Changing emphasis in end-of-life care

This month's journal contains a symposium on palliative medicine without any sections relating directly to cancer. This may be surprising for those who still understand palliative medicine as an oncological offshoot. The need for the adoption of the palliative care approach beyond the confines of oncology has long been recognized. Four years before the opening of the first modern hospice at St Christopher's in Sydenham, John Hinton (1963) demonstrated that the morbidity of patients with non-malignant conditions was as great or greater than those with cancer (National Council for Palliative Care, 2007).

Despite this, through the years of rapid expansion of palliative medicine the focus has largely remained on patients with malignancy. This has created the anomaly in which patients with cancer could access certain services while those sharing similar morbidities and prognoses, but of a non-malignant origin, could not. The National Council for Palliative Care (2007) reports that currently over 92% of all hospice inpatients have cancer, while cancer accounts for only 26% of deaths each year in the UK (Hill, 2009).

Beyond cancer

The expansion of palliative medicine beyond cancer to end-of-life care, 'Care that helps all those with advanced progressive incurable illness to live as well as possible until they die' (Department of Health, 2007), has received impetus with the UK government's End of Life Care Programme and Strategy (Department of Health, 2008), encouraging the delivery of palliative care services to patients irrespective of diagnosis or location.

The driving factors behind the End of Life Care Strategy, apart from combating 'diagnostic apartheid', include the demographic care crisis facing the country, and concerns about dying patients being unnecessarily admitted to hospitals because of lack of support in the community. With rapidly increasing numbers of single households, decreasing availability of family carers, deaths due to outnumber births by 2030 and a surge in the numbers of those over 85 years of age living with multiple co-morbidities, we all need to wonder who will be there to support us when our time comes.

The expansion of end-of-life care initiatives creates some anxiety among those working in the acute health sector, as it raises difficult issues surrounding prognostication, appropriate goals of treatment, sharing care and dealing with patient and family expectations. The ongoing drip feed of media-courting patients seeking to challenge legislation on physician-assisted suicide increases the pressure still further, as does the high incidence of complaints surrounding the care of the dying.

Across specialties

Acute specialists are increasingly scrutinized in delivering care for patients with advanced disease. We walk the fine line between accusations of 'giving up' if palliative care is mentioned to 'over-medicalizing' dying if treatment is deemed too aggressive. A large component of general medicine and care of the elderly, managing patients with chronic degenerative conditions, has, in reality, long been palliative by another name. It is hubris to think that palliative medicine specialists have total monopoly of expertise in these areas. Further, the traditional cancer model for delivering palliative care needs to be adapted appropriately for other conditions with different patient needs and disease trajectories. Such models will only be developed through close collaboration, and through growth of interprofessional trust.

The introduction of the Liverpool Care Pathway in hospitals across the country has, along with the Gold Standards Framework and the Preferred Priorities for Care programmes, been central to the Department of Health's strategy of addressing common impediments to quality end-of-life care. The pathway has had significant impact to this end, not least because of the audit trail it creates allowing for care at the end of life to be monitored. Criticism of the pathway has centred around uncertainties in diagnosing dying, especially in patients with non-malignant conditions where prognostication can be so difficult.

That the Liverpool Care Pathway has attracted so much criticism in the media recently is in part the result of a failure to provide the necessary ongoing training and support to make its use understandable, effective and beneficial to patients and staff.

Liverpool Care Pathway 'lite', the application of a cheaper, diluted system of end-of-life care management by junior medical and nursing staff without the crucial training, teamwork, and experienced leadership was never the intention of the original creators in Liverpool, and it seems unfair that they have received the criticism for it.

The cost of treatments which can contribute to the prolongation of life for patients with terminal illness has been highlighted by the government's change in policy allowing patients to 'top up' NHS standard care. This may have implications in a death denying society for how palliative care is perceived in the future: 'If you can pay there is treatment, for everyone else there is palliative care.'

Yet palliative medicine has never been primarily concerned with securing a cheaper option for patients but rather delivering a standard of care that we would all want for ourselves or members of our family at the end of life.

How to do this

Achieving this goal will not be resolved by merely expanding specialist palliative medicine services – the needs of patients far exceed the capacity for a single specialty, but by increased palliative training and competence among all those caring for patients nearing the end of life.

Such training would include assessment and symptom management as well as communication skills including how and when to initiate crucial conversations with patients around end-of-life issues.

Increased confidence in the use of advance care plans by patients supported by the legislation contained in the Mental Capacity Act will allow for greater patient participation in treatment choices, which in turn may reduce some of the pressures felt by medical staff to resort to the default position of maximal intervention.

Specialist palliative medicine will continue to have a particular role to play in managing especially challenging symptoms or psychosocial issues. However, it will be in the forging of relationships with other services and specialties, and in promoting the highest standards of palliative medicine by all those involved with patients at the end of life, that palliative specialists may have most impact. BJHM

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KEY POINTS

- The Department of Health's End of Life Care Strategy seeks to overcome the diagnostic apartheid that has traditionally limited the preserve of palliative medicine to patients dying with cancer.
- Most medical specialties need to become competent to deliver quality general palliative care services to meet the need of the rapidly ageing patient population.
- The one standard of palliative care that we should strive for is care that we would want for our own families at the end of life.
- Palliative care services are not primarily concerned with saving money but in delivering the best care possible at a time when patients and families are particularly vulnerable.