



## **NHPCO's Facts and Figures**

*Hospice Care in America*

*2013 Edition*

# 2013

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” (page 16) and to the footnotes for the source information and methodologies used to derive this information. Additional resources for NHPCO members are also provided on page 14.

### What is hospice care?

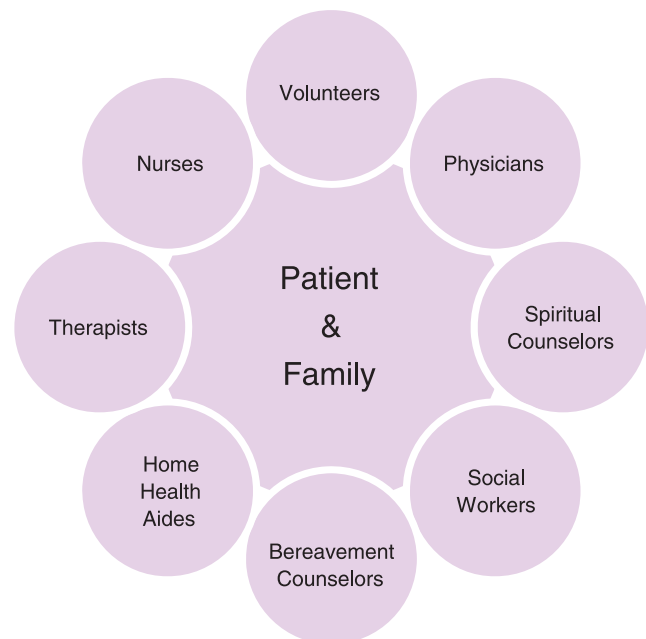
Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well.

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, hospice 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 2012, an estimated 1.5 to 1.6<sup>1</sup> million patients received services from hospice (Figure 2). This estimate includes:

- patients who died while receiving hospice care
- patients who received care in 2011 and who continued to receive care into 2012 (known as “carryovers”)
- patients who left hospice care alive in 2012 for various reasons including extended prognosis, desire for curative treatment, and other reasons (known as “live discharges”)

As shown in Figure 2, the number of patients and families served by hospice has steadily increased over the past several years.

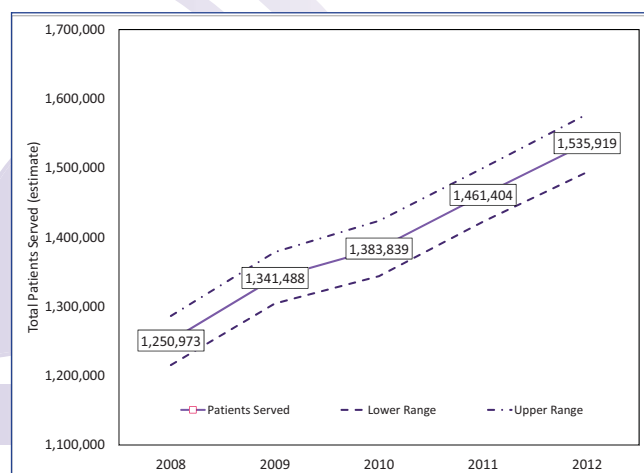


Figure 2. Total Hospice Patients Served by Year<sup>1</sup>

NHPCO continually examines, and when appropriate, revises the methodology employed in its data analysis. The estimate of patients served was generated utilizing a statistical model that NHPCO believes allows a better representation of the number of patients and families

accessing hospice services. This model, derived from a combination of NHPCO and CMS data, produces a range of possible values for the estimate rather than a single number.

### 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. NHPCO estimates that approximately 1,113,000 deaths occurred in the U.S. while under the care of hospice. However, currently CDC data on the number of U.S. deaths in 2012 is not available. Therefore, NHPCO is not able to report on the estimated percentage of all deaths while under the care of hospice. This report will be updated when the CDC data becomes available.

### Hospice Use by Medicare Decedents

Over the past decade, the hospice industry has been marked by substantial growth in the number of hospice programs and patients served. In an independent analysis of Medicare claims data, Dr. Joan Teno found similar growth in the proportionate use of the Medicare hospice benefit. Of all Medicare decedents in the year 2001, 18.8% accessed hospice for three or more days. By 2007 the proportion of Medicare decedents accessing three or more days of hospice services had increased to 30.1%.

Examination of the number of Medicare decedents with a cancer diagnosis found that 36.6% accessed three or more days of hospice care in 2001. The percentage grew to 43.3% in 2007 for Medicare decedents who received



with a dementia diagnosis received three or more days of hospice care. By the year 2007, that proportion had grown to 33.6%. This trend in hospice use for Medicare decedents from 2001 to 2007 is illustrated in Figure 4.

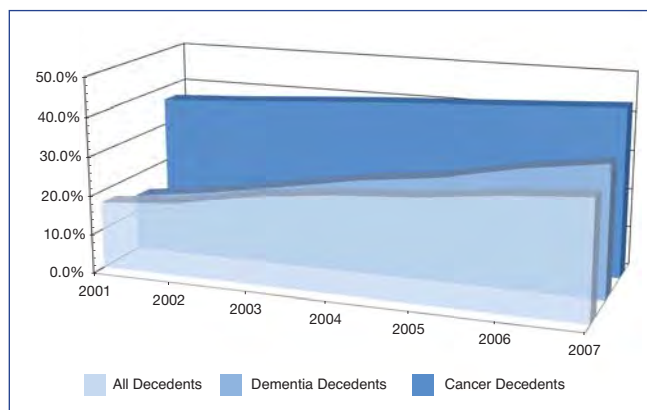


Figure 3. Proportion of Medicare Decedents Accessing Three or More Days of Hospice Care

### 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 2012 was 18.7 days, a decrease from 19.1 days in 2011<sup>1</sup>. 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 from 69.1 days in 2011 to 71.8 in 2012 (Figure 4)<sup>1</sup>. Over the past several years the median length of service has declined while the average length of service increased.

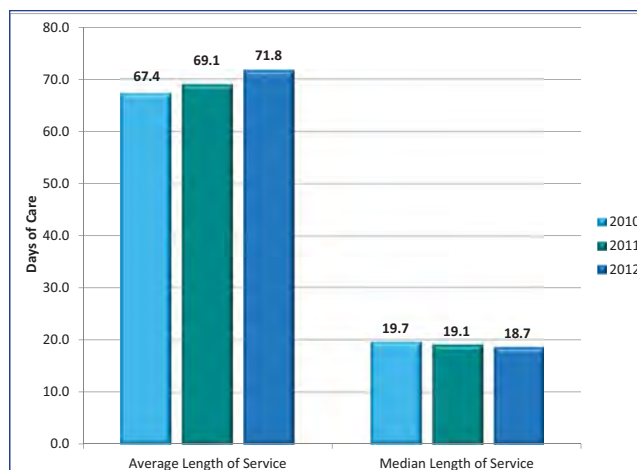


Figure 4. Length of Service by Year<sup>1</sup>

### Short and Long Lengths of Service

In 2012, approximately the same proportion of hospice patients (approximately 35.5%) died or were discharged within seven days of admission when compared to 2011 (35.7%)<sup>1</sup>. A slightly smaller proportion of patients died or were discharged within 14 days of admission when compared to 2011 (49.5% in 2012 and 50.1% in 2011)<sup>1</sup>. Approximately the same proportion of patients remained under hospice for longer than 180 days (11.4% in 2011 and 11.5% in 2012)<sup>1</sup>.

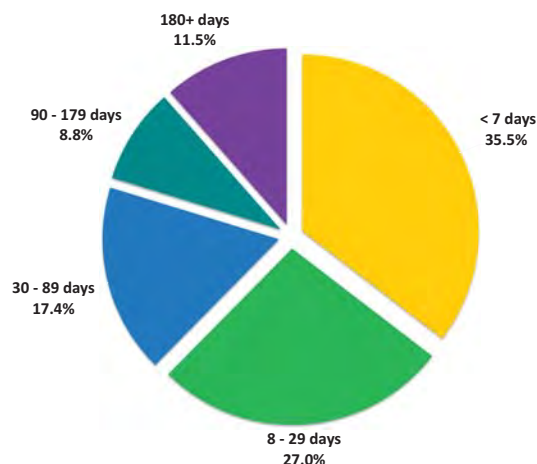


Figure 5. Proportion of Patients by Length of Service in 2011<sup>1</sup>

\* 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).



## 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 2012, 66.0%<sup>1</sup> of patients received care at home. The percentage of hospice patients receiving care in a hospice inpatient facility increased from 26.1% to 27.4%<sup>1</sup>.

*Table 1. Location of Hospice Patients at Death<sup>1</sup>*

| Location of Death            | 2012  | 2011  |
|------------------------------|-------|-------|
| Patient’s Place of Residence | 66.0% | 66.4% |
| Private Residence            | 41.5% | 41.6% |
| Nursing Home                 | 17.2% | 18.3% |
| Residential Facility         | 7.3%  | 6.6%  |
| Hospice Inpatient Facility   | 27.4% | 26.1% |
| Acute Care Hospital          | 6.6%  | 7.4%  |

## Inpatient Facilities and Residences

In addition to providing home hospice care, about one in five hospice agencies also operate a dedicated inpatient unit or facility<sup>1</sup>. 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.

## Hospice in the Nursing Home

As the average life span in the United States has increased, so has the number of individuals who die of chronic progressive diseases that require longer and more sustained care. An increasing number of these individuals reside in nursing homes prior to their death. This rise has been mirrored by growth in the number of hospice patients who reside in nursing homes.

A 2010 study by Miller et al., examined the growth of Medicare-certified hospices providing hospice in the

nursing home from 1999 to 2006. Using Medicare’s minimum data set (MDS), the study found that the proportion of nursing home decedents who received hospice care rose from 14.0% in 1999 to 33.1% in 2006; a growth rate that closely paralleled the increase in Medicare-certified hospice programs. The demographic characteristics of hospice patients in the nursing home changed little during that time and are very similar to the overall characteristics of hospice patients. Most nursing home hospice decedents were female (67%), white (90%), and were older than 85 years (55%)<sup>5</sup>.

## What are the 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<sup>1</sup>*

| Patient Gender | 2012  | 2011  |
|----------------|-------|-------|
| Female         | 56.4% | 56.4% |
| Male           | 43.6% | 43.6% |

### Patient Age

In 2012, 83.4%<sup>1</sup> 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<sup>1</sup>*

| Patient Age Category | 2012  | 2011  |
|----------------------|-------|-------|
| Less than 24 years   | 0.4%  | 0.4%  |
| 25 - 34 years        | 0.4%  | 0.4%  |
| 35 - 64 years        | 15.7% | 16.0% |
| 65 - 74 years        | 16.3% | 16.3% |
| 75 - 84 years        | 27.7% | 27.6% |
| 85+ years            | 40.5% | 39.3% |



## Patient Ethnicity and Race

Following U.S. Census guidelines, NHPCO reports Hispanic ethnicity as a separate concept from race. In 2012, more than 6%<sup>1</sup> of patients were identified as being of Hispanic or Latino origin (Table 4).

*Table 4. Percentage of Hospice Patients by Ethnicity<sup>1</sup>*

| Patient Ethnicity             | 2012  | 2011  |
|-------------------------------|-------|-------|
| Non-Hispanic or Latino origin | 93.1% | 93.8% |
| Hispanic or Latino origin     | 6.9%  | 6.2%  |

Patients of minority (non-Caucasian) race accounted for less than one fifth of hospice patients in 2011 (Table 5)<sup>1</sup>.

*Table 5. Percentage of Hospice Patients by Race<sup>1</sup>*

| Patient Race                            | 2012  | 2011  |
|---|-------|-------|
| White/Caucasian                         | 81.5% | 82.8% |
| Multiracial or Other Race               | 6.7%  | 6.1%  |
| Black/African American                  | 8.6%  | 8.5%  |
| Asian, Hawaiian, Other Pacific Islander | 2.8%  | 2.4%  |
| American Indian or Alaskan Native       | 0.3%  | 0.2%  |

## 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 (36.9%)<sup>1</sup> (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.<sup>4</sup>

The top four non-cancer primary diagnoses for patients admitted to hospice in 2012 remained debility unspecified (14.2%), dementia (12.8%), heart disease (11.2%), and lung disease (8.2%).<sup>1</sup>

*Table 6. Percentage of Hospice Admissions by Primary Diagnosis<sup>1</sup>*

| Primary Diagnosis                   | 2012  | 2011  |
|-------------------------------------|-------|-------|
| <b>Cancer</b>                       | 36.9% | 37.7% |
| <b>Non-Cancer Diagnoses</b>         | 63.1% | 62.3% |
| Debility Unspecified                | 14.2% | 13.9% |
| Dementia                            | 12.8% | 12.5% |
| Heart Disease                       | 11.2% | 11.4% |
| Lung Disease                        | 8.2%  | 8.5%  |
| Other                               | 5.2%  | 4.8%  |
| Stroke or Coma                      | 4.3%  | 4.1%  |
| Kidney Disease (ESRD)               | 2.7%  | 2.7%  |
| Liver Disease                       | 2.1%  | 2.1%  |
| Non-ALS Motor Neuron                | 1.6%  | 1.6%  |
| Amyotrophic Lateral Sclerosis (ALS) | 0.4%  | 0.4%  |
| HIV / AIDS                          | 0.2%  | 0.2%  |



## Who Provides Care?

### How many hospices were in operation in 2011?

The number of hospice programs nationwide continues to increase — from the first program that opened in 1974 to over 5,500 programs today (Figure 6). 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.

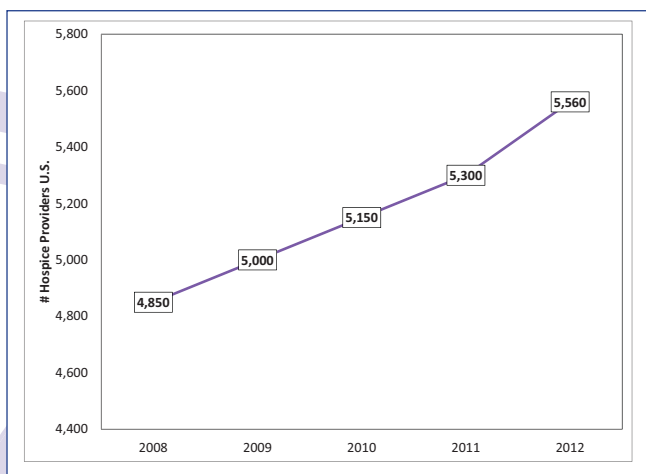


Figure 6. Total Hospice Providers by Year <sup>1</sup>

### 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 <sup>1</sup>

| Agency Type                       | 2012  | 2011  |
|-----------------------------------|-------|-------|
| Free Standing/Independent Hospice | 57.4% | 57.5% |
| Part of a Hospital System         | 20.5% | 20.3% |
| Part of a Home Health Agency      | 16.9% | 16.8% |
| Part of a Nursing Home            | 5.2%  | 5.2%  |

### 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 2012, 77.4%<sup>1</sup> of hospices had fewer than 500 total admissions (Table 8).

Table 8. Total Patient Admissions <sup>1</sup>

| Total Patient Admissions | 2011  | 2012  |
|--------------------------|-------|-------|
| 1 to 49                  | 15.7% | 15.4% |
| 50 to 150                | 28.7% | 29.3% |
| 151 to 500               | 33.0% | 34.2% |
| 501 to 1,500             | 17.7% | 16.7% |
| > 1,500                  | 4.9%  | 4.4%  |

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 2012, the mean average daily census was 148.5<sup>1</sup> patients and the median (50th percentile) average daily census was 92.2<sup>1</sup> patients. More than one third of providers routinely care for more than 100 patients per day (Figure 8).

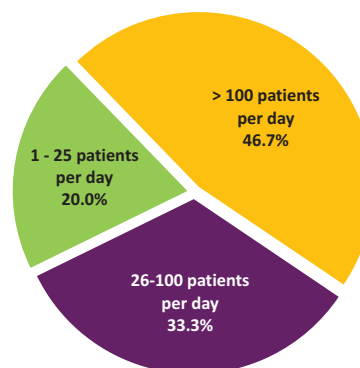


Figure 7. Average Daily Census <sup>1</sup>





## 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 analysis of CMS's Provider of Service (POS) file, 32%<sup>2</sup> of active Medicare Provider Numbers are assigned to providers that held not-for-profit tax status and 63%<sup>2</sup> held for-profit status in 2012. Government-owned programs, (e.g., hospices operated by state and local governments), comprise the smallest percentage of hospice providers (about 5%<sup>2</sup> in 2012.).

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 begun to decline over the same period.

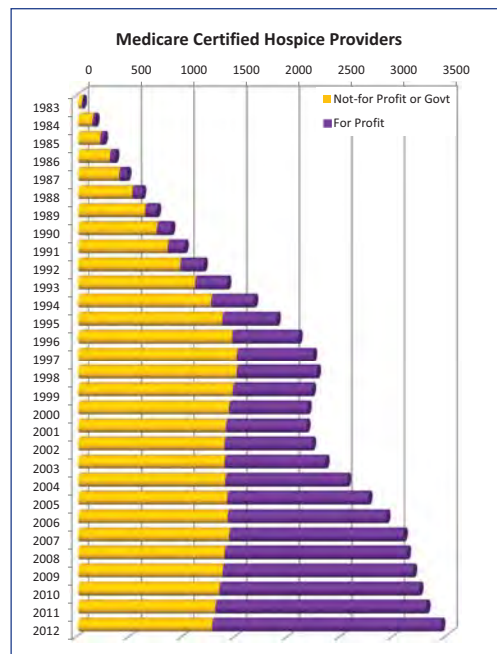


Figure 8. Growth in Medicare-Certified Hospice Providers<sup>2</sup>



## 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 83.7%<sup>1</sup> in 2012 (Table 9). The percentage of patient days covered by the Medicare hospice benefit versus other sources was 89.0%<sup>1</sup> (Table 10).

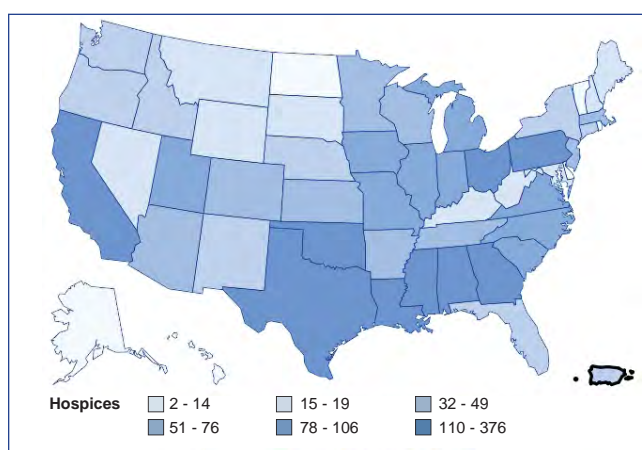
**Table 9. Percentage of Patients Served by Payer<sup>1</sup>**

| Payer                             | 2012  | 2011  |
|-----------------------------------|-------|-------|
| Medicare Hospice Benefit          | 83.7% | 84.0% |
| Managed Care or Private Insurance | 7.6%  | 7.7%  |
| Medicaid Hospice Benefit          | 5.5%  | 5.2%  |
| Uncompensated or Charity Care     | 1.2%  | 1.3%  |
| Self Pay                          | 0.9%  | 1.1%  |
| Other Payment Source              | 1.2%  | 0.7%  |

**Table 10. Percentage of Patient Care Days by Payer<sup>1</sup>**

| Payer                             | 2012  | 2011  |
|-----------------------------------|-------|-------|
| Medicare Hospice Benefit          | 89.0% | 87.9% |
| Managed Care or Private Insurance | 4.4%  | 5.0%  |
| Medicaid Hospice Benefit          | 4.3%  | 5.0%  |
| Uncompensated or Charity Care     | 0.8%  | 1.0%  |
| Self Pay                          | 0.6%  | 0.5%  |
| Other Payment Source              | 0.9%  | 0.6%  |

Most hospice agencies (93.1%<sup>1</sup>) have been certified by the Centers for Medicare and Medicaid Services (CMS) to provide services under the Medicare hospice benefit. In 2012, there were more than 3,700<sup>2</sup> certified hospice agencies. Figure 9 shows the distribution of Medicare-certified hospice providers by state.



**Figure 9. Medicare-Certified Hospices by State<sup>2</sup>**

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.



## 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, 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
- 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.

In 2012, 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<sup>1</sup>*

| Level of Care          | 2012  | 2011  |
|------------------------|-------|-------|
| Routine Home Care      | 95.0% | 97.1% |
| General Inpatient Care | 2.7%  | 2.2%  |
| Continuous Care        | 0.5%  | 0.4%  |
| Respite Care           | 0.3%  | 0.3%  |

### Staffing Management and Service Delivery

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

- 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: 70.4%<sup>1</sup> of home hospice full-time equivalent employees (FTEs) were designated for direct patient care or bereavement support in 2012.



The number of patients that a clinical staff member is typically responsible for varies by discipline. In 2012, the average patient caseload for a hospice aide was 11.0<sup>1</sup> patients, 11.3<sup>1</sup> patients for a nurse case manager, and 26.5<sup>1</sup> patients for a social worker.

## Volunteer Commitment

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. NHPCO estimates that in 2012, 400,000<sup>1</sup> hospice volunteers provided 19 million<sup>1</sup> hours of service. Hospice volunteers provide service in three general areas:

- Spending time with patients and families (“direct support”)
- 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 2012, most volunteers were assisting with direct support (60.8%<sup>1</sup>), 18.6%<sup>1</sup> provided clinical care support, and 20.7%<sup>1</sup> provided general support.

Hospice is unique in that it is the only provider whose Medicare Conditions of Participation requires volunteers to provide at least 5% of total patient care hours.

In 2012, 5.4%<sup>1</sup> of all clinical staff hours were provided by volunteers. The typical hospice volunteer devoted 44.4<sup>1</sup> hours of service over the course of the year and patient care volunteers made an average of 21<sup>1</sup> 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 2012, for each patient death, an average of 1.7<sup>1</sup> 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 (92.5%<sup>1</sup>) also offer some level of bereavement services to the community; community members account for about 13.5%<sup>1</sup> of those served by hospice bereavement programs.



## Assessing the Quality of Hospice Care

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 12.

**Table 12. Sample NHPCO Hospice Performance Measures**

| Performance Measure  | 2012  |
|--|-------|
| <b>Family Evaluation of Hospice Care (FEHC)</b>  |       |
| Overall Rating<br><i>Percent of individuals rating the quality of hospice care "excellent"</i> | 73.5% |
| Composite Score<br><i>Global measure of hospice quality based on 17 core measures</i>          | 85.8% |
| <b>Family Evaluation of Bereavement Services (FEBS)</b>  |       |
| How well services met the needs of the bereavement client (% "Very Well")                      | 75.8% |
| <b>Comfortable Dying Measure</b>   |       |
| Patient's pain brought to a comfortable level within 48 hours of initial assessment            | 66.7% |
| Patients still uncomfortable due to pain 48 hours after initial assessment                     | 12.6% |



## 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 webpage at [www.nhpc.org/nds](http://www.nhpc.org/nds).<sup>i</sup>

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. Patient Outcomes and Measures (POM) ([www.nhpc.org/outcomemeasures](http://www.nhpc.org/outcomemeasures))
  - Pain relief within 48 hours of admission (NQF 0209)
  - Avoiding unwanted hospitalization
  - Avoiding unwanted CPR
2. Family Evaluation of Bereavement Services (FEBS) ([www.nhpc.org/febs](http://www.nhpc.org/febs))<sup>ii</sup>
3. Family Evaluation of Hospice Care (FEHC) ([www.nhpc.org/fehcc](http://www.nhpc.org/fehcc))<sup>iii</sup>
4. Survey of Team Attitudes and Relationships (STAR)<sup>iv</sup> ([www.nhpc.org/star](http://www.nhpc.org/star))
  - Job satisfaction (hospice-specific)
  - Salary ranges
  - Provider-level results

<sup>i</sup> 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.

<sup>ii</sup> Participating agencies receive provider-level reports comparing their hospice's results to national estimates.

<sup>iii</sup> Participating agencies receive provider-level reports comparing their hospice's results to national estimates and peer groups.

<sup>iv</sup> The STAR national summary report is available for purchase by both NHPCO members and non-members through NHPCO's Marketplace.



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**Suggested citation:**

NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA:  
National Hospice and Palliative Care Organization, October 2013.

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## Appendix 1: Data Sources

1. 2011, NHPCO National Data Set and/or NHPCO Member Database.
2. 1st Quarter 2012, Centers for Medicare and Medicaid Services (CMS) Provider of Service File (POS).
3. Hoyert DL, Xu J,. *Deaths: Preliminary Data for 2011*, National Vital Statistics Reports, vol 61 no 6. National Center for Health Statistics, CDC, available online at: [http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61\\_06.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_06.pdf).
4. Murphy SL, Xu J, Kochanek KD. *Final Data for 2010*, National Vital Statistics Reports, vol 61 no 4. National Center for Health Statistics, 2013
5. Miller SC, Lima J, Gozalo PL, Mor V. *The Growth of Hospice Care in U.S. Nursing Homes*. JAGS. 2010 58:1481-88.





## Appendix 2: How Accurate are the NHPCO Estimates?

Estimation, especially when performed on a national level, is a challenging undertaking. NHPCO is continuously working to improve and validate the estimates that are provided to members and the greater hospice community. However, many of the national estimates rely on a less-than-optimal convenience sample of hospices voluntarily submitting data to the NHPCO National Data Set (NDS).

In the fall of 2010, NHPCO performed a comparative analysis with data obtained through a probabilistic sampling methodology – considered the gold standard sampling method – performed by the National Center for Health Statistics (NCHS). Earlier that year, the NCHS released data from its 2007 National Home and Hospice Care Survey (NHHCS). NHPCO first performed a complete analysis of hospice data from the 2007 NHHCS and then compared the results to estimates from the 2007 National Summary of Hospice Care.

The findings of the comparison provide strong corroborating evidence in support of NHPCO's national estimates. Analysis of similar data between the two data sets describes program and patient characteristics of very similar distributions. For statistical comparison, 95% confidence intervals (95% CI) were included in the estimates generated from the NHHCS data. When comparing results, most point estimates generated from the NDS data fell within the 95% CI of the NHHCS results. All such results are considered to be not appreciably different. Even those point estimates landing outside the 95% CI were often very close and also likely not to be statistically significantly different. However, statistical significance testing is needed to confirm that results are, in fact, not statistically significantly different.

An example of the representativeness of the NDS is the distribution of hospices by size, as measured by total unique patient admissions during a year. Table 1 shows the side-by-side comparison of estimates of the distribution of hospice sizes by total admissions generated from NHHCS and NDS data. In all cases, the NDS-based point estimates of the proportion of hospices in each size category were within the 95% CI of the estimate generated from the probabilistic-based NHHCS data. Comparison of results for the distribution of agencies by ownership type [freestanding NHHCS 56.3 (48.4 – 64.2) vs NDS 58.3 | non freestanding NHHCS 41.1 (33.6 – 48.7) vs. NDS 41.8] shows that differences between the two estimates are not appreciably different. Comparable variables were not available for other agency-level characteristics.

*Table 1. Distribution of Hospice Size by Total Patient Admissions (2006)*

| Total Patient Admissions | NHHCS Percent (95% CI) | NDS Percent |
|--------------------------|------------------------|-------------|
| 0 to 49                  | 15.9% (10.5 – 21.2)    | 17.9%       |
| 50 to 150                | 31.7% (23.7 – 39.7)    | 29%         |
| 151 to 500               | 30.9% (23.3 – 38.5)    | 34.1%       |
| 501 to 1,499             | 11.1% (7.2 – 15.1)     | 14.5%       |
| 1,500 or more            | 4.2% (2.5 – 5.9)       | 4.5%        |

Results for estimates of patient characteristics were also comparable between NDS and NHHCS data. Tables 2 through 4 show estimates of the distribution of patient characteristics. In all cases, the point estimates



generated from NDS data fall within the 95% CI of estimates generated from NHHCS data. These again are a strong corroborative indication that the characteristics of patients represented in the NDS are representative of patients on a national level.

**Table 2. Percent of Non-Death Discharges**

| <u>NHHCS</u><br>Percent<br>(95% CI) | <u>NDS</u><br>Percent |
|-------------------------------------|-----------------------|
| 15.6%<br>(13.8 - 17.4)              | 15.9%                 |

**Table 3. Patient Demographics**

| <u>Gender</u>    | <u>NHHCS</u><br>Percent<br>(95% CI) | <u>NDS</u><br>Percent |
|------------------|-------------------------------------|-----------------------|
| Male             | 44.9%<br>(42.4 - 47.4)              | 46.1%                 |
| Female           | 55.1%<br>(52.6 - 57.6)              | 53.9%                 |
| <u>Age (yrs)</u> |                                     |                       |
| 0 - 24           | 0.27%<br>(0.03 - 0.52)              | 0.5%                  |
| 25 - 34          | 0.29%<br>(0.02 - 0.57)              | 0.4%                  |
| 35 - 64          | 16.4%<br>(14.5 - 18.2)              | 16.5%                 |
| 65 - 74          | 15.4%<br>(13.6 - 17.2)              | 16.2%                 |
| 75 - 84          | 29.5%<br>(27.2 - 31.7)              | 30%                   |
| ≥ 85             | 38.2%<br>(35.7 - 40.7)              | 36.6%                 |

Not all comparisons were as closely matched as the examples above. In some cases, point estimates generated from NDS were outside the 95% CI of estimates from NHHCS data on one or more

**Table 4. Percent of Patients by Primary Payment Source**

| <u>Payment Source</u>              | <u>NHHCS</u><br>Percent<br>(95% CI) | <u>NDS</u><br>Percent |
|------------------------------------|-------------------------------------|-----------------------|
| Medicare                           | 79.3%<br>(77.2 - 81.4)              | 83.6%                 |
| Medicaid                           | 3.82%<br>(2.9 - 4.8)                | 5.0%                  |
| Managed Care/<br>Private Insurance | 9.2%<br>(7.7 - 10.7)                | 8.5%                  |
| Self Pay                           | 0.79%<br>(0.32 - 1.26)              | 0.9%                  |
| Uncompensated/<br>Charity          | 0.61%<br>(0.23 - 0.98)              | 1.3%                  |
| Other                              | 2.1%<br>(1.4 - 2.7)                 | 0.7%                  |

characteristics. Table 4 illustrates one such example. The NDS-based estimates for the proportion of patients whose primary payment source was either Medicare, Medicaid, Self-pay, or Other were all outside of the 95% CI of the estimates based on NHHCS data. In this example, it cannot be assumed that the proportion estimates are the same (not statistically significantly different); however, the NDS-based estimates were so close to the 95% CI that it is likely they are still not statistically significantly different. The result of the comparison of estimates of primary payment source is therefore inconclusive.

The tables provided are a sample of the total analysis performed by NHPCO. Overall, the estimates generated from NDS data are very similar to those generated from NHHCS data. These results provide evidence that, although derived from a convenience sample of data, the estimates NHPCO generates in its National Summary of Hospice Care and distributed in this Facts and Figures report are reliable and accurate.