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Shifting Hospital–Hospice Boundaries: Historical Perspectives on the Institutional Care of the Dying

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Abstract

Social forces have continually framed how hospitals perceive their role in care of the dying. Hospitals were originally conceived as places of hospitality and spiritual care, but by the 18th century illness was an opponent, conquered through science. Medicalization transformed hospitals to places of physical cure and scientific prowess. Death was an institutional liability. Equipped with new technologies, increased public demand, and the establishment of Medicare in 1965, modern hospitals became the most likely place for Americans to die—increasing after the 1940s and spiking in the 1990s. Medicare's 1983 hospice benefit began to reverse this trend. Palliative care has more recently proliferated, suggesting an institutional shift of alignment with traditional functions of care toward those facing death.

Keywords

hospice, palliative care, history of medicine, spirituality, Medicare, medicalization

Hospitals as Institutions of Soul Care

From their inception in Byzantium, Christian hospitals were communal houses of mercy, refuge, and dying, variously called xenodocheia, xenones, and nosokomeia.[1] These guesthouses represented an organized response to the impact of famines, wars, disease, migrations, and pilgrimages.[2] The social welfare function was paramount, and the institutions provided sanctuary, physical care, rest, food, clothing, spiritual comfort, and medical consultations for the poor, displaced, and homeless.[2,3] From the very start, the Christian tradition and secular authorities prominently employed their guesthouses for controlling epidemics by separating the sick from the healthy. As houses of segregation, some hospitals lodged individuals with infection considered threats to society such as leprosy and plague. Under these circumstances, prominent institutional fixtures such as death and dying were handled mostly outside the boundaries of medicine.[4] Within the Christian religious frame, medicine was only a secondary good serving, in the words of Basil of Caesarea (d. 379) as a "pattern for the healing of the soul."[5,6] Consequently, serious illness was viewed as a gateway to eternal heavenly bliss, a divinely ordained rite of passage anticipated, dreaded but also welcomed. Sharing beds in crowded wards, inmates routinely witnessed such events with a mixture of fear and comfort.[6,7]

During the Middle Ages, Christian life was seen as a pilgrimage of hardships, and hospitals often became the final destinations before the earthly journey ended. As a gateway to heaven, the dying process acquired a certain normative quality by the 14th century known as *ars moriendi* or the "art of dying."[8] Eventually codified and widely circulated, the good death as literary genre became part of efforts by the Church to educate the laity concerning the fundamentals of Christian religion.[9] Based on the notion that the soul was infinitely more important than bodily survival—a belief codified in 1215 by the Fourth Lateran Council[10]—the primary aim was soul care, shepherding the fearful ill and dying to a state of peace, hope, and love. Patients were urged to refocus on their souls and look forward to eventual resurrection instead of clinging to false hopes of regaining bodily health. Repentance and redemption would facilitate the transition.[10,11]

The notion of a Christian purgatory came to play an important role. Charitable activities such as preparing and assisting others during their dying through prayers, vigils, and ceremonies could lessen time in purgatory before entering eternal bliss. Especially before the Reformation, armies of lay religious brotherhoods and confraternities supplied the manpower for companionship and the performance of dying rituals. In

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partnering this momentous transition, practitioners of the art were conscious of the fears and struggles of the dying, attempting to cast the process as a battle between good and evil, Christ and the Devil, the latter tempting moribund persons to cling to their sinful lives and material possessions. Miraculous recovery could be seen as the result of a pact with the Devil to keep enjoying the pleasures of the flesh.[12]

While insuring a measure of physical comfort, most dying rituals were essentially preparations for the anticipated journey. Spiritual cleansing, confession of sins and absolution, anointing with oil, and communion administered by a priest were the standard activities. Together with the laying on of hands, the use of oil represented a general palliative or curative agent to be drunk or applied to the skin. By the 8th century, however, the Irish Church recast anointing as an agent of spiritual transformation. Communion, for its part, was the nourishment or *viaticum* needed for the journey to God. Given the impotent state of medicine to prevent death, physicians were precluded from administering remedies until the soul had been properly prepared through confession[13] and the administration of the sacraments.[14]

For the elderly individuals and poor, to die in a hospital was considered a privilege. Even through the 16th century, caregivers kept vigil, witnessing the ebbing of life and framing it with prayers and holy readings. Following death, the bodies were carefully washed, anointed, and wrapped, then carried in procession to the hospital's chapel for a requiem mass. Burial in consecrated ground adjacent to the hospital followed. Masses for the deceased inmates were said once a year at the anniversary of their deaths.[15] Witnessed by both inmates and staff, these communal actions softened death's sting and ameliorated individual fears surrounding this passage. A good Christian death remained a central pastoral concern, both inside and outside the hospitals, reflecting a religiously cohesive society.

Hospitals as Institutions of Recovery and Cure

During the Renaissance, as modern European states sought to protect and restore their productive members of society, the original religious shelters came under the jurisdiction of local municipalities and national governments. They now splintered into institutions with somewhat overlapping functions: hospitals, hospices, asylums, and prisons. In Catholic countries, large shelters or general hospitals warehoused a broad spectrum of individuals from the old, chronically ill to lunatics, vagrants, and criminals. Many institutions were transformed into houses of rehabilitation. Members serving in the armed forces needed to be mended and returned to active duty or retired as invalids. To serve their needs, nations created networks of military and naval hospitals. Workers were herded into civilian establishments for both physical and moral recovery. Such secular goals led some institutions to hire more members of the medical profession to interact with their caregiving staffs.[16] Similarly, the Protestant Reformation led to legislation that closed many monasteries and the hospital wards housed within them.[17] New hospitals emerged, but now no longer with direct ecclesiastical ties, relying instead on the financial support of local governments.[13,17]

By the 18th century, state power focused even more on economics and science. Health became both an individual and social good, death an undesirable outcome, kept at bay through good health management and medical treatment. As part of the Enlightenment's ideology, hospitals came to focus on the physical recovery of diseased individuals, striving to become houses of cure, overcoming human mortality through advancing technologies.[18] While shelter, food, clothing, and moral rehabilitation still remained institutional goals, medical and surgical treatments became paramount, at times even lifesaving. For physicians, death was a natural bodily event reflecting the cessation of vital functions. If powerless to stop the process, the only remaining hope was that patients would die "without a struggle," but there were no further obligations following death.[19]

As hospitals were medicalized, the very mission that sought to transform them into houses of recovery drastically changed the cultural meaning of institutionalized death, prompting a redrawing of the hospital's boundaries and displacement of the traditional hospice function. Indeed, dying patients quickly became institutional liabilities since mortality rates reflected adversely on hospital performance. High death rates threatened their reputation as healing places and jeopardized public and private support for their upkeep. After 1750, for example, the Royal Infirmary of Edinburgh was proud to consistently boast a low 4% mortality rate among its patients. Only admitting young people with acute, self-limited ailments who could recover spontaneously could achieve this statistical feat.[20] Hospitals also participated in the education of medical and later nursing professionals and contributed decisively toward the creation of new knowledge about health and disease, especially medical theory and practice. Emphases on systematic clinical observations, treatment, and experimentation with drugs, as well as bedside learning transformed hospitals into houses of teaching and research. People selected by academics for experimental management and teaching were segregated in teaching wards and subjected to postmortem dissections.[21] Very sick patients were often discharged well before a fatal outcome would mar the institutional record. Others left voluntarily to die at home surrounded by their family, friends, and possessions according to traditional customs.[22] During the 19th century, most Americans would continue to die at home, with only those without relatives dying in hospitals.[23]

Hospitals as Institutions of Technology and Dying

Thanks to new advances in knowledge and technology, the early 20th century witnessed the emergence of hospitals as houses of science and technology. During America's so-called golden age,[24] hospitals multiplied and expanded. They deliberately presented themselves as "houses of recovery" achieved by means of scientific insights and medical technology.[25] Equipped with clinical laboratories and x-ray facilities for diagnosis and treatment, hospital space was divided according to new medical specialties and equipment. Now affiliated with academic institutions, many hospitals were transformed into centers of biomedical research and training to bolster prestige.[25] In attempts to achieve social legitimacy and increase public demand, hospitals sought to drastically reduce mortality rates, shedding their remaining convalescent and dying functions by transferring chronic and terminal individuals to nursing homes and hospices. As acute, short-term facilities, hospitals even concealed death's presence through architectural design that relegated the morgue and pathology department to basement status.[25] Management of near death patients came to be focused almost exclusively on arresting or reversing their near fatal conditions in harmony with the basic disease orientation of biomedicine. In spite of their apparent futility, deathbed rituals in modern hospitals came to include specialized consultations and intensive care units (ICUs) with their aggressive employment of medications and technology, including sophisticated resuscitation techniques. By waging a relentless war on serious disease and multiple organ failures, hospitals sought doggedly to prolong life regardless of cost.[26,27] This campaign was rewarded in the United States, with the establishment of Medicare and Medicaid in 1965. A profusion of government funding turned hospitals into financial and bureaucratic powerhouses, equipped with expensive diagnostic and therapeutic devices. The influences of government, health insurance, and big pharma mutually reinforced one another, decisively consolidating the image of contemporary hospitals as houses of high technology.

Simultaneously, doctors shed their previous moral and spiritual authority[28] and emphasized the profession as a practice of science.[29] These measures were likely reasons for the exponential increase in American demand for health care in the 1930s and 1940s. However, more hope for healing through the powers of sophisticated and more aggressive hospital medicine[30] had a paradoxical effect of raising hospital mortality rates.[31] By 1940, approximately a third of deaths took place in hospitals.[31] As Americans fixated on cure rather than peace and a good death, estimates suggested that 54% to 61% would die as inpatients in hospitals by 1980.[32-34] Institutionalized death appears to have reached its apex in the mid-1980s (see Table 1) spurred on by both the creation of Medicare in 1965 and President Nixon's declaration of war on cancer in 1970. Both measures led to increased funding for hospital research and helped nurture a national psychology[26] in which death was an unacceptable outcome that should be prevented at all costs.[36] This omnipresent mentality—critiqued and resisted by some[37-39]—is revealed in one study reporting that 86% of chronically ill patients did not wish to talk with their physician about end-of-life issues, opting instead to "rather concentrate on staying alive than talk about death."[40] Meanwhile, hospital culture proved to be inhospitable to many dying patients resulting in poor communication between physicians and patients, severely unaddressed issues of pain, and a tendency toward intensive, technologically driven procedures.[34,41]

Table 1. Hospital and Institutional Death According to US Population.

Year	Inpatient hospital deaths	All institutional deaths
1949	39.5%[34]	49.5%[34]
1958	47.6%[34]	61%[34]
1980	54%-60%[32–34]	74%-76%[32–34]
1993	57.6%[35]	78.3%[35]
1998	41%[32]	63%[32]

Institutions of Cure or Care?

While hospitals have continued to be the most likely place for Americans to die, financial concerns, institutional structures, and curative expectations are perceived by some to stand in tension with the care of patients.[42] This tension is illustrated in the appearance of AIDS in the early 1980s.[30] Whereas death and dying had become almost invisible events in America,[43] the spread of a seemingly uncontrollable disease awakened public consciousness of death's ultimate reality. Because of their young age and stigmatized status, persons with AIDS frequently came to express doubts about the meaning of their truncated lives. These doubts were exasperated by a deeply held cultural assumption that hospitalization, if not resulting directly in cure, would at least significantly prolong life. But in the case of AIDS, modern medicine in the early 1980s displayed embarrassing limitations.[44] The specter of a slow and painful hospital death prompted terror about the reality of slowly losing control over a body ravaged by disease. Would AIDS' clinical manifestations and moral implications deny its patients a meaningful death within institutions of cure and technology?[45]

The San Francisco General Hospital (SFGH) model of AIDS care aimed to provide meaning, hope, and comfort despite a terminal diagnosis.[30] Defined as a multidisciplinary medical and nursing approach, it was created during the early years of the epidemic and functioned in a ward of the SFGH, a combined city and county institution. By 1983, a new 12-bed facility—ward 5B—primarily functioned as a combination of critical and hospice care unit with priority given to patient advocacy, care, and education rather than merely medical treatments. The medical component was based on multidisciplinary oncology models with strong primary nursing and social support. For this reason, the unit hired skilled male and female nurses with ICU and hospice backgrounds.

Dying concerned all patients hospitalized at ward 5B. In spite of somber perceptions, the unit's staff worked hard to establish a supportive environment that acknowledged the shifting expectations of those who perceived themselves as inmates on death row. The most important issues about their dying were some measure of control over the event and efforts to infuse it with meaning. Several patients had problems with the so-called death and dying industry. Construction of a new "good death" model involved issues of truth telling, autonomy, and understanding, mediated through a series of terminal care rituals. At SFGH, lack of a consensus about the "right" way to die hobbled both patients and their caregivers. Frustrated, some patients with AIDS improvised, creating unique blends of traditional religious as well as secular death narratives. Both heroism and liberation became associated with this final rite of passage, returning to models employed in early Christian hospitals.[30]

The SFGH's model was shaped by the realities of AIDS as perceived in the early 1980s when the disease afflicted gay white men. With insights into AIDS's ability to threaten patients' identity and integrity, many caregivers in ward 5B claimed to have achieved an intuitive understanding of their patients' suffering. Sharing meanings and values as well as socioeconomic status, both parties established a healing kinship, in spite of therapeutic failures and frequent institutional deaths. In this ward, it was believed that the hospital once more truly embodied the traditional hospitalitas or gift-relationship between caregivers and patients. However, such a work of mercy became gradually obsolete as the character of the epidemic and the ethnicity of the patients changed, allowing new constituencies to seize a segment of the fledgling AIDS industry.[46]

Emergence of Palliative Care in Hospitals

While the AIDS epidemic caused only transitory alterations to the technological aims of hospitals, it accomplished more permanent effects in the emerging field of palliative care. The hospice and palliative care movements in the United States, which slowly began in the 1970s, reflected both staggering economic concerns from overutilization of medicines and technology and a frustration toward institutions that provided poor quality care to terminally ill patients.[47] While many Americans expressed a wish to die at home,[48] only the establishment of a Medicare hospice benefit in 1982[49] appears to have begun shifting the location of death away from hospitals.[32,35] By 2009, 42% of all US deaths occurred at home or in nursing facilities while enrolled in hospice care.[50] The average days of hospice use among Medicare patients has increased from 12.4 days in 2003 to 18.3 days in 2007.[51] There has also been a decline in the number of in-hospital deaths among Medicare beneficiaries from 32% of all Medicare deaths in 2003 to 28% in 2007.[51]

Corresponding with these changes, palliative care programs have significantly increased within the past decade. Its growing popularity may be due to the financial burden of a technologically driven health care system threatening the US economy,[52,53] and palliative care's promised high-quality care and lower costs.[54,55] Concurrently, significant funding from private foundations including the Death in America Project funded by philanthropist George Soros and grants through the Robert Wood Johnson Foundation launched a series of educational and research initiatives seeding palliative care to be integrated throughout medicine.[56] By 2010, 63% of all US hospitals have a palliative care program (including 85% of 300 + bed hospitals).[49,54,57] While palliative care grew out of hospice utilization in the United States, palliative care proponents argue that they are not synonymous.[54] Now palliative care can be provided concurrently with a therapeutic aim of cure throughout the disease process, whereas the hospice benefit requires patients to forgo curative treatments, limited to the last 6 months of life.[49,54] Consequently, the growth of palliative care, rather than functioning primarily as a separate, parallel system from traditional medical institutions[50] has blossomed as a new medical discipline within hospitals focused on the relief of suffering, management of symptoms, attention to effective patient communication, decision making, and multidisciplinary psychosocial–spiritual support of patients and families at any stage of illness.[58,59] Palliative care includes general competencies for all professional caregivers[60] as well as a growing medical specialty requiring certification.[49] The underlying aim of palliative care is to systematically reintroduce the human dimensions of compassion and benevolence in the alleviation of suffering within illness.

Most recent data may indicate that the rise of the hospice benefit has begun to reshape how the United States as a nation faces death—with location of death serving as an important marker. Future growth of hospice utilization[50] may point to a critical epidemiological shift away from hospitals as the place where Americans die. What influence this external change might have on hospitals remains to be seen. Surely the 21st century patients will continue to desire sophisticated technology even near the end of life.[53] Simultaneously, the growth of palliative care within academic hospitals may point to internal changes within hospital ideology leading away from aggressive, technological treatments as the standard modus operandi.[61] Can hospital institutions alternatively provide both levels of care? The growth of palliative services within hospitals[57] and emerging signs of its integration within emergency departments,[62] ICUs,[63] and all fields of oncology[64] are indicators of new trends that may signal future changes. While future hospitals may not be the most likely place that patients die, they will almost surely remain the institutional agent guiding patients facing chronic illness and end of life. The growth of palliative care within contemporary hospitals is the clearest sign yet that our houses of technology, primed to cure patients at all costs, may expand their boundaries once again and embrace traditional functions of care and compassion at the end of human life.

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