

PART ONE

ADULT PALLIATIVE CARE

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Section One

History and Ethos of Palliative Care

Chapter 1

The history of palliative care

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Introduction

The history of palliative care is a fascinating story of how ideas and practices around the care of people with life-threatening illnesses have evolved against a background of social trends, changing public opinion and policy developments. Central to that story is the history of modern hospice care, from a promise of a window to a worldwide movement. This chapter will focus primarily on the UK, but will also locate that story within an international context.

Learning outcomes

Once you have read this chapter and completed the associated practice points you will be able to:

- Discuss the origins of palliative care
- Describe the influence of the modern hospice movement in the development of palliative care
- Identify ways in which palliative care is responding to contemporary challenges

The origins of palliative care

Whilst only recognised as an area of medical specialty in 1987, palliative care has a much longer history than that date would imply. The evolution into the services seen today can be traced to a few inspirational figures whose determination and dynamism spurred radical change in the care of the dying. Chief among these was Dame Cicely Saunders who is largely credited with inspiring the modern hospice movement. However, the origins of palliative care can be traced back considerably further.

The word palliative derives from the Latin *pallium*, meaning cloak or covering – reflected in the Middle Eastern blessing, ‘may you be wrapped in

tenderness, you my brother, as in a cloak'. The original meaning of the word 'hospice' was not derived, as many assume, from 'hospital', but was a term familiar to those on pilgrimages, meaning 'a resting place for weary travellers'.

The first use of the term hospice as a home for dying people is attributed to Madame Jeanne Garnier who, in 1842, created L'Association des Dames du Calvaire in Lyon, France (Clark et al. 2005). From her own experience as a widow and bereaved mother, she identified a need and strived to meet it.

In the nineteenth century, societal and medical developments were resulting in a gradual transition in both causes and places of death. Where death had once occurred, almost inevitably, at home, it became more commonplace in hospital or other institutions. Causes of death were changing too, as infection control, public hygiene services and medical innovations dramatically reduced the rate of fatal infections that had previously been the common precursor to a rapid death. Skills of prognosis advanced and awareness developed, in some quarters, of a need for explicit 'care of the dying'. Unsurprisingly, this resource did not initiate from within mainstream medical care – whose pronouncement was to remain for some years 'there is no more we can do for you'. Rather, it was religious orders that founded the first of these 'homes for the dying'. Our Lady's Hospice in Harold's Cross, Dublin, was opened by the Irish Sisters of Charity in 1879, and the same order sent five of its number to the East End of London in 1900 to care for the terminally ill there. As a consequence, St Joseph's Hospice, Hackney, London, was opened in 1905 – an establishment that would come to inspire the work of Cicely Saunders.

In the 1950s an upsurge of concern began to materialise, as an understanding of the medical profession's abandonment of dying people was acknowledged. This was not necessarily a wilful neglect but an understandable response from doctors who were consumed with such enthusiasm for evolving curative approaches that those patients seen as incurable would be either discharged or overlooked. The emerging profession of social work, coupled with social science research, identified the value of specific care for those with terminal illnesses. A greater understanding of the mind/body relationship, together with hitherto neglected philosophies such as patient autonomy and dignity, heralded a new perspective on the needs of dying people. One significant catalyst was a survey conducted by the Marie Curie Memorial Foundation in the mid 1950s (Doyle et al. 2005). Having interviewed thousands of cancer patients living at home, the survey report recommended more residential and convalescent homes, as well as improved equipment and clearer information for cancer patients. The Marie Curie Memorial Foundation responded by opening its own homes for terminally ill cancer patients. Within a short time, further research by Bailey (1959), Glynn Hughes (1960) and Hinton (1964), amongst others, confirmed that the issue of improved care for dying people was in the public arena, offering a challenge to the NHS as well as charitable and religious organisations. Much of the research had been conducted from a specific perspective, be that medical, social or epidemiological. One of the features of the remarkable influence of Cicely Saunders was her ability to unite these perspectives through

rigorous research, linked with studious observations and innovative clinical practice.

The modern hospice movement

The explosion of hospices across the UK over the past 40 years is largely attributable to the work and influence of Cicely Saunders. She originally trained as a nurse in the 1940s but back problems prevented her continuing, so she retrained as a medical social worker (then called almoners) and returned to work at St Thomas's Hospital, London. It was here that she encountered David Tasma, a terminally ill, 40-year-old Polish. The relationship, which began as professional, rapidly became close friendship as Cicely Saunders accompanied this lonesome man on his journey towards death. This journey sowed the seeds of Saunders' lifelong determination to improve and develop suitable services for dying people. In conversation with David Tasma, when offering to read to him, he responded to her, 'I only want what is in your mind and in your heart'. Cicely Saunders discussed with David Tasma what might have helped him on his journey and she tellingly comments:

'Not necessarily so much better on symptoms, because he didn't have a terribly difficult dying, but somewhere that could have helped him with what I was trying to do, which was to assure him that he was a worthwhile person, dying at the end of what he thought of as a rather empty life.'

(Clark et al. 2005, p. 16)

This poignant comment offers a prelude to a statement now endorsed by many hospices which was first published in the *Nursing Times* in 1976 –

'You matter because you are you and we will do all we can, not only to help you die peacefully, but to live until you die.'

(Thompson 2002, p. 27)

Through further conversations with patients, and meticulous record keeping, Saunders also developed the concept of 'total pain' (triggered by a female patient who told her, 'all of me is wrong'). This encapsulates the understanding that physical, spiritual and psychological pain can be interwoven, therefore suggesting the futility and counter-productivity of only responding to one area of need in a patient's life (Lloyd-Williams 2003).

Cicely Saunders appreciated the spiritual, emotional and psychological needs of the dying, as well as their physical care, and vowed to open the country's first purpose-built hospice. Beginning with £500 left to her by David Tasma ('I'll be a window in your hospice'), Saunders fund-raised doggedly, trained as a medical doctor in order to develop expertise in pain control, and opened St Christopher's Hospice, London, in 1967, where there is, indeed, a window dedicated to David Tasma (Potts 2005). Saunders herself was to comment years later, 'It took me 19 years to build a home around the window, but the core

principles of our approach were borne out of my conversations with him as he was dying' (Booth 2002). Today, St Christopher's is recognised as the model for the modern hospice movement and has a flourishing Education Centre that extends the evidence-based practice and research-informed theory emanating from twenty-first century palliative care.

Other early developments

Although the towering influence of Cicely Saunders in the modern development of palliative care cannot be denied, hers was one of the many important contributions. For instance, in 1911, Douglas Macmillan witnessed the pain and suffering experienced by his father and other people dying of cancer and established the Society for the Prevention and Relief of Cancer (later to become Macmillan Cancer Support). His vision, to bring expert symptom relief and support to those in most need, was realised with the creation of the first Macmillan Nurse post in 1975 (Macmillan Cancer Support 2006). Thirty years later, the charity has funded over 3000 Macmillan Nurse posts and 500 other health care professionals (Macmillan Cancer Support 2007).

Saunders also worked alongside and influenced a generation of clinicians in the field of pain and symptom relief. Robert Twycross, for instance, carried out important early studies on the most appropriate use of strong opioids (Saunders 2000). Colin Murray Parkes explored the psychosocial needs of family carers and their experiences of loss and grief. And Saunders' concerns for the psychospiritual needs of dying people were shared by Michael Kearney, later Medical Director at Our Lady's Hospice, Dublin. His conclusions were published in *Mortally Wounded: Stories of Soul Pain, Death and Healing* (Kearney 1996).

Much attention invariably focuses on Britain and Ireland when discussing the origins of palliative care. However, similar developments, albeit heavily influenced by events in the UK, took place in the US around the same time. Between 1967 and 1969, Elizabeth Kubler-Ross, a Swiss-born psychiatrist, interviewed dying patients at the University of Chicago's Billings Hospital (Newman 2004). Her findings, written up in the unlikely bestseller *On Death and Dying*, shocked many who regarded death as taboo, but also raised awareness of the complex communication needs associated with the end of life (Kubler-Ross 1970). Kubler-Ross, together with Florence Wald, former Dean of Yale School of Nursing, was influential in establishing the US hospice movement in the early 1970s (Hoffmann 2005).

Many other countries around the world have embraced the hospice ethos. Often, the catalyst for the process has been the vision and determination of a few individuals. For instance, the early growth of hospice care in Russia was in no small part due to the efforts of Victor Zorza, an English journalist, and Andrei Gneszdilov, a St Petersburg psychiatrist (Wright 2007). The support of palliative care experts from countries such as the UK where palliative care is well established is also beneficial, and will no doubt be aided by the recently formed Worldwide Palliative Care Alliance (Prail and Pahl 2007).

Practice Point 1.1

Hospices usually form only part of the palliative care provision available in any one locality. Find out which agencies provide palliative care services in your health authority, and what those services are.

Commentary:

What you will probably have discovered is that palliative care is provided by different agencies in your area. Some of these may be part of the independent hospice movement while others may be part of the NHS. The intention of Saunders and the other early hospice pioneers was to move the care of the dying out of the NHS 'so that attitudes and knowledge could move back in' (Saunders 1993). In practice, that process began almost immediately. The first home care service, in which care was shared between the hospice and primary care teams, was launched by St Christopher's in 1969 (Help the Hospices 2005). Thereafter, the first hospital palliative care service in the UK was established at St Thomas' Hospital, London, in 1977. Prior to that, in Ontario, Canada, a little-known urology surgeon, Balfour Mount, established a ward for dying people in 1973. The Royal Victoria Hospital Palliative Care Service he subsequently founded became an important centre of palliative care development in North America (Clark 2007). Balfour Mount's place in this history is particularly important because he is credited with the first use of the term 'palliative care' (Hospice History Project 2001).

Gaining recognition and setting standards for palliative care

In the early years of the UK hospice movement, professional attitudes to hospice philosophy and hospice care were mixed. Some pioneering hospices encountered reluctance from the health care establishment to refer patients or even to seek advice. However, several developments ushered in a more enlightened view of hospice and palliative care. Firstly, Cicely Saunders' vision of an evidence base for palliative care began to come to fruition, and the publication of the landmark textbook *The Management of Terminal Disease* in 1978 marked an important milestone in that process (Saunders 1978). Secondly, NHS-funded palliative care services continued to be established, leading to greater integration between palliative and established services. Thirdly, and perhaps most significantly, the public wanted hospices. By 1981 there were already 58 inpatient units and 32 home care teams in the UK, and by the mid 1980s, the rate of hospice building had risen to 10 new hospices per month (Clark et al. 2005). All of these developments also no doubt contributed to the momentum which ultimately led, in 1987, to the recognition by the Royal College of Physicians of the new sub-specialty of Palliative Medicine.

The increase in palliative care services in the UK and Ireland has continued to the present day, although the rate of that increase has slowed considerably, and there is more evidence of infilling of gaps, particularly in hospital-based

services. By 2008, the Hospice and Palliative Care Directory was listing 223 inpatient units, 304 hospital support teams, 283 day care services and 316 home care (community) services (Hospice Information Service 2008).

Those years of local expansion of hospice and palliative care services were swiftly followed by attempts to organise and regulate services, and to follow a more strategic course. The Help the Hospices charity was established in 1984 'to help hospices ensure that the best possible care is provided to all those affected by terminal illness' (Help the Hospices 2008). A move to Europe-wide coordination followed in 1988 with the establishment of the European Association for Palliative Care. Then, in 1991, the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (now the National Council for Palliative Care, NCPC) in England, Wales and Northern Ireland, and the Scottish Partnership Agency for Palliative and Cancer Care (now the Scottish Partnership for Palliative Care, SPPC) were set up as national umbrella bodies.

In 1990, the World Health Organization (WHO) set its first standards for palliative care. These were particularly significant in that they both cemented the ethos of palliative care and established internationally recognised benchmarks for palliative care services. What is particularly interesting is the very obvious influence of Cicely Saunders, particularly in the statements relating to active living and multi-disciplinary teamwork. The WHO guidelines were revised in 2002 (Sepulveda et al. 2002), but remain, quite unusually, a striking statement of the underlying philosophy for an approach to care.

National standards were also agreed in the UK. *The Principles and Provision of Palliative Care* was produced by the Standing Medical Advisory Committee and the Standing Nursing and Midwifery Advisory Committee in 1993, closely followed in 1994 by the *Palliative Cancer Care Guidelines* produced by the Scottish Partnership Agency and the Clinical Resource and Audit Group. Of major significance, around that time, was the recommendation by the National Council (and later endorsed by the NHS Executive) to distinguish three levels of palliative care: the palliative care approach, palliative interventions and specialist palliative care (NCHSPCS 1995; NHS Executive 1996). This development meant that two sets of benchmarks were now recognised: one applying to specialist services and one applying to other care providers. In Scotland, specialist standards were devised by the Clinical Standards Board (now Quality Improvement Scotland) and used to carry out the first national performance evaluation for specialist services in 2003 (NHS Quality Improvement Scotland 2004).

In the 40 years since the opening of St Christopher's Hospice, palliative care has come to be recognised as an important element of service provision, not only within the voluntary sector but also across the spectrum of UK health and social services (Matthew et al. 2003). In addition, over that period, palliative care has edged its way into national government's health and social policy. Recommendations over the period from 1986 to 2000, for instance, have included increasing the provision of palliative care services for people with non-malignant diseases, introducing palliative care at earlier stages in the disease process and promoting greater partnership working across agencies and sectors (Mathew et al. 2003).

Contemporary issues and future challenges

Those policy changes mentioned above have contributed to the numerous developments in UK palliative care practice witnessed over the last decade. Some of the most far reaching of these have been the introduction of the Liverpool Care Pathway, the Gold Standards Framework and the 'Preferred priorities of care' document, and their inclusion in the Department of Health's End of Life Care Strategy (Department of Health 2007).

Practice Point 1.2

Find out what progress your local health authority has made towards implementing palliative care pathways and service models.

Commentary:

The driving force behind the development of new care pathways and service models for palliative care has been the need to improve standards for all patients. The perception of hospices as being 'a little bit of heaven for the few' (Clark et al. 2005) has been borne out by studies which suggest differences in the quality of end of life care received by patients in these and other settings (Seale and Kelly 1997). Addressing this discrepancy is one of the principal priorities of palliative care today.

The Liverpool Care Pathway was developed specifically to transfer best practices from hospices into acute hospital settings (Ellershaw and Wilkinson 2003). The resulting document (together with its associated education programme) has been modified in the intervening years and is now available in hospital, community, care home and hospice versions (Marie Curie Palliative Care Institute Liverpool 2008).

The Gold Standards Framework was devised to improve cancer and palliative care in the community by tackling shortcomings in communication and planning. Early results suggest that dying at home can be improved if services and agencies are properly coordinated, and if family carers are kept informed and involved (Gold Standards Framework Scotland Project Team 2007).

One of the most contentious issues around the care of the dying has been choice of place to die (Gomes and Higginson 2004). Studies consistently report a wide discrepancy between patients' stated chosen place of death and their ultimate destination (House of Commons Select Committee on Health 2004). This situation has greatly exercised practitioners and policy makers alike, and resulted, in 2004, in the launch of the 'Preferred place of care' document (now modified to 'Preferred priorities of care') (Lancashire and South Cumbria Cancer Services Network Project Team 2004). This patient-held, advanced care plan offers a ready means of recording peoples' preferences and priorities for their end of life care (National Preferred Priorities of Care Team 2007).

In 2006, the Department of Health proposed an End of Life Care Strategy with the ambitious aim of meeting 'the health and social care needs and preferences of all adult patients in where they live and die' (National Council for Palliative Care 2006). The strategy included a commitment to roll out the three tools already discussed here. Early progress towards the realisation of the strategy has been positive (Department of Health 2007). In Scotland, palliative care services are currently coordinated by a framework of managed clinical networks (Scottish Partnership Agency for Palliative and Cancer Care 2000). However, in 2008, the Scottish Government accepted the recommendation of the Scottish Partnership for Palliative Care to implement a comprehensive palliative and end of life care strategy (SPPC 2007, 2008).

The case for improving the care of dying people across every care setting has already been successfully made – although the challenge of delivery has only just begun (Cooley 2007). An equally strong case has been made to make palliative care available to people across the spectrum of life limiting diseases. As will have become apparent, much of the early provision of palliative care in the UK was restricted to people with cancer. However that position has become increasingly indefensible, and current policy is strongly directed towards care on the basis of need, not diagnosis (NCHSPCS 1998, 2003; SPPC 2006).

There are other inequities of access related to ethnic background, old age, learning disability and so on which equally require to be tackled if the provision of palliative care is to be fair and equitable (Roscoe and Schonwetter 2006). Internationally too, we are far from meeting even the limited demand of Ahmedzai et al. (2004) that there should be guaranteed access to palliative care for every person with cancer. Unfortunately there are still areas of the world where affordable palliative care is completely unknown (Costello 2005; Milicevic 2002).

Palliative care at 40

If the birth of modern palliative care is agreed to have coincided with the opening of St Christopher's Hospice in 1967, then palliative care has now reached its early forties. But what does the future hold for a speciality which describes itself as 'an approach' and claims to be applicable across the spectrum of care settings and diagnoses, but (in the UK at least) is substantially provided by the voluntary sector?

Future funding of palliative care is certainly one issue which must be addressed. The most recent estimates suggest that 71% of inpatient hospice care is provided by independent charities, and organisations such as Macmillan Cancer Support and Marie Curie Cancer Care remain dependent on legacies and fundraising practice points for the bulk of their operating costs (Help the Hospices 2005). There is evidence from the US that some hospices are responding to financial pressures by introducing more efficient and innovative business practices (Kirby et al. 2007). However, this is only part of the answer, and government

commitments in terms of partial funding may have to grow if current service levels are to continue or increase.

Another challenge in contemporary palliative care is the maintenance of quality. Palliative care is highly labour intensive and, consequently, a relatively expensive model of care delivery. Funding bodies, whether statutory or voluntary, must be assured that they are receiving value for money. Measuring outcomes in palliative care is fraught with difficulties, not least because relief of suffering is a highly subjective concept and potential respondents are frequently too ill or too upset to comment on their experiences. However, systematic quality improvement in palliative care is achievable and sustainable if supported by policy reforms and local practice initiatives (Lynn et al. 2008).

And what will palliative care look like in another 40 years? Some important groups apparently continue to define palliative care in terms of cancer services (e.g. National Institute for Health and Clinical Excellence 2004; Ahmedzai et al. 2004) in spite of the momentum of the non-malignant agenda. There are calls for greater use of invasive interventions, but counter claims that the speciality is becoming over-medicalised (Clark 2002). The current proliferation of cancer support services in UK hospices suggests a move to the inclusion of palliation earlier in the disease process, but where does that leave the trend towards end of life initiatives? Finally, there is the issue of physician-assisted suicide – clearly rising up the political agenda with a bill before the House of Lords in 2006 (and a palliative care bill the same year) and a consultation before the Scottish Executive in 2005 (Finlay 2006; Joffe 2006; Purvis 2005). Perhaps, the way palliative care responds to this particular issue will define, more than any other factor, its future direction and values.

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