

## The evolution of palliative care

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The development by the second half of the twentieth century of new technologies and effective specific treatments for disease still left much suffering unaddressed. As Professor Patrick Wall wrote in 1986, 'Symptoms were placed on one side and therapy directed at [them] was denigrated'<sup>1</sup>. In the same vein, when Aneurin Bevan introduced the National Health Service Bill to Parliament, he stated that he would 'rather be kept alive in the efficient if cold altruism of a large hospital than expire in a gush of sympathy in a small one'<sup>2</sup>.

But what if no cure was possible and the end of life was inevitable? Referring particularly to the hospice movement, Wall added that 'The old methods of care and caring had to be rediscovered and the best of modern medicine had to be turned to the task of new study and therapy specifically directed at pain'. Care, matched with an increasingly sound evidence base, was by then underpinned by the concept of 'total pain'—defined in 1964 as including not only physical symptoms but also mental distress and social or spiritual problems<sup>3</sup>. This approach met ready audiences among nursing and medical students during lectures or in articles, as well as social workers and more gradually among senior members of the medical profession.

### AN EVIDENCE BASE

During the 1950s three important surveys of end-of-life care were undertaken. In 1952 a report based on the observations of district nurses throughout the UK of some 7050 cases, published by the Marie Curie Memorial Foundation<sup>4</sup>, revealed appalling conditions of suffering and deprivation among many patients dying of cancer at home. By 1960, Glyn Hughes had conducted a nationwide survey for the Gulbenkian Foundation<sup>5</sup>. This included widespread consultations, 300 site visits and contacts with 600 family doctors. Conditions in charitable homes were judged seriously inadequate, with deficiencies in financial support and staffing, and a large proportion of the nursing homes visited were deemed 'quite unsuited—and in some cases amounting to actual neglect when measured by standards that can reasonably be expected'. Hughes noted 'a serious gap in the National Health Service with an unanswered question of where and by whom the elderly

terminally ill would be cared for'. Finally, a unique detailed study of the physical and mental distress of the dying was published by John Hinton in 1963<sup>6</sup>. His observations from the wards of a London teaching hospital showed that much suffering remained unrelieved and also how most patients were well aware of their prognosis despite the lack of information normally given at that time.

### A PERSONAL HISTORY

In 1948, after experience of wartime nursing in the absence of nearly all our modern pharmacology, and as a social worker among patients and families devastated by unrelieved pain in terminal cancer, I encountered the Polish Jew whose few poignant words proved a powerful catalyst of a new world-wide movement. His statement 'I will be a window in your Home' gave a challenge to openness of all kinds; 'I want what is in your mind and in your heart', set scientific enquiry alongside personal encounter; his very personal journey, into peace, gave the demand for space for freedom of spirit in facing the mystery of death.

A hope of returning to nursing in this field was countered by the surgeon Norman Barrett who said 'Go and read medicine. It's the doctors who desert the dying and there's so much to be learned about pain. If you don't do it properly you'll only be frustrated, and they won't listen to you'.

There followed seven years of voluntary work as a nurse in an early 'home' which gave me the first experience of the effectiveness of small regular doses of oral morphine. This was combined with a medical training during the pharmacological explosion of the 1950s and led to seven years of clinical care and research at St Joseph's Hospice from 1958. The introduction of the detailed recording of an oral and regular regimen, and the development of symptom control with the drugs becoming available, led to the change expressed by one of the nuns nursing there as 'from painful to pain free'. The basic methodology of listening and tape-recording, coupled with a commitment to the day-to-day care of patients with advanced malignant disease in the 45 beds, was the basis of the analysis of 1100 cases in a punch-card system (this being the precomputer age). As in Hinton's seminal paper, patient's comments were used as illustrations—'It seemed that all of me was wrong'; 'It was all pain, but now it's gone and I'm free'; 'They used to

want me to hold on a bit longer—I was sweating with the pain—but now I feel so calm’.

### **A DEMONSTRATION PROJECT**

On the basis of the experience and evidence described above, a project to show how to address the proven gap in National Health Service provision was launched as a new charity. From 1959 onwards detailed memoranda presenting ‘the need’ and ‘the scheme’ were circulated to likely advisers and supporters. A steering group and countless correspondents were drawn into a rigorous discussion of the challenges and possibilities. Medical, social and spiritual issues had to be addressed before planning and fund-raising could begin.

The medical foundation was based on the clinical experience and research at St Joseph’s Hospice and all that had led up to it, alongside extensive reading in the library of the Royal Society of Medicine. Anecdote heavily outweighed studies but, by 1967, 184 references had been assembled. The work at the hospice had been enthusiastically welcomed because it had been possible to demonstrate that patients could be free of pain and still alert, responsive and remaining themselves. The Londoners from the disadvantaged East End joined gladly in the medical student teaching rounds. Their stories and the growing body of evidence that tolerance and drug dependence did not develop were the basis of lectures and articles<sup>7,8</sup>.

These beginnings pointed to work that would be conducted when the new hospice was finally built and opened for inpatient and home care and for research into the relief of distress. The methods used were those that could be widely transferable, with multiprofessional education planned to rely heavily on clinical experience.

The spiritual needs of patients and families struggling with what might seem pointless suffering were a greater challenge. Fear and grief were often inarticulate. How could we make sure the hospice was not seen as a ‘death house’? How would the earlier traditions of the religious charities be interpreted in an increasingly secular world? In the end, this new charity was based on extremely broad spiritual foundations. That ‘There shall be a Chapel, available for Christian worship’ emphasized that there would be no pressure on anyone, staff or patient, to enter it and no bar to other faiths doing so.

Finally, how to support the staff whose care had to be of a nature that would reach the most hidden places of distress? It was anticipated that there would be a more flexible commitment than among the nuns at St Joseph’s Hospice but with some form of community ethos. After much debate, I wrote, ‘I think we will know when we get there’ and, later, ‘We are a community of the unlike’. By

the end of 1960, these issues had been addressed and a basis laid for future development.

St Christopher’s Hospice opened in 1967 with a building for 54 patients, a 16-bed residential wing for the elderly, a nursery for staff children and a planned bereavement service. Home care, which had been incorporated in the plans from the beginning, started nearly two years later. Both the early drug studies and the home-care outreach were funded by the National Health Service. Currently, nearly ten times more patients are being cared for at home than as inpatients.

### **SPREADING CONTACTS**

The thousands of letters written during the years 1959–67, as these ideas were developed, are now preserved in extensive indexed archives. Correspondence with the Director of the National Cancer Institute at Bethesda, with the foreign desk of the American Cancer Society and with many others are housed in this comprehensive set of records. An eight-week tour of the United States in 1963 led to many links. Contact was made with Beecher, Houde and Wallenstein and other pain researchers, with the psychiatrist Avery Weisman and with social worker Ruth Abrams in Boston, to name a few. The continuing links and visits between the USA and the UK have proved enormously stimulating and helpful. Three sabbatical visits to St Christopher’s Hospice in the early years led to the setting up in Connecticut, New York and Montreal of teams in three different developments of modern palliative care. These were home-care teams, hospital-care teams without specific back-up beds, and a unit with a consulting team in a teaching hospital. All three patterns have been adopted widely around the world.

### **WHERE DID WE GO RIGHT?**

First, I make no apology for identifying as a correct starting-point the methodology of simple listening, recording and analysing. As Wall wrote in 1997, ‘Palliative care has succeeded in the face of two common myths which were shared by patients and doctors [of drug dependence and tolerance] swept aside by precise and convincing observation’<sup>9</sup>. The demonstration of appropriate, scientifically based and patient-centred treatment, first demonstrated in St Joseph’s Hospice and later in St Christopher’s Hospice, eventually led to the establishment of a recognized specialty in 1987 in Australia, New Zealand and the UK. The focus on cancer pain, which could be convincingly researched and published, led to a developing evidence base.

Secondly, the fostering of links with basic and clinical pain researchers and other allied workers on both sides of the Atlantic, through voluminous correspondence since

1960 and numerous visits, provided stimulating interchanges. Without these, other international links in palliative care would not have developed.

Thirdly, efforts to change attitudes to end-of-life care were, and still are, based on rigorous philosophical, political and spiritual discussions. From the beginning the emphasis was on 'living until you die'. The substantial body of indexed archives, attributable to a jackdaw-like character, offers material for a fruitful and stimulating study.

### WHERE DID WE GO WRONG?

On the minus side, over-enthusiastic lectures tended to arouse not only enduring commitments but also a tendency to perfectionism and élitism. Failures teach us more than successes and were not always faced in the early days.

Secondly, the focus on the diagnosis of cancer sometimes hindered the acceptance of challenges in other areas of need, HIV/AIDS being a case in point. But how do we balance need, skills and resources?

Thirdly, although we looked to a research and educational base, we were too slow in establishing full academic rigour (and still have some way to go). Indeed, learning and discovery must surely be endless.

Finally, the concentration in a building, at least in the UK, tended to outweigh the emphasis on home care. Palliative care is a philosophy based not on physical facilities but on attitudes and skills, as the many interpretations around the industrialized and developing world show forcefully.

### FOR THE FUTURE

There remains a clamant need to address attitudes to end-of-life care among the professions, the public and the media. The losses of parting cannot be removed but their devastating effects can be ameliorated. For this we must

give attention to the whole person, with all the insights the humanities can give us.

We need to focus more on the discrepancy between the developed and developing worlds in terms of medical care and research, epidemiological and clinical. Validated tools for assessing quality of life should be more widely used with this challenge in mind.

Psychological issues for patients and families should be studied, with recognition of profound (though often unarticulated) spiritual and existential distress. Academic centres with multiprofessional teams have the potential to develop recognized standards. These should be offered as part of the ongoing commitment to every person in need of care for progressive disease, and should incorporate the same urge for exploration as characterized at the earlier stages. Our common humanity demands no less.

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