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DEVELOPMENT OF HOSPICE AND PALLIATIVE CARE IN THE UNITED STATES

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ABSTRACT

More than 30 years have passed since palliative care was introduced in the United States, and what began as a small rebellion has evolved into a fairly large health care industry. Although the palliative care movement has considerably improved the care given to those at the end of life, many challenges remain for palliative care providers in the United States. This article discusses the history of hospice and palliative care in the United States, the Medicare Hospice Benefit, the growth of hospice and palliative care, and challenges such as the need for regulatory change, workforce issues, improving access to care, and improving the quality of palliative care.

INTRODUCTION

More than 30 years have passed since palliative care was introduced in the United States, and what began as a small rebellion has evolved into a fairly large health care industry. Although the palliative care movement has considerably improved the care given to those at the end of life, many challenges remain for palliative care providers in the United States. Some of these challenges have arisen out of the seeds planted in the early years of the U.S. hospice movement.

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EARLY U.S. HOSPICE HISTORY

Palliative care began in the United States through an effort to transplant hospice care from the United Kingdom to the United States. In 1963, Florence Wald, then Dean of the School of Nursing at Yale, invited Dr. Cicely Saunders from London to give a series of lectures on hospice care. Cicely Saunders, matriarch of the worldwide hospice movement, had developed approaches to managing pain and the total needs of the dying patients based on the philosophy of using a team to treat the whole person. Cicely's visit eventually led to the formation of the first U.S. hospice in Branford, Connecticut, which began serving patients at home in 1973.

It is significant that in the United States great emphasis was placed on care in the home, in contrast to the United Kingdom, where hospice care began primarily in inpatient settings. This reflected a number of U.S. factors including a desire for independence, a distrust of medical institutions, and a lack of resources for non-profit hospices operating outside mainstream medicine.

Although some have said that hospice began in the United States as an anti-physician movement, this is not precisely accurate. There was certainly, from the beginning, a strong involvement in hospice from nurses, chaplains, and psychosocial professionals. However, early pioneers in hospice care also included many physicians who, like their other professional colleagues, shared a concern for how the health care system was caring—or more accurately, not caring—for the dying.

Much has been written about the institutionalization of the U.S. health care system—the pervasive attitude of denial and the view of death as the enemy. What was happening in the middle 1970s in the United States as the nescient hospice movement was beginning, reflected the U.S. society as a whole. A consumer movement was underway to take back control of various social institutions, including churches, community services, and health care, from birth to death.

Another significant feature of hospice's development in the United States was the involvement of volunteers. In the beginning everyone was essentially a volunteer, either lay or professional. As hospice has progressed in the United States, lay volunteers have continued to play an important role and have been fundamental in establishing hospice. Today, approximately 400,000 volunteers work in U.S. hospices.

To nurture those in the hospice field, a series of national meetings were convened in Connecticut in 1975, in Boonton, New Jersey in early 1977, and in Marin County in early 1978. These meetings led to the formation of the National Hospice Organization (NHO) in 1978. The first large national NHO conference was held in Washington, D.C. in October 1978 and the first Standards of a Hospice Program of Care were published by NHO in 1979. In 1999, NHO changed its name to the National Hospice and Palliative Care Organization to reflect the melding of traditional hospice care with palliative care in the United States.

Even at this early stage of development, hospice leaders were working with key legislative leaders to develop a system to reimburse hospice care in the United States. Before reimbursement could occur, however, data had to be collected to demonstrate what hospice actually did and what costs were involved. The Health Care Finance Administration (now Center for Medicaid and Medicare Services) conducted a national demonstration project involving 26 hospices throughout the United States to study the effect of reimbursed hospice care. The results of this demonstration project enabled government and hospice representatives to develop a model for how hospice care could be organized and funded, and a bill was introduced to Congress creating a new Medicare entitlement for hospice care.

MEDICARE HOSPICE BENEFIT

The Hospice Medicare Benefit (MHB), which was established in 1982 through amendments to the Social Security Act, was included in the Tax Equity and Fiscal Responsibility Act (TEFRA). It was the only new benefit added to Medicare under President Ronald Reagan's administration, and included a three-year sunset provision requiring a report back to Congress on hospice's impact and reauthorization before becoming a permanent benefit in 1985.

The MHB was a unique addition to the U.S. health care system. Prior to implementation of the MHB, the government "reimbursed" providers for their cost in delivering care. With the MHB, a provider was paid a set amount under a prospective reimbursement system. By creating a set payment for hospice care, the government was sharing the risks with a provider. If a patient's cost exceeded the MHB payment, the hospice lost money or had to find other sources of payment. If the MHB payment exceeded a patient's cost, the hospice was allowed to keep the gain even though all hospices originally were not-for-profit organizations.

The set MHB payments were based on the cost of care in the original hospice demonstration project and assumed that each hospice was in compliance with all the standards of hospice care at the time. These standards were changed into Medicare *Conditions of Participation* or regulations that had to be met for a provider to receive payment. Key provisions of the *Conditions of Participation* required hospices to:

- admit eligible patients with a terminal illness with a prognosis of six months or less who chose not to continue curative treatment and agree to hospice care;
- re-certify surviving patients as being terminally ill at specified intervals;
- meet administrative requirements including a governing body, an interdisciplinary team, a plan of care for each patient, a medical record for each patient, a medical director, regular training, quality assurance, use of volunteers, and maintenance of professional management of the program; and
- provide core services by hospice employees including a physician, nurse, counselor, and medical social worker; and provide other non-core services

> including physical, occupational, and speech therapy, home health aides/homemakers, medical equipment and supplies, medications, and short term inpatient care for symptom management and respite.

MHB payment is made for each day of hospice care on a per diem basis at one of four rates: routine home care; continuous home care for crisis periods in lieu of hospitalization; general inpatient care for severe symptom management; and inpatient respite care to give up to five days break for caregivers.

GROWTH OF HOSPICE AND PALLIATIVE CARE IN THE UNITED STATES

Over the last 25 years, since the enactment of the MHB, hospice has grown considerably and is now the fastest growing benefit in the Medicare program. Even with that, it still represents less than 3% of Medicare expenditures. For the first 10 years following implementation of the benefit, there was slow growth as community-based hospices learned to adapt to meeting regulatory requirements. However, growth in the 1990s and through 2005 was enormous (see Figure 1) and in 2005 more than 1.2 million people received hospice care in the United States. That same year NHPCO estimates that at least one of every three deaths, of all causes, in the United States was under hospice care.

There have been a number of significant changes to the hospice population over the last 25 years. Initially, more than 90% of hospice patients had a primary diagnosis of malignancy. In 2005, the percent of hospice admissions with a cancer diagnosis had dropped to less than 50%. Also, length of service in hospice dropped from an average of around 70 days to less than 50 days. More concerning is that the median time in hospice dropped to around 20 days, with more than 30% of patients receiving service for seven days or less. These lengths of service have improved slightly in the last few years (see Figure 2), but are still historically low.

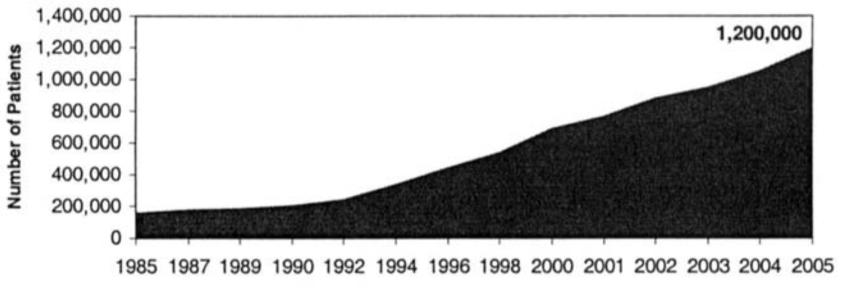

Figure 1. Hospice patients served 1985-2005.

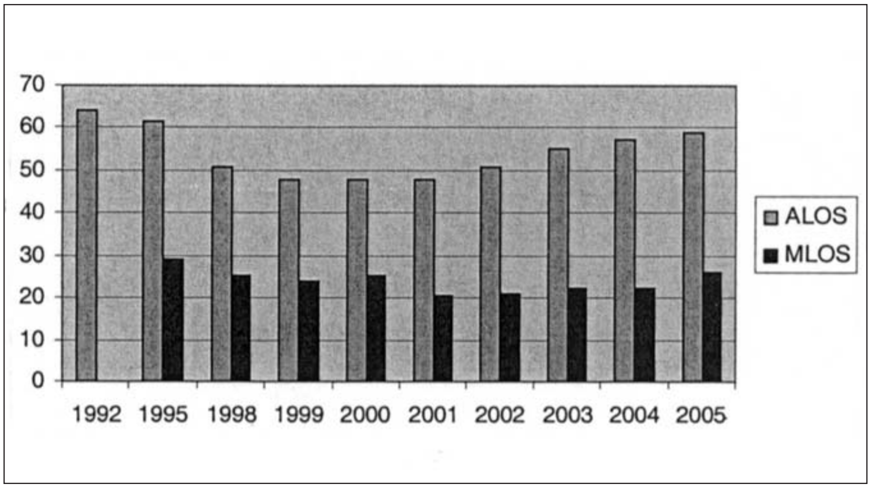

Figure 2. Average and median length of service 1992-2005.

The number of sites where hospice care is delivered has grown significantly in recent years (see Figure 3). Over a 20-year period, from 1985 to 2005, the number of hospice sites has increased from around 1,500 to more than 4,000. This growth has been fueled both by the MHB and by increased acceptance of hospice in the U.S. health care system. Also contributing to the growth of hospice has been the growth of for-profit hospices, with over a third of U.S. hospice organizations being for-profit corporations today.

In the last 10 years, there has been considerable growth in programs that deliver palliative care in hospitals and in the community. These programs mostly developed outside of hospices and were the result mainly of limitations on hospice eligibility and the need to provide palliative care more broadly to those who had symptom control problems and serious illness but who were not yet terminally ill. A study of end-of-life care in teaching hospitals in the United States (SUPPORT, 1995) revealed that hospitalized patients often had unmet needs for pain control and that treatment wishes were often unknown or ignored, even when useful information was readily accessible to physicians and specially trained nurses were available for patients and families.

The growth in specialist palliative care in the United States has been dramatic. The Center to Advance Palliative Care reports that the number of palliative care programs increased from 632 (15% of hospitals) in 2000 to 1,240 (30% of hospitals) in 2006—a 96% increase in only five years. Also, NHPCO reports that 64.6% of hospice providers now report the provision of some palliative care outside their hospice program.

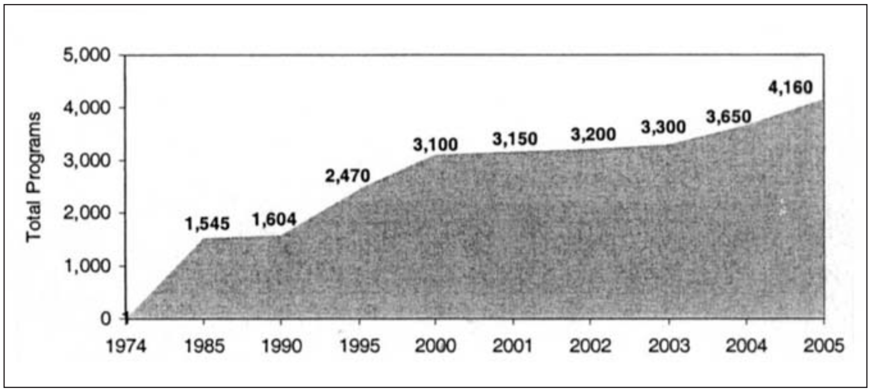

Figure 3. Growth in U.S. hospice programs: 1974-2005.

A number of additional new developments have shown that palliative care, including hospice, is becoming more accepted in the U.S. health care system. Recently, the American Board of Medical Specialties approved hospice and palliative medicine as a recognized sub-specialty. So far, 10 specialties have indicated their interest in allowing their members to sub-specialize in this field, including: Psychiatry and Neurology, Internal Medicine, Family Medicine, Radiology, Surgery, Anesthesiology, Physical Medicine & Rehabilitation, Obstetrics/Gynecology, Pediatrics, and Emergency Medicine.

Also, the Accreditation Council for Graduate Medical Education has begun to accredit fellowship programs in palliative medicine and the Hospice and Palliative Nurses Association offers certification for advanced practice nurses, registered nurses, and nursing assistants. The American Academy for Hospice and Palliative Medicine is growing into a professional society for physicians and the Center to Advance Palliative Care has initiated a National Palliative Care Research Center. While these developments indicate that hospice and palliative care are coming of age in the United States, there remain many challenges and inequities.

CHALLENGES FOR HOSPICE AND PALLIATIVE CARE IN THE UNITED STATES

Changes to the Hospice Medicare Benefit

Medicare reimbursement has been the driving force behind hospice's tremendous success in reaching people at the end-of-life in the United States. At the same time, however, regulatory requirements of the MHB have limited the provision of palliative care primarily to those near death. Palliative care services can be provided to patients under existing general Medicare requirements but do not facilitate interdisciplinary care that is essential to palliative care. Physicians and physician surrogates can bill for evaluation and management, licensed psychologists and social workers can bill for some psychological services, and home health agencies can provide general home care, but only under hospice is interdisciplinary care reimbursed as a package.

Some have called for the creation of a specific palliative care benefit in the United States that is separate from hospice. There is concern that creating a parallel palliative care benefit in the United States could result in competition between hospice and palliative care providers. What is needed most are payment provisions that reinforce provisions of good palliative care at various points in the continuum of care for patients with life-threatening illnesses.

Hospice and palliative care leaders in the United States acknowledge that a change is needed in the payment system for palliative care. There is also an understanding that changes to health care reimbursement will occur incrementally and not all at once. What seems to be needed is careful study of the impact of changes and additions to the payment system so that unintended negative consequences can be mitigated.

There is, for instance, a growing consensus that the current restriction on "curative" treatment is not helpful and is the primary cause of late referral to hospice. This treatment restriction was imposed on hospice providers by the director of the Reagan administration's budget office, out of fear that giving patients palliative care and allowing them to continue chemotherapies and other treatments would be too expensive.

While hospice providers at the time did not want to encourage patients to continue treatments that would make their symptom management more difficult and their quality of life poor, patient autonomy and each patient's right to make their own personal decisions about treatment was respected. In fact, the first National Hospice Organization standard for hospice programs of care in 1979 stated that hospice care was "appropriate" care and went on to define appropriate care as a combination of palliative and curative therapies.

A number of studies conducted through the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care program have demonstrated in various settings that removing the curative treatment restriction under the MHB would not in fact be more expensive to the Medicare program (see http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=1).

Current hospice providers have a considerable amount of flexibility in how they define curative and palliative treatments. Under Medicare regulations each hospice team determines whether a treatment is curative or not. Very few of the newer treatments available to cancer patients and others with life-threatening conditions can be viewed as curative. A growing number of hospices are implementing "open access" policies wherein all patients with limited prognoses are admitted without regard to their current treatment choices. The hospice then works with the patient and treating physicians to decide which are appropriate to continue based on the patient's goals for care. This approach usually results in earlier hospice referral and enough increased reimbursement to cover the added treatment costs.

Another significant regulatory barrier is the requirement that hospice patients have a prognosis of six months or less if the disease runs its normal course. This requirement is a barrier to timely hospice palliative care. However, to eliminate the six-month prognosis requirement necessitates replacing it with "something else" and that "something else" should not be more onerous than the original requirement.

This problem can be placed on a continuum, with one end being complete reliance on the use of physician judgment and the other end being the use of objective measurable criteria with no judgment involved. There are problems with either of these approaches. Physician judgment has been shown to be notably inaccurate (Christakis, 1999) and many problems are associated with the use of rigid criteria, notably with the application of home health skilled need or homebound criteria and rigid application of local coverage determinations by the Medicare fiscal intermediaries on who is eligible for hospice care.

Some have suggested expanding the six-month criteria to 12 months. This could make it easier for patients to acknowledge the possibility of their approaching death and physicians might find it easier to agree to making such a prognosis, much like the surprise question of "would you be surprised if this patient were alive a year from now?" However, expanding the prognostic criteria doesn't fundamentally change the issue of having to make a determination that death is approaching. Moreover, the federal government has indicated that such a change would be scored as a potential doubling of the cost of hospice care. Therefore, this approach is not likely to occur.

What is needed then is an expansion of hospice benefits to include reimbursement for interdisciplinary consults at an earlier stage of the illness and for care management services prior to admission to a formal hospice service. Such consults and services could be tied to the existence of a life-threatening diagnosis, rather than requiring a prognosis and would require a referral. Such consults are being done now on a limited basis in hospitals, nursing facilities, and residences. Care management programs are emerging; however, to be most effective, the provider needs to have the capacity to do more than just talk on the phone and give advice. To prevent hospitalization, it is sometimes necessary to go to the patient even if it is 2 A.M. Currently, hospices have the most well developed after-hour service delivery capacities.

Workforce Issues

Such an expansion of palliative care will require a substantial increase in a competent workforce. Now that hospice and palliative medicine has been accepted as a recognized sub-specialty, there may be increased incentive for new and existing physicians to enter the field. However, as seen in the sub-specialty of geriatrics, which has not grown in spite of a growing and recognized need, there need to be adequate incentives to attract competent physicians to the field.

Similarly for nursing, which will soon confront a much more significant shortage than has been reported due to large scale retirements, palliative care needs to attract caring and competent professional nurses and skilled nursing assistants. Certification by the National Board for Certification of Hospice and Palliative Nurses is growing and helping to ensure basic competency for nursing professionals. There are currently no recognized certification programs in hospice and palliative care for psychosocial professionals, chaplains, or hospice administrators.

Social workers have been providing the bulk of psychosocial services in hospice programs. This is due to the fact that social work is a required core hospice service and that social workers, if adequately trained in mental health, can also meet the hospice's required need for counseling services. However, there is growing concern that hospices and palliative care programs are not devoting adequate resources to psychosocial services, which are thought to be one of the defining characteristics of the field.

Certainly all team members, including physicians, nurses, and volunteers, can provide some psychosocial care, but social workers, psychologists, and psychiatrists are necessary to address the often complex dynamics and needs of families facing a death. Also, there has been much new knowledge in the field of mental health that may not be adequately applied to the dying and their families. Just providing active listening or providing "supportive" care is not enough. Opportunities for healing relationships and promoting growth at the end of life are major outcomes of good hospice care.

Spiritual and religious services are not as well developed as they could be in hospice and palliative care. Some hospices employ staff chaplains while most coordinate care with community clergy. Most clergy report that their seminarian training was wholly inadequate to prepare them to minister to the dying. Few clergy have undertaken chaplaincy training and when ministering to patients and families are at risk of doing as much harm as good; for example, when patients are left feeling their illness is punishment for misdeeds or lack of faith. Still, spiritual support is generally better in hospice care than in the general health care system and opportunities to help patients find meaning are among the most important of hospice interventions.

If current projections are correct, then more than twice as many hospice professionals and volunteers will be needed in the next 20 years to meet the unmet need for palliative care and the growing numbers of older people in our society. Already, hospices do not have enough physicians to provide optimal care and could use many more to enhance the quality of services.

Access and Quality

The challenge for hospice and palliative care providers can be boiled down to achieving unfettered access to quality palliative care for all who need it. Initially, hospice care in the United States was limited to mainly white suburban cancer patients. Over the past 30 years access has improved considerably and is close to but not yet at parity with population needs. A recent report (Connor et al., in press) demonstrates that blacks are now 7% less likely to receive hospice care than whites. Data for other minority groups is difficult to analyze and the U.S. society is growing increasingly multi-racial.

Significant improvement has been made in improving access to hospice for patients with non-cancer diagnoses, and hospice is now caring for about 60% of all patients who die from cancer. However, access to hospice for patients with solid organ failure, dementia, and frailty still has a long way to go and is limited by current regulatory requirements and prognostic uncertainties. Determining prognosis in non-cancer populations remains a challenge, though recent efforts to improve NHO's original prognostic guidelines are underway.

There remains considerable geographic disparity in access to hospice care (Connor et al., under review), with rates of hospice use ranging from 11% of all deaths in Alaska to 49% of all deaths in Arizona in 2002. Access to hospice and palliative care in very rural areas is a considerable concern.

Most users of hospice care report higher ratings of satisfaction than those dying in other settings (Teno et al., 2004). However, consumer expectations for end-of-life care are low to begin with and there is a general tendency toward leniency bias. Considerable work is now being done to develop sensitive and specific measures for providers of end-of-life care. As hospice and palliative care have grown in the United States, there has not been as much attention to quality as in the rest of the health care system.

Initial focus was on improving the quality of nursing home care, which has generated the most concern about poor quality. However, hospitals, home health agencies, physician practices, and other Medicare providers have now had to develop accountability measures, many of which are now publicly reported on Websites such as Home Health Compare and Nursing Home Compare. Hospice will join their ranks before long.

Most current efforts to measure quality in hospice and palliative care are aimed at drawing out from patients and families feedback about their perception and evaluation of the care they have received. This is only fair as these are important outcomes that we can't risk manage and are inherently important to consumers. We also need to look beyond this feedback to look at how our organizations are functioning, how our workforce is improving, and how we measure changes in the patient's condition in an increasingly electronic world of medical records.

In summary, the hospice and palliative care experiment in the United States is continuing to evolve and grow. While we were wrong to believe that the need for specialized palliative care would be eliminated by now, we can hope that in another 20 years we may see a health care system that provides easy access to palliative care throughout the continuum of care for all those with life-threatening illnesses and, in Cicely's words, is provided by people who can give with both their minds and hearts.

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