

PACE Study: plans and care expectations

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Summary

This study seeks to raise the standards of care for all people at the end of life through investigating the existence and nature of the transition to palliative and end of life care in two contrasting illnesses; incurable lung cancer and advanced chronic obstructive pulmonary disease (COPD).

Background

Research over the last 30 years has shown that whilst many people received excellent care in the last year of life from GPs and District Nurses, many do not due to late identification of nearing life's end, inadequate communication about the illness and its future implications, inadequate symptom control, insufficient nursing support and uncoordinated care out-of-hours. Raising the standard of care for all people remains a major challenge that this study will address through investigating the nature of transition to palliative and end of life care in two contrasting illnesses; incurable lung cancer and advanced COPD.

Over two thirds of lung cancer patients are incurable at presentation, some with a rapid trajectory to death that is potentially well served by current palliative care models. Others have a more gradual and chronic dying trajectory that may not fit so well with current services and care models. Death from COPD often occurs after a long period of functional decline, uncontrolled symptoms, emotional distress and social isolation. Current services frequently do not meet these patients' needs.

Using interview methodology this study seeks the views of patients with progressive cancer and COPD, as well as their lay carers and health professionals, on the appropriateness of a palliative care approach and conversations concerning the end of life. Interviews will explore their views on:

- The existence and nature of their transition from chronic illness to palliative and end of life care
- Their care, support and information needs at this stage of illness
- The aspects of care they regard as key markers of high quality care at this stage of illness

Early Findings

Data collection is now complete, with data analysis underway. Initial analysis is highlighting the following:

- Patients value professionals taking an holistic approach to care
- Patients value developing a trusting and caring relationships with their GPs and nurses.
- Family and friends are of great significance
- Both patients and their supporters need a 'safety net' when times are difficult.
- Transitions from chronic disease management to End of Life Care can be difficult to identify, especially for those with COPD.
- GPs often rely on Clinical Nurse Specialists to help provide continuity of care for their patients, a resource that is often less available for those with COPD than lung cancer.

Why is this work important?

This project will help identify best practice in service delivery, end-of-life care and support, and will involve people affected by cancer in research. The project also reflects the top priority research theme of the Macmillan Listening Study: the impact cancer has on life, how to live with cancer and related support issues.

The project will bring clear benefits to people affected by cancer by generating a better understanding of the nature of transition to palliative care for people living with cancer and non-cancer progressive illness, leading to:

- a) Improved provision of clinical care, support and information for patients and lay carers at this most difficult time of deteriorating health
- b) Identification of measures of good care of importance to patients, lay carers and health professionals that will serve to inform future developments of the NHS End of Life Care Strategy and the GP Quality and Outcomes Framework.

Publications

Several papers are in preparation.