

Claire Stark Toller looks at the need for increasing palliative care provision



PALLIATING

THE FUTURE

key points

Persistent requests for assisted dying are extremely rare when good palliative care is available. However palliative care, which should ideally be provided by both generalists and specialists, is unevenly available throughout the UK is mainly funded by the voluntary sector and is focussed on hospices. In spite of recent funding boosts, the provision of generalist, non-cancer and children's palliative care is particularly lacking. Recent initiatives like the National End of Life Care Programme, the Liverpool Care Pathway and the Gold Standards Framework have brought much needed improvements, but more funding and research is needed for the needs of dying patients in the UK to be met effectively.

Has there ever been another parliamentary bill to rival Lord Joffe's direct challenges both to Christian morality and to the prevailing ethos of medicine? Thankfully, his Assisted Dying for the Terminally Ill Bill, which sought to legalise physician-assisted suicide, was defeated in May.¹ One of the most powerful arguments used in the fight against it was that, if palliative care was available to everyone needing it, then very few patients would ask for assisted dying. The force behind this argument is the experience of palliative care doctors, 94 percent of whom oppose assisted dying legalisation.² But what are the key issues, ongoing needs and future challenges in the world of palliative medicine?

Inequalities

Ideally palliative care should be provided by generalists and specialists working together. Generalist palliative care (GPC) is provided by GPs, district nurses and hospital staff; whereas specialist palliative care (SPC) providers with specialist training - clinical nurse specialists and palliative care doctors - work in patients' homes, hospitals and hospices. Sadly though, palliative care services are unequally distributed around the UK. To understand why, we need to look at foundation and funding issues.

Postcode lottery

The majority of UK hospices were established because of local perception of need and charitable effort, resulting in uneven geographical distribution. Only recently, the North of England had a 30 percent above average need for palliative care but only half the average number of SPC beds; in contrast, Surrey had a need 20 percent below average but one of the highest ratios of SPC beds to population in the country.³ In 1999 the voluntary sector provided an estimated £170 million of the £300 million budget for all adult palliative care.⁴ However, little of this voluntary funding is directed towards GPC.

Cancer versus chronic disease

Patients with cancer access 95 percent of hospice and SPC services. Yet only 25 percent of the population die of cancer, whilst a further 300,000 patients with non-cancer related terminal illnesses would benefit from palliative care.⁵ The Alzheimer's Society suggested that ageism and stigmatisation have resulted in few dementia patients being offered palliative care, and The British Lung Foundation noted that patients with chronic lung diseases have limited access compared to patients with cancer.⁶ Furthermore, it is cancer that underlies the mapping and distribution of palliative care funding, and forms the basis for NICE guidance on palliative care.⁷

Children's care

The accessibility and availability of children's palliative care is still patchier. Most organisations support parents in caring for their children at home, with hospices providing respite care and complex symptom management. In 2004 there were 34 children's hospices but none had NHS funded beds.⁸ Different agencies compete for the small amount of available funding, leading to service fragmentation. The needs of adolescents and young adults are particularly poorly served.⁹ Furthermore, there is no consistent national strategy on children's palliative services.

Final resting place

Only four percent of deaths occur in hospices, in contrast to 56 percent in hospitals, 20 percent at home and 20 percent in care homes.¹⁰ So far, SPC provision has largely focussed on cancer patients in hospices and the community; it would be neither possible nor desirable to build sufficient hospices to manage more non-cancer deaths. So, the greatest need is for increased GPC and SPC provision for patients with non-cancer diagnoses in hospitals and at home.

Further funding

The New Opportunities Fund from the National Lottery allocated over £45 million in 2002 to support home palliative care services to patients in the most deprived areas, and improve access for black and ethnic minority groups.^{11,12} From 2002-2005 an additional £50 million per annum was provided for SPC only.¹³ £50 million has been given to Primary Care Trusts (PCT) since 2005 on the understanding that they support recurrent costs such as specialists' salaries. The Department of Health is also training community nurses in GPC.¹⁴ And since 2004 the government has been providing £12 million over three years to fund the National End of Life Care Programme. For children, in May the government announced an extra £27 million funding, in line with announcements in the Our Health, Our Care, Our Say White Paper and the Children's National Service Framework.¹⁵

In spite of these funding boosts, the more recent figures show that still only 35 percent of funding for English adult hospice and SPC services comes from the NHS. If these services are to continue, they will need to find ongoing funding from elsewhere. And in 2008 SPC funding will be radically altered by the introduction of Payment by Results. National tariffs will determine how much a PCT should pay for particular services such as inpatient hospice stays. Furthermore, PCTs will be obliged to fund core palliative care services (as outlined by NICE) instead of relying on the voluntary sector;¹⁶ this additional cost could be as much as £150-200 million. It is unlikely that PCTs will be able to meet this demand. One solution may be for the government to hold a central budget for adult palliative care services, as is the case already with children's palliative care services.¹⁷

Education, tools and research

Palliative care is an evolving specialty with new drugs and approaches being developed. Individuals wishing to improve their palliative care could consider either attending a course or undertaking self-directed e-learning modules.^{18,19}

GPC providers can enhance their practice through the use of tools as promoted by The National End of Life Care Programme. The Liverpool Care Pathway promotes the hospice care model in hospitals and has been introduced in 60 percent of all acute trusts.²⁰ The Gold Standards Framework offers primary health

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care teams an evidenced based programme to improve planning for the last nine months of life.²¹ And the Preferred Place of Care plan is a patient-held document with patients' thoughts and choices for their future care. By December 2005, 28 percent of GP practices and 0.75 percent of care homes were using a tool.²² These are encouraging figures, but the majority of dying patients remain uncovered.

Palliative care's research base remains small. Presently the needs of everyone with a life-threatening illness cannot be successfully palliated. If every group of patients' needs are to be met then further research is needed, especially with regards to the palliation of non-cancer diagnoses.

Non-cancer diagnoses

Perhaps the greatest challenge to palliative care is to widen its focus from patients with cancer to those with non-cancer diagnoses. The emphasis of palliative care is shifting from being perceived as a 'dying service' to focusing on improving patients' symptoms and quality of life months and even years from death. Specialists may need to step outside their comfort zones, and other healthcare professionals should consider asking for palliative care advice when managing patients with large symptom burdens.

Future mandate

No doubt there will be further attempts to legalise assisted dying, but there will be less sympathy for those of us opposing it if we continue to rely on the same argument of lack of palliative care. Together we need to support the fight for better funding and to ensure that our palliative skills, whether GPC and SPC, are optimal.

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