

September 2000

MEDICARE

More Beneficiaries Use Hospice but for Fewer Days of Care



G A O

Accountability * Integrity * Reliability

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Abbreviations

BBA	Balanced Budget Act of 1997
CDC	Centers for Disease Control and Prevention
CON	certificate of need
HCFA	Health Care Financing Administration
HHa	home health agency
HHS	Department of Health and Human Services
HMO	health maintenance organization
IOM	Institute of Medicine
MSA	metropolitan statistical area
OIG	Office of Inspector General
SNF	skilled nursing facility



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Health, Education,
and Human Services Division

B-284476

September 18, 2000

The Honorable Charles E. Grassley
Chairman, Special Committee on Aging
United States Senate

The Honorable John B. Breaux
Ranking Minority Member, Special Committee on Aging
United States Senate

The Honorable Ron Wyden
United States Senate

The Medicare hospice benefit was designed to serve terminally ill persons who choose not to continue medical treatment to cure or extend life but instead to receive services focused on comfort and pain relief as well as emotional and spiritual support. Although hospice services are available in inpatient settings, most services are provided in the patient's home or residence. The hospice benefit is available to beneficiaries with a prognosis that they have 6 months or less to live, but hospice users may receive services for longer than 6 months, provided that they are periodically recertified as eligible.

Some patient advocates, hospice providers, and others contend that certain Medicare beneficiaries for whom hospice care is appropriate may have difficulty in gaining access to hospice care or receiving services in a timely manner. However, officials of the Health Care Financing Administration (HCFA) and others assert that the benefit is basically working as intended and meeting the needs of those who choose to use it. You asked us to examine (1) the patterns and trends in hospice use by Medicare beneficiaries, (2) factors that affect the use of the hospice benefit, and (3) the availability of hospice providers to serve the needs of Medicare beneficiaries.

To address these issues, we analyzed HCFA claims and enrollment and provider data for a 9-year period ending in December 1999.¹ (A detailed description of our methodology is in app. I.) In addition, we interviewed

¹Data were not available before 1991.

officials of hospice programs representing various affiliations, enrollment sizes, and locations; officials responsible for processing Medicare hospice claims; HCFA officials; patient advocacy groups; experts in palliative medicine; and trade association representatives. We also reviewed relevant research as well as Medicare program regulations, manuals, and guidance. We performed this review from November 1999 through August 2000 in accordance with generally accepted government auditing standards.

Results in Brief

The number of Medicare beneficiaries choosing hospice services has increased substantially. In 1998, nearly 360,000 Medicare beneficiaries enrolled in a hospice program, more than twice the number who elected hospice in 1992. Of Medicare beneficiaries who died in 1998, about one in five used the hospice benefit, but use varies considerably across the states. Although cancer patients account for more than half of Medicare hospice patients, growth in use has been particularly strong among individuals with other common diagnoses such as heart disease, lung disease, stroke, and Alzheimer's disease. Although more beneficiaries are choosing hospice, many are doing so closer to the time of death. The average period of hospice use declined from 74 days in 1992 to 59 days in 1998. Half of Medicare hospice users now receive care for 19 or fewer days, and care for 1 week or less is common.

Many factors influence the use of the Medicare hospice benefit. Decisions about whether and when to use hospice depend on physician preferences and practices, patient choice and circumstances, and public and professional awareness of the benefit. Along with these factors, increases in federal scrutiny of compliance with program eligibility requirements may have contributed to a decline in the average number of days of hospice care that beneficiaries use.

The growth in the number of Medicare hospice providers in both urban and rural areas and in almost every state suggests that hospice services are more widely available to program beneficiaries than in the past. Between 1992 and 1999, the number of hospices participating in Medicare increased 82 percent, with large providers and those in the for-profit sector accounting for a greater proportion of the services delivered. At the same time, hospice industry officials report cost pressures from declining patient enrollment periods and increased use of more expensive forms of palliative care, such as radiation and chemotherapy for pain relief. Because reliable data on provider costs are not available, however, the effect of these reported cost pressures on the overall financial condition of hospice

providers is uncertain. As required by the Balanced Budget Act of 1997 (BBA), HCFA began collecting information in 1999 from hospice providers about their costs to allow a reevaluation of the Medicare hospice payment rate.

Background

The Medicare hospice benefit, authorized in 1982 under part A of the Medicare program, covers medical and palliative care services for terminally ill beneficiaries. A Medicare-certified hospice provides physician services, nursing care, physical and occupational therapy, home health aide services, medical supplies and equipment, and short-term inpatient hospital care for pain control and symptom management. In addition, the hospice benefit provides coverage for several services not generally available under the regular fee-for-service Medicare benefit. These include outpatient prescription drugs for treating pain and other symptoms of the terminal illness, homemaker services, short-term inpatient respite care, and bereavement counseling for the patient's family.²

Patients may receive services from freestanding hospice providers or from a hospice program based in a home health agency, hospital, or skilled nursing facility. For each day a beneficiary is enrolled, the hospice provider is paid an all-inclusive, prospectively determined rate, depending on the level of hospice care provided (routine home care, continuous home care, inpatient respite, or general inpatient care).³ Initial payment rates were based on cost data reported by 26 hospice programs that participated in Medicare's hospice demonstration project from 1980 to 1982.⁴ Since 1993, these rates have been updated by an annual statutory adjustment factor

²Outpatient medications and respite care are subject to limited coinsurance by beneficiaries. Beneficiaries pay 5 percent of the cost of drugs or \$5 per prescription, whichever is less, and they pay 5 percent of hospice payments for respite care but no more than the Medicare hospital deductible, which is \$776 for calendar year 2000.

³For routine home care, the hospice is paid a daily rate for each day a beneficiary is enrolled, regardless of whether or not services are provided each day. Routine home care is the default payment rate when other levels of care are not provided. In 1998, 97 percent of hospice care days were paid at the routine home care rate.

⁴Cost data included the kinds of services furnished, their costs, and the frequency of their provision.

tied to inflation in the hospital market basket (a measure of the cost of goods and services purchased by hospitals nationwide).⁵

Eligibility for hospice services requires that the beneficiary's physician and the hospice medical director (or other physician affiliated with the hospice) certify that the individual's prognosis is for a life expectancy of 6 months or less, if the terminal illness runs its normal course. Beneficiaries who elect hospice must waive all other Medicare coverage of care related to their terminal illness, although they retain coverage for services unrelated to their terminal illness. A beneficiary can cancel his or her election of hospice benefits at any time and return to regular Medicare, and beneficiaries are free to reselect hospice coverage at a later date. While there are currently no limits on the number of days an individual can receive hospice care, a beneficiary's prognosis must be reaffirmed at 90 days, at 180 days, and every 60 days thereafter.⁶

The hospice eligibility requirement that a beneficiary be certified as having a prognosis of 6 months or less has been an ongoing concern expressed by advocates and providers. The requirement has been challenged as difficult to implement and a deterrent to hospice referrals, especially for beneficiaries with noncancer diagnoses. Research suggests that it can be difficult for physicians to accurately predict whether a patient is likely to die within 6 months.⁷ It is particularly difficult to estimate life expectancy for persons with noncancer diagnoses because the course of their disease

⁵The daily base payment rates for fiscal year 2000 are \$98.96 for routine home care, \$577.59 for continuous home care, \$102.37 for inpatient respite care, and \$440.22 for inpatient hospital care. These base rates are adjusted by the hospital wage index to reflect differences in wage levels in different areas of the country.

⁶Before 1990, Medicare payments to hospices were limited to a 210-day lifetime maximum per patient. From 1990 to 1997, coverage was limited to a lifetime maximum of four benefit periods but an unlimited number of days.

⁷A recent study found that physicians are inaccurate in their predictions of how long their terminally ill patients have to live. See N. Christakis and E. Lamont, "Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients: Prospective Cohort Study," *British Medical Journal*, Vol. 320 (Feb. 19, 2000), pp. 469-73.

is likely to be erratic.⁸ For example, patients with heart disease are more likely to die suddenly than persons with cancer, who commonly have a period of steady decline before death. Similarly, very elderly people in frail health or with certain chronic illnesses may experience long periods of declining health punctuated by several medical crises—any one of which can be fatal. In such cases, physicians may find it difficult to justify a hospice referral for beneficiaries who appear to be relatively stable, and, as a result, the physicians may delay initiation of hospice services until a medical crisis occurs shortly before death.

The Number of Beneficiaries Using Hospice Has Grown as Average Days Used Have Declined

From 1992 to 1998, the number of Medicare beneficiaries enrolling in hospice more than doubled, with growth in all population subgroups and in all states. Growth was particularly rapid among beneficiaries with diagnoses other than cancer. At the same time, many beneficiaries had shorter stays. On average, the days of hospice service used per beneficiary declined by about one-fifth during the 7-year period and beneficiaries with diagnoses other than cancer experienced the sharpest reductions.

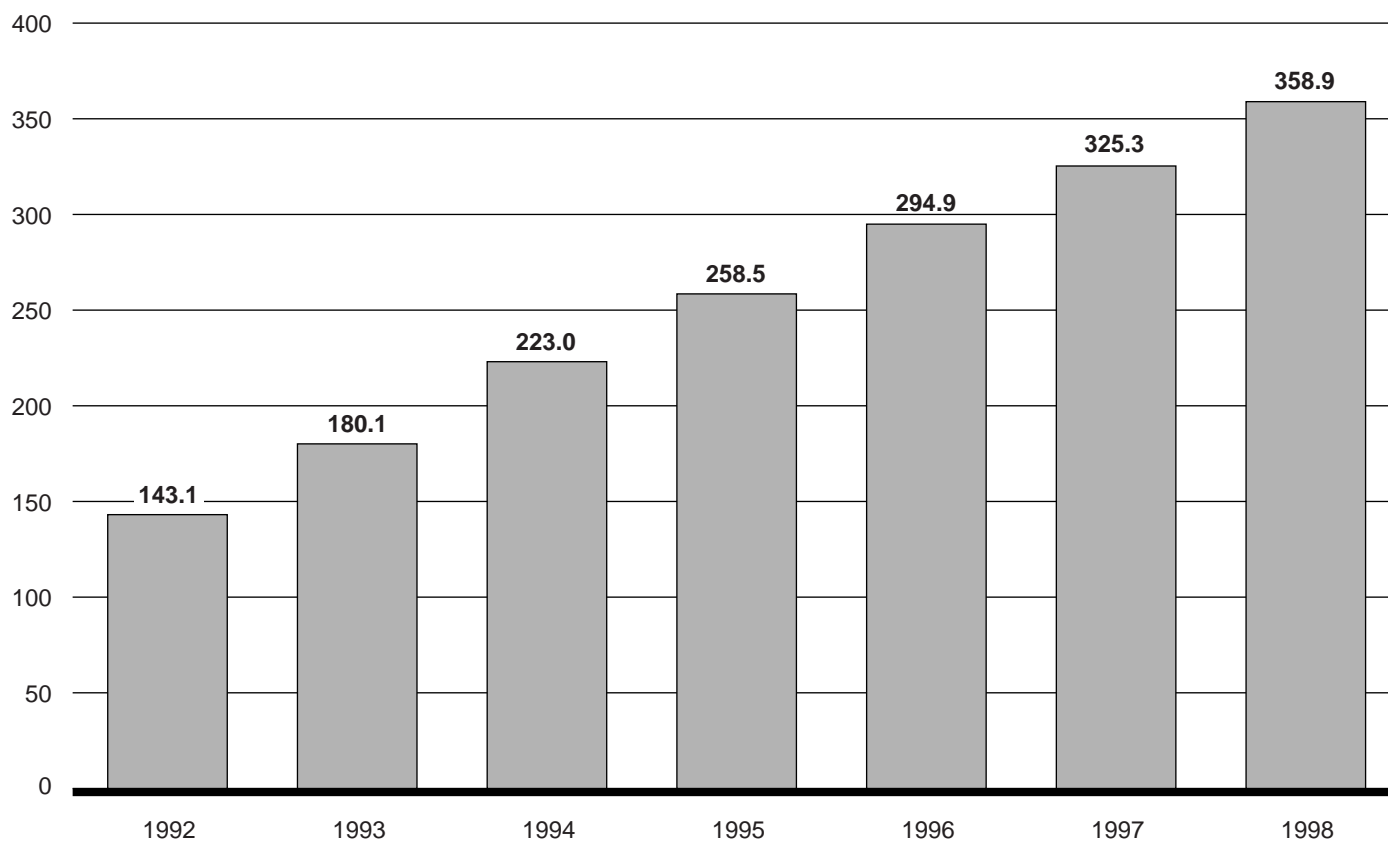
The Number of Medicare Hospice Users More Than Doubled in 7 Years

Our analysis of Medicare claims data indicates substantial growth in hospice use. The number of beneficiaries electing hospice care increased 2 ½ times from 1992 to 1998, from about 143,000 to nearly 360,000 persons annually. (See fig. 1.) Across most demographic groups, the use of hospice services has grown at a relatively consistent rate. Thus, hospice users today are similar to users in 1992; the distribution of enrollees by race has not changed (89 percent are white), and the proportion of enrollees who are women has climbed only slightly (from 50 to 54 percent). However, the use of hospice services grew more rapidly among beneficiaries aged 80 and older than it did among younger beneficiaries. This age group now makes up 47 percent of Medicare hospice enrollees, up from 35 percent in 1992.

⁸Researchers have found that for seriously ill hospitalized patients with advanced chronic obstructive pulmonary disease, congestive heart failure, or end-stage liver disease, it was not possible to accurately identify in advance those who would die within 6 months. For example, the most inclusive criteria excluded 58 percent of patients who died within 6 months of discharge, while 70 percent of patients identified as likely to die within 6 months survived longer. In contrast, the most restrictive criteria eliminated 99 percent of patients who died within 6 months but 53 percent of patients identified as likely to die within 6 months survived longer. See E. Fox and others, "Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients With Advanced Lung, Heart, or Liver Disease," *Journal of the American Medical Association*, Vol. 282, No. 17 (Nov. 4, 1999), pp. 1638-45.

Figure 1: Number of Medicare Hospice Benefit Users, 1992-98

Number in Thousands



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Overall, 19 percent of Medicare beneficiaries who died in 1998 received hospice services, compared with 8 percent in 1992.⁹ However, this measure understates the proportion of Medicare beneficiaries who choose hospice care among those for whom the benefit was intended. According to a former president of the National Hospice Organization, “when the number of deaths nationwide is adjusted to reflect only those that are likely to be appropriate for hospice care, the percentage of dying patients cared for in hospice care is probably about 40 percent.”¹⁰

Some groups of beneficiaries are more likely to choose hospice services than others. For example, 20 percent of white Medicare beneficiaries who died in 1998 elected hospice services, compared with 15 percent of black beneficiaries who died that year. Similarly, the use of hospice services is more common among beneficiaries who are enrolled in Medicare health maintenance organizations (HMO) at the end of life than among those in fee-for-service plans. Of the beneficiaries who died in 1998, 27 percent of those enrolled in an HMO elected hospice, compared with 18 percent of fee-for-service beneficiaries.¹¹ (See app. II for detailed information about hospice use rates among decedents.)

In addition, the proportion of Medicare decedents who used the hospice benefit varies widely by state. For example, in 1998, the number of hospice users as a share of Medicare decedents was more than four times higher in Arizona than in Maine. Table 1 shows states with the highest and lowest rates of hospice use in 1998.

⁹A recent study found that about 18 percent of Medicare beneficiaries who died in 1996 used hospice services. See Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, *Medicare's Hospice Benefit: Use and Expenditures, 1996 Cohort* (Mar. 2000).

¹⁰John J. Mahoney, “The Medicare Hospice Benefit—15 years of Success,” *Journal of Palliative Medicine*, Vol. 1, No. 2 (1998), pp. 139-46.

¹¹We classified Medicare beneficiaries as enrolled in an HMO or fee-for-service care at the end of life on the basis of their status in the month they died. When an HMO enrollee elects hospice, the monthly HMO payment is reduced, and the HMO then bills Medicare on a fee-for-service basis for any covered medical services unrelated to the terminal illness.

Table 1: Medicare Hospice Use Rates in Selected States and the District of Columbia, 1998

State	Hospice users as a percent of Medicare decedents
U.S. total	19%
Highest use	
Arizona	36
Colorado	30
Florida	29
Oregon	26
New Mexico	25
Nevada	24
Lowest use	
Alaska	6
Maine	8
South Dakota	11
Tennessee	11
Wyoming	11
Washington, D.C.	12

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and Medicare decedent data from the denominator file, an abbreviated version of HCFA's Medicare enrollment database.

The Growth in Hospice Use Is Strongest Among Beneficiaries With Noncancer Diagnoses

Although people who die from cancer are more likely to choose hospice services than are those who die from other conditions, the use of hospice services by beneficiaries with noncancer diagnoses has increased rapidly. From 1992 to 1998, hospice enrollment by beneficiaries with cancer increased 91 percent, while enrollment by beneficiaries with all other conditions increased 338 percent. The most dramatic growth in use was among individuals with other terminal conditions, such as heart disease, lung disease, stroke, or Alzheimer's disease. About 43 percent of beneficiaries who elected hospice in 1998 had noncancer diagnoses, compared with about 24 percent in 1992. Table 2 shows the distribution of new hospice enrollees by primary diagnosis.

Table 2: New Hospice Enrollees by Primary Diagnosis, 1992 and 1998

Primary diagnosis ^a	1992		1998	
	Number	Percent	Number	Percent
All cancer	108,232	75.6	206,190	57.4
Lung	29,966	20.9	57,841	16.1
Prostate	10,052	7.0	15,494	4.3
Breast	7,602	5.3	13,093	3.6
Colon	6,697	4.7	13,278	3.7
Pancreatic	6,359	4.4	12,116	3.4
Other	47,556	33.2	94,368	26.3
All noncancer	34,878	24.4	152,759	42.6
Congestive heart failure	6,141	4.3	24,248	6.8
Chronic obstructive pulmonary disease	4,112	2.9	15,765	4.4
Stroke	2,140	1.5	13,282	3.7
Alzheimer's disease	1,591	1.1	11,836	3.3
"Ill-defined conditions"	888	0.6	7,599	2.1
Other	20,006	14.0	80,029	22.3
Total	143,110	100.0	358,949	100.0

^aPatients entering hospice may have more than one medical condition or diagnosis. Data include only the first, or principal, diagnosis listed for each patient.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

For many of the leading causes of death, the proportion of elderly decedents who use the hospice benefit has increased. In 1997, about half of the people aged 65 and older who died from cancer had used hospice services, compared with about one-fourth in 1992.¹² This pattern generally held for breast cancer, lung cancer, and prostate cancer. However, the use of hospice services is even more common among persons with other types of cancer; roughly 75 percent of people age 65 and older who died from brain or liver cancer in 1997 used hospice services before death. The proportion of elderly decedents who used hospice services also increased among beneficiaries who died from other causes. Table 3 shows the change in hospice use rates from 1992 to 1997 for common hospice diagnoses.

¹²A recent study found that 51 percent of all 1998 Medicare cancer decedents used hospice care. See Medicare Payment Advisory Commission, *Medicare Beneficiaries Costs and Use of Care in the Last Year of Life* (May 2000).

Table 3: Hospice Use Rates for Selected Diagnoses, 1992 and 1997

Primary diagnosis	Hospice users as a percent of decedents aged 65 and older	
	1992	1997
Cancer	26%	47%
Breast	26	48
Colon	16	31
Lung	27	47
Pancreatic	30	53
Prostate	29	50
Noncancer^a	2	9

^aThe denominator used for calculating noncancer use rates includes people who died unexpectedly (for example, from a first heart attack or injuries sustained during an automobile accident) and thus are not candidates for hospice care.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and Centers for Disease Control and Prevention (CDC) mortality data from the WONDER/PC Data File. CDC's "Compressed Mortality" provides data through 1997 only.

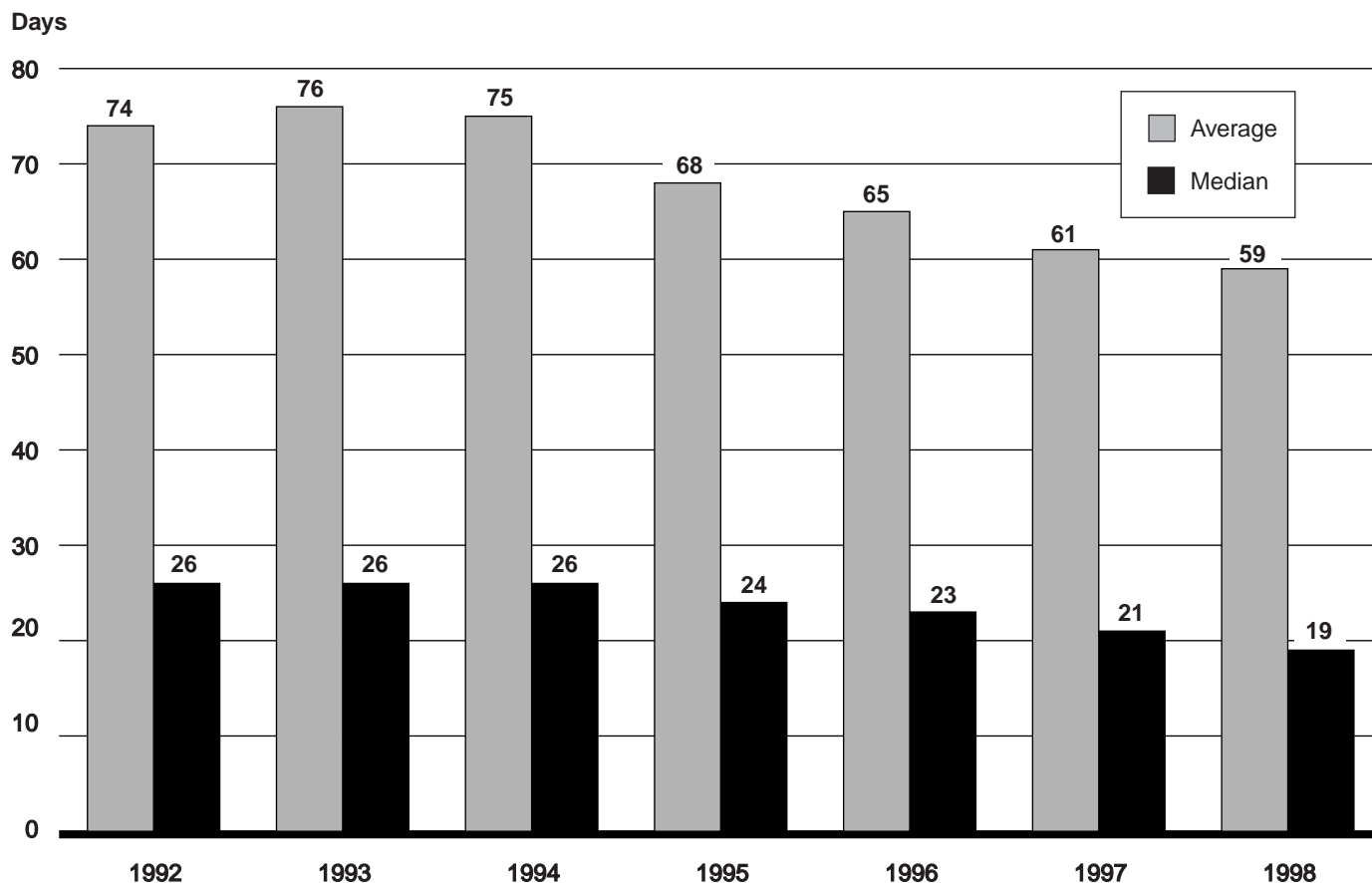
Beneficiaries Use Fewer Days of Hospice Care on Average

Although more Medicare beneficiaries are receiving hospice services, on average, they are receiving fewer days of care than did beneficiaries in the past.¹³ From 1992 to 1998, average length of stay declined 20 percent (from 74 to 59 days), while median length of stay declined 27 percent (from 26 to 19 days).¹⁴ (See fig. 2.)

¹³Not all beneficiaries who elect the hospice benefit die while in hospice care. Each year, between 10 and 14 percent of beneficiaries using hospice deselected the benefit. Slightly more than half of these beneficiaries die within 30 days of the time they stop receiving hospice services. Beneficiaries who received hospice services for longer than 6 months were twice as likely as those enrolled for less than 6 months (25 percent versus 12 percent) to leave hospice care alive. Similarly, beneficiaries with noncancer diagnoses were more likely than those with cancer to disenroll from a hospice program, although the difference was not as great—about 15 and 11 percent, respectively.

¹⁴The small proportion of beneficiaries with very long periods of enrollment skews the average length of hospice service. Annually, more than 80 percent of new hospice entrants complete their hospice use in the year in which they enroll, and 97 percent complete their hospice use by the end of the year following their initial enrollment. However, some of the remaining beneficiaries receive services for many more years. Because records of hospice use are not complete for beneficiaries who entered hospice during the later years of our study period, we adjusted the claimed days of hospice service for 1996 to 1998 to better account for beneficiaries with very long stays. See app. I for more information on our methodology.

Figure 2: Decline in Average and Median Hospice Lengths of Service, 1992-98



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

The overall decline in average length of service appears to have been driven by both (1) a reduction in the proportion of beneficiaries with very long hospice stays and (2) an increase in the share of users with very short stays.¹⁵ (See table 4.) From 1992 to 1998, the share of hospice enrollees with more than 6 months of service use declined from 9.3 to 7.3 percent. Over the same period, the proportion of beneficiaries who used hospice for

¹⁵The distribution of patients between cancer and noncancer diagnoses is the same for very long (more than 6 months) and very short (1 week or less) periods of hospice use, 47 percent and 53 percent, respectively.

a very brief period before death rose sharply. In 1998, 28 percent of all beneficiaries using hospice care did so for 1 week or less.

Table 4: Hospice Benefit Use by Weekly Intervals, 1992 and 1998

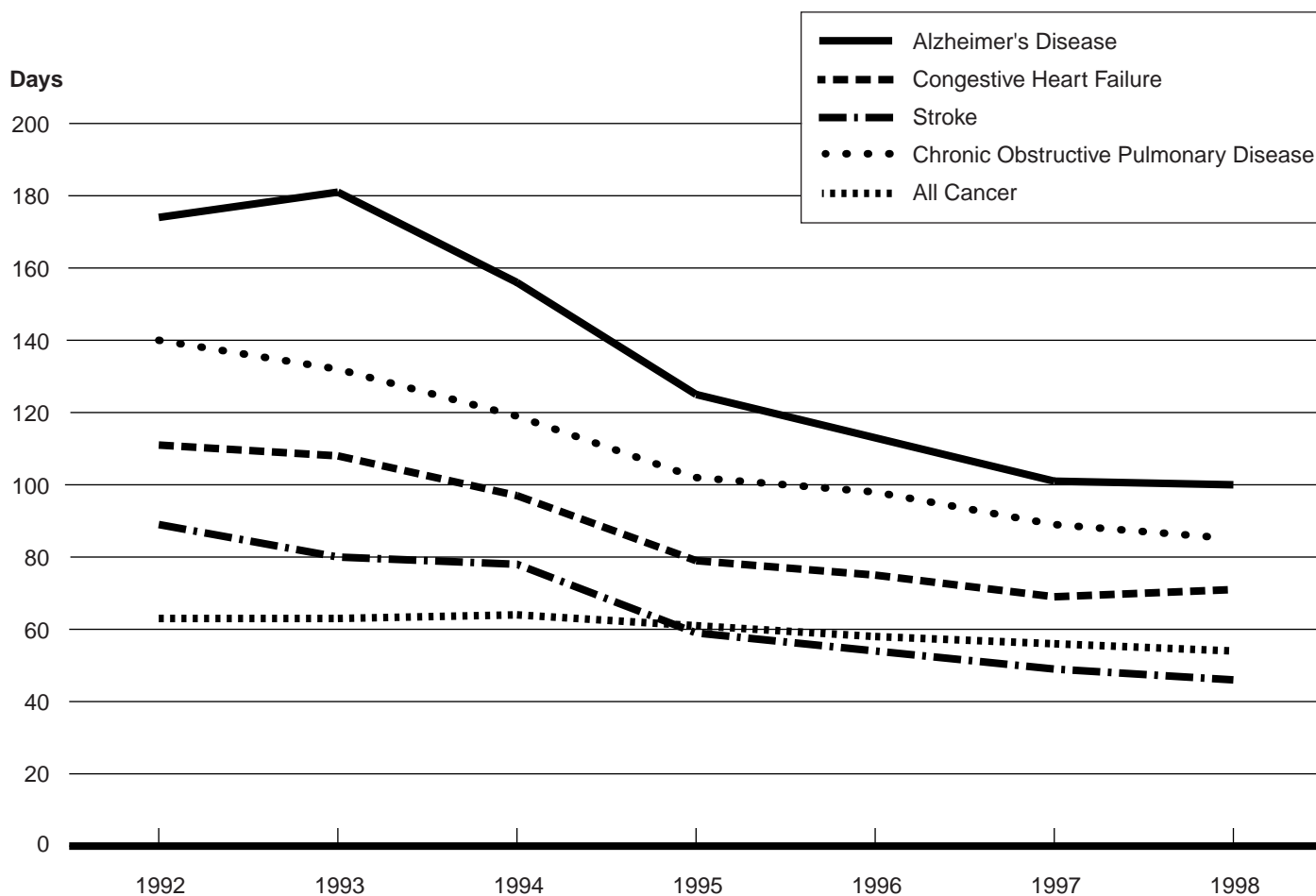
Weeks of hospice care used	Total hospice users		Total hospice days used ^a	
	1992	1998	1992	1998
1 or less	20.9%	28.0%	1.2%	1.8%
2	14.5	15.2	2.1	2.7
3	9.8	9.1	2.4	2.7
4	7.2	6.4	2.4	2.7
5 to 8	17.2	14.6	9.4	10.0
9 to 12	8.6	7.7	8.0	9.0
13 to 16	5.6	5.3	7.3	8.7
17 to 26	7.0	6.4	13.6	15.6
More than 26	9.3	7.3	53.6	46.8

^aIncludes all days of hospice care each beneficiary used.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

The decline in the average number of hospice days used has been especially dramatic among beneficiaries with a primary diagnosis other than cancer. While these beneficiaries historically had many more days of care than cancer patients, the average number of days used declined 38 percent between 1992 and 1998. In comparison, average days used by beneficiaries diagnosed with cancer declined by 14 percent. As a result, differences in length of stay across diagnosis categories have narrowed considerably. In 1998, cancer patients used an average of 54 days while noncancer patients used 68 days, on average. Figure 3 compares the decline in the average number of hospice days used for beneficiaries with cancer and noncancer diagnoses.

Figure 3: Average Days of Use for Cancer and Noncancer Patients, 1992-98



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

At the state level, average length of service declined in 42 of 50 states and the District of Columbia from 1992 to 1998, and variation in average length of service across states lessened considerably. (State data appear in app. II.) In 1992, 27 states had average service periods within 10 days of the 74-day national average. By 1998, 36 states had average service periods within 10 days of the 59-day average.

Multiple Factors Influence the Use of the Hospice Benefit

Several factors influence beneficiary choice about whether and when to use hospice care. These include physician preferences and referral practices, individual patient choice and circumstances, and general awareness of the benefit among the public and professional communities. In addition, recent federal oversight of compliance with patient eligibility requirements may have affected certain beneficiaries' use of the hospice benefit.

Physician Practices, Patient Preferences, and Public Awareness Affect Hospice Use

Although Medicare beneficiaries and their families make the decision about whether and when to initiate hospice services, physician willingness to discuss options for end-of-life care is important to the decision. However, the research literature indicates that not all physicians are comfortable discussing end-of-life care, and some may hesitate to suggest hospice care for other reasons, such as concerns about relinquishing control of their patients' care. Even when the issue has been broached, some beneficiaries choose instead to continue curative or life-extending treatments. Patient advocacy groups, several medical societies, and others have called for greater public and professional awareness of options for care of the dying, which has led to a range of educational efforts designed to increase awareness of hospice and its benefits.

Physician Preferences and Practices

The research literature indicates that because patients and their families rely heavily on physician recommendations for treatment, including recommendations for end-of-life care, physicians are an influential factor in patient entry into hospice. Physicians initiate most referrals to hospice, and they may continue to care for their patients after enrollment as part of the hospice team. However, research has shown that many physicians are poorly trained in the care of the dying and are often uncomfortable discussing options for end-of-life care or the cessation of curative treatment.¹⁶ A recent review of 50 top-selling textbooks from several medical specialties found that most provided inadequate information on end-of-life issues, with oncology textbooks among those particularly likely

¹⁶A recent study found that physicians commonly make errors in their predictions of life expectancy, most often predicting that patients have longer to live than they really do. The authors concluded that this may contribute to late referral to hospice care and noted that physicians are uncomfortable making predictions of expected life span, in part because neither medical training nor published literature treats prognostication as important. See Christakis and Lamont, pp. 469-73.

Patient Choice and Circumstances

to provide no information about key aspects of end-of-life care.¹⁷ Physician referral to hospice may be limited by other factors, as well. For example, experts in the area of palliative care, as well as the research literature, suggest that some physicians may not be aware that they can continue to provide services after a beneficiary has entered hospice and may delay referral out of concern about losing control of the patient's care.¹⁸

The use of hospice services by Medicare beneficiaries requires not just awareness of the benefit and a physician's certification of prognosis but also acceptance that death is the outcome of their illness and the choice by beneficiaries to give up a portion of their standard Medicare benefits in order to receive hospice care. Once enrolled, no other services related to a patient's terminal condition are covered under Medicare. HCFA officials and others also noted that improvements in cancer care and the addition of new treatment options may be prompting some beneficiaries to pursue new curative options until very shortly before death, thus contributing to the trend of shorter hospice stays. Other beneficiaries may favor continuing aggressive, life-extending treatments up until the time of death and not enter hospice at all. According to HCFA officials, it may be that some terminal patients do not want hospice care, and that should be their right.

Research suggests that beneficiaries who do not consider hospice care may be unwilling to confront the terminal nature of their illness, may not know that the alternative exists, or may misunderstand the services available through hospice care. The Institute of Medicine (IOM) noted that patients are influenced by the general unwillingness to accept limits of all types, including those of aging and death.¹⁹ A Gallup poll in 1996 found that although a majority of people expressed interest in hospice care, most also said that they would still seek curative care.

In some cases, a beneficiary's circumstances may complicate hospice enrollment. Hospice is designed to allow the beneficiary to remain at home

¹⁷M. W. Rabow and others, "End-of-Life Care Content in 50 Textbooks From Multiple Specialties," *Journal of the American Medical Association*, Vol. 283, No. 6 (Feb. 9, 2000), pp. 771-78.

¹⁸Visits by the patient's attending physician are not covered by the hospice payment and continue to be paid by Medicare part B coverage.

¹⁹IOM, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997).

during his or her last few weeks of life, where family and friends are expected to deliver most of the routine day-to-day care. Hospice staff offer more specialized care and respite care to give family members a break when they need one. Thus, some hospice programs limit participation to beneficiaries who have a caregiver at home. Others permit such beneficiaries to enter the hospice program with the understanding that transfer to a nursing home will be required when their needs for assistance reach a certain stage.²⁰

Public and Professional Awareness

Public and professional awareness also influences the use of the Medicare hospice benefit. The need for greater public and professional understanding of options for end-of-life care, including hospice, has been highlighted in several recent congressional hearings and in other public forums.²¹ In addition, several medical societies, patient advocacy groups, and the hospice industry have undertaken a variety of efforts to educate their members and the public about end-of-life care options. For example, the American Medical Association and the Robert Wood Johnson Foundation are developing a core curriculum for educating physicians in end-of-life care. The Medicare Rights Center, a consumer advocacy and education organization, is conducting a national campaign to increase awareness of the Medicare hospice benefit among health professionals. Also, the National Hospice and Palliative Care Organization has published a variety of materials on public education and outreach strategies for its members.

Federal Oversight of Eligibility May Have Had an Effect on Beneficiary Use of Services

Industry and patient advocacy groups contend that recent federal scrutiny of provider compliance with program eligibility requirements has inappropriately limited access to hospice for certain beneficiaries. While federal scrutiny may have contributed somewhat to the existing trend toward shorter hospice enrollment periods, continued growth in the

²⁰For a detailed discussion of hospice use by nursing home residents, see Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, *Use of Medicare's Hospice Benefit by Nursing Facility Residents* (Mar. 2000).

²¹U.S. Senate Special Committee on Aging, "The End of Life: Improving Care, Easing Pain and Helping Families" (July 17, 2000); U.S. House of Representatives, Committee on Government Reform, "Improving Care at the End of Life With Complementary Medicine" (Oct. 19, 1999); U.S. Senate, Committee on Health, Education, Labor, and Pensions, "Pain Management and Improving End-of-Life Care" (Oct. 13, 1999).

number of beneficiaries receiving hospice services makes it difficult to identify the extent to which federal scrutiny may have deterred access. Furthermore, the use of hospice services has increased most rapidly among beneficiaries with diagnoses other than cancer—those for whom arriving at a 6-month prognosis may be more difficult.

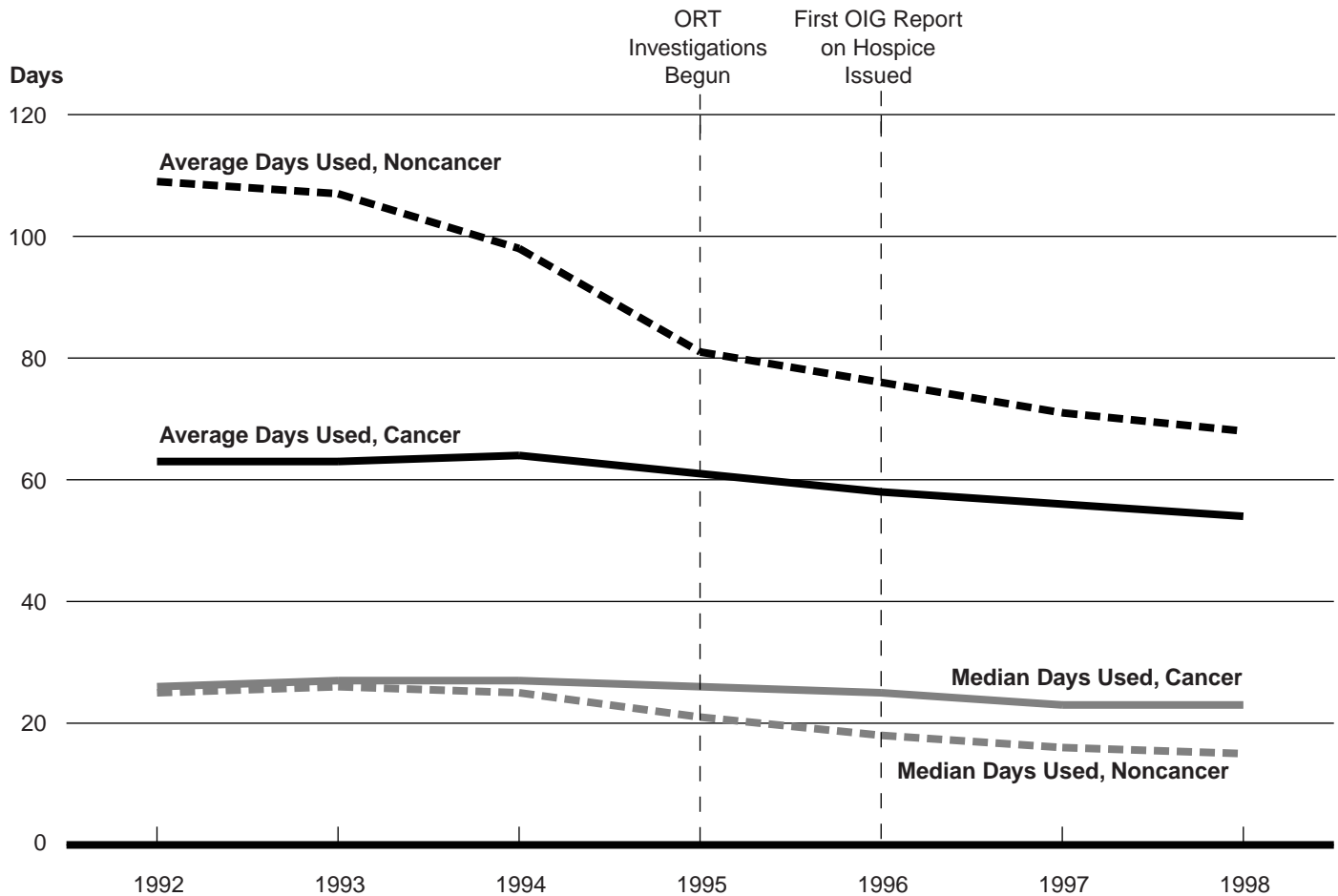
In 1995 and 1996, the Department of Health and Human Services' (HHS) Office of the Inspector General (OIG) investigated the eligibility status of Medicare beneficiaries receiving hospice services as part of a larger investigation of fraud and abuse in Medicare. Specifically, OIG reviewed the admission decisions made for hospice patients with very long stays at 12 hospices in four states; it found that many of these patients did not meet eligibility criteria upon admission to hospice. OIG followed this effort with other reviews of beneficiary eligibility, encompassing a larger sample of hospices, and found that the vast majority of Medicare beneficiaries receiving hospice services were eligible for such services.²²

Patient advocacy groups and the hospice industry assert that this federal scrutiny of compliance with the 6-month eligibility rule has had a chilling effect on entry into hospice for noncancer beneficiaries, for whom it may be more difficult to establish a 6-month prognosis with confidence. They contend that hospice providers are more cautious about admitting beneficiaries with noncancer diagnoses as a result, leading to delays in hospice entry for persons wishing to use the benefit. Although the percentage increase in beneficiaries electing hospice slowed somewhat from 1995 through 1998 compared with the prior period, it is difficult to know what portion of this slower growth is attributable to the effect of federal scrutiny and what portion is attributable to other factors, such as the larger base of beneficiaries already using hospice.

The OIG scrutiny of beneficiary eligibility may have contributed to later hospice entry for some beneficiaries, to the extent that hospice providers responded to the oversight with greater caution about beneficiary eligibility. However, the trend toward fewer days of hospice use began

²²OIG reported that 81 percent of beneficiaries in its sample were eligible for hospice care, while 7 percent were ineligible. OIG was not able to determine eligibility for 12 percent of beneficiaries. A larger proportion of hospice beneficiaries in nursing homes were found ineligible. See HHS, *Medicare Hospice Beneficiaries: Services and Eligibility*, pub. OEL-04-93-00270 (Apr. 1998). For a discussion of the OIG report, see HHS, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, *Important Questions for Hospice in the Next Century* (Mar. 2000).

before the period of federal scrutiny. As shown in figure 4, the average length of service for both cancer and noncancer hospice users peaked by 1994, before scrutiny of the hospice benefit increased. Furthermore, physician groups we spoke with did not cite caution among hospice providers about beneficiary eligibility as a primary barrier to the initiation of hospice services for their patients. According to the American Society of Clinical Oncology, barriers to timely hospice care for cancer patients include the attitudes of physicians and patients toward death and reluctance to talk about death until the very end of life.

Figure 4: Decline in Average and Median Days of Hospice Care for Cancer and Noncancer Patients, 1992-98

Note: Operation Restore Trust (ORT) was a joint initiative among HCFA, OIG, and the Administration on Aging designed to identify vulnerabilities in the Medicare program.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

While the OIG reviews were under way, the National Hospice Organization developed guidelines to assist physicians and hospices in determining a 6-month prognosis for patients with selected noncancer diagnoses. These included amyotrophic lateral sclerosis (ALS), dementia, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), heart disease, pulmonary disease, liver disease, stroke and coma, and kidney disease. In order to enhance accuracy and uniformity in the claims review process, HCFA distributed these guidelines to the intermediaries that process hospice claims for Medicare to use in assessing compliance with benefit requirements.²³ The intermediaries have since adopted these guidelines as formal local medical review policies.²⁴

Concerns have been raised that using these guidelines as a standardized basis for determining Medicare hospice eligibility limits access to hospice, particularly for patients with noncancer diagnoses. Industry representatives assert that the guidelines require further development to improve prognostic confidence and accuracy before they would be appropriate as formal medical review policies.

However, intermediaries point out that while medical review policies specify clinical criteria for establishing a patient's 6-month prognosis, they allow for variation in individual cases. For example, one intermediary's medical review policy for heart disease notes that "some patients may not meet the criteria, yet still be appropriate for hospice care, because of other comorbidities or rapid decline." According to Medicare program guidance to all hospices, the fact that a hospice patient lives beyond 6 months does not, by itself, constitute grounds for a determination that the patient was never eligible for hospice care or that Medicare does not cover services provided to the patient. Typically, if a question is raised as to whether a patient is terminally ill, the intermediary asks the hospice to furnish

²³Intermediaries contract with HCFA for paying providers for services provided to Medicare beneficiaries. They review all hospice claims for accuracy and completeness before payment and review a sample of claims to confirm that beneficiaries were eligible for the hospice services provided.

²⁴Local medical review policies are medical criteria, specific to a service or diagnosis, that may assist in determining compliance with program eligibility requirements. More recently, some intermediaries have adopted policies for adult failure to thrive, and policies for specific cancers are also under development.

information necessary to affirm the patient's prognosis. The rates of medical reviews of claims began increasing in 1995, at HCFA's direction.²⁵ Four of the five intermediaries reported that, by 1999, review rates ranged from 0.8 to 4.2 percent of all hospice claims processed.²⁶

Nearly all the hospice providers we spoke with said they consult their intermediaries' medical review policies as part of the admission screening process. Asked about the effect of the review policies on admitting patients, some hospices reported that using these criteria has decreased the likelihood of admitting patients with noncancer conditions, while others said that the review criteria have increased the likelihood of admissions or have had no effect at all.

Hospice Care Is More Widely Available, but Providers Report Cost Concerns

Sustained growth in the number of hospice providers participating in Medicare and in their distribution throughout the country suggests that hospice services are now more widely available to program beneficiaries. While all sectors of the hospice industry have grown over the past decade, recent growth has been particularly strong in the for-profit sector and among large hospice programs. At the same time, hospice industry officials report growing cost pressures from shorter patient stays and changes in the practice of palliative care. Because data on provider costs are not available, however, it is not clear how these cost factors affect providers and beneficiaries.

The Number of Hospice Providers Continues to Grow

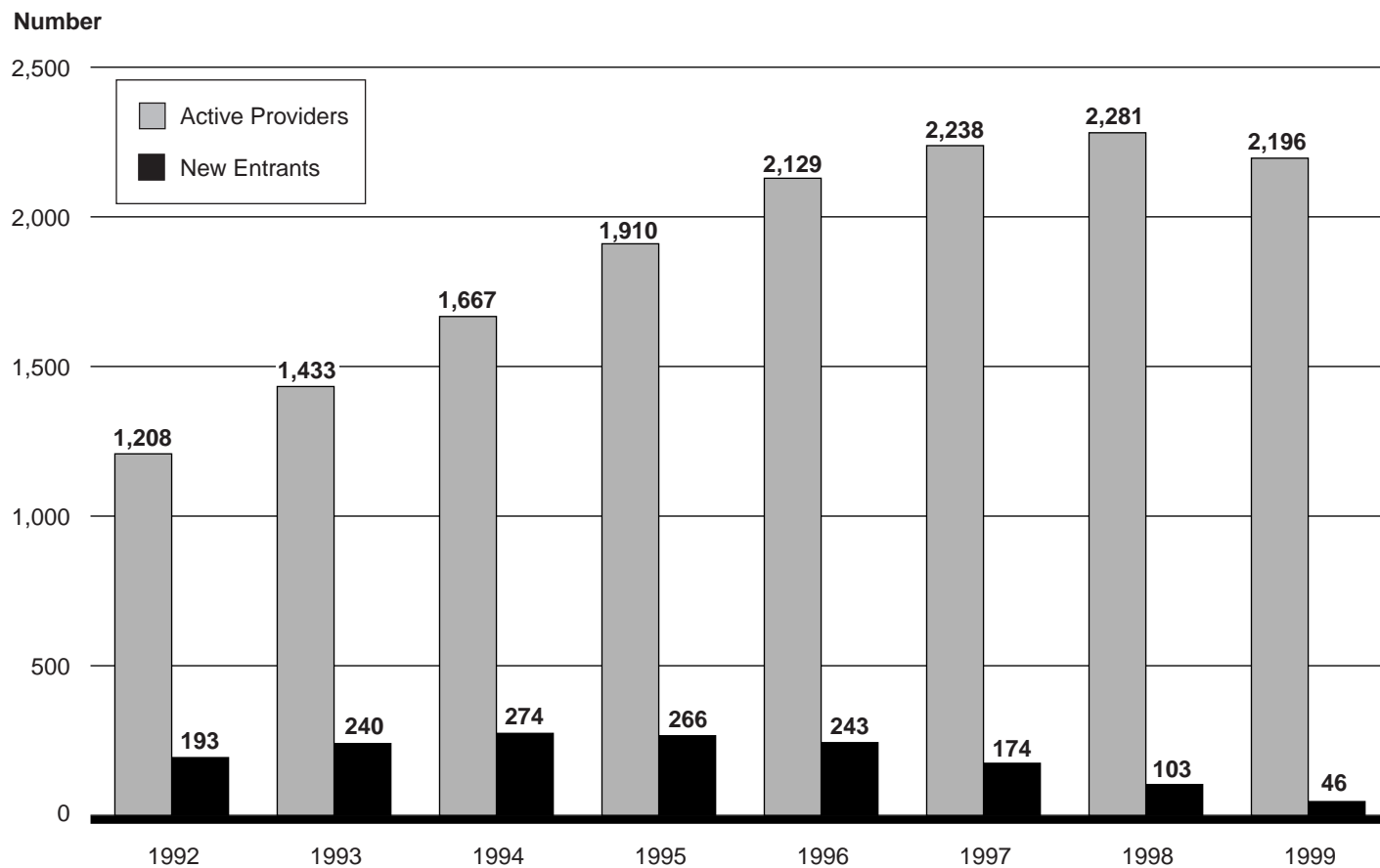
Although the overall rate of growth has slowed somewhat in the past few years, new hospice providers continue to enter the Medicare program every year. As shown in figure 5, the number of Medicare-certified hospice providers nationwide grew by 82 percent from 1,208 in 1992 to 2,196 in

²⁵Claims are selected for medical review on the basis of a variety of factors, including beneficiary length of stay, beneficiary diagnosis, and provider use of hospice continuous home care or inpatient care. Before 1995, intermediaries reviewed a very small proportion of hospice claims.

²⁶One fiscal intermediary did not provide consistent data on rates of medical review.

1999.²⁷ Each year during the period, additional hospice programs became certified for Medicare, although the number of new entrants declined from 274 in 1994 to 46 in 1999, and the number of hospices leaving Medicare exceeded the number of new entrants in 1999. (Many of those leaving were based in home health agencies (HHA) that may have closed because of changes in HHA payments enacted in BBA.) The increased number reflects not only new hospices but also growing participation in Medicare. (See app. II for more detail on changes in hospice supply and distribution.) In 1989, we estimated that only about 35 percent of the approximately 1,700 hospice providers nationwide participated in Medicare. By 1998, the National Hospice and Palliative Care Organization estimated that 80 percent of hospices were certified to serve Medicare patients.

²⁷The total number of Medicare hospice providers peaked at 2,281 in 1998. In 1998 and 1999, the 195 hospice program closures exceeded the 149 new program entrants for the first time. A disproportionate number of hospice closures were among those based in home health agencies (HHA). Although HHA hospices represent approximately one-third of all hospices, they accounted for 43 percent of those that closed over the 2-year period. As we reported in *Medicare Home Health Agencies: Closures Continue, With Little Evidence Beneficiary Access Is Impaired* (GAO/HEHS-99-120, May 26, 1999), 14 percent of HHAs closed between October 1997 and January 1999.

Figure 5: Growth in the Number of Medicare Hospices and New Entrants, 1992-99

Source: GAO analysis of annual Medicare Provider of Service Files.

Over this period, all types of hospice providers grew, in rural and urban areas and in almost every state. From 1992 to 1999, the rate of growth was greatest among for-profit providers and those in rural areas. Also, large providers accounted for an increasing share of the services delivered. (See table 5.) The number of for-profit providers increased nearly fourfold, and the number of large hospice programs (those serving 500 or more Medicare patients per year) more than tripled over the period.²⁸ In addition, the number of rural providers increased by 116 percent while the number of urban-based providers increased 64 percent. Even with high growth in these sectors of the industry, the majority of hospices are small programs (with fewer than 100 Medicare patients per year), organized as not-for-profit, and located in urban areas.

²⁸For-profit hospices provided about 30 percent of the hospice days beneficiaries used in 1998, up from 18 percent in 1992. Large hospices (those serving 500 or more patients in a year) provided 38 percent of hospice days in 1998 compared with 28 percent in 1992.

Table 5: Growth in Medicare Hospice Programs by Provider Characteristics, 1992 and 1999

Characteristic	Number of hospices		Percent change 1992-99
	1992	1999	
All hospices	1,208	2,196	82%
Affiliation			
Freestanding	466	877	88
Hospital-based	327	553	69
HHA-based	403	730	81
Control			
For-profit	151	593	293
Not-for-profit	957	1,365	43
Government	63	146	132
Other	36	75	108
Size^a			
Small	795	1,244	56
Medium	370	816	121
Large	43	136	216
Location^b			
Urban	823	1,350	64
Rural	384	829	116

Note: Detailed information was not available for all providers.

^aWe categorized hospices small if they served fewer than 100 Medicare beneficiaries during the year, medium if they served 100 to 499 patients per year, and large if they served 500 or more beneficiaries per year.

^bWe categorized a hospice urban if it was located within a metropolitan statistical area (MSA) and rural if it was located outside an MSA.

Source: GAO analysis of annual Medicare Provider of Service Files.

Even with certificate-of-need (CON) requirements that apply to hospice providers in 14 states, the number and size of Medicare hospice providers increased in almost every state from 1992 to 1998.²⁹ Among states with large Medicare enrollment and no CON requirements, the most dramatic growth was in Texas, where the supply of hospice providers relative to the

²⁹In 14 states, a hospice may be required to obtain a CON before becoming eligible to provide services. CON programs are run by state planning or regulatory agencies and are designed to limit the numbers of providers of a given type, based on established formulas or criteria for need.

size of the Medicare population nearly doubled. Among the CON states with large Medicare populations, providers increased the number of patients served, while growth in the number of providers was constrained. For example, in Florida and New York the number of hospices per million beneficiaries remained virtually unchanged; however, the number of beneficiaries each hospice served grew 66 and 105 percent, respectively. (See table 6.)

Table 6: Growth in Number and Size of Hospices in States With Large Medicare Populations, 1992 and 1998

State	1992		1998	
	Providers per million beneficiaries	Hospice users per provider	Providers per million beneficiaries	Hospice users per provider
U.S. total	35	118	60	157
California	25	152	48	189
Florida (CON)	15	579	14	961
Illinois	30	155	54	183
Michigan	39	133	54	219
New Jersey	29	141	37	210
New York (CON)	19	158	20	325
North Carolina (CON)	62	80	63	131
Ohio	36	129	53	212
Pennsylvania	30	85	56	155
Texas	35	153	69	162

Note: These 10 states combined accounted for 54 percent of all Medicare enrollees in 1998.

Source: GAO analysis of annual Medicare Provider of Service Files.

Industry Reports Increased Cost Pressures but the Effect on Providers Is Uncertain

Even as the hospice industry has grown, changes in the use of the hospice benefit and the delivery of hospice care have raised concerns about cost among providers. Most significantly, declines in the average enrollment period have resulted in fewer days over which providers can spread the fixed costs associated with a patient's stay in hospice. In addition, providers report that changes in the practice of palliative medicine have made the use of higher-cost services more common. However, because reliable data on provider costs are not available, it is not clear how these factors may effect hospices' financial status or their ability to serve Medicare beneficiaries.

Industry representatives point out several areas of change that they contend are adversely affecting the financial condition of providers. Specifically,

- Under Medicare's per diem payment system for hospice care, hospices have traditionally offset the higher-cost days that occur at admission and during the period immediately preceding death with lower-cost days of less intensive care.³⁰ For example, costs for admitting and assessing a new patient, establishing a care plan, and delivering medical equipment are incurred during the first few days of enrollment and do not vary with the patient's period of service. As enrollment periods have declined, hospices have had fewer days over which they can spread the higher costs associated with the start and end of a patient's stay.
- As more patients enter hospice later in the course of their terminal illness, they enter with higher levels of impairment and in need of more intensive services. In addition, the shift in the mix of patients by diagnosis may have increased the average service needs for the overall hospice population. According to the most recent National Home and Hospice Care Survey, hospice patients with noncancer diagnoses are somewhat more likely than those with cancer to be functionally impaired and thus may require more services on a regular basis from hospice agencies.³¹
- Physicians and patients are calling on hospice programs to provide a broader array of palliative services than in the past. Costly treatments such as chemotherapy and radiation—traditionally used for curative purposes—are increasingly used in the hospice setting to manage pain and other symptoms. Furthermore, some new palliative care treatment options, such as the transdermal administration of narcotic pain medication, may offer better symptom control for some patients but often at greater expense.

To the extent that hospice providers believe that Medicare payments do not adequately cover their costs, they may have an incentive to limit their acceptance of patients who need more intensive services or limit the types

³⁰Hospice representatives we interviewed reported that the hours of nursing, social work, and administrative time the typical patient requires are nearly twice as high during the first and last weeks of a patient's care as they are during the intervening weeks.

³¹National Center for Health Statistics, *The National Home and Hospice Care Survey: 1996*.

and amount of services they make available.³² Providers may also respond by choosing not to admit patients who are expected to be more expensive. However, hospice officials we interviewed reported being able to enroll most patients who were referred. With the exception of patients lacking sufficient informal caregiver support, the potential cost of care and payment rates were not generally cited as factors limiting the admission of eligible patients.

Data to assess how declining patient stays and changes in palliative care practices affect overall provider costs are not currently available. While certain more expensive services may be provided more frequently, the share of total costs that these services currently represent is unknown.³³ Furthermore, we do not know the extent to which providing more expensive medications or treatments to hospice patients may reduce the need for other services such as nursing visits. In response to BBA requirements, HCFA has begun collecting hospice cost data to use in evaluating the adequacy of current levels of Medicare reimbursement. Officials anticipate that audited hospice cost data will be available beginning in late 2001.

Conclusion

Trends in the use of the Medicare hospice benefit during the 1990s indicate that beneficiaries with all types of terminal illnesses are making use of hospice services in greater numbers every year. In particular, the types of patients selecting hospice have expanded broadly—from mostly beneficiaries with cancer to a nearly even split among those with cancer and those with other terminal conditions. In spite of these trends in use, and the widespread availability of hospice providers, patient advocates and the industry are concerned about the trend toward using fewer days of hospice care. Because many factors influence the use of hospice care, and potential demand is difficult to determine, the extent to which the Medicare hospice benefit may be underutilized is not clear.

³²IOM has expressed concern that Medicare's current system of paying a fixed amount per day may discourage the provision of care for some patients, such as the use of costly pain medications or equipment or the provision of late-night nursing visits or extensive counseling services. See IOM, *Approaching Death: Improving Care at the End of Life*.

³³Initial Medicare hospice rates were based on data from HCFA's 1980-82 hospice demonstration project, allocated over an average beneficiary enrollment period of 70 days. The rates took into consideration the kinds of services furnished, their cost, and the frequency of their provision at that time.

Agency Comments

We provided a draft of this report to HCFA for review. In its comments, HCFA discussed the importance of the hospice benefit to the Medicare program and efforts to ensure that beneficiaries, physicians, and hospice providers understand the benefits' coverage and eligibility criteria. Furthermore, HCFA stated that it does not believe the underutilization concerns of hospice advocates and the industry should be discounted. It noted that enrollment in hospice may not be an option for beneficiaries who lack family support at home or that it may be delayed for patients who wish to continue curative care treatments. HCFA's comments appear in appendix III. The agency made technical comments that we incorporated where appropriate.

As we agreed with your office, unless you publicly announce the report's contents earlier, we plan no further distribution of it until 30 days after the date of this letter. We will then send copies to the Honorable Donna Shalala, Secretary of HHS; the Honorable Min DeParle, Administrator of HCFA; and others who are interested. We will also make copies available to others on request.

If you or your staff have any questions, please call me at 202-512-7119 or Rosamond Katz, Assistant Director, at 202-512-7148. Other major contributors were Eric Anderson, Jenny Grover, Wayne Turowski, and Ann White.



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Associate Director, Health Financing and
Public Health Issues

Methodology for Developing Information on Medicare Hospice Use and Hospice Providers

Our study is an analysis of national hospice enrollment, use patterns, and industry developments from 1992 through 1998. We examined Medicare beneficiary claims data for hospice services to determine hospice use rates for different groups of beneficiaries. We also gathered descriptive information about the hospices that provided the services.

We used the Medicare Hospice Standard Analytic File of the Health Care Financing Administration (HCFA) to identify beneficiaries who enrolled in hospice during the study period and to determine their pattern of hospice use. To conduct an analysis of hospice enrollment by year, we assigned beneficiaries to the year of their first hospice claim. We excluded beneficiaries from our analysis if total payment for a beneficiary was less than \$75 or was \$1 million or more, if a beneficiary at the time of a first hospice claim was younger than 20 or older than 110, or if a beneficiary's residence was not in one of the 50 states or the District of Columbia.

Our analysis of beneficiary use includes information on

- age at the time of entry into hospice (younger than 65, 65 to 74, 75 to 84, 85 and older),
- gender,
- race and ethnicity (white, black, Hispanic, and other),
- state of residence,
- enrollment in managed care or fee-for-service Medicare (based on status in the month of death, from the HCFA denominator file), and
- primary diagnosis (three-digit International Classification of Disease code).

Analysis of the beneficiary claims data showed that 98 percent of beneficiaries had only one hospice provider, and 97 percent had only one diagnosis code. Therefore, we conducted all further analysis on the basis of the provider and diagnosis listed in the first hospice claim for each beneficiary. We calculated the period of enrollment by summing the number of days covered by each claim, even if they covered discontinuous periods of service, and excluded duplicate claims.¹ Because records of hospice use are not complete for beneficiaries who entered hospice during the later years of our study period, we adjusted the claimed days of hospice service for 1996 to 1998 to better account for beneficiaries with very long

¹Our analysis showed that 95 percent of all beneficiaries during the period of our analysis received hospice services during one continuous time period.

stays.² Our adjustment factor was calculated from 1992-95 data on the proportion of total beneficiary claim days accounted for within the first 2 calendar years of hospice use.

We also described hospice use rates among different groups of Medicare decedents. To calculate the rate of hospice use, we identified the number of Medicare decedents each calendar year who had used hospice before death. We used the HCFA Denominator File to identify all Medicare decedents belonging to each demographic group in our analysis.³ Because the HCFA Denominator File does not contain information about beneficiary diagnosis, we used Centers for Disease Control and Prevention (CDC) mortality data to determine the number of deaths among people aged 65 and older.⁴

We used annual Medicare Provider of Service Files to identify hospice characteristics. These files contain data on provider certification and status, such as facility and service characteristics, provider type, and location. We included hospices that received total Medicare payments of \$75 or more during our study period. The provider identification number from the first hospice claim for each beneficiary was matched with the Provider of Service file data available for that provider. We characterized providers by

- type of control (profit, not-for-profit, or government),
- affiliation (freestanding, hospital-based, home health agency, and skilled nursing facility),
- state,
- urban or rural location, and
- number of Medicare beneficiaries receiving services from each hospice each year (small defined as fewer than 100 beneficiaries, medium

²The small proportion of beneficiaries with very long periods of enrollment skews the average length of hospice service. Although 97 to 98 percent of all those electing hospice complete their hospice use by the end of the year following their initial enrollment, our data for 1992 and 1993 show that some of the remaining 2 to 3 percent of beneficiaries may receive services for as many as 6 or 7 years.

³The HCFA Denominator File includes information about all Medicare beneficiaries with entitlement (eligible for Medicare part A or part B) in a given year. We excluded decedents who were not eligible for Medicare part A benefits as well as those who lived outside the 50 states and the District of Columbia.

⁴Data collected from the dataset Compressed Mortality. This file provides mortality data through 1997 only.

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Methodology for Developing Information on
Medicare Hospice Use and Hospice Providers

defined as 100 to 499 beneficiaries, and large defined as 500 or more beneficiaries).

Patterns and Trends in Hospice Supply and Use

Table 7: Number of Hospice Providers by Control, Affiliation, Size, and Location, 1992-99

Category	1992	1993	1994	1995	1996	1997	1998	1999	Percent change 1992-99
Total providers	1,208	1,433	1,667	1,910	2,129	2,238	2,281	2,196	82%
New entrants	193	240	274	266	243	174	103	46	-76
Departures and closures	6	7	32	26	34	60	118	77	1,183
Control									
For-profit	151	220	303	410	531	599	623	593	293
Not-for-profit	957	1,088	1,201	1,313	1,384	1,418	1,425	1,365	43
Government	63	83	107	120	137	140	144	146	132
Other and unknown	37	42	56	67	77	81	89	92	149
Affiliation									
Freestanding	466	548	615	699	774	836	877	877	88
Hospital-based	327	371	420	476	526	557	570	553	69
HHA-based	403	502	615	713	804	814	802	730	81
Skilled nursing facility (SNF) based	11	11	14	19	20	22	21	19	73
Size^a									
Small	795	923	1,041	1,204	1,327	1,350	1,313	1,244	56
Medium	370	458	551	620	697	768	829	816	121
Large	43	52	75	86	105	120	139	136	216
Location^b									
Urban	823	954	1,073	1,231	1,357	1,421	1,423	1,350	64
Rural	384	478	591	676	767	808	847	829	116

Note: Detailed information was not available for all providers.

^aSmall = fewer than 100 patients a year. Medium = 100-499 patients a year. Large = 500 or more patients a year.

^bUrban = metropolitan statistical area. Rural = nonmetropolitan statistical area.

Source: GAO analysis of annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 8: Percentage of Hospice Providers by Control, Affiliation, Size, and Location, 1992-99

Category	1992	1993	1994	1995	1996	1997	1998	1999
Certified providers	1,208	1,433	1,667	1,910	2,129	2,238	2,281	2,196
Control								
For-profit	13%	15%	18%	21%	25%	27%	27%	27%
Not-for-profit	79	76	72	69	65	63	62	62
Government	5	6	6	6	6	6	6	7
Other and unknown	3	3	3	3	3	3	3	4
Affiliation								
Freestanding	39%	38%	37%	37%	36%	37%	38%	40%
Hospital-based	27	26	25	25	25	25	25	25
HHA-based	33	35	37	37	38	36	35	33
SNF-based	1	1	1	1	1	1	1	1
Size^a								
Small	66%	64%	62%	63%	62%	60%	58%	57%
Medium	31	32	33	32	33	34	36	37
Large	4	4	5	5	5	5	6	6
Location^b								
Urban	68%	67%	64%	64%	64%	63%	62%	61%
Rural	32	33	35	35	36	36	37	38

^aSmall = fewer than 100 patients a year. Medium = 100-499 patients a year. Large = 500 or more patients a year.

^bUrban = metropolitan statistical area. Rural = nonmetropolitan statistical area.

Source: GAO analysis of annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 9: Average Number of Days Beneficiaries Used Hospice by Provider Control, Affiliation, Size, and Location, 1992-98

Category	1992	1993	1994	1995	1996	1997	1998	Percent change 1992-98
All U.S. hospices	73.9	75.7	74.7	67.6	64.8	61.4	59.3	-20%
Control								
For-profit	83.1	87.1	87.7	79.8	77.8	74.6	71.4	-14
Not-for-profit	72.1	73.3	71.8	64.4	61.0	57.2	55.4	-23
Government	75.8	71.8	70.6	65.9	65.4	61.6	58.4	-23
Affiliation								
Freestanding	81.7	83.6	81.0	73.4	70.6	66.9	64.5	-21
Hospital-based	69.9	71.1	70.5	63.1	61.3	57.6	54.0	-23
HHA-based	64.4	66.8	67.9	61.5	57.7	54.5	53.7	-17
SNF-based	53.4	55.4	61.2	55.9	47.3	50.8	51.7	-3
Size^a								
Small	75.1	76.2	74.4	70.4	69.2	65.9	66.6	-11
Medium	73.2	75.3	74.9	67.5	64.2	61.3	59.5	-19
Large	74.0	76.0	74.6	66.2	63.5	59.4	56.3	-24
Location^b								
Urban	72.1	74.3	73.7	66.6	63.7	60.4	58.0	-20
Rural	86.8	85.2	81.2	73.9	71.8	67.6	66.9	-23

^aSmall = fewer than 100 patients a year. Medium = 100-499 patients a year. Large = 500 or more patients a year.

^bUrban = metropolitan statistical area. Rural = nonmetropolitan statistical area.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and provider data from annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 10: Use of Medicare Hospice Benefits by Cancer and Noncancer Patients, 1992-98

Category	1992	1993	1994	1995	1996	1997	1998	Percent change 1992-98
Medicare enrollees	34,852,914	35,557,195	36,169,499	36,758,101	37,268,560	37,633,245	37,998,035	9%
Medicare decedents	1,633,088	1,718,881	1,733,054	1,770,360	1,791,588	1,806,655	1,833,053	12
Hospice users	143,110	180,097	223,044	258,481	294,931	325,324	358,949	151
Cancer patients	108,232	128,678	151,701	169,080	182,038	195,114	206,190	91
Noncancer patients	34,878	51,419	71,343	89,401	112,893	130,210	152,759	338
Average days used	73.9	75.7	74.7	67.6	64.8	61.4	59.3	-20
Cancer	62.5	63.2	63.6	60.5	58.4	55.8	53.9	-14
Noncancer	109.2	106.9	98.4	80.9	76.3	70.6	67.8	-38
Median days used	26	26	26	24	23	21	19	-27
Cancer	26	27	27	26	25	23	23	-12
Noncancer	25	26	25	21	18	16	15	-40

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and provider data from annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 11: Number of Hospice Users by Selected Common Diagnoses, 1992-98

Primary diagnosis	1992	1993	1994	1995	1996	1997	1998	Percent change 1992-98
All patients	143,110	180,097	223,044	258,481	294,931	325,324	358,949	151%
Cancer	108,232	128,678	151,701	169,080	185,038	195,114	206,190	91
Breast	7,602	8,761	10,476	11,626	12,296	12,661	13,093	72
Colon	6,697	8,402	9,426	10,722	11,762	12,401	13,278	98
Lung	29,966	35,528	41,694	46,747	51,772	54,940	57,841	93
Pancreatic	6,359	7,597	8,860	9,771	10,592	11,371	12,116	91
Prostate	10,052	11,808	13,577	14,368	15,441	15,249	15,494	54
Other	47,556	56,582	67,668	75,846	83,173	88,492	94,368	98
Noncancer	34,878	51,419	71,343	89,401	112,893	130,210	152,759	338
Alzheimer's	1,591	2,549	4,060	6,050	7,839	9,608	11,836	644
Stroke	2,140	3,528	5,426	6,972	8,973	10,910	13,282	521
Chronic obstructive pulmonary disease	4,112	6,407	8,506	9,975	11,911	14,041	15,765	283
Congestive heart failure	6,141	9,118	12,432	15,172	18,293	20,661	24,248	295
"Ill-defined" conditions	888	991	1,306	1,651	2,593	4,845	7,599	756
Other	20,006	28,826	39,613	49,581	63,284	70,145	80,029	300

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 12: Percentage of Hospice Users by Selected Common Diagnoses, 1992-98

Primary diagnosis	1992	1993	1994	1995	1996	1997	1998
All patients	143,110	180,097	223,044	258,481	294,931	325,324	358,949
Cancer	75.6%	71.4%	68.0%	65.4%	62.7%	60.0%	57.4%
Breast	5.3	4.9	4.7	4.5	4.2	3.9	3.6
Colon	4.7	4.7	4.2	4.1	4.0	3.8	3.7
Lung	20.9	19.7	16.7	18.1	17.6	16.9	16.1
Pancreatic	4.4	4.2	4.0	3.8	3.6	3.5	3.4
Prostate	7.0	6.6	6.1	5.6	5.2	4.7	4.3
Other	33.2	31.4	30.3	29.3	28.2	27.2	26.3
Noncancer	24.4%	28.6%	32.0%	34.6%	38.3%	40.0%	42.6%
Alzheimer's	1.1	1.4	1.8	2.3	2.7	3.0	3.3
Stroke	1.5	2.0	2.4	2.7	3.0	3.4	3.7
Chronic obstructive pulmonary disease	2.9	3.6	3.8	3.9	4.0	4.3	4.4
Congestive heart failure	4.3	5.1	5.6	5.9	6.2	6.4	6.8
"Ill-defined" conditions	0.6	0.6	0.6	0.6	0.9	1.5	2.1
Other	14.0	15.9	17.8	19.2	21.5	21.4	22.3

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 13: Average Number of Days Beneficiaries Used Hospice by Selected Common Diagnoses, 1992-98

Primary diagnosis	1992	1993	1994	1995	1996	1997	1998
All patients	73.9	75.7	74.7	67.6	64.8	61.4	59.3
Cancer	62.5	63.2	63.6	60.5	58.4	55.8	53.9
Breast	85.1	88.0	86.3	80.4	78.1	73.9	70.0
Colon	62.8	64.6	67.3	63.8	62.1	59.8	58.6
Lung	56.7	57.1	58.0	56.2	54.6	52.5	51.0
Pancreatic	51.8	52.6	52.8	54.0	50.0	48.5	45.9
Prostate	80.6	79.7	81.5	76.9	70.8	67.4	64.5
Noncancer	109.2	106.9	98.4	80.9	76.3	70.6	67.8
Alzheimer's	173.7	180.9	156.3	125.1	113.4	100.9	99.7
Stroke	89.3	79.8	77.9	58.5	54.2	49.1	46.3
Chronic obstructive pulmonary disease	139.8	132.2	119.3	102.4	97.9	89.2	85.5
Congestive heart failure	110.7	108.2	96.7	78.8	75.3	69.1	70.9
"Ill-defined" conditions	124.8	132.4	108.6	95.6	96.9	86.4	77.9

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 14: Hospice Use and Supply by State, 1992 and 1998

State	1992				1998			
	Users	Providers	Average daily census	Average days of care	Users	Providers	Average daily census	Average days of care
U.S.	143,110	1,208	24	74	358,949	2,281	23	59
Ala.	2,162	29	15	74	7,112	66	23	85
Alaska	0	0	0	0	67	3	2	53
Ariz.	3,611	16	32	53	11,098	40	37	53
Ark.	1,138	27	11	95	3,621	59	12	81
Calif.	13,251	87	28	68	34,293	181	25	53
Colo.	2,332	26	15	61	6,179	38	20	48
Conn.	1,565	9	21	46	3,951	29	15	44
Del.	568	3	36	72	1,049	5	35	63
D.C.	238	2	18	60	472	3	16	44
Fla. ^a	21,407	37	120	76	38,422	40	148	63
Ga.	2,276	28	14	65	9,363	62	26	68
Hawaii ^a	394	7	8	55	1,074	7	17	43
Idaho	615	13	11	87	1,282	30	7	62
Ill.	7,276	47	34	78	16,147	88	24	55
Ind. ^a	1,009	17	11	69	6,066	61	16	62
Iowa	1,601	28	14	88	4,560	59	12	60
Kans.	1,025	17	17	97	2,562	32	14	65
Ky ^a	3,276	27	36	107	5,367	29	35	76
La.	1,462	21	12	63	4,065	38	15	57
Maine ^a	310	11	5	61	687	15	8	64
Md. ^a	1,906	22	14	58	5,387	30	22	47
Mass.	3,800	33	22	69	7,074	44	20	49
Mich.	6,670	50	26	70	16,186	74	30	56
Minn.	2,222	24	17	68	5,449	63	14	62
Miss.	611	12	12	86	2,925	39	17	94
Mo.	3,119	33	22	87	8,849	76	17	60
Mont.	402	9	10	78	1,008	17	10	65
Nebr. ^a	519	9	12	74	2,042	27	12	63
Nev.	794	4	43	78	2,589	9	37	50
N.H.	351	9	6	61	1,219	22	8	59
N.J.	4,652	33	25	66	9,225	44	27	50
N. Mex.	919	12	18	83	2,361	30	13	66

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Patterns and Trends in Hospice Supply and Use

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State	1992				1998			
	Users	Providers	Average daily census	Average days of care	Users	Providers	Average daily census	Average days of care
N.Y. ^a	7,743	49	27	62	17,540	54	44	52
N.C. ^a	4,696	59	22	100	9,022	69	24	71
N. Dak.	343	8	9	78	983	14	9	52
Ohio	7,492	58	23	68	19,073	90	27	50
Okla.	939	14	14	72	5,946	56	23	88
Oreg.	2,483	25	19	68	6,304	42	19	49
Pa.	5,200	61	14	60	18,286	118	21	52
R.I. ^a	646	7	19	73	1,478	8	22	50
S.C.	1,406	16	20	83	4,050	34	22	73
S. Dak.	248	6	9	78	691	13	8	54
Tenn. ^a	1,522	23	13	74	4,924	60	13	61
Tex.	10,427	68	39	93	24,517	151	26	69
Utah	168	4	5	48	1,747	17	14	50
Vt. ^a	308	8	6	56	561	9	7	46
Va.	1,349	10	30	83	5,994	46	11	58
Wash.	2,631	20	26	72	6,845	29	32	53
W. Va. ^a	1,078	12	18	69	2,294	21	18	70
Wis.	2,862	41	13	70	6,231	54	17	58
Wyo.	30	3	1	54	295	12	4	65

^aState has a certificate-of-need requirement for hospice.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and provider data from annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 15: Percentage Change in Hospice Use and Supply by State, 1992-98

State	Users	Providers	Average daily census	Average days of care
U.S.	151%	89%	-3%	-20%
Ala.	229	128	55	15
Alaska	a	a	a	a
Ariz.	207	150	17	3
Ark.	218	119	10	-14
Calif.	159	108	-11	-22
Colo.	165	46	33	-21
Conn.	152	222	-27	-1
Del.	85	67	-5	-10
D.C.	98	50	-14	-20
Fla. ^b	79	8	23	-17
Ga.	311	121	83	6
Hawaii ^b	173	0	126	-13
Idaho	108	131	-40	-27
Ill.	122	87	-28	-31
Ind. ^b	501	259	42	-9
Iowa	185	111	-16	-33
Kans.	150	88	-17	-38
Ky. ^b	64	7	-3	-31
La.	178	81	25	-12
Maine ^b	122	36	66	7
Md. ^b	177	36	58	-19
Mass.	86	33	-5	-28
Mich.	143	48	18	-21
Minn.	145	163	-21	-9
Miss.	379	225	51	13
Mo.	184	130	-26	-31
Mont.	151	89	1	-18
Nebr. ^b	293	200	0	-15
Nev.	226	125	-15	-36
N.H.	247	144	30	-2
N.J.	98	33	8	-23
N. Mex.	157	150	-27	-23
N.Y. ^b	127	10	66	-15

Appendix II
Patterns and Trends in Hospice Supply and Use

(Continued From Previous Page)

State	Users	Providers	Average daily census	Average days of care
N.C. ^b	92	17	9	-29
N. Dak.	187	75	6	-32
Ohio	155	55	14	-25
Okla.	533	300	67	20
Oreg.	154	68	1	-30
Pa.	252	93	49	-13
R.I. ^b	129	14	16	-34
S.C.	188	113	10	-12
S. Dak.	179	117	-13	-30
Tenn. ^b	224	161	1	-16
Tex.	135	122	-32	-26
Utah	940	325	161	11
Va.	344	360	-37	-29
Vt. ^b	82	13	19	-21
Wash. ^b	160	45	22	-26
W. Va. ^b	113	75	3	-3
Wis. ^b	118	32	26	-17
Wyo.	883	300	241	38

^aAlaska had no Medicare-certified hospice providers in 1992.

^bState has a certificate-of-need requirement for hospice.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and provider data from annual Medicare Provider of Service Files.

Appendix II
Patterns and Trends in Hospice Supply and Use

Table 16: Change in Percentage of Providers, Users, and Days of Care by Provider Type, 1992-98

Category	1992			1994			1996			1998		
	Providers	Users	Days	Providers	Users	Days	Providers	Users	Days	Providers	Users	Days
Control												
For-profit	13%	16%	18%	18%	19%	23%	25%	24%	28%	27%	26%	30%
Not-for-profit	79	81	79	72	77	74	65	73	69	62	71	67
Government	5	2	2	6	2	2	6	2	2	6	2	2
Affiliation												
Freestanding	39%	50%	55%	37%	49%	53%	36%	50%	54%	38%	52%	55%
Hospital-based	27	20	19	25	19	18	25	19	18	25	19	17
HHA-based	33	28	25	37	30	27	38	30	27	35	29	27
SNF-based	1	2	2	1	1	1	1	1	1	1	1	1
Size^a												
Small	66%	23%	23%	62%	18%	18%	62%	17%	18%	58%	15%	17%
Medium	31	49	49	33	51	51	33	50	50	36	49	50
Large	4	28	28	5	31	31	5	33	32	6	36	34
Location^b												
Urban	68%	88%	86%	64%	87%	86%	64%	86%	85%	62%	86%	84%
Rural	32	12	14	35	13	14	36	14	15	37	14	16

Note: Percentages indicate percentage shares.

^aSmall = fewer than 100 patients a year. Medium = 100-499 patients a year. Large = 500 or more patients a year.

^bUrban = metropolitan statistical area. Rural = nonmetropolitan statistical area.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and provider data from annual Medicare Provider of Service Files.

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Patterns and Trends in Hospice Supply and Use

Table 17: Variation in Hospice Use Among Medicare Decedents by State, 1998

State	Hospice users as percent of Medicare decedents
Ariz.	36%
Colo.	30
Fla.	29
Oreg.	26
N. Mex.	25
Nev.	24
Mich.	23
Ohio	22
Tex.	22
Del.	21
Okla.	21
Calif.	20
Ga.	20
Ill.	20
Wash.	20
Ala.	19
Iowa	19
Utah	19
Idaho	18
Kans.	18
Ky.	18
Minn.	18
Mo.	18
R.I.	18
Hawaii	17
Md.	17
Pa.	17
Ark.	16
Conn.	16
Nebr.	16
N.H.	16
N.J.	16
N.C.	16
N. Dak.	16

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Patterns and Trends in Hospice Supply and
Use

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State	Hospice users as percent of Medicare decedents
S.C.	16
Wis.	16
Mass.	15
Mont.	15
N.Y.	15
Ind.	14
Va.	14
W. Va.	14
La.	13
Miss.	13
Vt.	13
D.C.	12
S. Dak.	11
Tenn.	11
Wyo.	11
Maine	8
Alaska	6
U.S. total	19

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File and Medicare decedent data from the denominator file, an abbreviated version of HCFA's Medicare enrollment database.

Comments From the Health Care Financing Administration



DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

The Administrator
Washington, D.C. 20201

DATE: SEP - 8 2000

TO: Janet Heinrich
Associate Director
Health Financing and Public Health Issues

FROM: Nancy-Ann Min DeParle *Nancy-A DeParle*
Administrator

SUBJECT: General Accounting Office (GAO): "Medicare: More Beneficiaries Use Hospice, But for Fewer Days of Care," (GAO/HEHS-00-182)

We appreciate the opportunity to review the draft report on the trends and patterns in hospice use by Medicare beneficiaries; the factors that affect use of the hospice benefit; and the availability of Medicare hospice providers. We appreciate GAO's support for our effort to ensure that beneficiaries have access to hospice care.

Hospice care is an essential benefit in Medicare, bringing important extra sensitivity, a focus on patient and family, and a special form of care to the dying. Hospices provide comfort, counseling and relief from pain, rather than curative care. HCFA is committed to ensuring that beneficiaries receive appropriate care tailored to their own needs at the end of life and that they understand their rights and options.

Under the law, Medicare beneficiaries are eligible for hospice care when they decide to choose palliative and other care from a hospice, and a physician and the hospice medical director certify that they have a medical prognosis of six or fewer months to live if their illness runs its normal course. The Balanced Budget Act of 1997 (BBA) made important changes to the law to ensure that patients whose prognosis improves or who choose to resume curative care can leave hospice and return at a later date.

HCFA is concerned that some individuals who want and could benefit from hospice care may not be receiving it or may be receiving it late in the course of their illness because difficulty in making end-of-life prognoses may affect their access to hospice care. There also is a misperception that hospices and beneficiaries will be penalized if a patient lives longer than six months. This is untrue. Due to good fortune, there have been some terminally ill patients who lived longer than predicted by a well-intentioned physician.

In no way are hospice beneficiaries restricted to six months of coverage. As long as the beneficiary meets the eligibility criteria, there is no limit on how long an individual beneficiary can receive hospice services. Furthermore, as long as a physician continues to recertify the six-month prognosis, a beneficiary can continue to receive the hospice benefit.

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In fact, our records show that about 10 percent of Medicare hospice beneficiaries stay longer than six months. Also, as mentioned above, the BBA changed the law to make it easier for beneficiaries to transfer in and out of hospice if their prognosis improves or they want to resume curative care, and then reenroll in hospice.

To address this confusion and help ensure that all eligible beneficiaries who want and can benefit from hospice care receive it, we will work to develop a voluntary pre-authorization pilot program for hospice beneficiaries in cooperation with the hospice associations. A pre-authorization program would help beneficiaries and providers in cases where prognosis is difficult by preempting concerns about denial of claims, and thereby promoting earlier enrollment for more beneficiaries who want and are eligible for hospice care.

We believe education and training are critically important to the hospice program. Beneficiaries and their families need to know when and how to determine whether to recommend hospice care to an individual patient, as well as what criteria to consider when certifying a patient's eligibility. Therapists and other ancillary providers need to understand the special sensitivities required in treating hospice patients.

For beneficiaries and their families, we have a brochure that describes how the hospice benefit works, what their rights and obligations are under the benefit, and how to contact national and state hospice organizations. We worked with the National Hospice and Palliative Care Organizations as it developed guidelines on how to determine hospice eligibility for patients with an illness other than cancer which can make the prognosis more uncertain. Terminal disease prognosis is not an exact science, and many hospice patients live longer than six months. HCFA has shared information with hospice providers stressing the necessity for physicians and hospices to document the clinical factors that lead them to the six-month prognosis, and more frequent review of a patient's condition in cases where prognosis is less certain.

The BBA included a requirement that hospices submit data on their costs to the Department of Health and Human Services Secretary for each fiscal year beginning after October 1, 1998. HCFA has begun collecting hospice cost data to use for evaluating the adequacy of current levels of Medicare reimbursement. As indicated in your report, this data will be available beginning in late 2001.

HCFA is concerned about the provider and practitioner reaction to "Operation Restore Trust" and the public's perception of its impact on a hospice. Therefore, we plan to release a letter to all hospice providers assuring that we are committed to the hospice benefit and that we do not expect absolute certainty in determining prognosis.

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The Medicare hospice benefit is an important part of the total array of benefits available to Medicare beneficiaries. Although trends in use of the Medicare hospice benefit show that beneficiaries are making use of hospice services and hospice providers are increasing in numbers, we do not believe the underutilization concerns of hospice advocates and the industry should be discounted. We know that the needs of the population aged 65 and over is changing because of changes in the family structure. There are a number of elderly beneficiaries who do not have family in close proximity or other care givers to attend to their needs. As such, these individuals may be choosing other types of health care entities to provide end-of-life care. These other types of providers could be nursing homes, hospitals, or assisted living facilities. This one variable could have an impact on the utilization practices related to hospice care. Additionally, the development of new curative care treatment maybe contributing to beneficiary decisions to delay the election of hospice care until shortly before death.

We hope that the study of trends in hospice care delivery continues over the next several years to assist us in developing policies that will enhance the quality of health care provided to Medicare beneficiaries. We are committed to ensuring that, at the end of life, beneficiaries receive appropriate care tailored to their own needs and they understand their rights and options.

We look forward to working with the Congress and GAO on this important Medicare benefit.

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