National Hospice and Palliative Care Organization

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

FACTS AND FIGURES

HOSPICE CARE IN AMERICA

2017 EDITION

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INTRODUCTION

About This Report

NHPCO Facts and Figures: Hospice Care in America provides an annual overview of hospice care delivery. This overview provides specific information on:

- Hospice patient characteristics
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Volunteer and bereavement services

Currently, most hospice patients have their costs covered by Medicare, through the Medicare Hospice Benefit. The findings in this report reflect only those patients who received care in 2016 through the Medicare Hospice Benefit and the hospices certified by the Centers for Medicare and Medicaid Services (CMS) to care for them.

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 family 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 facilities, hospitals, and 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, 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

What services are provided?

The interdisciplinary hospice team:

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

Location of Care

The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).

Levels of Care

Hospice patients may require differing intensities of care during the course of their disease. While hospice patients may be admitted at any level of care, changes in their status may require a change in their level of care.

The Medicare Hospice Benefit affords patients four levels of care to meet their clinical needs: Routine Home Care, General Inpatient Care, Continuous Home Care, and Inpatient Respite Care. Payment for each covers all aspects of the patient's care related to the terminal illness, including all services delivered by the interdisciplinary team, medications, medical equipment and supplies.

- Routine Hospice Care (RHC) is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- General Inpatient Care (GIP) is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has a registered nurse available 24 hours a day to provide direct patient care.
- Continuous Home Care (CHC) is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- Inpatient Respite Care (IRC) is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long term care facility that has sufficient 24 hour nursing personnel present.

Volunteer Services

The U.S. hospice movement was founded by volunteers and continues to play an important and valuable role in hospice care and operations. Moreover, hospice is unique in that it is the only provider with Medicare Conditions of Participation (CoPs) requiring volunteers to provide at least 5% of total patient care hours. 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")
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a board of directors ("general support")

Bereavement Services

Counseling or grief support for the patient and loved ones is an essential part of hospice care. After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, and support groups. Individual counseling may be offered by the hospice or the hospice may make a referral to a community resource. Some hospices also provide bereavement services to the community at large.

WHO RECEIVES HOSPICE CARE

How many Medicare beneficiaries received hospice care in 2016?

1.43 million Medicare beneficiaries were enrolled in hospice care for one day or more in 2016*. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2015 and continued to receive care in 2016
- Left hospice care alive during 2016 (live discharges)

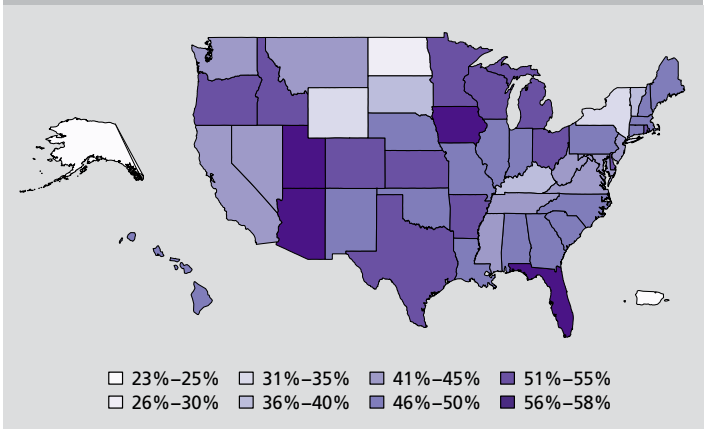
**includes all states, Washington D.C., and Puerto Rico.*

What proportion of Medicare decedents were served by hospice in 2016?

Of all Medicare decedents in 2016, 48% received one day or more of hospice care *and* were enrolled in hospice at the time of death.

As illustrated in Figure 2, the proportion of Medicare decedents enrolled in hospice at the time of death varied across states from a low of 23% (PR) to a high of 58% (UT).

FIGURE 2. GEOGRAPHIC VARIATION IN THE PROPORTION OF MEDICARE DECEDENTS WHO DIED WHILE RECEIVING HOSPICE CARE IN 2016



What are the characteristics of Medicare beneficiaries who received hospice care in 2016?

Patient Gender

In 2016 more than half of hospice Medicare beneficiaries were female.

Female	58.6 %
Male	41.4 %

Patient Age

In 2016 about 64% of Medicare hospice patients were 80 years of age or older.

TABLE 1. PERCENTAGE OF PATIENTS BY AGE

Age Category (Years)	Percentage
< 65	5.3 %
65 - 69	7.7 %
70 - 74	10.0 %
75 - 79	12.8 %
80 - 84	16.7 %
> 84	47.5 %

*Patient Race**

In 2016 a substantial majority of Medicare hospice patients were Caucasian.

TABLE 2. PERCENTAGE OF PATIENTS BY RACE*

Race	Percentage
Caucasian	86.5 %
African American	8.3 %
Hispanic	2.1 %
Asian	1.2 %
Other	1.0 %
Native American	0.4 %
Unknown	0.4 %

** Categories correspond to those used by CMS in the Hospice Limited Data Set*

TABLE 3. DEATH/SERVICE RATIO BY RACE*

Race	Percentage
Caucasian	48.9 %
African American	35.6 %
Hispanic	37.4 %
Asian	31.7 %
Other	36.2 %
Native American	32.9 %
Unknown	34.3 %

**Percentage of Medicare decedents who died under hospice care by race.*

Principal Diagnosis

The principal hospice diagnosis is the diagnosis that has been determined to be the most contributory to the patient's terminal prognosis. In 2016 more Medicare hospice patients had a principal diagnosis of cancer than any other disease.

TABLE 4. PERCENTAGE OF PATIENTS BY PRINCIPAL DIAGNOSIS

Principal Diagnosis	Percentage
Cancer	27.2 %
Cardiac and Circulatory	18.7 %
Dementia	18.0 %
Respiratory	11.0 %
Stroke	9.5 %
Other	15.6 %

HOW MUCH CARE IS RECEIVED?

*Length of Service**

The average length of service (ALOS) for Medicare patients enrolled in hospice in 2016 was 71 days. The median length of service (MLOS) was 24 days.

** LOS calculation is based on the total days of care for patients who received care in 2016. Days of care have been combined for patients who had multiple episodes of care in 2016. Days of care occurring in other years are not included.*

*Days of Care**

In 2016 hospice patients received a total of 101 million days of care paid for by Medicare.

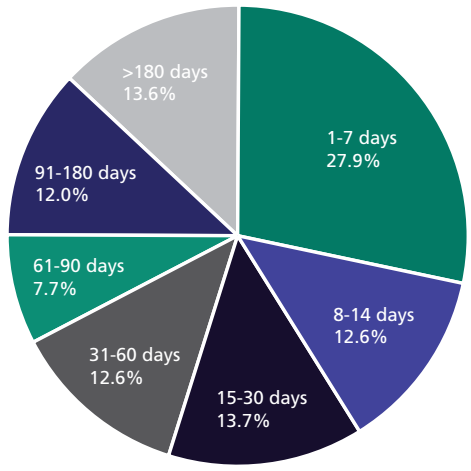
In 2016, a greater proportion of Medicare patients (27.9%) were enrolled in hospice a total of seven days or fewer compared to all other length of service categories.

TABLE 5. DAYS OF CARE CATEGORIES BY PERCENTAGE OF PATIENTS*

Total Days of Care	Percentage of Patients
1 – 7	27.9 %
8 – 14	12.6 %
15 – 30	13.7 %
31 – 60	12.6 %
61 – 90	7.7 %
91 – 180	12.0 %
> 180	13.6 %

**These values are computed using only days of care that occurred in 2016. Days of care occuring in other years are not included. Days of care have been combined for patients who had multiple episodes of care in 2016.*

FIGURE 3. PROPORTION OF PATIENTS BY DAYS OF CARE IN 2016



In 2016 over half (54.2%) of patients were enrolled in hospice for 30 or fewer days.

TABLE 6. DAYS OF CARE OVER MULTIPLE YEARS BY PERCENTAGE OF PATIENTS*

Total Days of Care	Percentage of Patients
1-60	61.6 %
61-180	18.3 %
181-365	10.7 %
>365	9.4 %

**These values are computed using all days of care that occurred in 2016 and, for patients who received care in 2014 and 2015 as well as in 2016, days of care from those years are also included.*

Patients with a principal diagnosis of dementia had the largest number of days of care on average in 2016.

TABLE 7. DAYS OF CARE BY PRINCIPAL DIAGNOSIS*

Principal Diagnosis	Mean # Days of Care	Median # Days of Care
Cancer	46 days	19 days
Cardiac and Circulatory	79 days	30 days
Dementia	104 days	54 days
Respiratory	71 days	21 days
Stroke	77 days	22 days
Other	62 days	16 days

**These values are computed using only days of care that occurred in 2016. Days of care have been combined for patients who had multiple episodes of care in 2016. Days of care occurring in other years are not included.*

Deaths

In 2016 1.04 million Medicare beneficiaries died while enrolled in hospice care. Close to half of the deaths occurred in a home and almost a third in nursing facilities.

TABLE 8. LOCATION OF DEATHS

Location of Death	Percentage
Home	44.6 %
Nursing Facility*	32.8 %
Hospice Inpatient Facility	14.6 %
Acute Care Hospital	7.4 %
Other	0.7 %

** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.*

Discharges and Transfers

In 2016, live discharges comprised 16.8% of all Medicare hospice discharges.

TABLE 9. DISCHARGES BY TYPE OF DISCHARGE*

Type of Discharge	Percentage
Deaths	83.2 %
Live Discharges - Patient Initiated	
Transfers (change in hospice provider)	2.1 %
Revocations	6.4 %
Live Discharges - Hospice Initiated	
No longer terminally ill	6.6 %
Moved out of service area	1.3 %
Discharged for cause	0.3 %

**Calculations are based on total number of discharges which includes patients who were discharged more than one time in 2016.*

Level of Care

In 2016 the vast majority of days of care were at the Routine Homecare (RHC) level.

TABLE 10. LEVEL OF CARE BY PERCENTAGE OF DAYS OF CARE

Level of Care	Percentage of Days of Care
Routine Home Care (RHC)	98.0 %
Continuous Home Care (CHC)	0.2 %
Inpatient Respite Care (IRC)	0.3 %
General Inpatient Care (GIP)	1.5 %

RHC by Location of Care

56.5% of RHC days of care occurred in a private residence, 42.5% in a nursing facility and 1.0% in a hospice inpatient facility, an acute care hospital, or an unspecified location.

Location of Care

In 2016 most of days of care were provided at a private residence.

TABLE 11. LOCATION OF CARE BY PERCENTAGE OF DAYS OF CARE*

Location	Percentage of Days of Care
Home	55.6 %
Nursing Facility*	41.9 %
Hospice Inpatient Facility	1.3 %
Acute Care Hospital	0.5 %
Other	0.8 %

** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.*

HOW DOES MEDICARE PAY FOR HOSPICE?

Medicare paid hospice providers a total of 16.9 billion dollars for care provided in 2016.

Spending per Patient

The average spending per Medicare hospice patient was $11,820.00.

TABLE 12. MEDICARE SPENDING PER HOSPICE PATIENT

First Quartile	Median	Third Quartile
$1,904.00	$5,384.00	$16,110.00

Spending by Days of Care

In 2016 just under half of Medicare spending for hospice care was for patients who received 180 or fewer days of care.

TABLE 13. MEDICARE SPENDING BY DAYS OF CARE

Total Days of Care*	Percentage of 2016 Medicare Payments for 2016
1-60	19.2 %
61-180	25.1 %
181-365	26.5 %
>365	29.2 %

**Includes days of care that occurred in 2014 and 2015 as well as 2016.*

Spending by Diagnosis

In 2016 close to 25% of Medicare hospice spending was for patients with a principal diagnosis of dementia.

TABLE 14. MEDICARE HOSPICE SPENDING BY PRINCIPAL DIAGNOSIS

Principal Diagnosis	Percentage of Medicare Payments
Cancer	19.6 %
Cardiac and Circulatory	20.2 %
Dementia	24.9 %
Respiratory	10.9 %
Stroke	10.4 %
Other	14.0 %

Spending by Level of Care

In 2016 the vast majority of Medicare spending for hospice care was for care at the Routine Home Care level.

TABLE 15. MEDICARE SPENDING BY LEVEL OF CARE

Level of Care	Percentage of Medicare Payments
Routine Home Care	92.3 %
Continuous Home Care	1.3 %
Respite Care	0.3 %
General Inpatient Care	6.1 %

WHO PROVIDES CARE?

How many hospices were in operation in 2016?

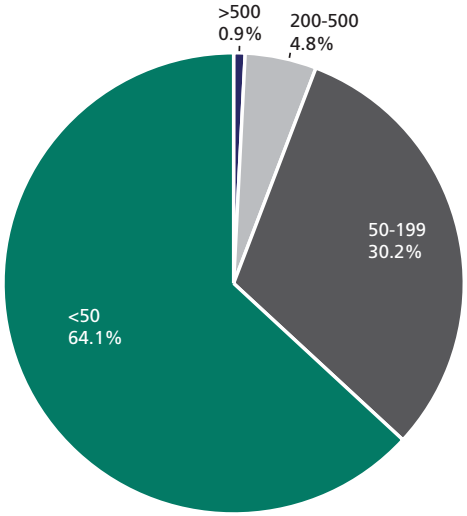
Over the course of 2016, there were 4,382 Medicare certified hospices in operation.

Hospice Size

One indicator of hospice size is average daily census (ADC) or the number of patients cared for by a hospice on average each day.

In 2016 the mean ADC was 63 and the median 31. The majority of hospices had an ADC of less than 50 patients.

FIGURE 4. AVERAGE DAILY CENSUS



Tax Status

62.5% of active Medicare Provider Numbers were assigned to hospice providers with for-profit tax status and 24.7% with not-for-profit status. Government-owned hospice providers comprised 12.8%.

Patient Volume

Admissions

In 2016 hospice providers performed a total 1.2 million unduplicated admissions* of Medicare hospice patients.

** Unduplicated admissions include patients who were part of the census at the end of 2015, carried over into 2016, discharged in 2016 and readmitted within the year.*

Volume of Deaths

In 2016 the highest number of hospice providers served 50 or fewer patients who died while enrolled in hospice care.

TABLE 16. VOLUME OF DEATHS

Total Deaths in 2016	Percentage of Hospice Providers
0 – 50	33.1 %
51 – 100	17.8 %
101 – 200	18.2 %
201 – 500	18.6 %
501 – 1000	8.1 %
>1000	4.1 %

Volunteers

In 2016 the majority of volunteer time was for direct patient care and the majority of volunteers were designated as direct care volunteers.

TABLE 17. VOLUNTEER TIME*

Type of Volunteer Sevice	Percentage of Volunteer Time
Direct Patient Care	42.7 %
Clinical Support	29.9 %
Non Clinical	27.4 %

**2015 and 2016 combined*

DATA SOURCES

The primary data source used for the findings in this report is CMS hospice claims data included in the hospice standard analytical file Limited Data Set (LDS). The NHPCO National Data Set (NDS) is the data source for the Volunteer and Bereavement statistics. The FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements is the source for the Tax Status statistics.

Hospice Limited Data Set (LDS)

The hospice standard analytical file contains final action claims submitted by hospice providers. Once a beneficiary elects hospice, all hospice related claims are included in this file. Selected variables within the files are encrypted, blanked, or ranged.

The LDS file includes:

- the level of hospice care received (e.g., routine home care, inpatient respite care),
- terminal diagnosis (ICD-9/10 diagnosis),
- the days of service,
- reimbursement amounts,
- hospice provider number and beneficiary demographic information.

Federal Register 82: 36638

Aug. 4, 2017 (42CFR418)
"FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements"

This document, prepared by CMS, contains certain descriptive information about hospice in 2016.

NHPCO National Data Set (NDS)

The NDS is a voluntary data collection initiative that gathers information on a wide range of hospice operations. NDS summary results provide useful information to hospices for defining strategic goals, setting operational targets, and improving care delivery.

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