people with COPD themselves view their illness in the context of a life limiting long term condition that is fatal and therefore requires making choices about future treatment. Coupled with this there is limited evidence that this has been explored with reference to older people cared for by acute medical and respiratory specialists in secondary care (Gott et al 2009).

Also the need to consider advance care planning for this group of patients is warranted yet health professionals remain unsure of how and when to discuss this with their patients (Walshe et al 2008). It is known that the relationship between health professionals and patients affects communication and this also varies according to the type of decision making model used (Caress et al 2005). Exploring why this does not happen with reference to ageing and identifying when such discussions should occur is essential in developing a coordinated approach to COPD palliative care management in the context of secondary care and its interface with services that meet the needs of older people.

Research Aim

To examine decision making in relation to acute and palliative care for older patients with COPD in contrasting care settings, identify factors underlying different orientations towards the provision of care (involvement of patients and carers, cure or palliation) and factors that facilitate or impede access to palliative care.

Research questions

- 1) How do older patients and their carers make choices for treatment and care as the emphasis in COPD management shifts to palliative care?
- 2) How does the concept of ageing influence health professionals when supporting older people with COPD in their decision making processes?
- 3) When do health professionals decide to shift to a palliative care emphasis in their management of older patients with COPD?

The pilot study

The study will use a qualitative design using methods that are consistent with this type of research. Data will be collected from a number of sources: firstly, by in-depth interviews with patients and their carers' and health professionals, and secondly, by observation to observe discussion and decision making between patients and their carers and health professionals. The research will be conducted in secondary care settings and in patients' homes.

Sample/Recruitment

The sample will consist of patients with moderate to severe COPD and the key staff who care for them in acute secondary care services. It is anticipated that 4 patients will be interviewed, as well as carers for some patients and members of the respiratory, palliative and acute medicine care teams who are involved in their care.

Patient recruitment: Adults will be recruited with moderate to severe COPD who have been admitted to hospital with an exacerbation of their COPD and identified as a suitable patient by medical staff for inclusion in the study. Patient recruitment will be stratified to select both patients who are already identified as in the palliative phase of their illness and those who are currently receiving acute care, but who may be anticipated to be moving to a palliative phase of illness within the next 18 months.

Carer recruitment: Adult carers will be recruited if they are providing informal care to patients and identified as being the lead informal carer (by the patient or health professionals) as part of the study. The target recruitment is for one carer to be recruited per patient who has been interviewed.

Health care professional recruitment: All healthcare professionals will be invited to participate if they provide continuing care related to COPD management of recruited patients.

Data Collection

In-depth interviews with patients: An interview guide will be developed from published literature and in consultation with a service user and carer group. Patients will be interviewed after discharge, either in their home or on return for follow up in the out-patient clinic.

In-depth interviews with carers: Some of the patients' main carers will be interviewed separately and asked about their understanding of COPD and treatment options and about issues identified from published literature. Again the interview guide will be developed in consultation with a service user and carer group. The interviews will take place once the patient has been discharged home.

In-depth interviews with health care professionals: A selection of the interdisciplinary team in the acute care and specialist respiratory care settings will be interviewed to obtain their views on illness trajectory in COPD and how, when and with whom they would initiate palliative care management with their patients.

Observation: Observation will be conducted in the patient's home or out-patient clinic to observe discussion, interactions and decision making between patients, their carers and health professionals. Data collection will be guided by findings from initial observations and interviews, consultation with the service user group, and literature reviews. Data will be collected using hand written field notes and, if full consent is obtained, audio recordings of discussions that take place during meetings.

Data analysis

Analysis will follow the principles of Framework Analysis, as an advantage of this method is that it is matrix based and enables data to be moved back and forth between different levels of abstraction, without losing sight of the raw data, in a rigorous and transparent manner. Computer assisted software will be used to facilitate this process. From this, conclusions to aid the development of a specific research proposal can be made.

Specific Outcomes

The findings of the study will be used to develop a proposal for submission to the NIHR SDO/HSR and to Age UK within 6 months of completing the pilot study. One paper will be presented at an ageing focussed conference and a paper will be submitted for publication.

References

- Department of Health (2011) An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) & Asthma in England.
- Caress, A., Beaver, K, Luker, K, et al (2005) Involvement in treatment decisions: what do patients with asthma want? Results of a cross sectional survey. *Thorax* 60, 199-205
- Gardiner, C, Cobb, M, Gott, M. & Ingleton, C (2011) Barriers to providing palliative care for older people in acute hospitals. *Age and Ageing* (2011) 40, 233-238
- Jarvis, S, Ind, P & Shiner, P.J. (2007) Inhaled therapy for older people with COPD: time for re-evaluation? *Age and Ageing* 36, 213-218
- Price, L. C, Lowe, D, Hosker, D, et al (2006) UK National COPD Audit 2003 and impact of hospital resources and organisation of care on patient outcome following admission for acute COPD exacerbation. *Thorax* 61, 837-842
- Spathis, A. and Booth, S. (2008) End of life care in chronic obstructive airways disease: in search of a good death. *International Journal of COPD* 3, 1, 12-29
- Walshe, C, Todd, C, Caress, A et al (2008) Judgements about fellow professionals and the management of patients receiving palliative care in primary care: a qualitative study. *British Journal of General Practice* 58, 264-272
- World Health Organisation (2004) Better Palliative Care for Older People. www.eapcnet.org/ accessed 30/12/11