

Between hope and acceptance: the medicalisation of dying

David Clark

Palliative care has encouraged medicine to be gentler in its acceptance of death, yet medical services in general continue to regard death as something to be resisted, postponed, or avoided. David Hart examines the challenge facing doctors to balance technical intervention with a humanistic approach to their dying patients

We have grown used to speaking of medicalisation as a byword for all things negative about the influence of modern medicine on life and society. The term has become synonymous with the sense of a profession reaching too far: into the body, the mind, and even the soul itself. Its use is now almost always pejorative, negative, and antagonistic. When Ivan Illich developed his original critique of medicalisation in the mid-1970s, he highlighted its particular impact upon the dying process in modern culture and could claim that modern medicine had “brought the epoch of natural death to an end” (box 1).¹

The rise of palliative care

Yet well before Illich a climate of concern was already developing about contemporary means of dying and medicine's part in them. The emergence of terminal and hospice care, and subsequent endorsement of the specialty of palliative medicine, is a clear expression of this.

Concerns about improving care at the end of life began to surface on both sides of the Atlantic during the 1950s. In Britain attention focused on the medical “neglect” of dying people; whereas in the United States a reaction to futile treatments in the face of suffering and inevitable death began to take root.

Four particular innovations can be identified.² Firstly, a shift took place in the literature on the care of dying people, from idiosyncratic anecdote to systematic observation and research. By the early 1960s leading articles in the *Lancet* and the *British Medical Journal* were drawing on such evidence to suggest ways in which terminal care could be promoted and indeed arguments for euthanasia might be countered. Secondly, a view of dying began to emerge that sought to foster concepts of dignity and of meaning along with a new openness about the terminal condition of patients. Thirdly, an active rather than a passive approach to the care of dying people was promoted in which the fatalistic resignation of the doctor (“there is nothing more we can do”) was supplanted by a determination to find new and imaginative ways to continue caring up to the end of life. Fourthly, a growing recognition of the interdependency of mental and physical distress created the potential for a more embodied notion of suffering, thus constituting a profound challenge to the body-mind dualism on which so much medical practice of the period was predicated—brilliantly captured in Cicely Saunders' notion of “total pain.”³

When Cicely Saunders, the outstanding innovator in the field, founded St Christopher's Hospice in Sydenham in 1967, it quickly became a source of inspiration to others. Within a decade it was accepted that the

Summary points

In the mid-1970s, Ivan Illich launched a powerful attack on the “medicalisation” of dying

The rise of palliative care has been one response to calls for greater dignity at the end of life

Yet the wider medical system continues to regard death as something to be resisted, postponed, or avoided

The charge of creeping medicalisation has also been levelled at palliative care

All physicians face the problem of balancing technical intervention with a humanistic orientation to their dying patients

principles of hospice care could be practised in many settings: in freestanding hospices and in home care and day care services. Likewise, hospital units and support teams were established, designed to bring the new thinking about dying into the very heartlands of acute medicine. The term “palliative care,” first proposed in 1974 by the Canadian surgeon, Balfour Mount,⁴ came to symbolise this broadening orientation.

Countervailing problems

Yet just as palliative care has encouraged medicine to be gentler in its acceptance of death, parallel developments in the medical system have redoubled efforts in the opposite direction. One aspect of this is the problem of futile treatments that either have a low probability of having an effect or produce an effect that is of no benefit to the patient. Further problems derive from the widespread assumption in society that every cause of death can be resisted, postponed, or avoided.⁵

Box 1: Illich's critique of the medicalisation of dying¹

- A loss of the capacity to accept death and suffering as meaningful aspects of life
- A sense of being in a state of “total war” against death at all stages of the life cycle
- A crippling of personal and family care, and a devaluing of traditional rituals surrounding dying and death
- A form of social control in which a rejection of “patienthood” by dying or bereaved people is labelled as a form of deviance

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In the United Kingdom almost a quarter of occupied hospital bed days are taken up by patients who are in the last year of life⁶ and some 60% of all deaths occur there. Thirty seven per cent of patients admitted to UK intensive care units die within six months,⁷ and the bill for these units in 1999 was estimated at between £675m (\$961m; €1095m) and £725m, increasing by 5% annually. Commenting on the modern epidemic of multiple organ failure, Bion and Strunin observe that “it costs twice as much to die in an intensive care unit as it does to survive.”⁸ One New York hospital found that among a group of elderly patients with advanced cancer or dementia, overall 47% received invasive non-palliative treatments during their final few days; 51% of patients with dementia and 11% of patients with cancer received enteral tube feeding, and all still had the feeding tube in place at death.⁹

Commentators on the widely cited SUPPORT study in the United States described dying patients as “caught up in a medical juggernaut driven by a logic of its own, one less focused on human suffering and dignity than on the struggle to maintain vital functions.”¹⁰ Seymour summarises a literature that has accumulated over the past 30 years on the social isolation of dying patients in hospital, of dehumanised dying, and of the failure of medical technology to coexist appropriately with dignified dying.¹¹ Small wonder that death in the hospital was recently described by one German physician as something akin to an “industrial accident” (Friedemann Nauck, personal communication, 2002).

Broadening the boundaries of palliative care

As these increasingly technical approaches to care at the end of life have gained influence, the newly formed specialty of palliative care has concentrated on two distinct issues.¹² First is the impetus to move palliative care further upstream in the disease progression, seeking integration with curative and rehabilitation therapies and shifting the focus beyond terminal care. Second is a growing interest in extending the benefits of palliative care to those with diseases other than cancer—to make “palliative care for all” a reality. The new specialty is therefore delicately poised. For some, integration with the wider system is essential for success and the only realistic way to address unrelieved

suffering at the end of life as a public health problem. For others, it marks the entry into a risky phase of new development where early ideals might be compromised. Modernisers claim that specialisation, integration, and the development of an “evidence based” model of practice and organisation are crucial to long term viability. Others mourn the loss of early ideals and regret the new emphasis on physical symptoms at the expense of psychosocial and spiritual concerns. In short, some have claimed that the dark forces of medicalisation and “routinisation” are taking hold and even that the putative “holism” of palliative care philosophy masks a new, more subtle form of surveillance of dying and bereaved people in modern society.¹³

Yet in print, in conferences, and in their daily clinical work, specialists in palliative care seem to lack clarity and confidence when defining precisely what they do and how it differs from other health care. Part of the problem lies in a field that “relates to a stage of a patient’s condition, rather than its pathology.”¹⁴ Palliative medicine thus has some of the hallmarks of a postmodern specialty:¹⁵ it lacks a specific disease, bodily organ, or life stage to call its own. For this reason it has been drawn towards a model that overarches the course of the illness and is unified by quality of life goals.

Yet the adoption of “quality of life” as a goal of palliative care conceals many problems, several of which are structural, economic, and social and lie beyond the immediate influence of clinical medicine.¹⁶ To attend to suffering rather than quality of life may therefore seem a more realistic aim for palliative care, one that is more compatible with the wider goals of medicine and which might help to address problems about futility and overtreatment. But this has raised fears of selling out to a medical model in which suffering is only a problem to be solved and specialists in palliative care become symptomatologists, in just another specialty.¹⁷ As the specialty develops, its medical attention tends to focus on pain and symptom management as a bounded set of problems within the relief of suffering. Here may lie the charge of creeping medicalisation. Yet it is in this biomedical area of palliative care that measurable and striking successes are to be found in the use of pain relieving and symptom controlling technologies. A recent study claims, for example, that in the palliative care unit of one Australian teaching hospital 81% of interventions were based on findings from randomised controlled trials or other trials or on convincing non-experimental evidence; yet of 24 problems listed, all but two (depression and delirium) were physical rather than psychosocial or spiritual in type.¹⁸ Not surprisingly, some consider this symptom analysis and management to lie at the heart of the specialty.¹⁹

Who wants the good death?

From the outset, achievement of the “good death” has figured as a goal of palliative care (box 2). But the shift from “terminal” to “palliative” care has brought about a diminished emphasis on the good death,²⁰ which now has a reduced significance in the discourse of pain and symptom management. “Mainstreaming” palliative care into the central functions of the healthcare system produces a greater concentration on the problems of the living than the dying population. A shift



In past centuries, death was accepted



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Have we now come too far in our resistance to death?

“upstream” to earlier stages in the disease process—and the inclusion of chronic, life limiting conditions—promotes the rhetoric of quality of life versus a good death. Consider the following, from an Italian study of quality of life and outcomes in palliative care: “Dying during the study period is a strong indicator of patients who entered the palliative care intervention in very poor health conditions. We expected and observed a worst [quality of life] outcome for patients like these.”²¹ The authors could be forgiven for implying that the patients had somehow got things wrong.

Is this evidence of the medicalisation of death? In part only. Paradoxically, what we are seeing is the medicalisation of palliative care, a specialty that opens up a space somewhere between the hope of cure and the acceptance of death. In doing so, it makes a classic appeal to the desires of “patients” in a modern culture, where we dread not so much the state of death as the process of dying. In this sense it is more appropriate to view medicalisation as the expected rather than unintended outcome of the growth of palliative care, especially in the British context, where medical pioneers are central to its history.

Conclusion

What light does this shed on the original critique of the medicalisation of dying? At the time Illich was writing, the mid-1970s, a much more unitary and optimistic view of medicine was in evidence than exists today, and this was a basis for his critique. Now the modern medical system is pervaded with doubt, scepticism, and a mistrust of expert claims. In a sense he has won the argument. Medicine has become more disassembled and further divided into micro-specialisms. In this context, is

Box 2: Elements of a “good death” in modern Western culture

- Pain-free death
- Open acknowledgment of the imminence of death
- Death at home, surrounded by family and friends
- An “aware” death—in which personal conflicts and unfinished business are resolved
- Death as personal growth
- Death according to personal preference and in a manner that resonates with the person’s individuality

palliative medicine contributing to the medicalisation of death, despite its early intentions? The answer is probably yes; and for some patients, pain and other physical suffering are better controlled as a result. It is inappropriate to see this as an example of either medical imperialism or the world we have lost. The challenge for palliative physicians is no different to that facing their counterparts elsewhere in medicine: how to reconcile high expectations of technical expertise with calls for a humanistic and ethical orientation for which they are largely unselected and only partially trained.

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Endpiece

Trapped between two evils

The consequences of this continuing modernist deconstruction of mortality have brought us to the current postmodernist impasse in which dying patients are trapped between two evils: a runaway medical technology of ventilators, surgeries, and organ transplants that can keep bodies alive indefinitely and—as if this prospect were not frightening enough—an understandable but reckless public clamor for physician-assisted suicide as the only alternative to such ignominious physician-assisted suffering.

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