NHPCO Facts and Figures:

Hospice Care in America

National Hospice and Palliative Care Organization

Released October 2008

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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., total patients served, gender, age, ethnicity, race, primary diagnosis, and length of service);
- Hospice provider characteristics (e.g., total number of providers, organizational type, size, and tax status);
- Location and level of care; and
- 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 to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to 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. At the center of hospice care is the belief that all people have the right to die pain-free and with dignity, and that their families will receive the necessary support to assist them.

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

How does hospice care work?

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 is Cared for by Hospice?

How many patients receive care each year?

In 2007, an estimated 1.4 million patients received services from hospice (Figure 2). This estimate includes:

- 930,000 patients who died under hospice care in 2007;
- 258,000 who remained on the hospice census at the end of 2007 (known as "carryovers"); and
- 222,000 patients who were discharged alive in 2007 for reasons including extended prognosis, desire for curative treatment, and other reasons (known as "live discharges").

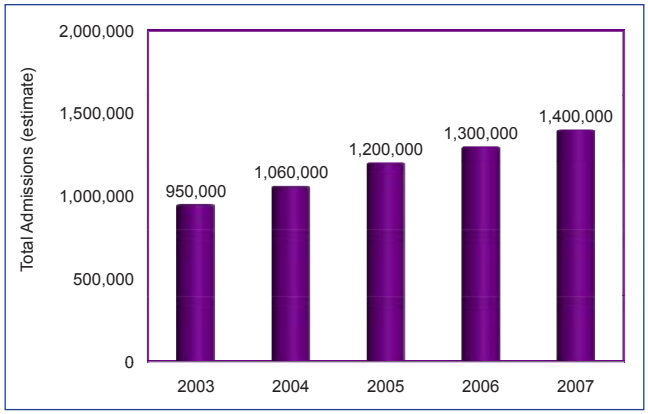

Figure 2. Total Hospice Patients Served by Year

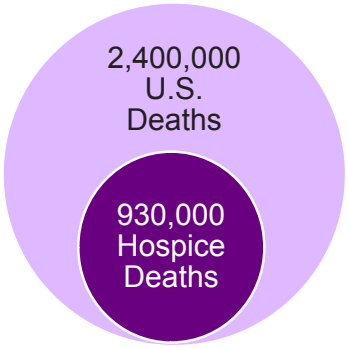

Figure 3. Hospice Utilization in U.S.

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 2007, NHPCO estimates that approximately 38.8% 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 2007 was 20.0 days, a slight decline from 20.6 days in 2006. 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 increased to 67.4 days (from 59.8 in 2006) (Figure 4).[1]

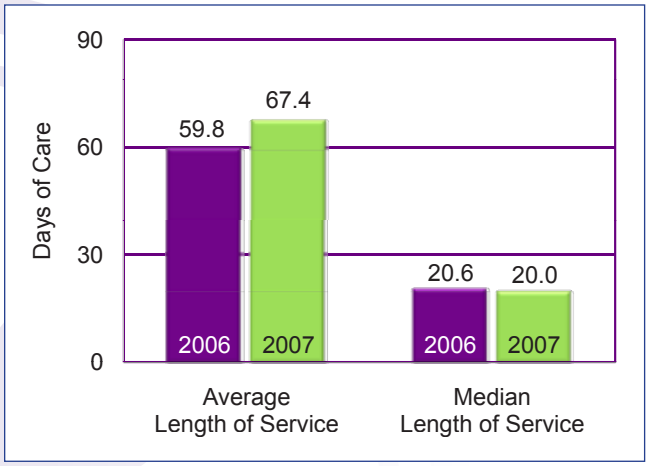

Figure 4. Length of Service by Year

Short and Long Lengths of Service

Approximately 30.8% of those served by hospice died or were discharged in seven days or less, and 13.1% died or were discharged in 180 days or more.

Impact of Hospice Care on Survival

Hospice care may prolong the lives of some terminally ill patients. In a recent 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. Researchers selected 4,493 terminally ill patients with either congestive heart failure or cancer of the breast, colon, lung, pancreas, or prostate. They then analyzed the difference in survival periods between those who received hospice care and those who did not.

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 also was significantly longer for the hospice patients with lung cancer (39 days) and pancreatic cancer (21 days), while marginally significant for colon cancer (33 days).

[1] Length of service can be reported as both an average and a median. The median, however, is considered a more accurate gauge in 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.

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 2007, 70.3% of patients received care at home. The percentage of hospice patients receiving care in an inpatient facility increased from 17.0% to 19.2%. Only 10.5% of patients died in a hospital setting that was not operated by a hospice team.

Table 1. Location of Death

Location of Death	2007	2006
Patient's Place of Residence	70.3%	74.1%
Private Residence	42.0%	47.1%
Nursing Facility	22.8%	22.5%
Residential Facility	5.5%	4.6%
Hospice Inpatient Facility	19.2%	17.0%
Acute Care Hospital	10.5%	8.8%

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 free¬standing or located on a hospital campus and 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. NHPCO estimates that more than 450 inpatient facilities were operating in the U.S. in 2007.

What are characteristics of the hospice patient population?

Patient Gender

Slightly more than half of hospice patients are female (Table 2).

Table 2. Percentage of Hospice Patients by Gender

Patient Gender	2007	2006
Female	53.9%	55.6%
Male	46.1%	44.4%

Patient Age

Four out of five hospice patients are 65 years of age or older — and more than one-third of all hospice patients are 85 years of age or older (Table 3). As the U.S. population ages, the number of patients ages 65 and older is expected to grow. The pediatric and young adult population accounts for less than 1% of hospice admissions.

Table 3. Percentage of Hospice Patients by Age

Patient Age Group	2007	2006
Less than 35 Years	0.9%	0.9%
35 – 64 Years	16.5%	17.3%
65 – 74 Years	16.2%	17.1%
75 – 84 Years	30.0%	31.4%
85 + Years	36.6%	33.2%

Hospice Utilization in 65+ Age Group

A recent in-depth analysis[3] 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 2007, 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	2007	2006
Non-Hispanic or Latino Origin	94.9%	95.1%
Hispanic or Latino Origin	5.1%	4.9%

Patients of minority (non-Caucasian) race accounted for nearly one out of every five hospice patients in 2007 (Table 5).

Table 5. Percentage of Hospice Patients by Race

Patient Race	2007	2006
Caucasian	81.3%	80.9%
Multiracial or Other Race	7.8%	8.8%
Black / African American	9.0%	8.2%
Asian, Hawaiian, or Other Pacific Islander	1.6%	1.8%
American Indian or Alaskan Native	0.3%	0.3%

Primary Diagnosis

When the U.S. hospice community 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 (41.3%) (Table 6). In fact, less than 25 percent of U.S. deaths are now caused by cancer, with the majority of deaths due to eventually terminal chronic diseases.[4]

In 2007, the top five chronic illnesses served by hospice included heart disease (11.8% of admissions), debility unspecified (11.2%), dementia (10.1%), and lung disease (7.9%).

[3] 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.

[4] Heron MP, Hoyert DL, Xu J, Scott C, Tejada-Vera B. Deaths: Preliminary data for 2006. National vital statistics reports; vol 56 no 16. Hyattsville, MD: National Center for Health Statistics. 2008.

Table 6. Percentage of Hospice Admissions by Primary Diagnosis

Primary Diagnosis	2007	2006
Cancer (malignancies)	41.3%	44.1%
Non-Cancer Diagnoses	58.7%	55.9%
Heart Disease	11.8%	12.2%
Debility Unspecified[5]	11.2%	11.8%
Dementia, including Alzheimer's Disease	10.1%	10.0%
Lung Disease, including Chronic Obstructive Pulmonary Disease	7.9%	7.7%
Stroke or Coma	3.8%	3.4%
Kidney Disease, including End Stage Renal Disease	2.6%	2.9%
Motor Neuron Diseases, including ALS	2.3%	2.0%
Liver Disease	2.0%	1.8%
HIV / AIDS	0.6%	0.5%
Other Diagnoses	6.5%	3.7%

Who Provides Care?

How many hospices were in operation in 2007?

The number of hospice programs nationwide continues to increase — from the first program that opened in 1974 to approximately 4,700 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.

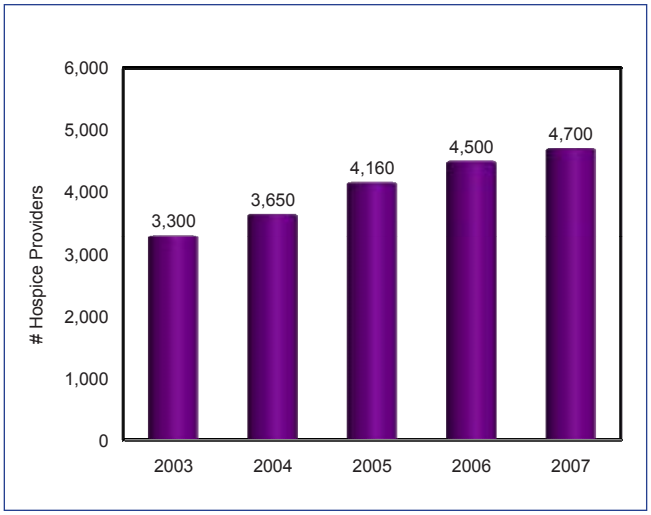

Figure 5. Total Hospice Providers by Year

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

Provider Type	2007	2006
Free Standing / Independent	58.3%	56.2%
Hospital Based	20.8%	22.6%
Home Health Based	19.7%	20.1%
Nursing Home Based	1.3%	1.2%

Agency Size

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

One measure of agency size is total admissions over the course of a year. In 2007, 79.4% of hospices had fewer than 500 total admissions (Table 8).

[5] Debility unspecified population include frail elders with multiple illnesses and steady deterioration.

Table 8. Percentage of Total Agency Admissions

Total Patient Admissions	2007	2006
1 to 49	18.5%	17.9%
50 to 150	28.0%	29.0%
151 to 500	32.9%	34.1%
501 to 1,500	16.1%	14.5%
More than 1,500	4.6%	4.5%

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 2007, the mean daily census was 90.2 patients and the median (50th percentile) daily census was 51.8 patients. Only 18.5% of providers routinely care for more than 100 patients per day (Figure 6).

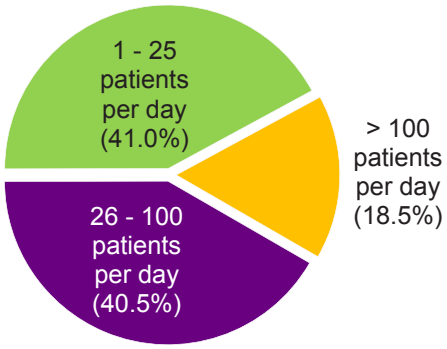

Figure 6. Average Daily Census

Organizational Tax Status

Hospice agencies are organized into three tax designations:

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

In 2007, 48.6% of providers reported not-for-profit tax status and 47.1% reported for profit status (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 (less than 5% in 2007).

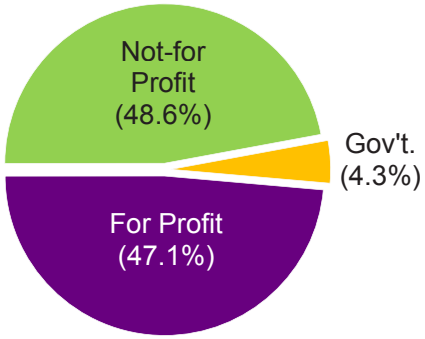

Figure 7. Tax Status Distribution

While the majority of hospice providers have not-for-profit tax status, industry growth is being seen in the for-profit sector (Figure 8).

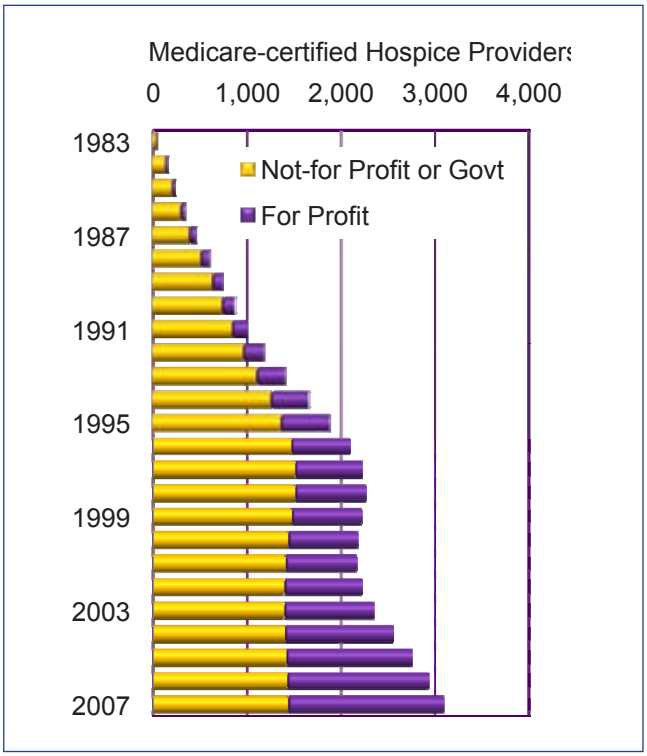

Figure 8. Growth in For Profit Hospice Providers

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 dominant source of payment for hospice care. The percentage of hospice patients covered by the Medicare Hospice Benefit versus other payment sources was 83.6% in 2007 (Table 9). The percentage of patient days covered by the Medicare Hospice Benefit versus other sources was 87.0% (Table 10).

Table 9. Percentage of Patients Served by Payer

Payer	2007	2006
Hospice Medicare Benefit	83.6%	83.7%
Private Insurance	8.5%	8.0%
Hospice Medicaid Benefit	5.0%	5.3%
Other Payment Sources	2.9%	3.0%

Table 10. Percentage of Patient Care Days by Payer

Payer	2007	2006
Hospice Medicare Benefit	87.0%	87.7%
Private Insurance	4.8%	5.3%
Hospice Medicaid Benefit	4.5%	4.8%
Other Payment Sources	3.7%	2.2%

Most hospice agencies (93.1%) have been certified by the federal agency, the Centers for Medicare and Medicaid Services (CMS), to file for reimbursement under the Medicare Hospice Benefit. In 2007, more than 3,000 hospice agencies were certified. The states with the largest number of certified providers are highlighted in Figure 9.

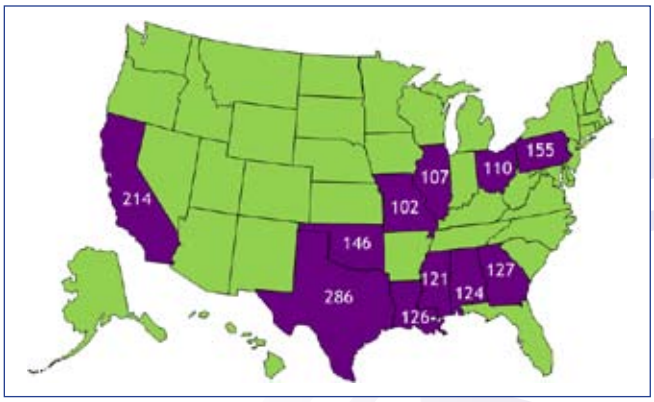

Figure 9. States With More Than 100 Medicare-certified Hospice Providers in 2007

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 be affiliated with a home health agency that has Medicare certification or it may be an all-volunteer program that covers patient care and staffing expenses through donations and the use of volunteer staff. NHPCO estimates that there are more than 200 all-volunteer programs in the U.S.

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 has been used for a longer period of time. For cancer patients, hospice use decreased Medicare costs up until 233 days of 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;
- Coaches 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; and
- 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 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 chronic 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 2007, routine home care comprised the majority of hospice patient care days (Table 11).

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

Level of Care	2007	2006
Routine Home Care	95.6%	96.4%
General Inpatient Care	3.3%	3.0%
Continuous Care	0.9%	0.4%
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; and
- Bereavement services.

Hospice staff time centers on direct care for the patient and family: 75.6% of home hospice full-time equivalent employees (FTEs) and 76.3% of total FTEs were designated for direct patient care or bereavement support in 2007 (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 2007, the average patient caseload for a home health aide was 9.5 patients, 11.2 patients for a nurse case manager, and 23.4 patients for a social service worker.

Table 12. Distribution of Paid Staff FTEs

Staff Discipline	2007	2006
Clinical	71.6%	71.9%
Nursing	33.8%	30.7%
Home Health Aides	19.8%	23.9%
Social Services	8.2%	8.5%
Chaplains	4.2%	n/a
Physicians	3.4%	2.6%
Other Clinical Staff	4.8%	6.9%
Non-Clinical Staff	23.7%	23.5%
Bereavement Staff	4.7%	4.6%

Volunteer Commitment

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. Hospice volunteers provide service in three general areas:

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

In 2007, most volunteers were assisting with direct patient care (58.7%); 25.1% provided patient care support and 18.2% provided general support.

Hospice is unique in that it is the only Medicare provider type whose Conditions of Participation requires volunteers to provide at least five percent of total patient care hours. In 2007, 6% of all clinical staff hours were provided by volunteers.

In 2007, the typical hospice volunteer devoted 45.1 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 can access bereavement education and support.

In 2007, 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 (94.7%) also offer some level of bereavement services to the community; community members account for about 18% of those served by hospice bereavement programs.

Assessing the Quality of Hospice Care

Table 13. Sample NHPCO Hospice Performance Measures

Source / Performance Measure	2007
Family Evaluation of Hospice Care	
Hospice team clearly explained plan of care (% Yes)	96.6%
Rating of care patient received while under care of hospice (% Excellent)	75.7%
Hospice response to evening / weekend needs (% Excellent)	66.0%
Family Evaluation of Bereavement Services	
How well caregiver needs were met by bereavement team in post-death year (% Very Well)	75.8%
End Result Outcome Measures	
Patient's pain brought to a comfortable level within 48 hours of admission to hospice (% Yes)	71.0%

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; and
- 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 census of U.S. hospice providers
- NHPCO Membership Survey
  - – Annual survey of NHPCO provider members

Secondary data sources:

- Medicare Provider of Services certification data;
- Medicare hospice cost report data;
- State hospice licensing surveys;
- State hospice association membership surveys; and
- Applicable studies published in peer-reviewed journals.

Suggested citation:

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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 will be available for purchase by both NHPCO members and non-members through NHPCO's Marketplace beginning in 2009.