

The Academic Hospice

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The academic hospice is a recent development in health care. Hospice programs and hospitals evolved from the same historical roots in Greek and Roman medicine. The academic hospital emerged as a place where patient care, education, and research are pursued as inextricable parts of the mission. The unique role of the academic medical center in health care is supported by the government, the medical profession, and the public. This article provides a perspective on the emergence of the academic hospice. Dr. Cicely Saunders, who died on 14 July 2005, founded the first such hospice in London, England, in 1967. The authors show that

the philosophy of hospice care has the same historical roots as standard health care and describe those elements that distinguish academic hospice programs from other kinds of hospice programs. Finally, the authors note that demographic and economic challenges in the United States and elsewhere only increase the need for academic hospice programs.

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In the second half of the 20th century, medical specialties and subspecialties, new diagnostic tools, and effective therapies emerged as a result of research and unprecedented government funding. There were several cultural consequences in medical practice. Specialists achieved prominence within the medical hierarchy (1), death was more apt to follow a period of chronic illness rather than acute illness, the role of the patient radically changed (2), and an erosion of trust between physicians and their patients began to be documented (3). The emergence of hospice care in the 1960s in England, followed in the United States and Canada in the 1970s, can be seen as a reaction to these changes in medical culture.

However, all hospice programs, like all hospitals, are not alike. Distinctions between hospice programs can be made on the basis of services that are provided; community needs that are met; philanthropy that is attracted; and relationships with professional schools of medicine, nursing schools, and other professional schools. One of the most interesting manifestations of this developmental process is the emergence of the academic hospice.

The purpose of this article is to provide a perspective on this development. First, we trace a history that links the philosophy of hospice care to the roots of medicine. Then, we describe those elements that distinguish academic hospice programs from other hospice programs. Finally, we note that demographic and economic challenges in the United States and elsewhere only increase the need for academic hospice programs.

HISTORY

In Greece in the sixth century BC, medicine was practiced by healers in what we would now call ambulatory clinics—sanctuaries located adjacent to temples of worship—or during home visits (4). The ill were not housed in a particular location for ongoing care. Until Hippocrates extended the role of the *physikoi* beyond that of natural

philosopher, there was no distinction between science and philosophy, or between body and mind. Physicians diagnosed and treated the whole person rather than just a disease. The evidence base for the emerging practice of medicine was formed from the accumulated observations passed on from teacher to student, through what we recognize as apprenticeships. The following quotation is as recognizable to physicians (and patients) in contemporary teaching settings as when it was written nearly 2000 years ago:

I felt a little ill and called Dr. Symmachus. Well, you came, Symmachus, but you brought 100 medical students with you. One hundred ice cold hands poked and jabbed me. I didn't have a fever, Symmachus, when I called you, but now I do (5).

The link between medicine and religion was inextricable until the Renaissance. Religious societies ran the earliest institutions called *hospices* that cared for the ill, primarily people who became ill while traveling. People either recovered and continued traveling, or died. The words *hospitality*, *hotel*, *hospice*, *hostel*, and *hospital* are all derived from the same Latin root word *hospes*, meaning "guest" (6). Hospitals as identifiable institutions evolved from these early efforts. For example, St. Bartholomew's Hospital in London was founded in 1123. At the time, there was no practical difference between the meaning of *hospital* and *hospice*. Hospitals as institutions for teaching evolved from the observation that the care and study of patients are more convenient for physicians if the patients are assembled in

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one place. The need for hospitals to “market” themselves also evolved. Records from 1544 from St. Bartholomew’s Hospital indicate that patients were not to be admitted if they had incurable diseases or conditions (7). The hospital apparently wanted a reputation for caring for people who could be cured. Subsequently, the term *hospice* was reserved for dedicated places for the care of patients who were incurably ill (and poor). These hospices were mostly administered and staffed by Christian religious orders in France, Ireland, Scotland, and England (6). In the United States, early examples of hospice care were the Dominican Sisters of Hawthorne (8, 9) and Calvary Hospital, both located in New York City (10, 11).

The teaching hospital as a particular kind of hospital gained momentum after Descartes articulated the difference between soul and body in the 17th century. This liberated the scientific study of the body from the church’s authority over the soul (12). In the 18th century, it was German physicians who most strongly advocated for a dedicated scientific faculty of medicine and a course of medical training that was firmly based in scientific observation and experiment. In the early 1900s, U.S. physicians who visited German and Austrian hospitals embraced the Flexner Report, calling for essential reforms in the standards, organization, and curriculum of medical schools in North America. Dr. William Osler was most famous among these physicians. He reported on the first large series of dying patients during his time at the hospital he helped to found at Johns Hopkins Medical School in Baltimore, Maryland (13).

The success of the growing investment in medical research in the first half of the 20th century produced unprecedented scientific discoveries and a change in the pattern of illness in the second half of the century (2). In the beginning of the 20th century, people in the United States usually died of infectious diseases or trauma. The paradigm of the scientific method was successfully applied to the causes of contemporary deaths, such as pneumococcal pneumonia and infectious diarrhea. By the second half of the century, Americans were living longer and were dying primarily of atherosclerotic diseases (myocardial infarctions, stroke, and congestive heart failure) and cancer. Instead of death occurring quickly (in days), there was an increasing period of chronic illness and dying that occurred over weeks to years.

Like most jests, the following statement, published in 1975, reflected an uncomfortable element of truth: “If only patients could leave their damaged physical vessels at the hospital for repair, while taking their social and emotional selves home” (14). This quotation captures the medicalization of dying as a physical failure that is the responsibility of medical professionals rather than an important event in the life of a patient and family.

In response, a lively discussion emerged about U.S. attitudes and practices related to death (15). For example, empirical research showed that patients with terminal illnesses wanted to talk about death when they were given

the opportunity to do so (16). The publication of *On Death and Dying* by Dr. Elisabeth Kübler-Ross (17) captured popular attention with a fortuitous combination of media exposure and timely substance. In one widely reported innovation, she interviewed dying patients during teaching sessions and used the information to instruct her students, as would be done for any medical subject. Another charismatic physician-speaker was Dr. Cicely Saunders. In 1967, she founded St. Christopher’s Hospice in a southern suburb of London, England, as the culmination of approximately 20 years of direct observation of the care of people who were terminally ill. St. Christopher’s was not the first hospice; however, it was the first modern academic hospice where research and education were inextricably conducted as part of meticulous patient care.

The idea of using the hospice as a place to teach and perform research then moved to the United States. In 1974, with advice from Dr. Saunders, Florence Wald, then dean of the School of Nursing at Yale University in New Haven, Connecticut, led the founding of The Connecticut Hospice (18). Dr. William Lamers, a psychiatrist who pioneered many of the early interactions between hospices and medical schools, was medical director of the second hospice program, Hospice of Marin in California. Dr. Balfour Mount, a urologic surgeon, founded the palliative care service at the Royal Victoria Hospital of McGill University in Canada as part of the teaching and research structure. Finally, in New York City, a consulting team began working throughout St. Luke’s Hospital in 1974 (19).

A grass-roots hospice movement in the United States resulted in the founding of hundreds, then thousands of hospice programs throughout the country. Many operated out of their founders’ homes. These pioneers pursued a vision of end-of-life care that was different from that which prevailed in the nation’s hospitals. To bring some standards to the care of patients, The Connecticut Hospice in New Haven sponsored a meeting for U.S. and Canadian hospice advocates. The National Hospice Organization, which promulgated standards for the rapidly growing patient care services, eventually emerged from this meeting (20).

THE ACADEMIC HOSPICE

It may seem implausible to view a hospice program as a setting for both palliative care and related education and research. However, the rationale is no different from that of academic hospitals or academic health care centers. Physicians and other health care professionals learn best at the bedside, where experts demonstrate skills by example and correct mistakes through direct observation of graduated responsibility for care. Individual cases lead to case series that spark the curiosity that drives the quest for the discovery of new knowledge. There is no reason to think that academic hospice programs would not or could not be leaders of innovation and provide an advanced level of care, analogous to the role played by academic hospitals. A

very small number of academic hospices have significantly contributed to the extraordinary early growth of hospice and palliative care around the world. Among these are St. Christopher's Hospice in London, St. Columba's Hospice in Edinburgh, and the Palliative Care Service of the Royal Victoria Hospital in Montréal. Physicians, nurses, and others who visited these programs returned home to advocate for similar programs and institutions in their own cities. This is no different from the way in which laparoscopic surgery or any other health care innovation gains widespread use.

In the United States, the role of the academic hospice is, in part, obscured by the observation that the term *hospice* already has 4 distinct meanings: a place to care for the dying; a patient-based and family-based approach to health care pursued mainly in the home; an agency developed to deliver hospice care; and a synonym for the Medicare Hospice Benefit that pays for most U.S. hospice care. However, if one looks broadly, it seems that there are at least 3 discernible kinds of hospice programs in the United States: traditional hospice programs, community hospice programs, and the academic hospice.

Traditional hospice programs provide care during the last 6 months of a patient's life when only palliative care is desired. Patients and families are the unit of care. Approximately 95% of care occurs in the patients' primary places of residence, including nursing homes, with the aim of achieving a safe and comfortable death. Bereavement care is provided to survivors. These traditional programs may have dedicated inpatient hospice units, and care is primarily paid for (and regulated) by the Medicare Hospice Benefit. The average hospice program in the United States has an average daily census of approximately 60 patients, with a median length of stay of 21 days. The National Hospice and Palliative Care Organization is the largest representative of these agencies, with 3300 organizational members caring for 950 000 patients in 2003 (21). Traditional hospice programs play a role similar to that of community hospitals and their associated physicians and outpatient programs.

The community hospice cares for patients with eventually fatal disease through various programs, only one of which is traditional hospice care. These programs may include hospital-based consultation and symptom management services; community speakers' bureaus; ambulatory clinics; fee-for-service bereavement and counseling services; and case management services for specific patients, such as those with AIDS, those who are frail and elderly, and those with congestive heart failure. These services generally operate under various licenses held by the parent organization. In 1994, a coalition of community hospice programs, the National Hospice Work Group, was formed to increase patients' access to the palliative competencies of hospice care, based on their need for care rather than their prognosis. There are currently 20 large and progressive programs among its membership. On average, these programs

Table. Features of the Academic Hospice

Education and research are essential elements of the mission
Dedicated resources (e.g., salaries, space) are provided in the core budget
Initiates and collaborates with medical, nursing, and other health care professional schools for the purposes of curriculum development, instruction, and clinical supervision
Initiates research and serves as a site for the approved research of other investigators
Hospice staff have faculty appointments in undergraduate and graduate schools
Demonstrates leadership in national professional meetings
Ensures protection of human subjects under federal research guidelines
Receives competitive and peer-reviewed funding for research
Publishes in peer-reviewed journals

care for approximately 800 patients per day, with the smallest serving 135 patients in rural and frontier portions of Colorado and the largest serving 5350 patients per day in 14 states. Many of these programs host students from medical and nursing schools and play a role similar to that of teaching hospitals and their associated programs.

In the academic hospice programs, the boards and administration view patient care, public health, education, and research as essential and inextricable elements of their mission. They have features in addition to those of the community hospice (Table). These institutions go beyond hosting students; they initiate and collaborate with medical, nursing, and other health care schools to provide education. Their staffs initiate their own studies and participate in the research of others to discover new knowledge that will advance the field of hospice and palliative care. They have dedicated staffs and budgets, and a formalized process for obtaining institutional review board approval of possible studies. They disseminate their work and advocate to affect the care of populations. Although there is no professional association of academic hospice programs, they compete for federal funding for research, employ faculty specifically for education and research, and participate in national meetings of health care professionals.

Although many community hospice programs host medical students and provide educational outreach, there are probably fewer than 6 independent hospice programs in the United States that we currently would consider academic hospices. Their size and budget permit them to invest in the academic mission. This same distinction is made between teaching hospitals and academic medical centers. One reason for the small number of programs in this category is that there is no government support specifically targeted to develop this feature of academic medicine, as there is for academic medical centers.

Of interest, the role of hospital-based hospice programs has not had much recent influence on the development of the field, with a few exceptions. At the beginning of hospice care in the United States, hospital-based hospice programs were in the majority. However, independent agencies soon surpassed them in number, size, and influence, in part because of the Medicare requirement that

hospice programs perform at least 80% of all care in patients' residences. The politics of being a small part of a large organization and the last in line for marketing and development may also be a factor.

If one looks at the recent reports of demographic needs (22) and the results of patients receiving hospice care (23), the academic hospice should become an important part of academic medicine for many reasons. First, medical progress occurs when research is rooted in the medical care of the population of interest. Routine dosing of oral morphine, now common in all areas of health care, was first studied in an academic hospice (24). Second, trainees learn best when they care for patients under the tutelage of experts. There is now copious evidence that the care of patients who are dying is better in hospice programs and that good care requires physicians to play a critical role (2). Third, curricula for trainees in palliative medicine address the core competencies of physicians now required by the Accreditation Council for Graduate Medical Education (25).

Academic hospice programs, similar to academic hospitals and academic health centers, require financial support that exceeds that required for direct patient care. The same argument has led to federal and state funding of new hospital construction, new medical school development, and the research enterprise. Similar investment is needed if the potential of the academic hospice to contribute to social well-being is to be realized.

SUMMARY

The roots of hospice care are similar to those of all of contemporary medicine. The contemporary hospice program that combines patient care, concern for public health, education, and research can rightly be called academic. The demographic and economic challenges that the world faces highlight the need for more education and research. At a minimum, it would seem obvious that every academic medical center will want to develop clinical, teaching, and research relationships with a hospice program. At an optimum, a few academic hospices will develop to inform the health care system in the way that a few academic hospitals have done.

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