A long and winding road

Over the years there has been impressive growth in the number of healthcare professionals involved in palliative care and in the number of professional associations. There are a number of peer-reviewed journals, such as this one, dedicated to palliative care, and palliative medicine is now a recognised specialty in the UK and many other countries, including this year in the USA.

Despite these developments, few academic palliative care programmes exist. This is of great concern, as research leading to developments in the way we assess and treat patients is produced overwhelmingly in academic institutions. Moreover, education and research in palliative care will have a direct impact on almost all patients and families, as well as on the majority of healthcare professionals. Hospitals and cancer centres frequently have minimal or no inpatient palliative care programmes even though each year they see hundreds of deaths and discharge thousands of patients to hospices or nursing homes, where they die within days or weeks. So what are the problems and how can we address them?

First, most of our programmes did not develop from academic medical centres or universities. Deans of medical schools should be asked to justify the absence of administrative structures for the delivery of palliative care education and research using benchmarks for comparisons in the same way as other established disciplines, such as oncology for example.

Hospital medical directors are responsible for the allocation of clinical resources, including appointments and bed use. They should be questioned about the level of care for terminally ill patients. Benchmarks include those institutions that have palliative care units and designated inpatient palliative care programmes.

Second, one of the main barriers is the limited number of centres capable of 'raising the bar'. Employers should therefore be pressured to generate appropriate academically oriented positions. For example, in the USA hospices have grown dramatically in number and size, but have largely failed to generate academic medical positions with appropriate university affiliations even though their financial situation is often better than ever in their history. There is an opportunity to create positions funded jointly by hospices and academic institutions capable of providing excellent education to undergraduate and postgraduate students and badly needed original research.

Third, the pharmaceutical industry, a primary source of research funding in most clinical medicine, has shown little interest in developing and testing drugs for palliative care because of the short duration of many palliative interventions and concerns over testing drugs in populations with high mortality. Another source of funding is needed.

It has become increasingly clear that palliative care is an ethical obligation and governments and insurance systems have progressively adopted it as a clinically funded programme. This provides an opportunity for philanthropy – which has traditionally provided well for palliative care – to support development of academically oriented positions rather than funding clinical positions exclusively.

Fourth, while other areas of healthcare, such as the elderly, have benefited from the strong advocacy of patients and families, palliative care patients are usually too ill to be strong advocates.

One important consideration is that all palliative care patients have an underlying diagnosis. Usually, this is cancer, congestive heart failure or chronic lung disease. Educating cancer, lung and heart organisations will help them advocate for better education and research on how to take care of their end-of-life patients.

Fifth, the establishment of palliative medicine as a specialty caused controversy in the UK, Canada and the USA. There has also been debate about research in palliative care. The European Association for Palliative Care and the American Academy of Hospice and Palliative Medicine have strongly endorsed research as a way of improving our ability to care for our patients and families. It is vital that our organisations continue to work towards a consensus regarding the importance of academic palliative care programmes in every university and large hospital around the world. This is the best way to ensure that care at the end of life will improve for ever.

Education and research in palliative care will have a direct impact on almost all patients and families as well as the majority of healthcare professionals

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