

Palliative care for all: challenges and implementation

Lynch M., Conway J., Edghill A.

Objective:

The Extending Access Study sought to determine how both specialist and non-specialist palliative care could extend to people with non-malignant diseases, with an initial focus on three conditions with high morbidity and mortality.

Methods:

The Irish Hospice Foundation and the Health Service Executive (HSE) undertook a joint study – the Extending Access Study - in 2007/08 on how specialist and non-specialist palliative care could be included in the care pathway of people with non-malignant conditions, with an initial focus on COPD, dementia and heart failure.

The physical and psychological symptom burdens of many life-limiting, non-malignant diseases compare to those of cancer and may be of longer duration. Palliative care has a role in the care pathway of people with non-malignant conditions, but traditionally specialist palliative care (SPC) services have been organised to respond to the needs of people with cancer.

The Project Team undertook a wide-ranging literature review and consultation through collaborative working groups with representation from specialists within the field of palliative care and clinical and professional representation from the specialist areas selected. These were guided by a national steering group. The draft report was made available for consultation over two months in 2008. The final Report of the study “Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks” was published in December 2008.

Results:

Seeking to incorporate appropriate levels of palliative care into the care pathway of people with non-malignant diseases will be challenging because of the complex relationships within health care provision. The study’s report “Palliative Care for All” outlines findings and recommendations on extending access to these patient populations. Challenges identified:

- Uncertain disease trajectories in non-malignant diseases
- Establishing clarity on the role of palliative care in non-malignancy
- Inconsistent access to specialist palliative care
- Lack of comprehensive chronic disease-management services in Ireland
- Developing collaborative approaches between disease-specific specialists, specialist palliative care, primary care and older persons’ services for those with advanced life-limiting conditions.

Conclusions:

The implementation of the report’s recommendations includes:

- Developing action research projects through the appointment of clinical facilitators to pilot and develop service models integrating palliative care within disease-specific frameworks.
- Evaluating the benefits of such service models and identifying how they can transfer to other sites.
- Generating disease-specific palliative care information material on non-malignant conditions including COPD, heart failure, dementia, chronic kidney disease, scleroderma, pulmonary fibrosis, cystic fibrosis and multiple sclerosis.
- Developing standardised eligibility and discharge criteria for access to SPC.
- Advocating and promoting awareness of palliative care for non-malignant diseases through production and dissemination of educational materials based on the study’s findings.