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MEDICINE PALLIATIVE CARE

Evolution and change in palliative care around the world

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Abstract

Palliative care developed in the later part of the twentieth century as a social movement and medical specialty. Central to its modern development were the ideas of Dr Cicely Saunders, whose vision for improving the care of the dying encompassed the physical, psychological, social and spiritual domains whilst emphasising the importance of rigorous clinical practice, training and research. St Christopher's Hospice, which she founded, inspired generations of practitioners and influenced the expansion of hospices nationally and internationally. Terminal care evolved into the discipline of palliative care, which applied holistic principles to the care of those earlier in their disease trajectory and in different settings such as hospitals and the community. Some countries now have national strategies for palliative care that are supported by government. Palliative care attracts increasing attention as an aspect of the public health system and there are calls for access to it to be recognised as a human right. Yet around the world, palliative care is not uniformly developed and it

still has much to do to attract full integration with prevailing health policies.

Palliative care still reaches only a tiny proportion of those who could benefit from it, especially those with diseases other than cancer. The global challenge for palliative care in the twenty-first century is to develop models and coverage appropriate to those in need, whatever their diagnosis, income or setting.

Keywords hospice; palliative care; cancer; terminal care; end of life care

Palliative care developed rapidly in western societies in the second half of the twentieth century as a response to the increasing marginalisation of death in society and the medicalisation of dying within the health care system; it also began to make progress in resource poor and developing countries as a reaction to the problem of avoidable suffering at the end of life. Today it enjoys increasing recognition as a medical specialty¹ but still faces major challenges of recognition on the part of professionals, patients and the wider public.

Twentieth century developments

Four key health care developments can be identified by the middle years of the 20th century:²

- The professional literature about the care of the dying started to shift from anecdote to systematic observation.
- A new view of dying began to emerge which sought to foster concepts of personal dignity, autonomy and meaning at the end of life.
- An active rather than a passive approach to the care of the dying was promoted with increasing vigour.

- A growing understanding developed about the interdependency of mental and physical distress

Within this context, Dr Cicely Saunders began to forge a modern philosophy of terminal care combining a powerful religious and moral conviction alongside a rigorous approach to observation, research and clinical innovation. Originally a nurse, she subsequently trained in social work and medicine before becoming a research fellow at St Mary's Hospital in 1958, undertaking her studies at St Joseph's Hospice in Hackney, London.³ By listening carefully to patients' stories of illness, disease and suffering, she evolved the concept of "total pain".⁴ This view of pain moved beyond the physical to encompass the social, emotional and spiritual aspects of suffering. Yet it was also linked to a hard-headed approach to pain management. Her message was simple: "constant pain needs constant control".⁵ In a ground breaking series of papers published in the late 1950s and early 1960s⁶, Dr Saunders demonstrated that powerful analgesics could be used safely and with confidence. Despite considerable medical scepticism at the time,⁷ she argued that if a method of regular giving of analgesia was employed, then pain could be prevented in advance, rather than alleviated once it had become established.

When Cicely Saunders founded St Christopher's Hospice, in South London, in 1967, it quickly became a source of inspiration to others. As the first "modern" hospice, it was unique in combining three key principles: excellent clinical care, education, and also research. It therefore differed significantly from the more modest goals of other homes for the dying and established itself as a centre of excellence in a new field of care. As services expanded – in the independent sector and in the National Health Service - the focus of care also widened from care of the actively dying to those

earlier in their disease progression with symptom problems, thus helping patients live their remaining life to the full. Practitioners began to question the use of *terminal care* to describe their work and over time preference shifted to *palliative care* (Box 1)⁸, the term coined by Canadian surgeon Balfour Mount in 1974.⁹ As hospice and palliative care developed in the UK, there was growing interest in establishing it as a specialty. In 1987, palliative medicine became a sub-specialty of general medicine, initially on a seven year ‘novitiate’, which once successfully concluded, led to the creation of a specialty in its own right.¹⁰

Box 1: WHO definition of palliative care

Palliative care is 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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Policy and development: UK

In recent years the UK government has exhibited a growing commitment to palliative care. In 2003-04 it provided cancer networks with £50 million per year, for three years, to assist palliative care improvement and, in December 2003, it committed a further £12million to enable three specific end of life care initiatives in England to extend the principles of end of life care for cancer patients to those dying of other diseases¹¹:

- The Gold Standards Framework (GSF) which focused on the improved co-ordination of end of life care for patients in the primary care setting¹².
- The Liverpool Care Pathway (LCP) which promoted optimal care and support for patients in their last days of life¹³.
- The Preferred Priorities of Care (PPC) instrument, an example of Advanced Care Planning, which aimed to help patients and carers decide, and record in a patient held record, where they wish to be cared for at the end of their life¹⁴.

The aim of these initiatives was to “improve choice, quality and responsiveness for all adult patients nearing the end of life”¹⁵.

A more wide-ranging End of life Care Strategy for England, in which these initiatives became core tools, came into effect in 2008¹⁶. The National End of Life Care

Programme¹⁷ aims to meet the health and social care needs of all adult patients in where they live and die and to provide a practical framework that health and social care services can use to build high quality provision for people nearing the end of life. It covers 12 key areas of end of life care, including profile raising, commissioning, research, education and training, service planning and delivery and support and involvement of carers. In the second annual report of the strategy¹⁸ examples of progress included a £40 million capital grant to improve hospice environments, the launch of the Dying Matters coalition to raise public awareness on end of life issues and the creation of the National End of Life Care Intelligence Network.¹⁹ Similar initiatives have also developed in Scotland²⁰, Wales²¹ and in Northern Ireland²².

The international perspective

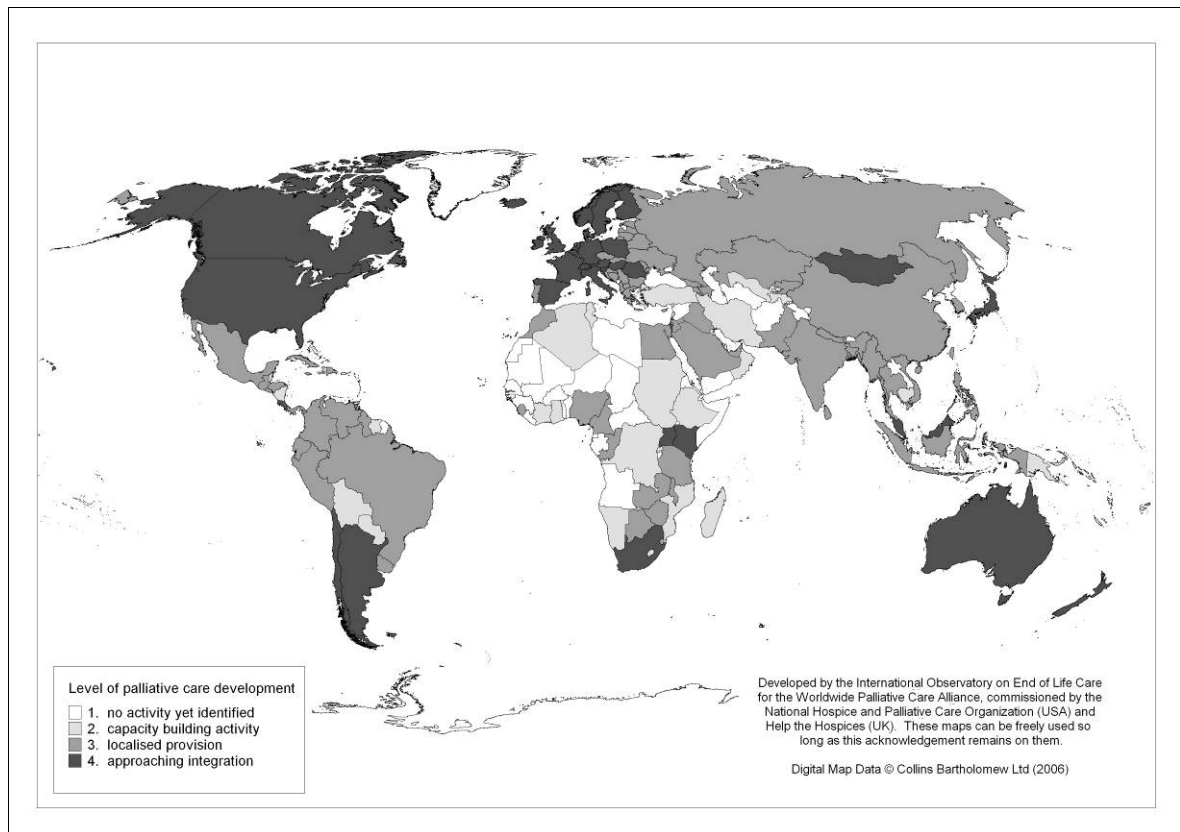
Since 2000 key developments have been taking place in palliative care globally. Everywhere palliative care leaders identify the same challenges: a lack of public recognition and understanding of their work; professional indifference on the part of many health and social care providers; a lack of third party funding to set up demonstration projects; poor recognition of palliative care within the architecture of both national and international health policy; weakly developed training programmes with few routes for accreditation and professional recognition; and a limited evidence base about the efficacy of palliative care and its costs and benefits.

It was not until 2003 that the first ‘summit’ on international palliative care development took place in The Hague. Others followed in Seoul in 2005, Nairobi in 2007 and Vienna in 2009 - leading that year to the creation of the Worldwide Palliative Care Alliance²³. In 2007, a collaboration of 25 organizations developed a list of essential medicines for palliative care in response to a request from the Cancer

Control Program of the World Health Organization (WHO). The list comprised 34 medications of which 14 were already included in the WHO list as essential in the treatment of several conditions, some of which are common in palliative care²⁴.

A series of studies on international palliative care issues conducted by the International Observatory on End of Life Care led to an ambitious attempt to map the level of palliative care development for every country in the world, using a four part typology.²⁵ The total countries in each category were: 1) no identified activity 78 (33%); 2) capacity building 41 (18%); 3) localised provision 80 (34%) 4) approaching integration 35 (15%). The typology differentiated levels of palliative care development in both hemispheres and in rich and poor settings. It showed that only half of the world's countries had some form of designated palliative care service.

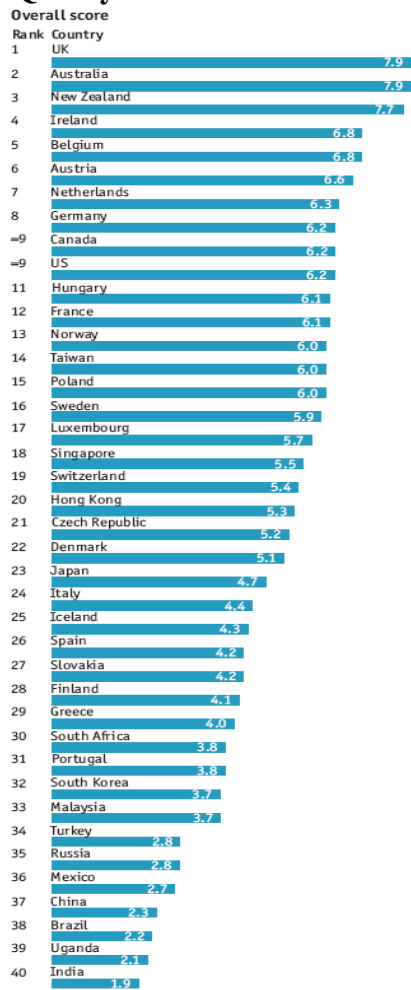
Figure 1 The 'world map' of palliative care development, 2008



Building on this work a study commissioned by the Lien Foundation in Singapore and carried out by the Economist Intelligence Unit was published in 2010²⁶. This too attempted a ranking of palliative care development in 40 countries of the world, with a more complex set of indicators. The Quality of Death Index scored on 24 indicators in four categories, each with a separate weighting: 1) basic end-of-life healthcare environment (20%) 2) availability of end-of-life care (25%) 3) cost of end-of-life care (15%) 4) quality of end-of-life (40%). There was considerable synergy with the evidence of the ‘world map’.

Figure 2

Quality of death index



Source: Economist Intelligence Unit.

Palliative care and public health

Recent years have seen growing interest in the twin ideas that palliative care is both a public health and a human rights issue. One assumes the insertion of palliative care into the public health system, thereby positioning it within a framework of ‘need’, ‘supply’ and ‘resource allocation’. Several ‘public health’ palliative care demonstration projects are now in operation - in Africa, India as well as in the wealthier nations. The other approach seeks recognition for palliative care within human rights legislation²⁷ - for example by incorporating access to palliative

medication into a resolution of the United Nations Commission on Human Rights.²⁸

But palliative care remains poorly framed within evidence-based global policy making. Much more needs to be done to demonstrate the role and efficacy of palliative care, not only in relieving physical and psychological distress, but also in promoting community cohesion and personal resilience. Such recognition is vital if the world's palliative care needs are to be met in an equitable and culturally sensitive manner.

Conclusion

Some 56 million deaths occur worldwide each year and it is estimated that 60% of these could benefit from some form of palliative care. Current palliative care provision reaches only a tiny proportion of those in need. The history of modern palliative care covers less than five decades. During that time it has established itself as an integral part of the care of the cancer patient in the UK and beyond.²⁹ Now the lessons learned need to be transferred to the care of all dying people, regardless of diagnosis and location. A massive challenge remains to be overcome if palliative care is to be delivered to all people in the world who may benefit from it.

¹ Clark, D International progress in creating palliative medicine as a specialized discipline. In G Hanks et al *Oxford Textbook of Palliative Medicine*, 4th edition. Oxford: Oxford University Press, 2010, pp 9-16.

² Clark D. Cradled to the grave? Pre-conditions for the hospice movement in the UK, 1948-67. *Mortality* 1999; 4(3): 225-47.

³ Winslow M, Clark D. *St Joseph's Hospice, Hackney: A century of caring in the East End of London*. Lancaster: Observatory Publications; 2005.

⁴ Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders 1958-67. *Social Science and Medicine* 1999; 49(6): 727-36.

⁵ Saunders C. Drug treatment in the terminal stages of cancer. *Current Medicine and Drugs* 1960; 1(1) July: 16-28.

⁶ Clark D. An annotated bibliography of the publications of Cicely Saunders - 1. 1958-67. *Palliative Medicine* 1998; 12(3): 181-93.

⁷ Faull C, Nicholson A. Taking the myths out of the magic: establishing the use of opioids in the management of cancer pain. In: Meldrum M.L. (ed) *Opioids and pain relief: a historical perspective*. Seattle: IASP Press, 2003:111-130.

⁸ Sepulveda C, Marlin A, Yoshida T, Ulrich A. Palliative care: the World Health Organisation's global perspective. *J Pain Symptom Manage* 2002;24:91-96

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- ⁹ Mount B. The Royal Victoria Hospital Palliative Care Service: a Canadian experience. In: Saunders C, Kastenbaum R. eds. *Hospice Care on the International Scene*. 1997; New York: Springer.
- ¹⁰ Doyle D Palliative medicine: the first 18 years of a new sub-specialty of General Medicine. *Journal of the Royal College of Physicians of Edinburgh*. 2005; 35:199-205.
- ¹¹ http://www.dh.gov.uk/en/consultations/Responsestoconsultations/DH_4068391
- ¹² Shaw, KL Clifford, C Thomas, K Meehan, H. Improving end-of-life care: a critical review of the Gold Standards Framework in primary care *Palliative Medicine April 1, 2010* 24: 317-329 .
- ¹³ Veerbeek L, van Zuylen L, Swart SJ, et al. *The effect of the Liverpool Care Pathway for the dying: a multi-centre study. Palliative Medicine* 2008;22(2):145-151.
- ¹⁴ <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>
- ¹⁵ www.endoflifecare.nhs.uk/eolc/AboutUs/
- ¹⁶ <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>
- ¹⁷ <http://www.endoflifecareforadults.nhs.uk>
- ¹⁸ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_118810
- ¹⁹ <http://www.endoflifecare-intelligence.org.uk/home.aspx>
- ²⁰ <http://Scotland.gov.uk/Publications/2008/10/01091608/0>
- ²¹ <http://www.wales.nhs.uk/sites3/home.cfn?orgid=831>
- ²² http://www.dhsspsni.gov.uk/palliative_and_end_of_life_care_strategy_-_consult.pdf
- ²³ <http://www.thewpca.org/>
- ²⁴ <http://www.hospicecare.com/resources/pdf-docs/iahpc-em-summary.pdf>
- ²⁵ Wright, M Wood, J Lynch, T Clark, D (2008) Mapping levels of palliative care development: a global view. *Journal of Pain and Symptom Management* 35(5): 469-85.
- ²⁶ http://www.eiu.com/site_info.asp?info_name=qualityofdeath_lienfoundation&page=noads
- ²⁷ Harding R. Palliative care: a basic human right. id21 Insights Health, 8 Feb 2006:1-2. <http://www.id21.org/zinter/id21zinter.exe?a=9&i=InsightsHealth8Editorial&u=458167f2>
- ²⁸ Commission on Human Rights Resolution 2004/26: Item 7c calls on states ‘... to promote effective access to such preventive, curative or palliative pharmaceutical products or medical technologies.’ available via <http://www.ohchr.org/english/>
- ²⁹ Clark D. From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncology* 2007; 8:430-38