

Hospice: A Vital Service Facing Increasing Demands

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Introduction

For three decades hospice providers in the United States have been changing the care for dying Americans and their families by providing options and choices that enable patients to be in control of their care at the end of life. Yet, hospice faces a number of challenges. The healthcare landscape is changing along with the demographic profile of the nation. In order to meet present and future challenges relating to end-of-life care, it is imperative that hospices build on the successes of the past and carefully listen to the needs of the changing populations served.

The Care Americans Want

The hospice movement in the United States can be traced back to the work of Dame Cicely Saunders at St Christopher's Hospice in the United Kingdom. Hospice care in America grew out of the need for more compassionate care for dying persons. In the American paradigm, hospice is not a place, but an interdisciplinary offering of palliative and support services that allows the terminally ill to be cared for primarily at home. 'Home' is defined by the patient, this may be: the patient's own home, the home of a loved one, an assisted living facility, a long-term care facility, or a hospice residence. The care that the hospice provides reflects the specific care that is in demand. Nearly 90% of adults reported that they would prefer to be cared for in their own or a family member's home if they were terminally ill and had six months or less to live.¹

Many studies^{1-4,23} have documented that when considering issues of death and dying, the American public's chief priorities and concerns include:

- home-based care;
- patient control and choice about the services available to them;
- emotional and spiritual support for patients and families;
- pain control customized to the patients wishes; and
- freedom from financial worry.

In 1982, Congress voted to support the Medicare Hospice Benefit (MHB). In providing a government funding mechanism, Congress established an all-inclusive benefit for hospice that has enabled millions of Americans to receive quality end-of-life care. More than 96% of hospices in the United States are Medicare-certified and just over 80.9% of patients claimed Medicare as their payment source in 2002.⁵ Most private insurance plans, health maintenance organizations, managed care providers, and Medicaid in the majority of states also cover hospice services.

The Nation's Demographics Are Changing

Availability of hospice and palliative care is a critical issue as many more Americans begin dealing with end-of-life care decisions, for themselves and older family members. The aging post-World War II generation is bringing on a significant demographic shift that is unprecedented. The elderly population in the United States is expected to double between 2000 and 2030. By 2030, there will be approximately 70 million Americans over the age of 65. The proportion of the elderly falling into the 85 years of age and older category is increasing. This group is expected to increase from 4.2 million in 2000 to 8.9 million in 2030. Never have the chances of reaching 100 years of age been better. It is estimated that more than 72,000 people in the United States are over 100 and by 2050 that number is expected to be 834,000.⁷

As our population ages and life expectancy increases, more sophisticated and costly medical interventions will be required to provide for the nation's healthcare needs. More people will live with long-term illness that requires significant care. The number of deaths will also increase. In 2001, 2.4 million people died in the United States from all causes. The National Center for Health Statistics estimates that the number of deaths per year will grow at such a rate that in 57 years, the number will be almost 5.7 million people annually.⁷ These statistics demonstrate a need to prepare for a patient base that is already changing. In order to adequately provide care, access to hospice and palliative care must expand and capacity must increase. An

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understanding of how hospice has successfully served the dying in the past will provide a foundation for future care.

Three Decades of Growth

By virtually any measure, the system of hospice care provided in the United States has been successful. One of the most dramatic measures of success has been the growth in beneficiaries. In 1975, there were 1,000 hospice admissions in the United States. By 2002, that number had grown to 885,000 annually. Over 95% of hospice patient visits are for routine home level of care reflecting Americans' preference to be in a home environment at the end of life.⁶

Today's hospice must address a broader range of terminal disease states and a wider range of palliative care services.¹⁰ Hospice providers in the mid-1970s primarily served cancer patients, and the demographic profile of the patient population was almost entirely white and middle-class.⁹ By 2002, cancer patients accounted for 50.5% of admissions. Hospices are also serving patients with end-stage heart, kidney and liver disease, along with dementia, lung disease, and other conditions (see Table 1).⁸ America's hospices have taken a leadership role in the care of patients with HIV/AIDS as well.

Treatments such as chemotherapy and radiation, traditionally associated with curative care, are being increasingly used in hospice for pain and symptom management. In fact, advances in medical practice and technology for palliative, end-of-life care have prompted a significant increase in the intensity and frequency of services delivered to the hospice patient.¹¹ Outreach and increased access for diverse populations is also necessary. In 2002, 9.2% of hospice patients were African-American, 4.3% were Hispanic or Latino, 8% were Asian or Hawaiian/Pacific Islander, and 3.7% were classified as multiracial or 'another race.'⁸

More Americans Could Benefit from Hospice

Statistics suggest that more terminally ill Americans could gain access to the benefits of hospice. The United States General Accounting Office reported in 2000 that, while more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of one week or less are common. This study and other reports attribute this phenomenon to a variety of factors, including physician practices, patient preferences, concerns about compliance with Medicare eligibility requirements, and lack of awareness of the MHB among both the public and professionals.¹² A closer look at the trend toward shorter hospice service periods shows that the average length of service (ALOS) in hospice has declined dramatically since the initial Medicare demonstration project of 1983. The median length of service (MLOS) illustrates the effect of enrollments taking place days

before death, and in 2002, 34.7% of those served died in seven days or less.⁸

The trend toward shorter lengths of service, combined with the greater intensity of today's hospice services, is also creating severe financial pressures for hospice providers. The government's original reimbursement mechanism under the MHB assumed a 70-day average length of service, with a per-patient, per-day rate that spread total cost over that 70-day period. With the drop in ALOS, hospices have a shorter period of patient stability over which to spread the high front-end and back-end costs that are unavoidable with hospice care.¹¹

Cost of Care

A 1994 Lewin-VHI study found that Medicare saved \$1.52 in Medicare Part A and Part B expenditures for every dollar it spent on hospice. That 1995 study also showed that in the last month of life, per-patient savings totaled \$3,192, "as hospice home care days often substituted for expensive hospitalizations."¹³

Other more recent studies suggest that the use of hospice and advance directives saves up to 10% in the last year of life, 10% to 17% in the last six months of life, and 25% to 40% in the patient's last month.⁹ The dollar value of such savings is dramatic when one considers the staggering costs that can result from efforts to extend life futilely through hospitalization in an intensive care unit (ICU). It has been estimated that the cost of caring for certain categories of cancer patients in an ICU can range from \$95,000 to as much as \$450,000 per patient for each year of life gained.¹³

Methods of reimbursement for services that are outside current hospice reimbursement streams must be explored and developed. Providers should not depend on the Medicare Hospice

Benefit as the only source of reimbursement. Alternative funding sources include foundation grants, research projects, physician fellowships, charitable contributions, and institutional subsidies. These must all be aggressively explored. Providers must think beyond billing income to cover costs of care and operation.²²

The cost of caring for the terminally ill is a critically important

public policy issue, given the fact that one third of all federal Medicare dollars are spent on patients who are dying.¹⁴ However, increasing hospice referrals is not just an economic measure. Hospice provides compassionate, high-quality care with consistently high patient approval ratings.^{15,16}

Public Policy Changes

Congress has recognized the need to improve access and care through adjustments to the Medicare Hospice Benefit. While recent legislative changes may not address all the concerns related to access and capacity, they should prove beneficial. In

Table 1.
Hospice Deaths in the United States, 2002

Diagnosis at admission	2002
Cancer	50.5%
End-stage heart disease	10.7%
Dementia	8.3%
Lung disease	6.7%
End-stage kidney disease	3.0%
End-stage liver disease	1.6%

December 2003, Congress approved a far-ranging package of Medicare reforms, the Medicare Modernization Act of 2003.

There are a number of provisions designed to improve access and make hospice care more available to patients and families earlier in their illnesses. These include an educational consult for patients who would be appropriate for hospice care but have not yet been referred, the ability for hospices to contract for core or specialized services, a provision for nurse practitioners not employed by hospice to continue caring for patients under hospice, and a rural hospice demonstration project to evaluate care delivery.

Demonstration Projects

Additional methods to improve access, capacity, and ensure financial viability could be identified through national and community demonstration projects. Demonstrations that could lift current reimbursement guidelines, offset patients with very short stays, or examine how hospice patients could benefit from higher cost treatments would provide data that would potentially improve access to care for all. Projects that explore ways in which service providers can combine hospice and disease-modifying therapies at the same time must also be examined. There has also been much debate regarding Medicare eligibility requirements—currently, a physician must certify that a patient could die within six months if the terminal illness follows its expected course. Eligibility has often been confused with limits in length of service. A better understanding of how this has become a real and perceived barrier to care should be researched, ultimately leading to improved public and professional outreach and engagement.

Public and Professional Education

Another recognized barrier to greater public education about hospice is the character of American society, with its emphasis on youth, curative treatment, and the reversal of aging.¹⁷ While not everyone with a terminal illness may be receptive to hospice, research suggests that most Americans—including physicians—are not sufficiently educated about hospice to make an informed choice. Also, within the physician community, studies indicate an aversion to the open discussion of death with patients and a lack of medical education about end-of-life issues.^{3,18,19,21} An article in the *American Journal of Hospice & Palliative Care* reported that physicians often withhold the truth of a terminal diagnosis from their patients, resulting in the patient not realizing that death is likely until the last month of life.²⁰

The national Institute of Medicine published a 1997 study, *Approaching Death: Improving Care at the End of Life*, that reported “the education and training of physicians and other healthcare professionals fail to provide them the attitudes, knowledge and skills required to care well for the dying patient.”⁹

Hospital-Hospice-Palliative Care Partnerships

Important opportunities for hospice providers and hospitals in the United States can be found in hospital-hospice partnerships. A report released by the National Hospice and Palliative Care Organization (NHPCO) and the Center to Advance Palliative Care, *Hospital-Hospice Partnerships in Palliative Care*,¹⁹ explores the relationship between hospitals and hospices that actively collaborate in providing appropriate care. The report indicates that partnerships tend to move in two directions. First, an enhanced utilization of the Medicare Hospice Benefit is seen as closer relationships between the hospice and hospital develop. Also, education surrounding hospice care, the creation of in-patient units, and reduction in barriers to hospice admission are documented.

The second trend is the development of palliative care services. In April 2004, the Clinical Practice Guidelines for Quality

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Palliative Care²⁴ were released by the National Consensus Project, a consortium of five national organizations in the field intensely interested in improving care for patients and their families at the end of life. The consortium includes the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, Last Acts Partnership, and the National Hospice and Palliative Care Organization. These Guidelines describe core precepts and structures of clinical palliative care programs and are the culmination of more than two years of work. They provide guidance for the assessment and treatment of pain and other symptoms; help with patient-centered communication and decision-making; and coordination of care across settings and through serious illness and are written for any healthcare provider who is interested in a developing palliative care program. More information on these guidelines can be found at www.nationalconsensusproject.org.

Building on What Works

The success of hospice is well documented, yet ongoing challenges in the field are recognized. End-of-life care providers must respond and adapt to the changing environment. The general public has an awareness of hospice, but the vast majority of people lack the specific understanding and knowledge to

gain full access to hospice benefits. Physicians are also reluctant to discuss the specifics of death with their patients, and they lack the comprehensive medical education in end-of-life care that would lead to more referrals (and earlier referrals) to hospice. Changing demographics will greatly impact the number of Americans who must be served and the care that must be provided at the end of life.

It is critical that hospice and palliative care providers take their full knowledge and expertise regarding care at the end of life and make it available further upstream, reaching more Americans much earlier in the course of a life-limiting illness. The hospice philosophy of care should be utilized to help

patients make the transition from more aggressive therapies to holistic palliative care services. Increasingly, hospitals and critical care units are using the skills of palliative care to more appropriately serve patients in their care.

The National Hospice and Palliative Care Organization (NHPCO) is the oldest and largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their families.

More information is available at www.nhpco.org. **NCMJ**

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