

Palliative medicine: the first 18 years of a new sub-specialty of General Medicine

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ABSTRACT In 1987 the UK became the first country in the world to make palliative medicine a subspecialty, to be followed by Australia, Hong Kong, New Zealand, Poland, Romania, Singapore, and Taiwan. Eighteen years later there are, in the UK, 310 consultant specialists, 161 SpRs, 6 professorial chairs, increasing research and palliative medicine is taught in all medical schools. This paper looks at the history of the subspecialty, the criteria that had to be met for specialist status, developments in palliative care provision in the UK and the challenges facing the young specialty, and those undergoing training.

Published online September 2005

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A fuller version of this paper with more tables plus information about the situation in other countries where palliative medicine is, or is expected to become, a specialty can be found online: http://www.rcpe.ac.uk/publications/the_journal.php

KEYWORDS Academic palliative medicine, JCHMT, palliative medicine, recruitment, specialisation, training.

LIST OF ABBREVIATIONS Community palliative care service (CPCS), Fellow of the Royal College of Anaesthetists (FRCA), Fellow of the Royal College of Radiologists (FRCR), general professional training (GPT), higher professional training (HPT), hospital palliative care team (HPCT), joint committee for higher medical training (JCHMT), Member of the Irish College of General Practitioners (MICGP), National Institute for Clinical Excellence (NICE), physician-assisted suicide (PAS), specialist palliative care services (SPCS), Specialist Registrar (SpR), World Health Organisation (WHO)

DECLARATION OF INTERESTS No conflict of interests declared.

THE HISTORY OF HOSPICE AND PALLIATIVE CARE

Hospices were to be found on the trading routes and military roads of Europe and the Middle East at least 1100 years ago. In AD 819, the caliph Al-Tabari Muhammad ibn Jarir gave an order 'Set up hospices where sick Muslims can find shelter, and appoint custodians for these places who will treat the patients with kindness and physicians who will cure their diseases'.¹ The first 'modern' hospice was opened in France in the mid nineteenth century followed by one in Dublin in 1905 but the 'hospice movement' is generally regarded as starting when Dame Cicely Saunders opened St Christopher's Hospice, London in 1967, insisting that it would not only give high quality care but that it would be scientifically based and committed to professional education and research.

In the next few years many more hospices opened (one fifth of them operated by the NHS, the others by the voluntary sector) all served by consultants (several of whom worked full time in the unit) or principals in general practice giving their services on a part-time basis.

In October 1987, Britain became the first country in the world where palliative medicine was given sub-specialty status, to be followed over the next 17 years by Australia and New Zealand, Hong Kong, Poland, Singapore, Taiwan and Romania. (See online version of this paper.) This paper reviews the first 18 years of the sub-specialty.

By 1985, when negotiations began for sub-specialty status, there was a newly-launched peer-reviewed multi-professional journal *Palliative Medicine* (now one of eight) and a National Council for England, Wales and Northern Ireland (the Scottish Partnership for Palliative Care having been formed the year before) to be followed shortly afterwards by a European Association for

TABLE 1 Palliative care services in the UK, 2004²

Country	IP	Units	Communit Teams	Day Units	HPCTs
Scotland	23	52	23	28	
Wales	17	30	20	19	
N Ireland	5	10	4	14	
England	172	264	211	22	

Palliative Care, bringing together representatives of all the professional groups involved in palliative care (doctors, nurses, nurse tutors, social workers, managers, chaplains and the many professionals allied to medicine) from both the NHS and the voluntary sector, with government observers.

By 2005 there were:

- 220 adult units with 3,156 beds;
- 33 children's units with 255 beds;
- 358 community palliative care services;
- 104 'hospice at home' services (offering 24-hour 'hands-on' care);
- 263 palliative care day units;
- 293 HPCTs;
- 68 hospital support nurses working alone where there are no teams.

In spite of this remarkably rapid rate of growth even in its early years, there was more public support and acclaim for palliative medicine than there was professional acceptance and understanding. Amongst the palliative medicine consultants there developed a widely felt need for palliative medicine to be accorded specialist status:

- to give it more professional credibility and authority;
- to give palliative care a higher profile. (The UK spends only 0.18% of its total government and charitable funding for cancer research on end-of-life and palliative care);³
- to promote better education and training in the discipline;
- to foster robust research;
- to encourage and enable other doctors to accept and incorporate its principles into everyday clinical practice.

Before sub-specialty status was granted in the UK evidence had to be produced:

- that there was a demonstrable need for such a sub-specialty;
- that doctors would avail themselves of specialist advice from colleagues in palliative medicine;
- that there was a substantial and growing knowledge base;
- that there was on-going commitment to high quality research;
- that there was a peer-reviewed journal dedicated to the subject;
- that there was a professional association/body representing those working in palliative medicine;
- that a sufficient number of physicians would be prepared to make it their lifetime career;
- that a rigorous specialist training programme would be devised to comply with the regulations and recommendations of the JCHMT.

WHAT IS PALLIATIVE MEDICINE?

In recent years the WHO has produced several definitions of palliative care (the last in 2002), using the word 'care' to embrace the total care given by a team of nurses, professions allied to medicine and pastoral care workers as well as that given by the doctors (*palliative medicine*) The WHO definition 2002, described palliative care as:

'...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'⁴

A more succinct definition, created specifically for the new medical specialty, states that 'Palliative medicine is the care and study of people with active, progressive, far-advanced illness for whom the life expectancy is short and the focus of care is the quality of life.'⁵ It will be noted that no mention is made of pathology because, although most patients receiving hospice/palliative care in the pioneering days had malignancies, it was soon recognised that the principles were equally relevant to those with life-threatening cardiac, respiratory, neurological and many other conditions. No time limit is mentioned in the definition because studies soon showed that much poorly relieved suffering was experienced even when 'curative' or 'life-sustaining' treatment was being given, and that many patients appeared to live longer than expected when their suffering had been relieved.

Palliative or hospice?

Even today some confusion exists about the two words 'hospice' and 'palliative', the former better known to and apparently preferred by, the public. However, it was when this work developed in French-speaking Canada where 'hospice' had a different meaning that 'palliative' was first used and, better describing the type of care, has now been adopted for professional and administrative use ever since. Nevertheless, in its introduction to the specialty, the UK's JCHMT speaks of palliative medicine offering 'an interesting and varied career spanning hospital, hospice and community settings.'⁶ The apparent interchangeability of 'palliative medicine' and 'palliative care' has also led to some confusion. The former refers to the work and professional discipline of doctors, the latter to the care given by any health care professional.

At the time of the negotiations for sub-specialty status there was much discussion about the most appropriate name for it. 'Hospice Care' and 'Hospice Medicine' were rejected as being too 'soft' and not being adequately descriptive. 'Continuing Care' the term used by the NHS to describe their hospice-type units was also rejected for

similar reasons. The fact that 'palliative medicine' had been adopted in Canada, that there was a journal called *Palliative Medicine* and a professional association with that name simplified the decision making.

The response to sub-specialty status for palliative medicine

Those with recognised higher qualifications, already working in it full or part time, were delighted as were many overseas colleagues who felt that they and their work might soon have the professional recognition they felt they deserved. Some doctors with no higher qualifications, working conscientiously in hospices, as they had done for years, felt that a two-tier system was being created, elitism was creeping in and their commitment to palliative care going unrecognised. Predictably a small number continued to ask why palliative care, far less a new medical specialty, was needed. Were the terminally ill not receiving excellent care already? A much larger number of doctors asked why a subject whose principles were, after all, an integral feature of all good clinical care needed speciality status. Surely every doctor practised them whether the patient was in hospital or at home, whatever his illness, age, colour or creed? The answer for them all was the ever-increasing number of papers demonstrating suffering that was sometimes not reported, or inadequately relieved even after admission to hospital; disappointment with general practitioners and hospital doctors – in short, a spectrum of physical, psychosocial and spiritual suffering for which most doctors had had little or no training or preparation.^{7, 8, 9, 10, 11} The distinction between general and specialist palliative care has been well expressed by Currow in Adelaide, Australia:³⁹

'A general palliative care approach can be distinguished from the care of people with more complex problems where access to inter-disciplinary palliative care teams is likely to improve outcomes. We define specialist palliative care services (SPCS) as additional clinical services supplementing primary nursing and medical carers; SPCS generally include nursing and medical specialists or consultants in palliative care working in an interdisciplinary team. This acknowledges that the vast majority of palliative care is provided by primary carers with specialist consultative backup'

SPECIALIST PALLIATIVE MEDICINE SERVICES 2004

The JCHMT named three sites – home, hospital and hospice – where today's specialists work.

Home/Community

Today in the UK, the percentage dying at home is falling (though most people express the wish to die at home if possible), and increasing numbers die in hospital or nursing homes. (See Figure 1)¹²

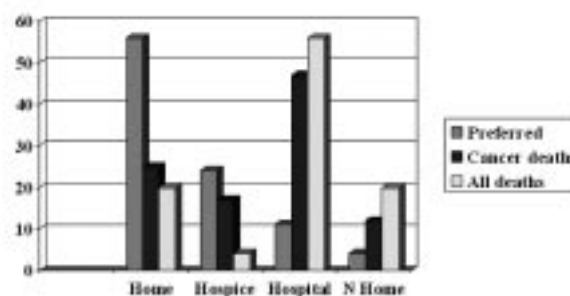


FIGURE 1 Preferred place of death versus reality in the UK, 2003.¹²

- 11% want to die in a hospital, but 56% do so.
- 56% want to die at home, but only 20% do so.
- 24% want to die in a hospice, but only 4% achieve that wish.
- Only 4% want to die in a nursing home, but 12% of cancer deaths and 20% of all deaths occur there.

The percentage who want to die at home differs little between the 16–24 year olds (61%) and those 65+ (49%). However, where people die bears little relation to where they received most care in their final year of life, it having long been known that most of that year is spent at home, most of the professional care being given by primary care teams, and almost all of the prescriptions being issued by general practitioners with most of the non-medical care being given by relatives. The need for palliative medicine specialists to be available to advise on those being cared for at home is obvious. They work in community palliative care teams, often linked with specialist palliative care units.

Hospitals

In the past 15–20 years many studies have identified the very similar spectra of suffering of cancer, chest and cardiac patients, nearing the end of life,^{13, 14, 15, 16, 17} and how some symptoms are not brought under control, even after the patients have been admitted to hospital.¹¹ More HPCTs have been established to assist in the care of patients with malignant and non-malignant condition. Today they represent the major growth area in palliative care provision.^{18, 19, 20} (See Table 7)

Official endorsement and encouragement

In June 1998, the UK government issued guidelines²¹ in effect endorsing the recommendations of the National Council for Palliative Care for improved care in hospitals and encouraging more hospital teams. One of them was that 'there should be a team whose core membership should comprise specialists in palliative medicine, clinical nurse specialists in palliative care and administrative support'.

This recommendation has more recently been repeated in the NICE Guidance on Improving Supportive and

TABLE 7 Palliative care services in 1987 and 2005 compared.²

Type of Service	1987	2005
NHS in-patient units	33	64
Voluntary units	84	156
TOTAL UNITS	117	220
Community Palliative care services	169	358
Palliative day care units	60	263
Hospital palliative care services	18	361

Palliative Care (published in March 2004).^{22, 23, 34, 40} Furthermore in an unpublished report for the Department of Health (December 2003), the Sheffield School of Health and Related Research recommended that '... a Cancer Centre should have a minimum of 1.5 consultants in palliative medicine and that a Cancer Unit should have 0.5 consultants.'²³ These latter recommendations have been incorporated in the National Council's recent publication on Population-based Needs Assessment,^{24,25} itself endorsed by Professor Michael Richards, National Cancer Director for England.

Paediatric palliative medicine

The world's first children's hospice – Helen House, opened in Oxford in 1982 – has spawned many others in the UK, North America and Australia. They cater for children with life-shortening and usually life-threatening conditions rather than offering 'end-of-life care'.^{26,27} In the UK in 2004, there were 30 with a total of 229 beds. Scotland's second unit will open in 2005. Most are free-standing, a few attached to adult palliative care units. There are 55 doctors staffing them and 2 consultants in paediatric palliative medicine in the UK. Both the University of Cardiff and King's College, London offer courses in paediatric palliative care.

Entry requirements for palliative medicine

When the specialty was recognised in 1987, those already working full-time in hospices (almost all consultants in other specialties) were granted specialist registration. For the next five years those with MRCP(UK), MRCGP, FRCS, and MRC Psych were eligible to enter higher medical training in the new specialty. Since 2002, the accepted qualifications have been MRCP(UK), FRCR, FRCA, MRCGP or MICGP. Where the postgraduate qualification is not MRCP(UK) it is stipulated that GPT should have included a minimum of 24 months involved with direct patient care, at least six months of which has been concerned with acute unselected medical intake. In practise, most recruits into the specialty today have had several years experience in general medicine, oncology or radiotherapy, after gaining their higher qualification, but only a few have had experience of specialist palliative medicine as an SHO.

Higher professional training

The duration for palliative medicine is four years, two of which must be spent in specialist units or teams where the full range of palliation services detailed above are provided, including day care and bereavement counselling. One and up to two years may be spent in General Medicine or other relevant specialties such as oncology, infection, radiotherapy, care of the elderly, pain management or in a general practice approved for this level of training. A period of supervised research of high quality is desirable and may contribute up to 12 months towards the duration of HPT. The need for palliative medicine physicians to have had experience in disciplines other than oncology is becoming pressing now that HPCTs are asked to see patients with a spectrum of conditions other than malignancy. Table 4⁵ (online) shows the GMT background of today's consultants and SpRs in the UK (2003), and Table 5 (online) their postgraduate qualifications.⁵

It suggests that most are entering the sub-specialty with wide experience, a smaller proportion of SpRs than consultants have had much experience in general practice, psychiatry and pain clinics, but more have worked in care of the elderly units and general internal medicine.

The sub-specialty of palliative medicine in the UK today

When negotiations were taking place (1985–87) there were thought to be about 20–25 doctors of consultant grade working in UK hospices. By 1999, there were 94 palliative medicine physicians holding NHS contracts in England, a figure predicted to rise to 164 for 2003/4 and to 221 by 2005/6, and increase of 135% over the whole period.²⁵ A census carried out by the Association for Palliative Medicine in 2003, identified 310 consultants in England, Scotland, Wales and Northern Ireland, and 161 SpRs. It revealed that the average age of palliative medicine consultants is 40, that 45% are female, and that 58% of consultants and 33% of SpRs work part-time.⁵ For their postgraduate qualifications see Table 4 online.

Evidence of the Royal College of Physicians of London to the House of Commons Health Committee Inquiry into Palliative Care 2004, stated that

'From a medical perspective, there is unsatisfied demand for consultants in palliative medicine. At least 100 posts are unfilled in England alone. There are also 70 newly funded posts as a result of the 34 English Cancer Networks' investment plans. Some areas of the country have so few consultants that they are not in a position to be able to train SpRs even if training numbers (NTNs) and funding were to be available.'²⁸

It will be noted that that the '100 unfilled posts' are real vacancies and not aspirations or targets.

Palliative medicine in UK medical schools

Even before the sub-specialty was created the principles of palliative medicine were being taught in all UK medical schools, and made examinable in several, most of the teachers being physicians and associated staff from local palliative care services. The principles of palliative medicine are now taught to junior doctors, general practitioners and specialists in other specialties as well as to palliative medicine SpRs.^{29,30,37}

Most SpRs in palliative medicine attend courses in health service management and counselling, and many elect to develop their teaching skills in special 'Training the Trainers' courses, learning teaching methods, lecturing techniques, workshops, role-play, PowerPoint, setting and marking examinations, student evaluations. Similar courses are now being offered in many other countries.

Academic palliative medicine

The first UK chair in palliative medicine – the Sainsbury Chair – was established in St Thomas' and Guys Hospital, London in 1991, to be followed by others in the UK – Bristol, Sheffield, Cardiff, Glasgow, and King's College, London – as well as about 20 others in Australia, New Zealand, Canada, Poland, Norway, and the USA. Recent evidence points to some difficulty in filling vacated or newly created posts.

Discussion

The criteria set for sub-specialty status have been, and continue to be, met and exceeded; the number of 20 or so whole time equivalents, doctors working in hospice care in 1987 has grown to 310 (a figure to be put alongside the 150 medical oncologists and 421 clinical oncologists in the UK) and there are 161 SpRs in training, an increasingly number of whom have doctorates. The knowledge base continues to grow, good research is being published (on average 350 original scientific papers in the 5 main peer-reviewed palliative medicine journals annually); the journal *Palliative Medicine* is read and cited worldwide; more than 50 reference books and textbooks on the subject are now published in the UK alone, excellent recruits continue to come into the sub-specialty, and colleagues in many other specialties increasingly call on the expertise of palliative medicine. Published studies increasingly point to improved care and patient/lay carer satisfaction.^{9, 18, 19, 20, 39, 41, 42, 43} Worldwide, with about 8,000 palliative care services, the UK is respected as both the place where it all started and where significant advances in palliative care provision and education are to be seen.

It is widely acknowledged that much of this progress in the UK can be attributed to its sub-specialty status, leading several other countries to negotiate specialty status. How much of the worldwide growth and

development that can be attributed to the granting of sub-specialty status for palliative medicine is difficult to judge. It was happening before 1987 albeit at a slower pace. As demonstrated in Table 7 the growth in UK services since 1987 when palliative medicine became a sub-specialty has been remarkable. Community services have doubled in number, day care services increased 4-fold and HPCTs increased 20-fold.

However, many challenges face the young sub-specialty. One is recruitment, which is no longer keeping pace with the vacancies created by burgeoning services and retirements. Particularly this is the case for academic palliative medicine which is attracting few applicants. Reasons for this need to be explored. The question of recruitment and HPT raises several questions. Many of the pioneers of palliative medicine in the UK and some developing countries were noteworthy for their charismatic enthusiasm and religious faith. (Indeed several were ex-missionaries.) Should those characteristics be expected of today's recruits, living as we do in an increasingly secularised society, but yet one where 75% of the dying raise existential questions for which, in the past, there were religious responses?^{35,36} Will future recruits expect/need to receive more training in psychosocial, spiritual and cultural care, as well as in a wider spectrum of other medical specialties, especially if they plan to work in HPCTs? Should experience in general practice be a pre-requisite if more is to be done to enable people to die at home if this is their wish? Some of the old hierarchy of our hospitals has gone and traditional roles are changing, but recruits will need to be prepared to work in teams alongside nurses and allied health professionals who may have had much more training in aspects of palliative care, even to degree level, than they have. Those considering work in hospices may want to bear in mind that 40% of colleagues there have considered resigning because of poor support from managers and trustees.⁴¹

It was never envisaged that palliative medicine specialists would provide day-to-day care for most of the terminally ill but rather would be available to advise on the uncommon, complex and complicated problems that others might never have heard of or know how to deal with.³⁹ With fewer dying at home and more of the elderly dying in nursing homes (in spite of their expressed wishes) it must be asked if the sub-specialty is in danger of inadvertently de-skilling other doctors, in the patients' homes and in the general wards of our hospitals, where the clinical responsibility can now so easily be handed over to a palliative care team. There is anecdotal evidence of this happening. How can today's consultants help their GP and hospital colleagues to employ the principles of palliative care for the 'uncomplicated dying' when the societal trend is for dying people to be transferred to a hospital or to a palliative care unit even when they do not need specialist care? How will this trend be affected by so many GPs opting out of 24-hour clinical responsibility?

Perhaps more importantly it must be asked if having specialists to care for the dying might not increase rather than diminish any taboo surrounding death in our society. 'How complicated and difficult it must be if specialists are needed!' In spite of more resources going into community care and general hospitals to improve palliative care, shall we continue to see fewer people dying where they have expressed a wish to die – in their own beds or cared for by clinicians who have come to know them, sometimes over years? Some would argue that the trend is less than a few years ago perhaps as a result of palliative care and the media coverage it receives.

In the UK the hospices run by the voluntary sector have always largely depended on charity funds (currently estimated at more than £300,000,000 annually, not including the donations to major cancer charities). Today, largely as a result of specialisation, the boundaries between the NHS and voluntary sector are becoming blurred. Patients may see the same consultant in the hospital as in the hospice and, quite rightly, expect the same quality of care wherever they are. This will challenge hospices to define more clearly, as indeed many are now doing, which patients they are there to serve (many, whilst benefiting from their stay, do not need specialist input) and to be as scrupulous in their audit and standards as their NHS partners. With high quality palliative care available in hospitals as well as hospices there may be less incentives for the public to give to their local hospice as it loses its 'uniqueness'.

Those who would legalise euthanasia and PAS will predictably continue to confuse palliative medicine with euthanasia (claiming that death is often brought on by the 'double effect' of opioids) whilst at the same time saying there would be little need for euthanasia if everyone had access to high quality palliative care services. Having frequently to spend time explaining that palliative medicine is the antithesis of euthanasia can be stressful.

Palliative medicine as described in this paper is a blend of modern science and sensitive compassion, the former the clinical pharmacology of pain and symptom management, the latter the attention needed for psychosocial and existential issues, ever present in the terminally ill but difficult to research. Detractors call the latter 'soft' medicine and pour scorn on it. Research-funding bodies are not often eager to fund such research but if it is

accepted that palliative care is truly holistic that aspect of palliative care cannot go unresearched if we accept that the dying themselves say they need and want such holistic care. A challenge facing the young sub-specialty is to espouse and demonstrate the principles of palliative care ('integral to all good clinical care') whilst at the same time developing the unique skill and knowledge base of specialist palliative care, and work to ensure the two are not confused.³⁸ This skill and knowledge base is a big challenge now that patients are being referred with every major pathology. Whilst the principles are the same for all, recent studies suggest that there are important differences between the needs of cancer patients and some non-malignant patients.⁴³ Will the time come when sub-specialties within the sub-specialty will be needed: for those working with cardiac, respiratory, neurological or AIDS patients? The recruitment and training implications would be daunting. Will the palliative medicine specialists of the future function like the general physicians of the past, dealing with a spectrum of problems in different systems?

Tension may continue to exist between the 'hard' side of palliative care (the management of physical symptoms) and the 'soft' one (psychosocial and spiritual issues), the former better researched than the latter and arguably easier to teach and demonstrate, the latter regarded by some as the core of palliative medicine. It is the balance between them that constitutes the holistic nature of palliative medicine. In theory at least palliative medicine should act as a catalyst to high quality holistic care worldwide.

ACKNOWLEDGEMENTS

The author acknowledges with gratitude the generous help given by Professor N Macdonald (Canada), Dr K S Chan (Hong Kong), Dr C Goh (Singapore), Professors J Luczak and K de Walden-Galuszko (Poland), Dr E Lai (Taiwan), Dr D Mospiu (Romania), Professor R McLeod and Dr W Landman (New Zealand) Dr R Woodruff (Australia), Dr CJ Furst (Sweden) and Dr M Minton (JCHMT, London). Each ensured that the information related to their country was accurate and up-to-date.

The Association for Palliative Medicine of Great Britain and Ireland and Hospice Information who kindly collected many of the statistics and made them available for this paper.

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