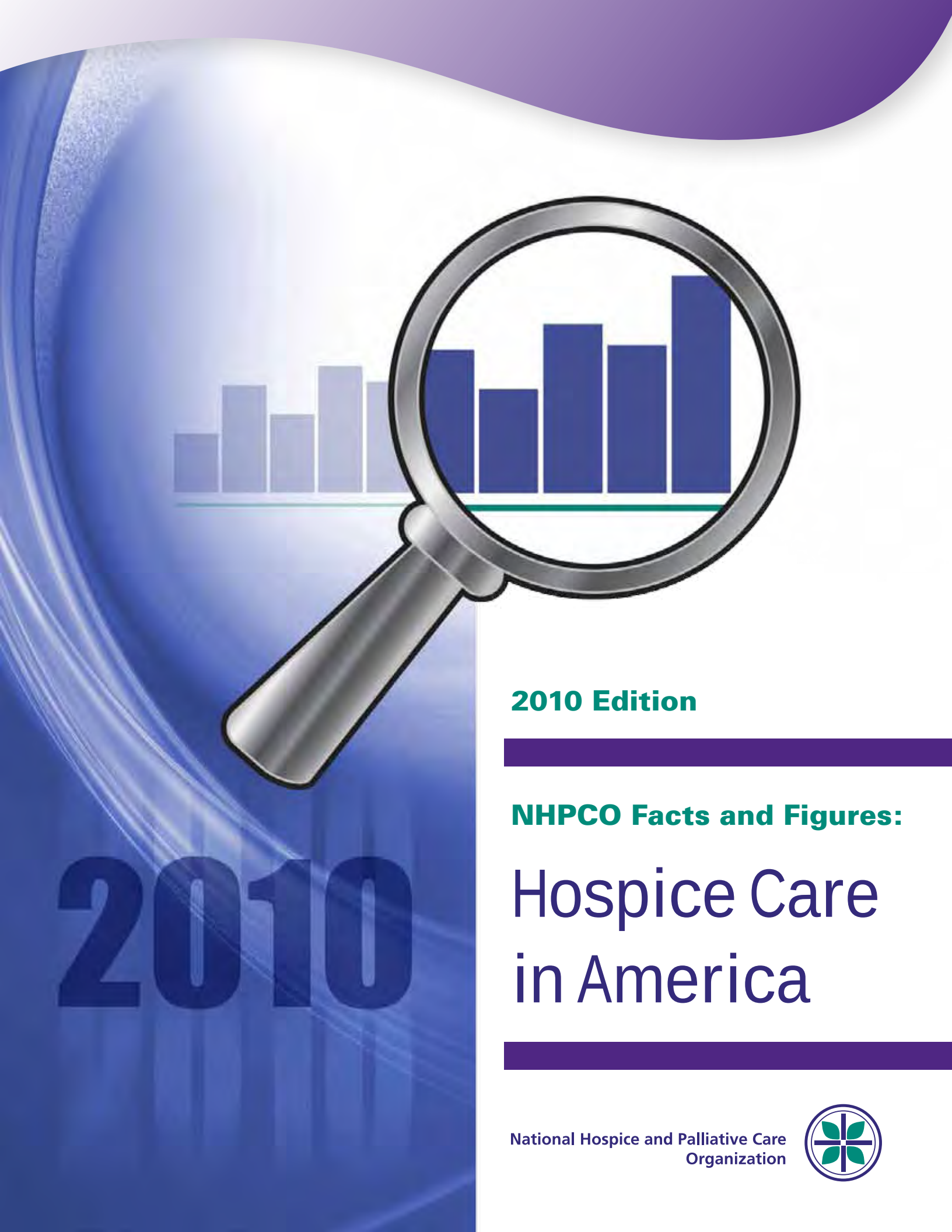

2010 Edition

NHPCO Facts and Figures:

Hospice Care in America

National Hospice and Palliative Care Organization

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Introduction

About this Report

NHPCO Facts and Figures: Hospice Care in America provides an annual overview of important trends in the growth, delivery and quality of hospice care across the country. This overview provides specific information on:

- Hospice patient characteristics (e.g., gender, age, ethnicity, race, primary diagnosis, and length of service)
- Hospice provider characteristics (e.g., total patients served, organizational type, size, and tax status)
- Location and level of care
- Role of paid and volunteer staff

Please refer to "Data Sources and Methods" (page 14) or to the specific footnotes for the source information and methodologies used to derive this information. Additional resources for NHPCO members are also provided on page 15.

What is hospice care?

Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well.

Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice centers, hospitals, nursing homes, and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race.

How is hospice care delivered?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. This interdisciplinary team, as illustrated in Figure 1 below, usually consists of the patient's personal physician, hospice physician or medical director, nurses, home health aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists, if needed.

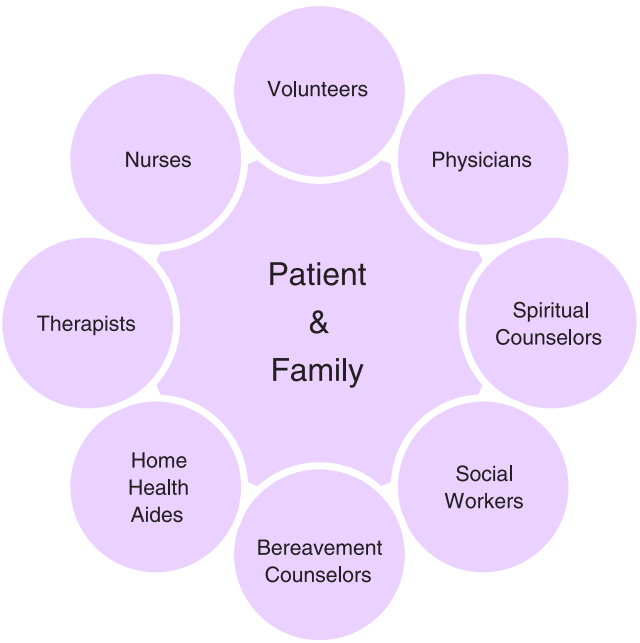

Figure 1. Interdisciplinary team

Who Receives Hospice Care?

How many patients receive care each year?

In 2009, an estimated 1.56 million patients received services from hospice (Figure 2). This estimate includes:

- 1,020,00 patients who died under hospice care in 2009
- 294,000 who remained on the hospice census at the end of 2009 (known as "carryovers")
- 243,000 patients who were discharged alive in 2009 for reasons including extended prognosis, desire for curative treatment, and other reasons (known as "live discharges").

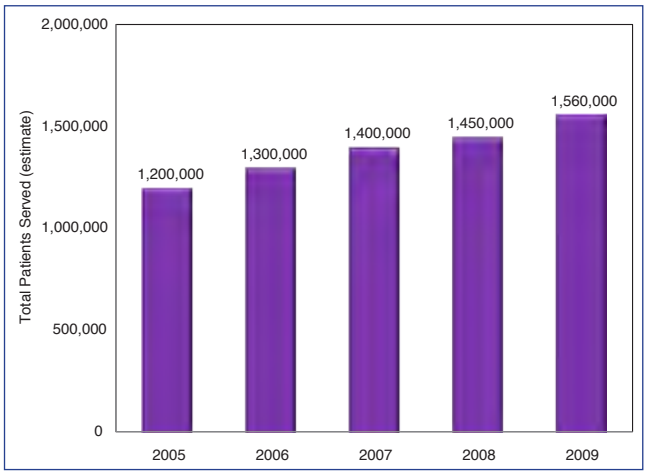

Figure 2. Total Hospice Patients Served by Year

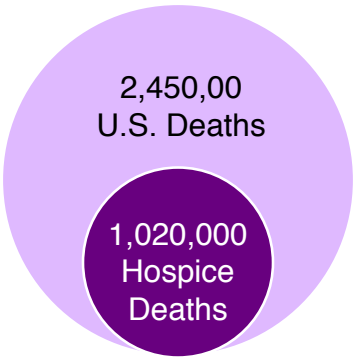

Figure 3. Hospice Utilization in U.S.

What proportion of U.S. deaths is served by hospice?

The percent of U.S. deaths served by hospice is calculated by dividing the number of deaths in hospice (as estimated by NHPCO) by the total number of deaths in the U.S. as reported by the Centers for Disease Control and Prevention. For 2009, NHPCO estimates that approximately 41.6% of all deaths in the United States were under the care of a hospice program (Figure 3).

How long do most patients receive care?

The total number of days that a hospice patient receives care is referred to as the length of service (or length of stay). Length of service can be influenced by a number of factors including disease course, timing of referral, and access to care.

The median (50th percentile) length of service in 2009 was 21.1 days, a slight decrease from 21.3 in 2008. This means that half of hospice patients received care for less than three weeks and half received care for more than three weeks. The average length of service decreased from 69.5 days in 2008 to 69.0 in 2009 (Figure 4).[1]

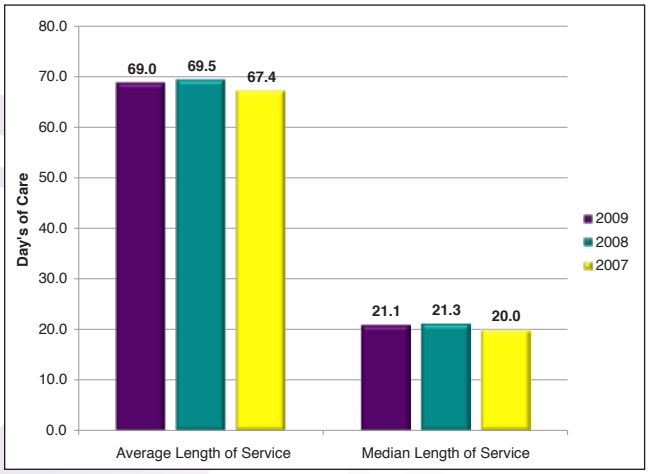

Figure 4. Length of Service by Year

Short and Long Lengths of Service

In 2009, a slightly smaller proportion of hospice patients (approximately 34.4%) died or were discharged within seven days of admission when compared to 2008 (35.4%). However, a slightly larger proportion of patients died or were discharged within 14 days of admission when compared to 2008 (48.5% and 48.4% respectively). Fewer patients remained under hospice for longer than 180 days (11.8% in 2009 compared to 12.1% in 2008). This trend toward shorter lengths of service is consistent over the past several years.

Impact of Hospice Care on Survival

Hospice and palliative care may prolong the lives of some terminally ill patients. In a 2007 study, the mean survival was 29 days longer for hospice patients than for non-hospice patients.[2] In other words, patients who chose hospice care lived an average of one month longer than similar patients who did not choose hospice care. Longer lengths of survival were found in four of the six disease categories studied. The largest difference in survival between the hospice and non-hospice cohorts was observed in congestive heart failure patients where the mean survival period jumped from 321 days to 402 days. The mean survival period was also significantly longer for hospice patients with lung cancer (39 days) and pancreatic cancer (21 days), while marginally significant for colon cancer (33 days).

In a 2010 study published in the *New England Journal of Medicine*, lung cancer patients receiving early palliative care lived 23.3% longer than those who delayed palliative treatment as is currently the standard. Median survival for earlier palliative care patients was 2.7 months longer than those receiving standard care. The study authors hypothesized that "with earlier referral to a hospice program, patients may receive care that results in better management of symptoms, leading to stabilization of their condition and prolonged survival."[3]

[1] Length of service can be reported as both an average and a median. The median, however, is considered a more meaningful measure for understanding the experience of the typical patient since it is not influenced by outliers (extreme values).

[2] Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. J Pain Symptom Manage. 2007 Mar;33(3):238-46.

[3] Ternel JS, Greer JA, Muzinkansky A, et. al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. N Engl J Med. 2010 Aug;363(8):733-42.

Where do most hospice patients receive care?

The majority of patient care is provided in the place the patient calls "home" (Table 1). In addition to private residences, this includes nursing homes and residential facilities. In 2009, 68.6% of patients received care at home. The percentage of hospice patients receiving care in an inpatient facility increased slightly from 21.0% to 21.2%.

Table 1. Location of Death

Location of Death	2009	2008
Patient's Place of Residence	68.6%	68.8%
Private Residence	40.1%	40.7%
Nursing Home	18.9%	22.0%
Residential Facility	9.6%	6.1%
Hospice Inpatient Facility	21.2%	21.0%
Acute Care Hospital	10.1%	10.1%

Inpatient Facilities and Residences

In addition to providing home hospice care, nearly one in five hospice agencies also operate a dedicated inpatient unit or facility. Most of these facilities are either freestanding or located on a hospital campus and may provide a mix of general inpatient and residential care. Short-term inpatient care can be made available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time.

What are characteristics of the hospice patient population?

Patient Gender

More than half of hospice patients were female (Table 2).

Table 2. Percentage of Hospice Patients by Gender

Patient Gender	2009	2008
Female	53.8%	56.6%
Male	46.2%	43.4%

Patient Age

In 2009, 83.0% of hospice patients were 65 years of age or older—and more than one-third of all hospice patients were 85 years of age or older (Table 3). The pediatric and young adult population accounted for less than 1% of hospice admissions.

Table 3. Percentage of Hospice Patients by Age

Patient Age Category	2009	2008
Less than 24 years	0.4%	0.4%
25 - 34 years	0.4%	0.5%
35 - 64 years	16.3%	15.9%
65 - 74 years	16.3%	16.2%
75 - 84 years	28.7%	29.2%
85+ years	38.0%	37.8%

Hospice Utilization in 65+ Age Group

A recent in-depth analysis[4] of all Medicare beneficiaries age 65+ who died in 2002 validated what previous, smaller studies have shown about this population: female decedents use hospice services more than their male counterparts (30% vs. 27% in 2002); white decedents use hospice services more than blacks (29% vs. 22% in 2002); and close to one in three older Americans use hospice services (28.6% in 2002).

Hospice use was also found to be higher for diseases that impose a high burden on caregivers, or diseases for which prognostic accuracy is easier to achieve. The three causes of death with the highest hospice utilization rates (malignancies, nephritis/kidney disease, and Alzheimer's disease) correspond to diseases that commonly impose high burdens of caregiving on family caregivers and/or that make it easier for decision makers to predict the time frame of death.

Patient Ethnicity and Race

Following U.S. Census guidelines, NHPCO reports Hispanic ethnicity as a separate concept from race. In 2009, five percent of patients were identified as being of Hispanic or Latino origin (Table 4)

Table 4. Percentage of Hospice Patients by Ethnicity

Patient Ethnicity	2009	2008
Non-Hispanic or Latino origin	94.7%	94.4%
Hispanic or Latino origin	5.3%	5.6%

Patients of minority (non-Caucasian) race accounted for nearly one of every five hospice patients in 2009 (Table 5).

Table 5. Percentage of Hospice Patients by Race

Patient Race	2009	2008
White/Caucasian	80.5%	81.9%
Multiracial or Other Race	8.7%	9.5%
Black/African American	8.7%	7.2%
Asian, Hawaiian, Other Pacific Islander	1.9%	1.1%
American Indian or Alaskan Native	0.2%	0.3%

Primary Diagnosis

When hospice care in the United States was established in the 1970s, cancer patients made up the largest percentage of hospice admissions. Today, cancer diagnoses account for less than half of all hospice admissions (40.1%) (Table 6). Currently, less than 25 percent of U.S. deaths are now caused by cancer, with the majority of deaths due to other terminal diseases.[5]

The top four non-cancer primary diagnoses for patients admitted to hospice in 2009 were debility unspecified (13.1%), heart disease (11.5%), dementia (11.2%), and lung disease (8.2%).

[4] Connor SR, Elwert F, Spence C, Christakis NA. Geographic variation in hospice use in the United States in 2002. J Pain Symptom Manage. 2007 Sep;34(3):277-85. Connor SR, Elwert F, Spence C, Christakis NA. Racial disparity in hospice use in the United States in 2002. Palliat Med. 2008 Apr;22(3):205-13.

[5] Xu J, Kochanek KD, Murphy SL, Tejada-Vera B. Deaths: Final Data for 2007; National Vital Statistics Reports; vol 58 no 19. Hyattsville, MD. National Center for Heatlh Statistics, 2010

Table 6. Percentage of Hospice Admissions by Primary Diagnosis

Primary Diagnosis	2009	2008
Cancer	40.1%	38.3%
Non-Cancer Diagnoses	59.9%	61.7%
Debility Unspecified	13.1%	15.3%
Heart Disease	11.5%	11.7%
Dementia	11.2%	11.1%
Lung Disease	8.2%	7.9%
Other	4.5%	4.4%
Stroke or Coma	4.0%	4.0%
Kidney Disease (ESRD)	3.8%	2.8%
Non-ALS Motor Neuron	1.9%	1.5%
Liver Disease	1.8%	2.1%
HIV / AIDS	0.4%	0.5%
Amyotrophic Lateral Sclerosis (ALS)	0.4%	0.4%

Who Provides Care?

How many hospices were in operation in 2009?

The number of hospice programs nationwide continues to increase — from the first program that opened in 1974 to approximately 5,000 programs today (Figure 5). This estimate includes both primary locations and satellite offices. Hospices are located in all 50 states, the District of Columbia, Puerto Rico, Guam and the U.S. Virgin Islands.

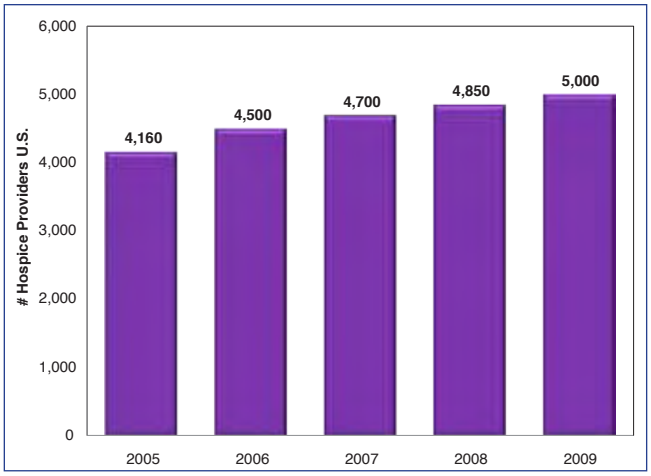

Figure 5. Total Hospice Providers by Year

Agency Type

The majority of hospices are independent, freestanding agencies (Table 7). The remaining agencies are either part of a hospital system, home health agency, or nursing home.

Table 7. Agency Type

Agency Type	2009	2008
Free Standing/Independent Hospice	57.7%	57.5%
Part of a Hospital System	21.4%	21.8%
Part of a Home Health Agency	19.5%	19.4%
Part of a Nursing Home	1.4%	1.4%

Agency Size

Hospices range in size from small all-volunteer agencies that care for fewer than 50 patients per year to large, national corporate chains that care for thousands of patients each day.

One measure of agency size is total admissions over the course of a year. In 2009, 79.4% of hospices had fewer than 500 total admissions (Table 8).

Table 8. Total Patient Admissions

Total Patient Admissions	2009	2008
1 to 49	17.1%	18.1%
50 to 150	29.4%	29.5%
151 to 500	32.9%	32.1%
501 to 1,500	16.1%	16.1%
> 1,500	4.5%	4.2%

Another indicator of agency size is daily census, which is the number of patients cared for by a hospice program on a given day. In 2009, the mean average daily census was 116.3 patients and the median (50th percentile) average daily census was 63.8 patients. Almost one quarter of providers routinely care for more than 100 patients per day (Figure 6).

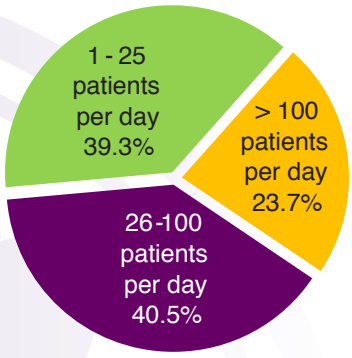

Figure 6. Average Daily Census

Organizational Tax Status

Hospice agencies are organized into three tax status categories:

1. Not-for-profit [charitable organization subject to 501(c)3 tax provisions]
2. For-profit (privately owned or publicly held entities)
3. Government (owned and operated by federal, state, or local municipality)

Based on NHPCO membership and survey data, 49.0% of providers held not-for-profit tax status and 47.0% held for-profit status in 2009 (Figure 7). Government-owned programs, such as U.S. Department of Veterans Affairs medical centers and county-run hospices, comprise the smallest percentage of hospice providers (about 4% in 2009).

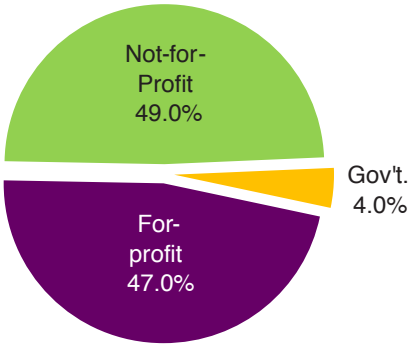

Figure 7. Tax Status Distribution

The number of for-profit Medicare-certified hospice providers has been steadily increasing over the past several years. (Figure 8). In contrast, the number of Medicare-certified not-for-profit or government providers has remained almost constant over the same period.

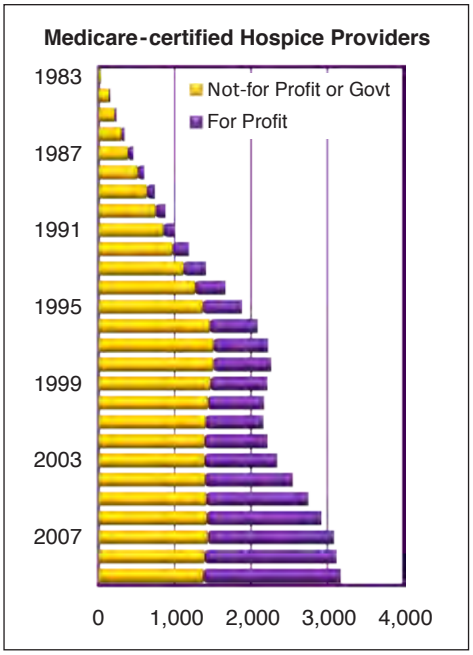

Figure 8. Growth in Medicare-Certified Hospice Providers

Who Pays for Care?

Financial concerns can be a major burden for many patients and families facing a terminal illness. Hospice care is covered under Medicare, Medicaid, and most private insurance plans and patients receive hospice care regardless of ability to pay.

Hospice Participation in Medicare

The Medicare hospice benefit, enacted by Congress in 1982, is the predominate source of payment for hospice care. The percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 83.4% in 2009 (Table 9). The percentage of patient days covered by the Medicare hospice benefit versus other sources was 89% (Table 10).

Table 9. Percentage of Patients Served by Payer

Payer	2009	2008
Medicare Hospice Benefit	83.4%	84.3%
Managed Care or Private Insurance	8.6%	7.8%
Medicaid Hospice Benefit	4.9%	5.1%
Uncompensated or Charity Care	1.6%	1.3%
Self Pay	0.7%	0.7%
Other Payment Source	0.8%	0.8%

Table 10. Percentage of Patient Care Days by Payer

Payer	2009	2008
Medicare Hospice Benefit	89.0%	88.8%
Managed Care or Private Insurance	4.8%	5.0%
Medicaid Hospice Benefit	4.3%	4.3%
Uncompensated or Charity Care	0.9%	0.9%
Self Pay	0.4%	0.4%
Other Payment Source	0.6%	0.6%

Most hospice agencies (93.0%) have been certified by the Centers for Medicare and Medicaid Services (CMS) to provide services under the Medicare hospice benefit. In 2009, there were more than 3,400 certified hospice agencies. Figure 9 shows the distribution of Medicare-certified hospice providers by state.

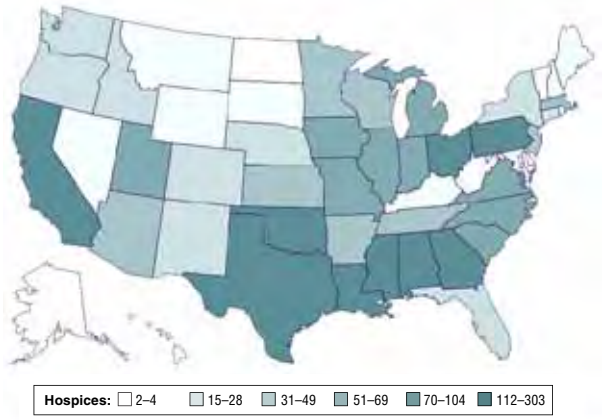

Figure 9. Medicare-Certified Hospices by State

Non-certified providers fall into two categories:

1. Provider seeking Medicare certification (e.g., a new hospice);
2. Provider not seeking certification. This group includes providers that 1) may have been formerly certified by Medicare and voluntarily dropped certification, or 2) have never been certified. The provider may have an arrangement with a home health agency to provide skilled medical services, or it may be an all-volunteer program that covers patient care and staffing expenses through donations and the use of volunteer staff.

Does hospice save money?

Findings of a major study demonstrated that hospice services save money for Medicare and bring quality care to patients with life-limiting illness and their families.[6] Researchers at Duke University found that hospice reduced Medicare costs by an average of $2,309 per hospice patient. Additionally, the study found that Medicare costs would be reduced for seven out of 10 hospice recipients if hospice was used for a longer period of time. For cancer patients, hospice use decreased Medicare costs up until 233 days of hospice care. For non-cancer patients, there were cost savings seen up until 154 days of care. While hospice use beyond these periods cost Medicare more than conventional care, the report's authors wrote that "More effort should be put into increasing short stays as opposed to focusing on shortening long ones."

How Much Care is Received?

What services are provided to patients and families?

Among its major responsibilities, the interdisciplinary hospice team:

- Manages the patient's pain and symptoms
- Assists the patient with the emotional and psychosocial and spiritual aspects of dying
- Provides needed drugs, medical supplies, and equipment
- Instructs the family on how to care for the patient
- Delivers special services like speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to treat at home, or the caregiver needs respite time
- Provides bereavement care and counseling to surviving family and friends.

What level of care do most hospice patients receive?

There are four general levels of hospice care:

Home-based Care

1. Routine Home Care: Patient receives hospice care at the place he/she resides.
2. Continuous Home Care: Patient receives hospice care consisting predominantly of licensed nursing care on a continuous basis at home. Continuous home care is only furnished during brief periods of crisis and only as necessary to maintain the terminally ill patient at home.

Inpatient Care

3. General Inpatient Care: Patient receives general inpatient care in an inpatient facility for pain control or acute or complex symptom management which cannot be managed in other settings.
4. Inpatient Respite Care: Patient receives care in an approved facility on a short-term basis in order to provide respite for the caregiver.

[6] Taylor DH Jr, Ostermann J, Van Houtven CH, Tulsky JA, Steinhauser K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? Soc Sci Med. 2007 Oct;65(7):1466-78.

In 2009, routine home care comprised the vast majority of hospice patient care days (Table 11).

Table 11. Percentage of Patient Care Days by Level of Care

Level of Care	2009	2008
Routine Home Care	95.9%	95.9%
General Inpatient Care	2.9%	2.9%
Continuous Care	1.0%	1.0%
Respite Care	0.2%	0.2%

Staffing Management and Service Delivery

Hospice team members generally provide service in one or more of the following areas:

- Direct clinical care, including patient care delivery, visits, charting, team meetings, travel, and the arrangement or coordination of care
- Non-clinical care, including administrative functions
- Bereavement services.

Hospice staff time centers on direct care for the patient and family: 69.7% of home hospice full-time equivalent employees (FTEs) and 69.6% of total FTEs were designated for direct patient care or bereavement support in 2009 (Table 12). Nursing staff continues to comprise the largest percentage of FTEs by discipline, while bereavement staff represent the smallest.

The number of patients that a clinical staff member is typically responsible for varies by discipline. In 2009, the average patient caseload for a home health aide was 9.8 patients, 10.8 patients for a nurse case manager, and 24 patients for a social worker.

Table 12. Distribution of Paid Staff FTEs

Staff Position	2009	2008
Clinical (direct patient care)	65.5%	65.3%
Nursing	30.7%	31.2%
Home Health Aides	18.1%	17.6%
Social Services	9.0%	9.1%
Physicians (excludes volunteers)	2.2%	2.1%
Chaplains	3.9%	3.4%
Other Clinical	2.1%	2.7%
Nursing (indirect clinical)	8.1%	8.2%
Non-clinical (administrative/general)	22.4%	24.2%
Bereavement	4.2%	4.2%

Volunteer Commitment

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. NHPCO estimates that in 2009, 468,000 hospice volunteers provided 22 million hours of service. Hospice volunteers provide service in three general areas:

- Spending time with patients and families ("direct patient care")
- Providing clerical and other services that support patient care and clinical services ("clinical support")
- Helping with fundraising efforts and/or the board of directors ("general support").

In 2009, most volunteers were assisting with direct patient care (57.6%), 21.5% provided patient care support and 20.9% provided general support.

Hospice is unique in that it is the only provider whose Medicare Conditions of Participation requires volunteers to provide at least five percent of total patient care hours.

In 2009, 5.6% of all clinical staff hours were provided by volunteers. The typical hospice volunteer devoted 46.6 hours of service over the course of the year and patient care volunteers made an average of 18 visits to hospice patients.

Bereavement Support

There is continued commitment to bereavement services for both family members of hospice patients and for the community at large. For a minimum of one year following their loved one's death, grieving families of hospice patients can access bereavement education and support.

In 2009, for each patient death, an average of two family members received bereavement support from their hospice. This support included follow-up phone calls, visits and mailings throughout the post-death year.

Most agencies (91.9%) also offer some level of bereavement services to the community; community members account for about 18.2% of those served by hospice bereavement programs.

Assessing the Quality of Hospice Care

Table 13. Sample NHPCO Hospice Performance Measures

Performance Measure		2009	2008
Family Evaluation of Hospice Care (FEHC)			
Hospice team clearly explained plan of care.	% "Yes"	96.6%	96.5%
Rating of care patient received under care of hospice.	% "Excellent"	75.6%	75.4%
Hospice response to evening / weekend needs.	% "Excellent"	66.4%	65.9%
Family Evaluation of Bereavement Services (FEBS)			
How well services met the needs of the bereavement client.	% "Very Well"	76.9%	76.7%
End Result Outcome Measures			
Patient's pain brought to a comfortable level within 48 hoursof admission to hospice.	% "Yes"	70.5%	71.8%

A system of performance measurement is essential to quality improvement and needs to be a component of every hospice organization's quality strategy. For optimal effectiveness, performance measurement results should include internal comparisons over time as well as external comparisons with peers.

NHPCO offers multiple tested performance measures that yield useful, meaningful, and actionable data that can be used to:

- Identify components of quality care
- Discover what areas of care delivery are effective
- Target specific areas for improvement

NHPCO also provides comparative reporting of results for these performance measures as a member benefit. In addition, NHPCO is engaged in the development of new performance measures, plus ongoing refinement and enhancement of the current measures. Several examples of NHPCO measures can be found in Table 13.

Data Sources and Methods

The National Hospice and Palliative Care Organization tracks key demographics on hospice patients, caregivers, and providers. These findings include analysis of both primary and secondary data sources.

Primary proprietary data sources:

- NHPCO National Data Set survey
  - Annual organizational level data collection from NHPCO members
- NHPCO Membership Database

Secondary data sources:

- Medicare Provider of Services certification data
- Medicare hospice cost report data
- State mandated data submission
- State hospice association membership surveys
- Applicable studies published in peer-reviewed journals

Suggested citation:

NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, September 2010 .

Questions may be directed to:

National Hospice and Palliative Care Organization

Attention: Research

Phone: 703.837.1500

Web: www.nhpco.org/research

Email: Research@nhpco.org

Additional Statistics for NHPCO Members

National Summary of Hospice Care

Active hospice and palliative care provider members of the National Hospice and Palliative Care Organization may access additional statistics in NHPCO's ***National Summary of Hospice Care***. This annual report includes comprehensive statistics on provider demographics, patient demographics, service delivery, inpatient services, and cost of care. It is provided exclusively to NHPCO members at no cost, and it can be downloaded from the National Data Set survey Web page at www.nhpco.org/nds.[7]

A partial list of summary tables includes:

- Inpatient facility statistics
  - Level of care
  - Length of service
  - Staffing
- Length of service by:
  - Agency size
  - Agency type
  - Primary diagnosis
- Palliative care services
  - Percent providing palliative consult services
  - Percent providing palliative care services at home or in an inpatient facility
  - Percent of physician hours devoted to palliative clinical care
- Patient visits
  - Visits per home care admission
  - Visits per day
  - Visits per week
- Payer mix by:
  - Agency tax status
  - Agency type
- Revenue and expenses

NHPCO Performance Measure Reports

NHPCO members also have access to national-level summary statistics for the following NHPCO performance measurement tools:

1. End Result Outcome Measures (EROM) (www.nhpco.org/outcomemeasures)
   - Pain relief within 48 hours of admission
   - Avoiding unwanted hospitalization
   - Avoiding unwanted CPR
2. Family Evaluation of Bereavement Services (FEBS) (www.nhpco.org/febs)[8]
3. Family Evaluation of Hospice Care (FEHC) (www.nhpco.org/fehc)[9]
4. Survey of Team Attitudes and Relationships (STAR)[10] (www.nhpco.org/star)
   - Job satisfaction (hospice-specific)
   - Salary ranges
   - Provider-level results

[7] A valid NHPCO member ID and password are required to access the NHPCO National Summary of Hospice Care report. This report is only available to current hospice and palliative care members of NHPCO.
[8] Participating agencies receive provider-level reports comparing their hospice's results to national estimates.
[9] Participating agencies receive provider-level reports comparing their hospice's results to national estimates and peer groups.
[10] The STAR national summary report is available for purchase by both NHPCO members and non-members through NHPCO's Marketplace.