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Policy and the Re-Formation of Hospice: Lessons from the Past for the Future of Palliative Care

Joy Buck, PhD, RN[Associate Professor]

School of Nursing & Department of Family Medicine, West Virginia University, Eastern Division,
2500 Foundation Way, Martinsburg, West Virginia, 25401

Abstract

During the twentieth-century, dramatic changes in the manner and location of care for the dying resulted in the conception and birth of the modern American hospice movement. Idealistic nurses, clergy, and others concerned about the plight of terminally ill cancer patients launched hospice as a necessary health care reform. As new hospice programs opened across the country, the idealism of the early leaders gave way to more pragmatic issues such as program viability. As hospice was studied and integrated into the health care system, it came to be redefined by the politics of health policy and the health care industry. As a result, there is a disarticulation between the needs of seriously ill persons and their families and the health care that is available to them. Important lessons can be learned from the history of the Medicare hospice benefit to help guide current palliative care policy initiatives. While formalized reimbursement for hospice enhanced organizational sustainability, many critical issues remain.

Keywords

policy; hospice; Medicare; nursing; outcomes

“Hospice is many things. Hospice is home care with inpatient back-up facilities. Hospice is pain control. Hospice is skilled nursing. Hospice is a doctor and a clergyman coming to your home...But most of all, hospice is the humanization of our health care system.”

-Senator Edward Kennedy, 1978

Kathy, a nurse colleague, was forty-six when she had her first heart attack and was permanently disabled by a stroke she sustained during her coronary bypass surgery. For the next eight years, Kathy was plagued by endless fatigue, breathlessness, and pain. Unable to work, she lost her health insurance. Collectors repossessed her car when she could no longer pay her escalating medical bills. By the time Kathy was enrolled in hospice at the age of fifty-four, she was living in poverty and tethered by disability to a trailer that like her fragile health, was crumbling around her. It is not clear why Kathy was not referred to hospice earlier – according to Medicare guidelines, she was “medically eligible” for services for at least two years before the cardiologist finally referred her. Regardless of the reason, she stabilized and remained in hospice for two years before being discharged because she had long outlived her prognosis. She did not qualify for other programs to assist her. In the three

jbuck@hsc.wvu.edu, 304-264-9202 extension 6314.

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months following her discharge, she was hospitalized twice before being admitted to the only Medicaid nursing home bed available fifty miles away from her family. It is there that she died, alone, at the age of 56¹.

Kathy is just one of the over 90 million Americans with one or more chronic illness who experience debilitating symptoms for many years as their health declines ². They too might benefit from many of the types of services that hospice and palliative care promises. Yet, they rarely receive more than basic medical services that are poorly coordinated in a fragmented system that reinforces a false dichotomy between care for the “living” and care for the “dying.” In large part, this is due to the way that health care is organized and financed in the United States with policy and regulations that seek to balance access to quality services while containing costs.

Policy influences almost every aspect of the American health care system and such is the case with hospice and palliative care. The American hospice movement was a subset of the larger death and dying movement that gained momentum in the United States during the mid-twentieth century. American advocates followed the lead of Dame Cicely Saunders and Elisabeth Kubler-Ross in their efforts to advance hospice as a necessary health care reform for dying patients and their families. Politicians validated hospice as a cost-effective alternative to standard care with passage of the Medicare hospice benefit in 1982 and again in 1986 when the benefit became permanent. While American hospices provide much needed services to 1.2 million persons annually, similar to Kathy, 212,000 persons were discharged from hospice alive in 2008 ³. Palliative care leaders cite the limitations of hospice as they call for significant reforms to fill the widening policy-induced gaps in care. Yet, the parallels between the early years of hospice and the palliative care movement today are striking and warrant further inspection. This essay provides such an inspection and offers the history of hospice as a cautionary tale of how and why contemporary policy solutions might well hold the seeds of tomorrow’s problems. In the case of hospice, the Medicare hospice benefit offered a degree of financial security for hospices across the nation. Nevertheless, it also served as the basis for many of the critical issues remain ⁴.

St. Christopher’s in the Field

By most accounts, the seeds to the modern hospice movement were sown in 1963. This is the year that British physician Cicely Saunders began visiting American institutions and lecturing about her work and research on medical management of terminally ill cancer patients at St. Joseph’s Hospice in London ⁵. Saunders’ approach represented a radical departure from standard medical care for terminally ill cancer patients within an intensely curative medical milieu. She called for professionals to use technology as a means to alleviate suffering rather than causing it. Her eloquent descriptions of her vision for St. Christopher’s Hospice particularly struck a responsive chord with Florence Wald, an American nurse who was then Dean of the Yale School of Nursing ⁶.

Florence Wald was an ardent and idealistic social reformer and is considered by many to be the American hospice midwife. Having learned psych/mental health nursing under the mentorship of Hildegard Peplau, Wald was at a critical point in her life when she first heard Saunders speak ⁷. She adamantly believed that nurses should be equal partners with physicians. Saunders’ conceptualization of hospice and the centrality of nursing within it offered Wald a framework to forge health care reform and make her mark on clinical nursing. At Wald’s invitation, Saunders returned to Yale in 1966 as the Annie Goodrich Visiting Professor of Nursing. This visit culminated with an Institute on Care of the Terminally Ill that set for hospice to emerge as a necessary and viable terminal care reform ⁸.

Hospice and Health Care Reform

Saunders' initial visit came at a critical point in time in the history of the United States. Due to a variety of social, economic, and political factors, care for the dying had moved from home to hospital, from the moral to technical order, and with that move, control over care decisions was transferred to medical professionals. By the end of the 1950s, over 61 percent of deaths occurred in hospital⁹. Research funded by the United States Public Health Service Division of Nursing documented the stark realities of institutionalized dying: pain control was virtually non-existent and terminally ill cancer patients frequently died in a room at the end of the hall, in exquisite pain and alone¹⁰⁻¹². Too often, the needs of patients and their families gave way to institutional and professional emphasis on medical knowledge, technology, and cost-efficiency¹³.

These conditions not only impacted patients and their families, but also had severe implications for staff on units where the death rate was high. New York psychiatrist Samuel Klagsbrun spoke of his experiences working on a cancer ward when he was interviewed for an article published in *Time Magazine*. When Klagsbrun arrived on the unit, he found the morale of both "staff and patients abysmal." The doctors and nurses considered the patients "walking dead." Patients constantly complained about "uncaring doctors," "unavailable" nurses, and experimental drugs that they thought were being used on them as if they were guinea pigs¹⁴.

While the medical mainstream remained relatively silent about the plight of the terminally ill in hospitals, many nurses did not. Nursing education focused on alternative approaches to care, ethical and spiritual issues related to death and dying and research as a means to improve clinical practice¹⁵. Social movements proliferated that laid a foundation for a growing public discourse about the quality of life, patients' rights, and the place of informed consent in the medical system^{16,17}. Stories of how cancer patients suffered while undergoing aggressive curative treatment were widely publicized in the popular press. Despite the promise of curative medicine, many began to wonder if the quest for cure was worth the human toll in suffering¹⁸. It was within this context that the American hospice movement was born and Wald and the many others nurses who followed her lead emerged as central figures to its conception and birth.

As early as 1966, Wald had a firm commitment to the hospice ideal. By 1968, she had stepped down as Dean and was poised to launch an initiative to research and reform care for the dying in the New Haven, Connecticut area. She convened a group of like-minded social reformers, including Reverend Edward Dobihal, an evangelistic Methodist minister who was then Chaplain at a New Haven hospital, to help her build a "St. Christopher's in the Field". From 1968–1971, she conducted the *Nurse's Study of the Terminally Ill Patient and His Family*, and the subsequent *Interdisciplinary Study of the Dying Patient and his Family* with funding from the U.S. Public Health Division of Nursing and the American Nurses Foundation. The transcripts from these observational studies provide a rare and detailed account of how the research team negotiated their professional and disciplinary boundaries as they worked together to reform care for the terminally ill. In particular, the studies offered a vehicle by which Wald worked within a medical center to agitate for individual and institutional change. They also carefully document the first two years in the development of Hospice, Inc., one of the first modern hospice programs in the United States⁸.

Navigating the Connecticut Medical System

Between March and May 1971, the newly founded Hospice, Inc. steering committee expended a considerable amount of time developing a statement of philosophy and underlying assumptions about hospice care. The group quickly agreed on three assumptions.

First, their hospice was a “total community” that included staff, patients, and their families. Second, the hospice facility would be physically structured to maximize socialization and community participation. Unlike St. Christopher’s “open ward” structure, adaptations in the environmental design would be made to accommodate the “American routine and expectations” for privacy and autonomy. Third, the group would use an interdisciplinary approach to their work. Professional roles would be blurred to allow professionals to “substitute” for each other and “call on each other for help.” Wald and Saunders agreed that nurses were omnipresent and played a central role central by blending various approaches in the care of patients and their families. As such, the hospice would be a nursing facility with other disciplines, such as the hospice chaplain, social worker, and physician, being brought in as consultants to the nurse¹⁹. A fourth assumption, concerning the role of religion, resulted in a protracted debate over whether the religious foundations of hospice should be implicit or explicit. The group struggled to find the proper language that would accommodate myriad faiths and personal philosophies, including Catholicism, Judaism, and humanism. In the end, the group finally agreed on a philosophy statement that reflected their idealistic fervor and utopian visions for hospice²⁰.

Despite the group’s idealism, pragmatic issues such as funding, organization, and structure were paramount. Unlike Saunders, who chose to remain independent of the British National Health Service, the group sought integration into the American system early in the planning stages^{21,22}. Hospice did not fit neatly into any of the existing structures and the group needed to strike a balance between refining hospice so it would fit while avoiding the appearance of duplication and/or competition for existing programs. Navigating the turbulent waters of the Connecticut medical system in an era of shifting political agendas for health care reform proved to be no small feat²⁰.

In 1971, Hospice, Inc. steering committee members met with deans from the nursing, divinity and medical schools and administrators from the Yale-New Haven hospital to discuss their plans and solicit feedback and advice. Wald made good use of her existing contacts with Yale alumni, faculty, and community nurses; Dobihal worked with local clergy and religious organizations. Wald and Dobihal, accustomed to “preaching to the choir” in New Haven, did not fully appreciate the politics of federal and state regulatory agencies, and what was entailed in health planning for the construction of a hospice. They contacted various funding agencies for guidance on what was fundable and how best to acquire it²³. For example, Wald contacted was Dr. Rita Chow, a nurse associated with the Social Analysis Branch of the Department of Health, Education, and Welfare (HEW). Chow advised her that maintaining university affiliation was important to financial and management issues and interdisciplinary work. Despite her support, during this era of deinstitutionalization, HEW was not interested in building new types of facilities, and thus, not interested in the project²⁴. Although these were the official reasons given, in reality, there was little support for hospice - the idea was too new, offbeat and untested²⁵.

Wald and Dobihal spent considerable time trying to learn the nuances and politics of the Connecticut health care system during this era of regionalization. The 1966 Comprehensive Health Planning Act (CHP) (P.L. 89–749) provided funding to public or nonprofit groups for better area-wide comprehensive health planning projects. Whereas the legislation encouraged federal/state partnerships with private planning groups to make better use of manpower, facilities and financial resources for comprehensive health-care delivery, it also forbade the CHP groups from interfering with existing patterns of public and private professional practice of medicine, dentistry and related healing arts. According to a nurse who was intricately involved in health care planning during this era, the end result was an unwieldy and fragmented system that perpetuated biases toward physician and hospital dominance and acute, episodic and institution-based medical care²⁶.

Undaunted by the challenges they faced, Hospice, Inc. optimistically submitted a draft proposal to the Connecticut Regional Medical Program (CRMP) for comment in April, 1971. They also met with Dr. Arthur Jarvis, a representative of the Connecticut State Department of Health, to discuss it; Wald was surprised when they met with a chilly response. Jarvis had difficulty grasping the hospice concept and expressed concerns about “segregating” terminally ill patients in a special unit. He was also troubled that hospice could be construed as a form of euthanasia. His final critique was on their plans for medical education and research at the facility which he likened to a “laboratory for the use of students to experiment on dying patients”⁷.

Jarvis nevertheless offered solid advice on several options for hospice licensure. It could be licensed as a nursing home, a chronic-disease hospital, or a specialized unit within an existing acute-care facility. Each option had significant barriers. For example, Hill-Burton funds, a federal program for new hospital construction, could not be used to build a new nursing home because there were already enough licensed beds in Connecticut. Another barrier was the interdisciplinary nature of hospice and the skill required to assess, diagnose and treat symptoms, hospice was more than “nursing-home care,” which was considered to be primarily custodial. If they chose this chronic-disease hospital approach, they would have to comply with federal mandates for facility design, including Hill-Burton requirements for two-bed patient rooms with solid floor-to-ceiling walls. The hospice facility had been planned to have groups of four-bed rooms to increase socialization among patients and their families. They considered calling the rooms “intensive care units” to circumvent the issue. The final option was to seek a new category chronic disease hospital licensure as a “hospice”²⁷. Regardless of the approach, they needed to clearly define hospice as a patient-care model that was “distinctly different from care in nursing homes or hospitals,” so they would not be seen as duplicating services or competing with existing programs²⁸. This competition clause was critical because it was a requirement of funding under the CRMP guidelines.

While the planners were working out the details for the facility, Dr. Sylvia Lack, a British physician who had trained under Saunders at St. Christopher’s was hired as the Medical Director that began operations in 1974. Soon after, the National Cancer Institute issued a call for proposals for their Hospice Demonstration Project. Hospice, Inc. was the only group funded during the first round^{29,30}. Home care flourished, yet they still faced a long and hard uphill battle to achieve licensure for their facility. It soon became clear that if the hospice was to succeed, they needed someone who was politically savvy. Dennis Rezendes fit the bill and was retained as a consultant to the board. This politically astute and well-connected consultant possessed the skills and knowledge to help move the hospice forward. In 1976, he achieved a political victory for state legislation that liberalized Medicaid eligibility criteria for home care for terminally ill patients. Financial backing for the facility was secured and in 1978, legislation was passed that designated hospice as a distinct type of health care provider *and* health care facility under Connecticut State Law⁴. That same year, Rezendes joined forces with Don Gaetz and Hugh Westbrook, two hospice entrepreneurs from Wisconsin and Florida, to form the National Hospice Organization (NHO) and the National Hospice Education Project (NHEP)³¹. Their mission was to both create and corner the market for hospice at the national level, and standardization of hospice was a critical element of their potential success.

The Hospice Medicare Benefit

By the mid-1970s, hospice had struck a responsive chord in America and new hospices opened rapidly across the country. Similar to Hospice, Inc., they were voluntary initiatives that were shaped by their founders and the environments in which they evolved. While they

were all committed to the hospice ideal, each group, and arguably each individual, interpreted what this care should entail and who should provide it albeit differently. There were three basic models of hospice organization structures and variations in the type, configuration and types of services among them. Hospital-based hospice programs typically consisted of administrative staff, a medical and nursing director, staff nurses, social worker and chaplain. As a rule, they did not utilize nurse aides or volunteers as part of the team. Home hospice programs were usually affiliated with urban/suburban Visiting Nurses Associations (VNAs), were staffed almost entirely by nurses, with aides and homemakers providing the bulk of personal care to patients. Most had small volunteer programs and the majority of patients had in-home family caregivers. Independent hospices, such as Hospice, Inc., evolved from community-based volunteer efforts to reform care of the dying. Most relied on charitable giving and funding from foundations to hire program coordinators and develop formal relationships with local VNAs and hospitals¹⁷. For the most part, volunteer nurses provided nursing services. Because many of these volunteers had full-time jobs in other clinical settings, they typically were only able to see two hospice patients per day.

By 1978, hospice had appeared on the political radar screen and NHO was front and center to help educate legislators about its cost-effectiveness. Cost containment was paramount to Congressional leaders who called for an independent study of hospice to learn more about its potential. The resultant Government Accounting Office study identified fifty-nine organizations that provided “at least one” hospice-type service; another seventy-three organizations were in various stages of planning. There was a wide variability of the configuration, type and quality of services these programs provided. Only one state, Connecticut, had regulations specific to hospice licensure³². Although the National Cancer Institute Demonstration projects provided baseline data, the data were limited. Serious national program planning required a more comprehensive analysis prior to nationalization. At this juncture, a private/public partnership was formed between the newly formed Health Care Finance Administration (HCFA) and two foundations to fund the National Hospice Study (NHS). At the time the NHS was initiated, it was the largest study undertaken to evaluate the hospice’s potential as a health care reform³³.

Two hundred fifty hospice programs responded when the call for proposals for the NHS or HCFA waiver, as it was called, was issued. HCFA selected 26 of the 40 participating sites for the waiver program. The waiver program provided funding for hospice services that were not already covered under Medicare³⁴. HCFA was particularly interested in how the organizations would respond to the availability of special funding for care provision. In particular, they wanted to know if the additional funding would stimulate the provision of “unnecessary” services. Data collection began in 1980, with a final report due in 1984¹⁷. It was at this point that the voluntary nature of the hospice movement began to shift. In order to obtain cost data, hospices that relied on volunteers had to hire full-time nurses to increase their productivity.

Re-defining Hospice

Hospice was continually refined and re-defined during the 1970s. Both the NHO and the International Work Group on Death, Dying, and Bereavement (IWG), a group of scholars, including most notably Cicely Saunders, Florence Wald, and Balfour Mount, were concerned with developing a guiding framework for hospice and palliative care³⁵. Although the general principles underlying terminal care as written by the IWG were similar to NHO’s definition, which mirrored the Connecticut legislation, there were some striking philosophical differences. For example, earlier definitions of hospice clearly outlined the important role of the nurse, patients, and families in the team. The NHO guidelines, consistent with their medical-based policy, increasingly grouped nursing, social work and

pastoral care into one category under the direction of the physician. The NHO's emphasis on medical supervision was an important political move to afford the movement's credibility, allay community and legislative fears of unsupervised nursing care, and assuage opposition by the powerful physician groups. By contrast, the IWG was based on the premise that hospice required the "...collaboration of many disciplines working as an integrated clinical team"³⁵. Therefore, the interdisciplinary team was composed of patient, family and professionals, with all disciplines being equal partners without privileging one discipline over another.

The IWG guidelines further emphasized the complementary nature of curative and palliative medical care and the need to connect the two. This approach required openness, interchange and overlap between the two systems continues to serve as the basic premise underlying the broader palliative care movement. The NHO guidelines focused on hospice and the coordination of inpatient and outpatient hospice care, but there was no explicit mention of curative care. The NHO guidelines, which were explicitly created for a hospice benefit under Medicare, were the most influential in its development ²⁰.

The National Hospice Organization had the support of powerful Congressional leaders, many of whom believed that hospice was a possible answer to the "problem of long-term care" for the elderly, despite the fact that hospice was developed specifically for cancer patients. In 1979, the House Ways and Means Committee Subcommittee on Health held a hearing; the topic of discussion was amendments to the Medicare program, with particular attention given to methods to rein in the overall Medicare costs. Two primary reform tools were considered: the use of Health Maintenance Organizations (HMOs) to "streamline" the Medicare program, and the liberalization of eligibility criteria for the reimbursement of home care under Medicare as an incentive to shift care away from expensive medical institutions back into the home ³⁶. A Government Accounting Office (GAO) study concluded that home care was more economical than long-term care for the elderly, primarily due to the shift in the focus of care and the burden of care from professionals to the family. Despite the harsh political discourse alleging fraud and abuse of proprietary home health agencies, legislators continued to emphasize deinstitutionalization and the use of market-based strategies, such as privatization to constrain and control Medicare and Medicaid expenditures ²⁰.

The political stage was set and a policy window opened for hospice to enter as a promising humane and cost-effective means to improve the quality and reduce the cost of care for terminally ill persons. NHO leaders worked closely with Representative Leon Panetta, a Democrat from California who sponsored legislation in 1980 and again in December 1981, to amend Title XVIII (Medicare) of the Social Security Act to define hospice as a particular type of care for the terminally ill, and allow beneficiaries to elect hospice care in lieu of certain other Medicare benefits for terminal diagnoses. A companion bill, S. 1958 was introduced in the Senate. The hospice benefit had both bipartisan and bicameral support. The broad public support that hospice enjoyed notwithstanding, the newly elected President Ronald Reagan introduced a new type of federalism that relied heavily on deinstitutionalization, privatization and the use of market-based strategies to contain costs ³⁷. During this era of retrenchment and reform, the prospects for new entitlement programs looked grim.

The debates surrounding the Medicare hospice benefit were heated. Congressional testimony reveals that the home-health and hospice industries' representatives were aligned in their support for the liberalization of Medicare home-care requirements and argued for the elimination of stringent eligibility criteria. There were, however, differences of opinion about how these reforms should be enacted. The debates were framed by four major

constituencies: 1) the NHO, which supported the bill; 2) the home-health industry, which believed the benefit would result in duplication of services and increased competition which could threaten its financial viability; 3) legislators, who were divided on the issue for a variety of political and economic reasons; and 4) the Reagan administration, which argued against it because of its desire to reform Medicare and the lack of conclusive cost data on hospice. Despite the lack of “hard cold data” and intense lobbying by hospitals, the home health, nursing home and insurance industries against the bill, the House Ways and Means Committee passed H.R. 5180 in July 1982³⁷. The Senate passed the bill by unanimous vote on July 22, 1982.

To the legislators’ dismay, many hospices chose to forgo Medicare certification; it simply wasn’t worth the trouble. By February 1984, only thirty-nine programs were certified. A 1985 Inspector General Report estimated that only 20 percent of the nation’s hospices had become certified due to three primary reasons: 1) the cap of \$6,500 per patient was inadequate to cover the cost of service provision; 2) some hospices believed that eligibility requirements forced a choice between the palliative needs of patients and the organization’s financial viability; and 3) the role of the hospice medical director was viewed as being in conflict with that of the patient’s primary physician³⁸. The limited response was of concern to NHO and hospice advocates in Congress alike. Unless Congress voted to make the hospice benefit a permanent entitlement under Medicare, authorization for it would expire in 1986. It became a legislative imperative to decrease barriers to hospices electing to become Medicare certified. They were successful in their efforts and the entitlement became permanent in 1986.

Looking Back and Seeing Forward

Over time, hospice has been steadily integrated into the American medical system. In 1985, the Consolidated Omnibus Budget Reconciliation Act (COBRA) allowed for reimbursement for hospice under Medicaid programs, and the benefit became available to the military in 1991. The provisions contained in the Medicare hospice benefit served as a template for reimbursement for hospice under these programs. By the mid-1990s, most commercial health-insurance policies typically covered comprehensive hospice services. According to the Centers for Medicare and Medicaid Services (CMS) estimates, Medicare spending under the hospice benefit exceeded \$10 billion in fiscal year (FY) 2007^{39,40}. This figure represents more than Medicare spends on inpatient rehabilitation hospitals, critical access hospitals, long-term care hospitals, psychiatric hospitals, comprehensive outpatient rehabilitation facilities, or ambulatory surgical centers. Medicare spending for hospice is expected to more than double in the next 10 years and it is the target of CMS scrutiny. In addition, recent research reveals variability in the quality and cost-effectiveness of hospice programs, differences in the types of service provided based on location and ownership type and disparities in access to services among marginalized populations^{41,42}.

Contemporary debates over health-care reform raise critical questions of the relationships among profit incentives, methods of symptom management and the quality of the care provided. These problems have persistently plagued the American health-care delivery system since the early 1900s. Reimbursement streams continue to be biased toward technological intervention in acute-care settings, thereby creating is a financial incentive to treat patients in a manner to maximize reimbursement. In 2008, a report on the hospice benefit noted the significant changes that occurred in hospice since 1982, the majority of which were observed from 2001 forward³⁹. The major changes noted were the increased numbers of proprietary hospices and the coinciding rapid increases in Medicare expenditures. Such proprietary hospices were incentivized by the Medicare hospice benefit. Similar allegations of fraud and abuse among home health agencies were brought forth in

the 1970s when legislators began experimenting with market-based strategies for health care reform⁶. This pervasive problem and the variability in the quality and cost-effectiveness of hospice programs based on location and ownership types⁴³⁻⁴⁶ illustrates the dangers of having preset policy solutions and politicians looking for a problem to apply them to, regardless of the fit.

The other important way that hospice was both helped and hindered by the Medicare benefit is evidenced by the fluctuations in the average hospice lengths of stay (LOS). In 1983, the average LOS was 70 days, which was optimal from the perspective of the hospice's effectiveness both in terms of care and costs^{47,48}. In 2000, almost two-thirds of patients received hospice care for less than 30 days and one-third of these patients were in hospice programs for less than a week before dying⁴⁰. The decline in LOS has been attributed to a variety of factors including provider practices, patient preferences, public awareness, federal oversight and regulation, and hospice program closure. The shorter LOS and rapid transitions from curative to palliative care are distressing for everyone involved. In the first decade of the twenty-first century, however, the average LOS increased by 40 percent, or from 48 days in 2000 to 67 days in 2005³⁹. This change is attributed to the increased numbers of hospice patients with serious chronic illness with elusive prognoses, including dementia, adult failure to thrive, and debility. The dramatic shift in population demographics that continue today loomed large in the political landscape when the hospice Medicare benefit was born. Accordingly, hospice was marketed as a promising model for all persons with limited life expectancy despite the lack of evidence to support it. This is yet another lesson from the past to take forward.

Parting Words

Negotiating and bridging the systems of care and cure, while striking a balance between ideals and organizational realities, is an exceedingly complex task. Such was and is the case with hospice. At the inception of the hospice movement, the hospice philosophy of care was defined by idealistic health professionals and based on the premise that each person approaches the process of dying, death and bereavement in their own time and in their own way. As the hospice concept was rewoven into the fabric of the American medical system, the ideal was reshaped in accordance with the personal ideologies, professional paradigms, and the environments in which they were created. The ideal was further re-formed as it was studied and marketed to conform to the prevailing policy template for reform. As hospice was translated into a reimbursable model of care, regulations served to render hospice patients into living and dying components, thus creating and requiring them to straddle two divergent systems of care⁴⁹. At this juncture, it is imperative that we continue to analyze the forces that shape health policy and the subsequent impact on its various intended targets. As we move forward in our efforts to integrate palliative into all health care settings and secure reimbursement for such care, it is incumbent upon us to heed hospice's cautionary tale. There is little doubt that the ideals of palliative care will be altered as they are integrated into the existing system. The question is: What will be gained and what will be lost in translation?

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Hospice Timeline, Eras of Political Reforms, and Key Legislation, 1963 – 1986

Year	Hospice	Political Reforms/Legislation
1963	Saunders' first visit to United States	Era of health system expansion
1965		<i>Medicare/Medicaid signed into law</i>
1966	Institute on Care for Dying at Yale	<i>Health Planning Act</i> Regional Medical Programs
1969	Wald's research funded by Division On Death and Dying published	President Nixon declares "crisis in healthcare – 75% Americans agree
1971	Hospice, Inc. founded	
1972	National Hospice Advisory Council New hospice groups form	<i>Death with Dignity Act</i> passed
1974	Hospice, Inc. Home Care Program	Era of cost-containment Political reforms - Deinstitutionalization, DRGs, HMOs, insurance, managed competition
1975	Hospice concept gains popularity Hospice, Inc. only NCI Demonstration site selected	NCI Hospice Demonstration Project
1976	59 hospice groups	<i>CT Medicaid for/terminal home care</i>
1978	National Hospice Organization National Hospice Education Project	<i>CT State Licensure for Hospice</i>
1979	National hospice movement coalescing around Medicare benefit	Senators call for GAO Report on Hospice National Hospice Study commissioned
1980	National Hospice Study underway	Medicare Hospice Benefit introduced and dies in committee Era of retrenchment and reform Political reforms – Market-based strategies, pro-competition vs. price setting
1981	Hospice movement momentum growing	President Reagan - "it's time to control the uncontrollable."
1982	Mean Hospice LOS 80days	<i>Tax Equity and Fiscal Responsibility Act</i> includes Medicare Hospice Benefit.
1984	100,000 hospice patients	Political reforms - DRGs and capped payments for services. Lackluster benefit uptake – ongoing negotiation with hospice industry to increase numbers of Medicare certified hospices. <i>COBRA allows hospice under Medicaid</i>
1985	Nurses organizing to form HNA	<i>Hospice becomes permanent entitlement</i>
1986	1,505 hospices HNA (now HPNA) founded	