

I. THE HISTORICAL AND FUTURE IMPLICATIONS FOR HOSPICE

The term “Hospice” has grown from a little-known European concept to a growing form of care for the dying in America today. It offers an alternative to futile aggressive treatment at the end-of-life and provides a wide array of services bringing an interdisciplinary team approach right to the person’s home. Defined in Florida Administrative Code (F.A.G.) 59C-1.035, the term “hospice” is a “program that provides a continuum of palliative and supportive care for the terminally ill patient and his/her family.” The state regulations further specify that hospice services “...must be available to all terminally ill persons and their families without regard to age, gender, national origin, sexual orientation, disability, diagnosis, cost of therapy, ability to pay, or life circumstances.”

The following section provides a brief history of the hospice movement and its place as a benefit under Florida’s Medicaid Program. This historical perspective illustrates that the continued evolution of hospice has yet to realize its true benefits in terms of human gains in self-directed living at the end-of-life. Concomitantly, the societal costs of unwanted and unnecessary invasive health care expenditures at a critical point in one’s life, makes hospice a clear alternative not only to the individual, but also to the community as a whole. Despite these benefits, hospice has yet to be widely embraced or acknowledged. Nonetheless, it continues to evolve as one of the most effective modalities for enhancing the quality of life for people in the final stages of terminal illness.

A. EVOLUTION OF HOSPICE

Although hospice is a relatively new concept in the spectrum of health care services, its roots can be traced to medieval times. The word comes from the Latin, “hospitium,” meaning guesthouse. The root is the same as our words for ‘hospital’ and ‘hospitality.’

Early medieval hospices were places of rest for weary travelers returning from religious pilgrimages, and later as a place for wounded crusaders to rest, receive treatment for wounds, or to die. These first hospices combined the functions of hotels, hospitals and rest places. There are references to hospice in Chaucer’s *The Canterbury Tales*, and to this day on the Isle of Rhodes one can see the earliest hospices that were run by various individual states such as England, France and Spain.

The hospice concept evolved during the late 1860’s under the direction of the Irish Sisters of Charity, which opened a home for dying persons in Dublin. In 1902 the sisters established St. Joseph’s Hospice, which served as an important model for other British hospices of the time. St. Joseph’s still exists today in Dublin.

The modern hospice movement began in the 1967 when Cicely Saunders, a British physician, established St. Christopher’s Hospice near London. Her program was the first to combine the compassionate care for the dying that hospices had always offered, with modern pain control techniques. Because of its high quality patient care, effective

management and excellent educational programs, St. Christopher's became the flagship of the hospice movement in England.

The first American hospice was a home care program established in New Haven in 1974. Partly fueled by Elizabeth Kubler-Ross's book *On Death and Dying* in 1969, the hospice movement grew through the '70's in various local communities -- spontaneously, without a national leader, usually by people who, through personal experience, saw the need for hospice-type services in reaction to the existing medical care system.

In 1979 Florida became the first state to recognize hospice care as a medical/legal alternative for the terminally ill, and set standards that hospices must meet. The Florida Hospice Act became the basis for hospice licensure laws in nearly 30 states and became the foundation for national Medicare legislation. The bill was introduced into the Florida Legislature by Representative (now Congresswoman) Carrie Meek, and sponsored in the Senate by Jack. D. Gordon.

In 1980 26 hospices across the United States were selected to be Hospice Demonstration sites in a Medicare study. The demonstration hospices developed clinical protocols and procedures which became the model for many hospice programs across the country.

In 1982 Senator Dole and Congressman Panetta led a bipartisan effort to pass the Medicare Hospice Benefit which passed in 1984. In 1986 the act was amended to include Medicaid patients and to ensure that residents of nursing homes are offered access to hospice care.

Hospice, as a care modality, has experienced explosive growth since Medicare coverage was put in place. During the years between 1984 and 1996 there was a 70-fold increase in the number of hospices participating in Medicare. According to the National Hospice and Palliative Care Organization (NHPCO), there are 3,100 hospice programs operating in all 50 states and U.S. territories, reflecting its growing presence throughout the country. Individuals cared for by hospice rose from 200,000 in 1992 to an anticipated 700,000 plus in 2001.

B. HOSPICE CARE AND HEALTH CARE COST SAVINGS

Policymakers and hospice industry representatives commonly accept the idea that it costs less to provide hospice care than hospital or skilled nursing home care for terminally ill persons. Hospice involves less invasive technological intervention and, with timely referral, less staff time than acute care or skilled nursing care.

Enrolling patients in a timely manner into hospice can help manage Medicare and Medicaid expenditures. Hospice saves significant money by preventing the medical crises that send patients to more costly hospitals and nursing homes. More timely referrals might save Medicare and Medicaid even more money on unnecessary treatments.

The first indication of significant savings in hospice was introduced in a study conducted by the Health Care Financing Agency in 1988, which showed savings of \$1.26 for every

Medicare dollar spent on hospice. A 1995 Lewin-VHI study, commissioned by the National Hospice Organization and supported by Hospice Foundation of America, showed that for every dollar Medicare spent on hospice, it saved \$1.52 in Medicare Part A and Part B expenditures. The 1995 study also showed that in the last year of life, hospice patients incurred \$2,737 less in costs than those not enrolled under the Medicare Hospice Benefit. These savings totaled \$3,192 in the last month of life, as hospice home care days often substituted for expensive hospitalizations.

In 1999 this translated into a savings of \$1.675 billion in Medicare skilled nursing and hospital reimbursements (State Initiatives in End-of-Life Care, August, 2001). The 525,000 Medicare hospice beneficiaries in 1999 represent about 22% of all persons who died that year, and who would have been eligible for hospice. If hospice referrals had been double, the savings could be projected over \$3.2 billion. Therefore, it is reasonable to assume that increased hospice referrals in both the federal Medicare program and the Medicaid programs will result in savings to the larger health care system. Medicare expenditures for hospice care have grown to \$2.2 billion in the 18 years since 1983, but **still represent only 1% of the Federal Medicare budget.**

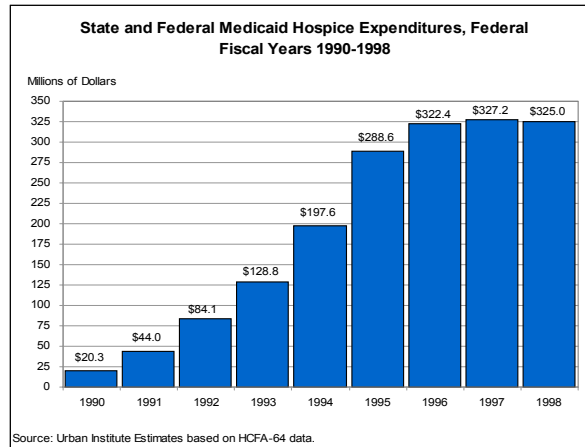
It should be noted that it is risky to portray hospice as a cost-cutting measure. New developments and refinements in palliative techniques requiring technological interventions such as radiation for pain relief, costly pharmacological and outpatient therapies will raise the cost of hospice care, and are already having an impact on hospice operations and policy in 2001. Also, the earlier cost benefit studies were based primarily on cancer patients, and in the last several years the number of non-cancer patients being cared for by hospice has risen dramatically. There is no data on the cost of providing hospice care to non-cancer patients, but anecdotal evidence indicates the cost may be higher than for cancer patients.

C. HOSPICE AND THE MEDICAID PROGRAM

In 1986 Congress authorized hospice as a covered service through state Medicaid programs that elected to offer the benefit. Most states that offer the optional hospice benefit closely parallel Medicare's benefit, which provides a range of medical and palliative services to persons who have a prognosis of six months or less to live. According to the National Hospice and Palliative Care Organization (NHCPO), every state but Connecticut, Nebraska, New Hampshire, Oklahoma, and South Dakota covered hospice under Medicaid in 2001, with Maine being the most recent state to include coverage in 2001.

Federal and state Medicaid spending on hospice, although small, has grown rapidly. Medicaid hospice expenditures amounted to \$129 million in fiscal year 1993 and more than doubled by 1998, reaching \$325 million by fiscal year 1998. (See Figure I-A). However, expenditures have leveled in recent years and Medicaid hospice expenditures actually declined slightly between fiscal years 1997 and 1998. Comparatively, Medicare hospice expenditures also grew during this period from fiscal year 1993 to fiscal year 1998, almost doubling to the \$2.2 billion figure.

Figure I-A



Despite these dramatic increases, hospice represented significantly less than 1% of the total Medicaid payments in 1997 and even these expenditures may be significantly inflated due to the inclusion of nursing home room and board costs in Medicaid payments to hospices. This systemic weakness in the reimbursement system continually overstates hospice payments and serves as a source of misunderstanding to policy makers and the public alike. Even so, the 327.3 million dollars in Medicaid payments for hospice are in stark contrast to nursing home payments, which represented 24.7% or 30,503.8 million dollars for the same period, which may be understated, for the reason noted above. (See Table I-1).

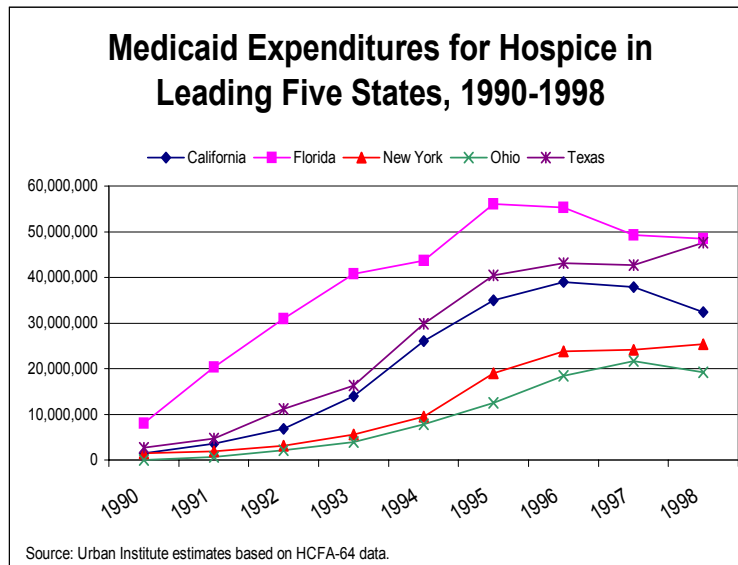
**Table I-1
Medicaid Payments by Type of Service, FY 97**

Type of Service	Amount (\$Millions)	Percent of Total
Inpatient Hospital	23,142.6	18.7
Nursing Home	30,503.8	24.7
Physician	7,041.0	5.7
Outpatient Hospital	6,169.0	5.0
Hospice	327.3	0.3
Prescription Drugs	11,972.3	9.7
Intermediary Care Facility/Mental Retardation (ICF/MR) Services	9,798.3	7.9
Other	22,360.1	18.1
Total Payments	123,551.00	100.0

Source: HCFA, Division of Medical Statistics. Data are from Form HCFA-2802, with the exception of hospice data which are from form HCFA-64.

Medicaid federal and state spending for hospice care varied markedly among the states. For those states with a hospice benefit, total expenditures in fiscal 1998 ranged from a low of several hundred thousand dollars to \$48 million in Florida and in Texas¹. Figure I-B displays the growth among the leading five states in Medicaid expenditures from 1990 to 1998². It should be noted however, that these states are also among the most populated.

Figure I-B



Fiscal year 1998 spending for each beneficiary receiving hospice averaged \$6,284 for the U.S. and ranged from \$3,094 in Louisiana to \$18,022 in Michigan. Florida was slightly above the national average in 1998 at \$6,389 per patient.

In 1998, the total number of Medicaid hospice patients was 51,722 in the United States. Patient group sizes ranged from no reported patients in some states to 7,583 in Florida. Demographic data on users of Medicaid hospice services are not available to display for state by state comparisons.

D. CHALLENGES TO THE HOSPICE MOVEMENT

Although the hospice movement began in the United States more than 27 years ago, the concept of hospice has grown in acceptance throughout the country as a reimbursable service over the past two decades. Despite this gain however, there is still a lack of information and frequent misunderstandings of its actual benefits by both the general public and medical professionals. Evidence suggests that American physicians are uncomfortable dealing with end-of-life issues (*SUPPORT Study*, Robert Wood Johnson

¹ Outlier states such as Tennessee and Alaska have been excluded due to their low participation.

² These data should be used with caution as they may be inflated due to the inclusion of nursing home room and board pass through funds which are administered by hospice provider organizations.

Foundation, 1995). Further evidence also suggests that most physicians have received little training on delivering the news of terminal illness to patients and families, and many claim to be unprepared and uncomfortable in the role of counselor or communicator of these difficult and sensitive issues. Consequently, inappropriate and futile care is often delivered to many who are terminally ill. Such efforts to prolong life frequently leave people dying alone, in pain and attached to life support machines.

Unfortunately, physicians are not the only ones lacking sufficient awareness of hospice. Patients and their families also are not fully informed of the options of hospice and palliative care. Accordingly, they often do not access hospice services, which are clear alternatives to aggressive treatment that is often painful for the patient, uncertain in its outcome, and expensive for the state. When Americans think of hospice, they often think it is a place to go to die, and few know of its pain management expertise or its interdisciplinary approach that offers critical medical, psychological and spiritual support right in the home.

Another factor to consider is the confusion that occurs about what constitutes the difference between hospice care and other forms of end-of-life care. Hospice is a medical system that delivers pain control and comfort care to people with a terminal illness that is no longer responding to curative therapies such as radiation, chemotherapy and surgery. It encompasses a wide array of services and also addresses the social, psychological and spiritual needs of terminally ill patients and their families. Since hospice is associated with death, many care providers may delay referrals due to the general reluctance in our society to discuss death and the dying process. An alternative may be the provision of palliative care, which is a type of care that focuses on pain management and comfort care. Palliative care may provide a bridge to non-curative treatment; however, it does have some limitations. For example, palliative care does not have a commitment to aftercare and is not as inclusive of the holistic service components as hospice. Palliative care is also usually provided in the hospital, but there are not clear payment mechanisms for it. Given the above, there continues to be a lack of clarity about the differences between these two care modalities and education is needed for making appropriate referrals.