DEEP-SEATED BARRIERS TO END-OF-LIFE CARE IMPROVEMENT IN THE TWENTY-FIRST CENTURY

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Emily K. Abel. *The Inevitable Hour: A History of Caring for Patients in America*. Baltimore: Johns Hopkins University Press, 2013. viii + 226 pp. Illustrations, notes, and index. $32.95.

By the late nineteenth century, the people of Europe and North America were living longer and had rising expectations of health and well-being, but with the benefits of longevity and the diminished threat of early death came other consequences. The predominant causes of death started to shift ground—from the sudden demise brought on by infection, disaster, and plague to protracted dying associated with the emerging chronic diseases of the modern era—not least cancer and tuberculosis. Whereas in the Middle Ages in Europe, the death that came too swiftly was something to be feared and defended against, now concerns began to grow about lengthy dying and the suffering it might entail. Mid–nineteenth-century popular culture presented idealized images of a slow and controlled farewell to the world, with family members gathered around and confidence in a passage to another and better world. But, by the close of the century, preoccupations were emerging about the manner of dying—now coming to be seen not only as a social and cultural event but also as potentially a medical process. This brought growing unease in the disposition towards dying. Changing personnel around the deathbed, secrecy about the imminence of death, as well as the desire to quell the threat of pain and suffering—all reveal a new *anxiety* that opened up a space for medical intervention.

The nineteenth century, for the French historian Phillipe Ariès, was associated with the emergence of new sentimental orientations to death that reflected, in particular, major changes within the culture and structure of family life. As the meaning of family relationships deepened and became more nuanced, parting with a dying relative and subsequent grief for that loss became increasingly emotional and expressive. A growing emphasis fell on the emotional pain of separation and on keeping the dead alive in memory. This was enhanced by new developments in photography that enabled carefully staged postmortem images to be captured and preserved for posterity. It also meant elaborate rituals of mourning and funeral observance as well as the emergence of the cult of the grave as a family resting-place. Undoubtedly, it led to new representations of the deathbed itself. The wider Romantic movement contributed to notions of the "beautiful death," to *la mort de toi* ("thy death") personified in the death of a loved one. Ariès also shows that, in the nineteenth century, the rise of modern science brought challenges to religious authority and, specifically, in this context, to the necessity of dying in the presence of the official representatives of formal religion.

For Ariès, medical men began to replace priests, clergy, and ministers at the bedsides of the dying. But this created a moral vacuum. For if the role of medicine was to focus on the technical preoccupations of attending to the relief of pain and the easing of physical distress, who was to address the fears of the dying, the distress of the bereaved, and the achievement of the "good death"? There has been a tendency to see this as the period in which dying was drained of meaning by science and medicine—forcing life's end to retreat from its public and family dimensions into the sequestered spaces of hospitals and other institutions. This was also strengthened by the growing tendency to shield the dying person from the reality of their fate. For Ariès, the mid-nineteenth century was therefore the origin

of “the lie” wherein the gravity of the dying person’s situation was kept from them—and death was on the way to becoming “shameful and forbidden.”

Emily Abel’s thoroughly researched book steps into this broad historical narrative and gives context, detail, and definition. Focused on the American experience, and with some stretching of the period at either end, she takes us from the close of the nineteenth century to the mid-1960s, explaining how the movement to improve end-of-life care developed more toward the end of this period and why it continues to face significant hurdles. Abel challenges three prevailing assumptions in the social and historical analysis of death and dying. She rejects the notion that medicine actively sought dominion over the dying process during these years. Neither does she accept that medicine eclipsed the role of families and religion at the deathbed. Finally, she has no truck with the idea that problematic and dehumanizing death within hospitals and other institutions is a product of the recent technological era; she sees widespread problems over a much longer timescale. For Abel, medicine’s ability to control acute infectious disease was quickly offset by its difficulties in engaging with a rising tide of chronic conditions within which the route to death could be protracted and unpredictable. Whether these patients were labelled “incurable” (in the earlier period) or “terminal” (somewhat later), she asserts that they were, by and large, “devalued and avoided” (p. 6).

Abel’s accounts of nineteenth-century home death in New England are compelling and insightful. She seeks to understand the cultural values that shaped contemporary descriptions of dying and bereavement—rather than to isolate any definitive truths about death in that period. She attends to the costs and benefits of family caregiving, the role of religion, the care of the dead, and the feelings of loss. She explains how bereaved relatives

could take comfort that a “good death” completed might indicate the promise of eternal salvation in the life to come.

Abel also shows how physicians were largely absent from the nineteenth-century deathbed, even though, as early as 1847, the American Medical Association had drawn up a code urging doctors not to abandon the incurably ill and those imminently dying. But skills in relieving pain at the end of life lagged far behind those relating to pain after surgery, and the code also warned against making gloomy prognostications close to the end. So the stance of American medicine towards the dying could appear limited and detached. In 1873, America had only 120 hospitals, from which the dying were, in the main, actively excluded. Most people died at home and were cared for by relatives who, even into the twentieth century, continued to view dying as a social and spiritual event, for the management of which they were largely responsible.

In the early twentieth century, this started to change. The influence of physicians such as William Munk and William Osler could still be felt—with their sensitive and reflective writing on the care of the dying patient and the management of death—but now an era got underway in which the needs of those at the end of life had little prominence in the thinking and practice of modern medicine. There was growing faith in medicine’s abilities and the power of science to overcome disease, if not death itself. But as Alfred Worcester noted, the onward progress of medical science seemed to have the effect of sidelining clinical interest in the care of the dying. The subject had little prominence in the burgeoning medical schools, where it was largely absent from the curriculum and from the available textbooks. Moreover, physicians were urged to avoid “the fatal mistake of caring” (p. 37), and a deepening chasm appeared between their biomedical knowledge and the lay understandings of patients and their families. Even nurses learned to cultivate a sense of

detachment from individual patients and from the experience of death. If medical schools developed an increasing interest in the study of the dead body, it was largely at the expense of the care of the dying person.

This neglect of dying and death within the medical schools appears to have its counterpoint in the rise of special hospitals of one sort or another, in particular those for impoverished "incurables." For a short time, religious foundations and charitable institutions took up these causes; but as the twentieth century advanced, they too came under criticism for their fatalistic approaches, for instilling a lack of hope in their patients, and for their failure to adopt the wider sense of hubris that was sweeping the medical establishment. Likewise, as the cancer hospitals raised their ambitions for curative interventions, the proportion of terminally ill patients within them had, perforce, to be reduced.

After World War Two, there was unprecedented optimism about what medicine could achieve. By the early 1950s, there was hope of "a penicillin for cancer" (p. 91). There even began to be more openness about the disease, which might no longer be the death sentence of the past. New chemotherapeutic agents were thought to have the potential to eradicate even metastatic disease. The sick-role theory of illness behavior, promulgated by Talcott Parsons from the early 1950s, was entirely predicated on the power of medicine to restore health in short order to the suitably compliant patient—even one with cancer.

Meanwhile, death, when it occured, was increasingly likely to take place in hospital. Hospital care expanded from the late 1940s; by 1960, 50 percent of all deaths were taking place there. Abel maintains that many of these patients were subjected to invasive medical and surgical treatments of an experimental nature, which they readily endured in the belief that death could be kept at bay and avoided almost indefinitely. Social scientists and

researchers, rather than clinicians, were the first to articulate a concern about the direction of travel and growing denial of death within medical culture and practice. Herman Feifel's 1959 edited volume *The Meaning of Death* broke new ground. The work of Barney Glaser and Anselm Strauss, Jeanne C Quint and David Sudnow—all based on field studies in American hospitals in the early to mid-1960s—generated a new critique of the culture of dying. At the same time, social workers and health services' researchers began to uncover details of the inadequacies of care for the terminally ill, particularly those with cancer. Late diagnosis and disclosure were both common occurrences. Reports from Chicago and Boston showed the disastrous consequences of sending home poor and disadvantaged terminally ill patients without adequate support. But the alternatives seemed no better: "In most instances, enrolling relatives in terminal care facilities meant sending them away to die alone" (p. 135).

This detailed layering of the American medical system and its aversion to and marginalization of the care of the dying is Abel's central theme. It is convincing and detailed but never polemical. For her, it explains how the late twentieth-century entry of hospice and palliative-care thinking and practice has proved so challenging and why progress has been slow and difficult. The British physician Cicely Saunders had links with like-minded colleagues at Yale from the early 1960s, and together they promulgated a new model of hospice care. It seemed to hook onto a growing mood in the country, one inspired by civil rights, personal autonomy, pluralism, and community action. Hospice proliferated in the United States as a reaction against the wrong sort of involvement of medicine with the dying. It reintroduced the idea of the family as the unit of care and placed a strong emphasis on care in the home. In reacting against the excesses of hospital care of the dying, hospice

offered a new model of holistic care that combined the physical and social needs of patients with their psychological concerns and spiritual preoccupations.

Sadly, Abel devotes little space to the major developments that followed. Gaining sparse attention in her conclusion are the impact of the hospice Medicare provision, as well as the role of strategic philanthropy, research, and advocacy in raising greater awareness of end-of-life care as a public health and societal issue. But the case has been made. Such endeavours must be realistic and modest in their goals, for they operate in a context where they contend with over a century of medical and social history that has served to marginalize the care of the dying, deny resources for those at the end of life, and portray death as a medical failure. In the face of such obdurate conditions, the reformist zeal of American hospice and palliative care meet their ultimate challenge—one that they must somehow find ways to overcome.

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