

End of life care for non-cancer patients

Jason Boland, Senior Lecturer and Honorary Consultant in Palliative Medicine, Hull York Medical School, Hertford Building, University Of Hull, HU6 7RX, UK

Email: .boland@hyms.ac.uk; Tel: 01482 463482; Fax: 01482 464705

Miriam Johnson, Professor of Palliative Medicine, Hull York Medical School, Hertford Building, University Of Hull, HU6 7RX, UK

The Authors declare that there is no conflict of interest.

The origins and early development of palliative care focussed on patients with cancer, apart from sporadic developments in a few non-malignant diseases such as MND and HIV. In the UK, this has been compounded by the setting of palliative care outside the National Health Service, principally funded by cancer-related charities who, at the time were instituted to relieve the suffering associated with cancer. When the modern hospice movement began, the course of malignant disease was seen as more predictable, with a defined palliative phase when anti-cancer treatments were no longer indicated. In the UK and many areas of the world where it was first adopted such as the Canada, USA, mainland Europe and Australia, this led to the traditional model of palliative care services, involved only in people with a prognosis of a few weeks or months. As a result, services have focused primarily on cancer leading to service and symptom management inequalities for equally needy patients with non-malignant diseases.

Meanwhile, advances in cancer therapy have changed the course of malignant diseases, in some cases, to mirror that of long term conditions. Many palliative care services have been able to adapt their service model to one of integrated care alongside the oncology team. Although an integrated approach to palliative care access appears to be more difficult to do in the USA and other countries where funding for such services remain linked to the traditional “either/or” model(1), recent evidence from the USA supports earlier access to palliative care services in metastatic non-small-cell lung cancer in terms of improved quality of life, and more surprisingly, survival(1).

The move to palliative care services for people with cancer according to need rather than prognosis resonates with literature that highlights patients with non-malignant conditions having an equivalent, or in some studies greater, symptom and carer burden compared with those with cancer(2, 3). Although the needs of patients with diseases other than cancer may last longer, they have less access to supportive and palliative care(4). The call for specialist palliative care services to accept patients according to need rather than diagnosis is embedded in the 2008 End of Life Strategy in the UK(5). However, compliance with this aspect of policy remains inconsistent so that many local

services fail to support patients with a wide range of diagnoses. The referral rate for patients with non-malignant diseases is improving in the UK, but remains comparatively low and does not yet match the need of patients and their carers.(6)

Over 15 years ago, extrapolating from cancer data, it was estimated that, of those who die from non-malignant disease in England and Wales each year, over 71,000 people may need specialist palliative care.(7) Recent reports from Germany and Australia indicate that non-cancer patients are still in the minority within specialised inpatient palliative care institutions(2, 3). It is only now, as palliative medicine is expanding into non-malignant diseases, that a picture is emerging and symptom based research in patients dying of non-malignant disease is beginning to reveal the true extent of patient and carer needs in this population.

Challenges for specialist palliative care services

In North America and Europe, the population is growing older with a consequential increase in the prevalence of long term conditions. It is estimated that by 2031 people aged over 65 will make up 22% of the UK population with a concomitant rise in the death rate, along side the prevalence chronic conditions (8). However, one of the biggest challenges to health and social care services is the increase in those with dementia, multiple co-morbidity and frailty. Inherent in these demographic changes is a reduction in the number of spouses and contemporaries able to do the informal caring. With the age of retirement rising, employment may claim the 60 to 70 year olds who currently provide many hours of unpaid support for those at the end of life. This landscape is very different from the traditional cancer-related palliative care services in hospices and specialist units.

Changing funding structures and service performance assessments

Hospice and palliative care services have been slow to embrace outcome measurements to demonstrate the benefits of their services(9). Palliative care services need sustainable funding to provide the best possible care for the patient population that require their skills. In an ever harsher financial climate, funders need to be convinced, perhaps now more than at any other time in the history of the hospice movement, of the cost effectiveness, in terms of net-benefit, of palliative care services. Such net benefit should be recognised as important and relevant to patients, caregivers, clinical staff, and the health system providing care with clear outcome measures for each domain (9).

The future of hospice care

As long ago as 1963, Hinton observed that distress in the dying was not necessarily greatest in those with cancer(10). Fifty years later, palliative care services are starting to respond to the needs of those with other conditions. However, radical changes are required in order for them to ensure their relevance to patients, carers, clinicians and commissioners. In a patient outcome driven health service, it is vital that they engage in competition for funding, ensuring appropriate competencies and establishing a role in the new world of multi-morbidity, dementia and frailty. Skills with symptom management, communication and care of the dying patient are deeply rooted, valuable and transferable; but evidence regarding the best way for palliative clinicians to disseminate these skills in the care of people with non-malignant disease is still of low quality. A UK Commission into the Future of Hospice Care led by Help the Hospices (a major UK charity) has been set up in response to this required change in direction and is expected to report in the autumn of 2013.

If we accept the premise that provision of adequate palliative care, particularly at the end of life for patients with all diseases, is a matter of equity, then services will be required to change. The nature

of the change required to achieve equity of provision is less clear. The imperative of palliative care service provision for those with non-malignant disease raises three very important questions for the future of specialist palliative care service provision in this much broader context:

- What are the palliative care needs of changing populations?
- What is the role of specialist palliative care services in addressing these needs for patients with all diagnoses?
- What is the most cost-effective way to provide such services systematically throughout health services?

In this issue, we see some welcome exploration of the challenge, but guess what? Further urgent research is vital.

References:

1. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;**363**:733-42.
2. Ostgathe C, Alt-Epping B, Golla H, et al. Non-cancer patients in specialized palliative care in Germany: what are the problems? *Palliat Med*. 2011;**25**:148-52.
3. Currow DC, Agar M, Sanderson C, et al. Populations who die without specialist palliative care: does lower uptake equate with unmet need? *Palliat Med*. 2008;**22**:43-50.
4. Murray SA, Boyd K, Kendall M, et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *Bmj*. 2002;**325**:929.
5. Department of Health. End of Life Care Strategy, Promoting high quality care for all adults at the end of life. 2008; Available from: [://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy](http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy) (last accessed 3 January 2013).

6. National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services. MDS Full Report for the year 2010-2011. 2012; Available from: [://www.ncpc.org.uk/sites/default/files/MDS%20Report%201011%20A4_1.pdf](http://www.ncpc.org.uk/sites/default/files/MDS%20Report%201011%20A4_1.pdf) (last accessed 3 January 2013).
7. Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. *Palliat Med.* 1998;**12**:417-27.
8. Bayliss J, Sly F. Ageing across the UK. Regional Trends 42: 2010 edition. 2010; Available from: <http://www.ons.gov.uk/ons/rel/regional-trends/regional-trends/no--42--2010-edition/ageing-across-the-uk--.pdf> (last accessed 4 January 2013).
9. Currow DC, Abernethy AP, Bausewein C, et al. Measuring the net benefits of hospice and palliative care: a composite measure for multiple audiences-palliative net benefit. *J Palliat Med.* 2011;**14**:264-5.
10. Hinton JM. The physical and mental distress of the dying. *Q J Med.* 1963;**32**:1-21.