

# Advance Data



From Vital and Health Statistics of the CENTERS FOR DISEASE CONTROL AND PREVENTION/National Center for Health Statistics

## Characteristics of Hospice Care Users: Data From the 1996 National Home and Hospice Care Survey

by Barbara J. Haupt, D.V.M., Division of Health Care Statistics

### Abstract

*Objective*—This report presents numbers and percents of hospice care current patients and discharges by characteristics of the agencies from which the care was received, patient and discharge characteristics, services provided, types of personnel that provided the services, admission diagnoses, and procedures.

*Methods*—The data used for this report are from the National Center for Health Statistics' 1996 National Home and Hospice Care Survey. This is a sample survey through which data are collected on the use of hospices and home health care agencies in the United States.

*Results*—During 1996, there were an estimated 59,400 patients receiving hospice care services from 1,800 hospices and home health care agencies in the United States. These agencies had 393,200 discharges from hospice care during the year prior to the survey. The agencies tended to be voluntary nonprofit, certified by Medicare and Medicaid, and located in a metropolitan statistical area. About a third were part of a chain or group of agencies and 40 percent were operated by a hospital. Fifty-five percent of the current patients and 50 percent of the discharges were women. Both current patients and discharges tended to be 65 years of age and over, white, married or widowed, lived in a private or semiprivate residence, and had a primary caregiver. The most common diagnoses at admission were malignant neoplasms and heart disease. About a fifth of the patients and discharges had a surgical or diagnostic procedure related to their admission for care. The most common ones were miscellaneous diagnostic and therapeutic procedures.

**Keywords:** National Home and Hospice Care Survey • long-term care • current patients • discharges • malignant neoplasms

### Introduction

This report presents statistics on hospice care from the 1996 National Home and Hospice Care Survey (NHHCS), a nationwide sample survey that was first conducted by the National

Center for Health Statistics in 1992 (1–4). The NHHCS, a segment of the long-term care component of the National Health Care Survey (5), was developed in response to the rapid growth in the number of home health and hospice care agencies throughout

the United States. This growth led to a need for information on the availability and utilization of services offered by these agencies. Through the NHHCS, data are collected on the use of home health and hospice care agencies in the United States. Information is collected about the agencies, their current patients, and their discharges.

At the time of the survey in 1996, 13,500 home health and hospice care agencies were providing services to 2,486,800 patients and had 8,168,900 discharges from care during the year prior to the survey. Of these, 1,800 agencies were providing hospice care to 59,400 patients and had 393,200 discharges during the year (6). Reports have been published about hospice care current patients and discharges for 1994 (7,8). By focusing on the users of hospice care, these reports provide statistics on a relatively small but important area of the health care industry.

Hospice care services are provided by both home health care agencies and by hospices. These agencies are usually defined in terms of the focus of the type of care they provide. Home health care is provided to individuals and families in their home or place of residence for promoting, maintaining, or restoring health, or for maximizing the level of



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
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independence while minimizing the effects of disability and illness, including terminal illness. Hospice care is defined as a program of palliative and supportive care services that provides physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones. Although home health care agencies may provide hospice care as well as home health care, hospices generally provide only hospice care services.

Hospice care in the United States began in the early 1970's and relied heavily on professional and lay volunteers. It has since grown into a more formal, regulated industry. Since 1983, hospice care services have been available through Medicare for persons with a terminal illness whose life expectancy is 6 months or less. Reimbursement for hospice care services is also provided by Medicaid and by many private insurance programs. The goals of hospice care are to provide a good quality of life for the dying patient and to help the patient and his/her family to deal with the approaching death in an appropriate manner. Emphasis is on palliative care of the patient, rather than on curing the disease or extending life. Control of pain—physical, mental, social, and spiritual—is stressed. Although hospice services are available in inpatient settings, most of these services are provided in the patient's home or usual place of residence (6–10).

## Methods

Data collection for the 1996 NHHCS was conducted between July and December 1996. Data were collected on a sample of current patients and discharges from a representative sample of hospices and home health care agencies. Patient data were obtained from the medical records of the sampled patients. An overview of the data collection methods and estimation and testing procedures for the NHHCS, as well as definitions of selected terms used in this report, are in the [Technical notes](#).

Statistics presented are estimated numbers and percents of current hospice care patients and discharges by various

items of interest. A limited amount of information about the agencies providing the services is also given. For this report, agencies providing hospice care services are limited to those agencies that had at least one current hospice care patient at the time of the survey or that had at least one discharge from hospice care during a designated month prior to the time of the survey. Current patients are patients who were on the rolls of the agency as of midnight on the day immediately before the date of the survey. Discharges refer to patients who had been removed from the rolls of the agency (including those whose episode of care ended because of death) during a designated month (October 1995–September 1996) that was randomly selected for each agency.

Agency characteristics examined include ownership, Medicare and Medicaid certification, affiliation, and location. Ownership refers to the type of organization that controlled and operated the agency at the time of the survey. Affiliation status is limited to affiliation with a hospital or a group of agencies (such as a chain). Not all agencies are affiliated, and some may have other types of affiliation that are not included in this survey. Two types of location are reported: geographic region and metropolitan statistical area.

Patient and discharge information included in this report consist of demographic characteristics (sex, age, race, and marital status), living arrangements, and primary caregiver status. Statistics are also presented about the services provided to the patients and discharges, types of personnel providing the services, diagnoses at admission, and diagnostic or surgical procedures related to the admission of the patient to the agency. Diagnoses and procedures are coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

The tests of significance used to test all comparisons mentioned in this report are based on the Bonferroni multiple comparisons using the z-test with an overall 0.05 level of significance. Not all differences were tested, so lack of comment in the text does not mean that the difference was not statistically significant. Estimates in this report have

been rounded to the nearest hundred. Therefore, detailed figures may not add to totals. Percents were calculated using unrounded figures and may not agree with computations made from the rounded data.

## Results

In 1992, 1,500 agencies were providing hospice care services to 52,100 patients and had 219,300 discharges from hospice care during the year prior to the survey ([figures 1–3](#)). These numbers increased to 1,600 agencies, 61,000 current patients, and 328,000 discharges in 1994. By 1996, 1,800 agencies were serving 59,400 current patients and had 393,200 discharges. The differences between the number of agencies and the number of current patients between each year (1992–94, 1994–96, and 1992–96) were not statistically significant; the number of discharges increased significantly from 1992–94 and 1992–96, but not from 1994–96.

### Agency characteristics

[Table 1](#) shows the number and percent distribution of agencies that provided hospice care according to selected agency characteristics. The numbers and percent distributions of current patients and discharges from these agencies are also shown. Most of the facilities—1,500, or 84 percent—were voluntary, nonprofit agencies. Forty percent were operated by a hospital and 37 percent were part of a group or chain of agencies. Ten percent of the agencies providing hospice care were in the Northeast region, 35 percent were in the Midwest, 40 percent were in the South, and 16 percent were in the West. Sixty-three percent of the agencies were located in a metropolitan statistical area (MSA).

The vast majority (94 percent) of the agencies were certified under Medicare and/or Medicaid as a hospice or a home health agency. Of the Medicare-certified agencies, 49 percent were certified as both a hospice and a home health agency and 32 percent were certified only as a hospice ([figure 4](#)). A similar distribution exists for the Medicaid-certified agencies—46 percent

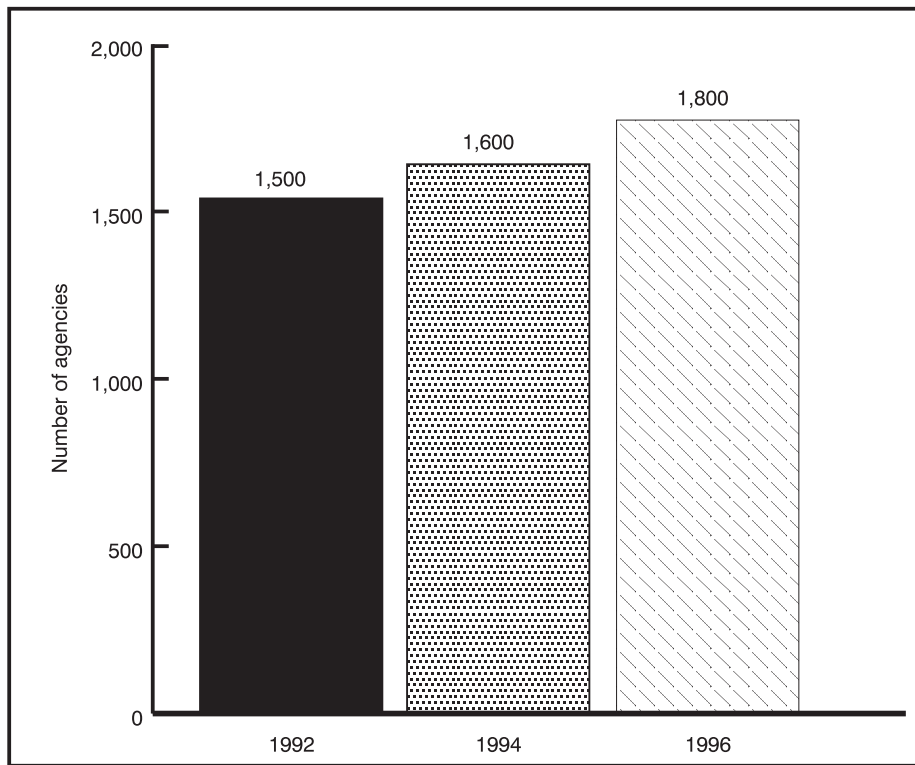


Figure 1. Number of agencies providing hospice care: United States, 1992, 1994, and 1996

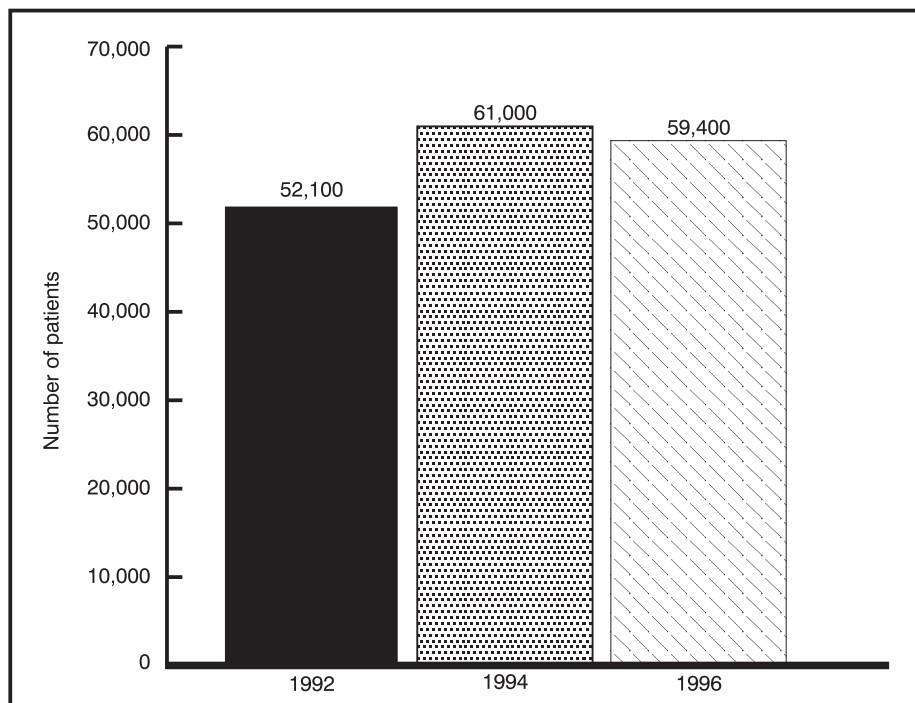


Figure 2. Number of current hospice care patients: United States, 1992, 1994, and 1996

that were part of a chain or group of agencies served 35 percent of the current patients and had 34 percent of the discharges.

Of the current patients, 15 percent were served by agencies in the Northeast region, 36 percent from agencies in the Midwest, 32 percent from agencies in the South, and 17 percent from agencies in the West. Eighteen percent of the discharges were from agencies in the Northeast, 25 percent from agencies in the Midwest, 39 percent from agencies in the South, and 18 percent from agencies in the West. Although 63 percent of the agencies were located in a metropolitan statistical area (MSA), these agencies served a significantly larger percent of current patients and discharges (81 percent and 84 percent, respectively). Ninety-eight percent of the patients and discharges were from an agency that was certified under Medicare and/or Medicaid as a hospice, a home health agency, or both.

### Patient and discharge characteristics

Table 2 shows the number and percent distribution of current hospice care patients by selected demographic characteristics. A significantly larger percent of the patients were female—55 percent were women compared with 45 percent who were men. The majority—78 percent—of the current patients were 65 years of age or older, and a significantly larger proportion of women than of men were 85 years of age or older. Eighty-four percent of the patients were white and 10 percent were black and other races. Race was unknown for 7 percent of the patients.

Forty-four percent of the current patients were married at the time of the survey. Of those who were not married, the majority (64 percent) were widowed. The marital status of men, however, was quite different than that of women. Men were more likely to be married than were women, whereas women were more likely to be widowed than were men.

Most of the current hospice care patients—78 percent—were living in a private or semiprivate residence at the

certified as both a hospice and a home health agency and 30 percent certified as only a hospice.

The majority of both current patients and discharges (85 percent)

received services from voluntary, nonprofit agencies (table 1). Twenty-seven percent of the current patients and 32 percent of the discharges were served by a hospital-affiliated agency. Agencies

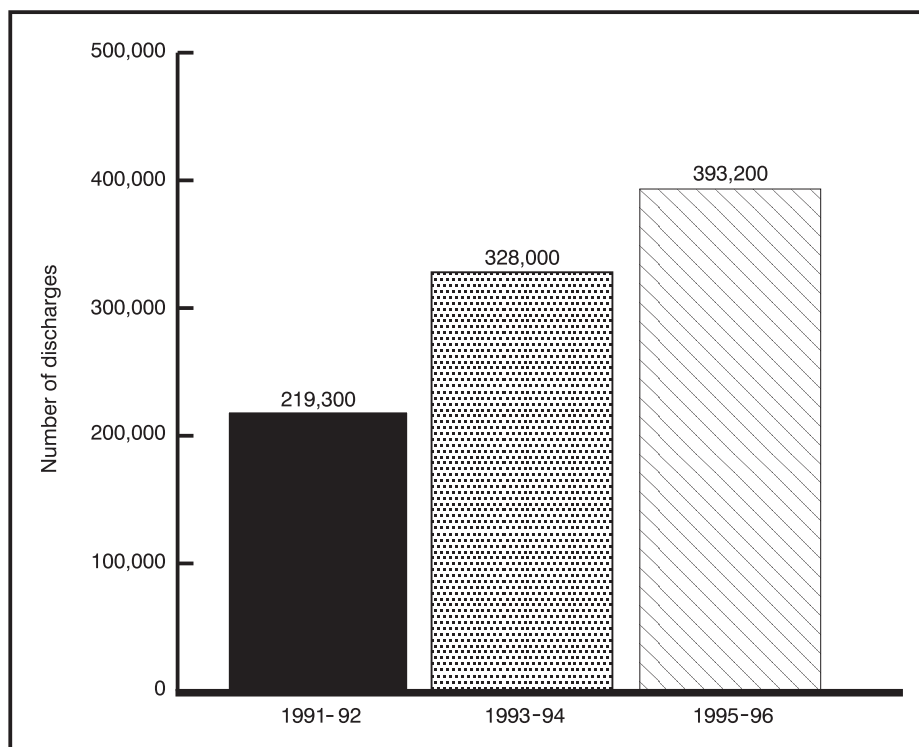


Figure 3. Number of discharges from hospice care: United States, 1991-92, 1993-94, and 1995-96

time of the survey, and 11 percent were residents of an inpatient health facility (table 3). Of the noninstitutionalized patients, 79 percent lived with family members, 14 percent lived alone, and 7 percent lived only with nonfamily members. A significantly larger percent of men than of women lived with family members. Women, on the other hand, were more likely to live alone than were men.

Information on primary caregiver status of current patients is given in table 4. The majority of the patients had a primary caregiver, that is, an individual or organization that is responsible for providing personal care assistance, companionship, and/or supervision to the patient. Most of the patients with a primary caregiver lived with their caregiver. Differences in caregiver status occurred between the two sexes. Men were more likely than were women both to have a caregiver and to live with their caregiver.

Table 1. Number and percent of agencies providing hospice care, current hospice care patients, and hospice care discharges by selected agency characteristics: United States, 1996

Agency characteristic	Agencies		Current patients		Discharges	
	Number	Percent	Number	Percent	Number	Percent
Total	1,800	100.0	59,400	100.0	393,200	100.0
Ownership						
Proprietary	*	*	6,500	11.0	52,400	13.3
Voluntary nonprofit	1,500	83.5	50,200	84.6	334,900	85.2
Government and other	*100	*4.8	2,600	4.4	*5,900	*1.5
Affiliation <sup>1</sup>						
Operated by hospital	700	40.1	16,300	27.4	123,700	31.5
Part of group or chain	700	36.7	21,000	35.4	132,700	33.8
Geographic region						
Northeast	200	9.7	8,900	15.0	71,700	18.2
Midwest	600	34.5	21,300	35.9	99,000	25.2
South	700	39.5	19,000	32.0	151,200	38.5
West	300	16.3	10,100	17.1	71,400	18.1
Location of agency						
Metropolitan statistical area	1,100	63.0	48,100	81.1	331,300	84.2
Nonmetropolitan statistical area	700	37.0	11,200	18.9	62,000	15.8
Certification status <sup>1</sup>						
Certified	1,700	93.9	58,000	97.7	385,400	98.0
Both Medicare and Medicaid	1,600	89.3	55,100	92.9	360,200	91.6
Medicare only	*	*	*2,300	*3.9	*14,600	*3.7
Medicaid only	*	*	*	*	*	*
Not certified	*	*	1,400	2.3	*7,800	*2.0

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30-59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Numbers may not add to totals because not all agencies are certified or affiliated and/or an agency may have more than one type of certification or affiliation.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

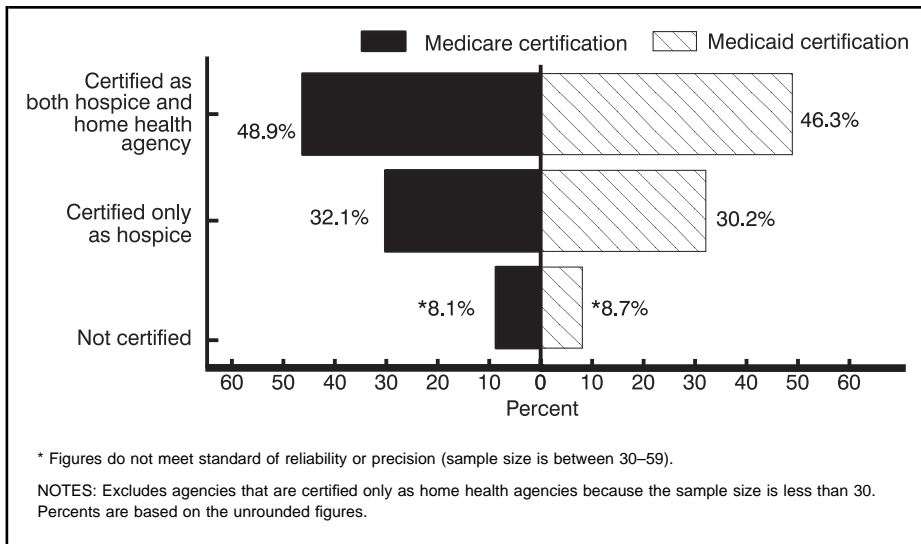


Table 5 shows the number and percent distribution of hospice care discharges by selected demographic characteristics and reason for discharge. The majority of all discharges were elderly, that is, 65 years of age and over. Half of the discharges were male. However, women were more likely to be elderly than were men (74 percent of women compared with 61 percent of men were 65 years of age or older).

Seventy-nine percent of the discharges were white and 12 percent were black and other races. Race was unknown for 9 percent of the discharges.

About one-half (48 percent) of the discharges were married at the time of discharge. Of those who were not married, the majority (65 percent) were widowed. As with current patients, the marital status differed significantly between the sexes. That is, men were more likely to be married at the time of discharge, and women were more likely to be widowed.

**Figure 4. Percent of agencies providing hospice care by type of certification: United States, 1996**

Although the primary caregiver was most often a relative of the patient, the type of relationship was very different for the two sexes. Men were more likely

than women to have a spouse as their primary caregiver. In contrast, women were more likely than men to be cared for by a child or a child-in-law.

**Table 2. Number and percent distribution of hospice care current patients by selected patient characteristics, according to sex: United States, 1996**

Patient characteristic	Sex <sup>1</sup>					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
All patients . . . . .	59,400	26,600	32,700	100.0	100.0	100.0
Age at admission <sup>1</sup>						
Under 65 years . . . . .	13,100	6,100	7,000	22.1	22.9	21.4
Under 45 years . . . . .	4,300	2,400	1,900	7.3	8.9	5.9
45–64 years . . . . .	8,800	3,700	5,100	14.8	14.0	15.5
65 years and over . . . . .	46,100	20,400	25,700	77.7	76.6	78.6
65–69 years . . . . .	5,000	2,800	2,200	8.4	10.6	6.6
70–74 years . . . . .	9,600	5,800	3,800	16.2	21.9	11.5
75–79 years . . . . .	9,800	4,900	4,900	16.6	18.4	15.0
80–84 years . . . . .	9,100	3,300	5,800	15.2	12.2	17.7
85 years and over . . . . .	12,700	3,600	9,100	21.3	13.4	27.8
Race						
White . . . . .	49,700	22,000	27,700	83.7	82.5	84.6
Black and other <sup>2</sup> . . . . .	5,700	3,100	2,500	9.6	11.8	7.8
Black . . . . .	4,900	2,600	2,300	8.3	9.8	7.1
Unknown . . . . .	4,000	*1,500	*2,500	6.7	*5.7	*7.6
Current marital status						
Married . . . . .	25,900	17,600	8,300	43.7	66.1	25.4
Not married <sup>3</sup> . . . . .	29,700	8,200	21,500	50.0	30.9	65.6
Widowed . . . . .	19,100	3,000	16,100	32.2	11.4	49.1
Unknown . . . . .	*3,700	*	*2,900	*6.3	*	*9.0

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes unknown.

<sup>2</sup>Includes race other than white and unknown.

<sup>3</sup>Includes separated.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

**Table 3. Number and percent distribution of current hospice care patients by current residence and number and percent distribution of noninstitutionalized current hospice care patients by living arrangements, according to sex: United States, 1996**

Characteristic	Sex <sup>1</sup>					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
All patients . . . . .	59,400	26,600	32,700	100.0	100.0	100.0
Current residence <sup>1</sup>						
Private or semiprivate residence <sup>2</sup> . . . . .	46,600	22,100	24,500	78.4	83.0	74.7
Board and care or residential care facility . . . . .	5,800	*1,400	4,300	9.7	*5.3	13.3
Health facility (including mental health facility) . . . . .	6,700	3,100	3,600	11.3	11.6	11.0
Living arrangements <sup>3</sup>						
Noninstitutionalized patients . . . . .	46,600	22,100	24,500	100.0	100.0	100.0
Lives with family members . . . . .	36,700	19,200	17,500	78.9	86.7	71.8
Lives alone . . . . .	6,400	1,300	5,100	13.8	6.0	20.9
Lives with only nonfamily members . . . . .	3,100	*1,500	*1,700	6.7	*6.7	*6.8

\* Figure does not meet standard of reliability or precision and should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes other and unknown.

<sup>2</sup>Includes private residence, rented room, boarding house, and retirement home.

<sup>3</sup>Excludes those for whom living arrangements are unknown.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

**Table 4. Number and percent distribution of current hospice care patients by primary caregiver status and relationship to primary caregiver, according to sex: United States, 1996**

Characteristic	Sex <sup>1</sup>					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
All patients . . . . .	59,400	26,600	32,700	100.0	100.0	100.0
Primary caregiver status						
Has no primary caregiver or status unknown . . . . .	4,700	*1,100	3,600	8.0	*4.0	11.1
Has primary caregiver . . . . .	54,600	25,600	29,100	92.0	96.0	88.9
Lives with primary caregiver . . . . .	42,200	21,100	21,100	71.1	79.1	64.6
Relationship of primary caregiver to patient						
Patients with primary caregiver . . . . .	54,600	25,600	29,100	100.0	100.0	100.0
Spouse . . . . .	22,200	16,000	6,300	40.7	62.5	21.5
Child/child-in-law . . . . .	17,800	3,600	14,200	32.6	14.3	48.7
Sister or brother <sup>2</sup> . . . . .	2,400	*1,500	*900	4.4	*5.8	*3.2
Other relative . . . . .	3,900	*1,300	2,600	7.1	*5.0	8.9
Friend or neighbor . . . . .	*2,000	*1,300	*	*3.6	*5.1	*
Hired help or staff of residential facility . . . . .	4,500	*1,700	2,800	8.2	*6.7	9.5
Other nonrelative or unknown . . . . .	*1,900	*	*	*3.4	*	*

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes unknown.

<sup>2</sup>Includes sister- or brother-in-law.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

The most common reason for discharge was death of the patient (82 percent of the discharges of both sexes were deceased). Five percent of the discharges occurred because the patient was to be provided services from another source (for example, the patient was discharged to another hospice or

home health care agency, to an inpatient health care facility, or the family resumed care of the patient).

Most of the discharged hospice patients—74 percent—were living in a private or semiprivate residence during their episode of care, and about 21 percent were residents of an inpatient

health facility (table 6). Of the discharges for noninstitutionalized patients, 84 percent lived with family members, 9 percent lived alone, and 4 percent lived only with nonfamily members. As with current patients, a significantly larger percent of discharged



**Table 5. Number and percent distribution of hospice care discharges by selected patient characteristics, according to sex: United States, 1995–96**

Patient characteristic	Sex					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
Total	393,200	197,700	195,500	100.0	100.0	100.0
Age at admission <sup>1</sup>						
Under 65 years	121,100	74,000	47,100	30.8	37.4	24.1
Under 45 years	31,700	20,000	*11,700	8.1	10.1	*6.0
45–64 years	89,400	54,000	35,300	22.7	27.3	18.1
65 years and over	265,200	120,900	144,400	67.5	61.1	73.8
65–69 years	34,100	16,200	18,000	8.7	8.2	9.2
70–74 years	61,300	30,100	31,200	15.6	15.2	15.9
75–79 years	57,000	29,200	27,800	14.5	14.8	14.2
80–84 years	48,300	19,100	29,300	12.3	9.6	15.0
85 years and over	64,500	26,300	38,200	16.4	13.3	19.5
Race						
White	310,300	157,500	152,800	78.9	79.7	78.1
Black and other <sup>2</sup>	48,500	*21,100	27,400	12.3	*10.7	14.0
Black	43,900	*18,200	25,700	11.2	*9.2	13.1
Unknown	34,500	*19,200	*15,300	8.8	*9.7	*7.8
Marital status at discharge						
Married	190,300	131,600	58,600	48.4	66.6	30.0
Not married <sup>3</sup>	177,700	59,500	118,100	45.2	30.1	60.4
Widowed	115,600	24,800	90,800	29.4	12.5	46.5
Unknown	25,300	*	*18,800	6.4	*	*9.6
Reason for discharge <sup>1</sup>						
Deceased	322,200	161,600	160,600	81.9	81.7	82.1
Services provided by another source	21,300	*16,700	*4,600	5.4	*8.5	*2.4
Other reason for discharge <sup>4</sup>	52,100	*19,600	33,400	13.2	*9.9	17.1

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes unknown.

<sup>2</sup>Includes race other than white or unknown.

<sup>3</sup>Includes separated.

<sup>4</sup>Includes unknown.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

men than of women lived with family members.

The primary caregiver status of discharges was similar to that of current patients (table 7). That is, the majority had a primary caregiver, and men were more likely than women both to have and to live with their caregiver. Again, as with current patients, the primary caregiver of discharges was most often a relative, with type of relationship differing for the two sexes. Men were more likely to have a spouse as their primary caregiver, while women were more likely to be cared for by a child or a child-in-law.

**Services and diagnoses**

Information on services received and type of service provider seen is

shown in table 8 for current patients. Most of the patients received skilled nursing services (93 percent), social services (79 percent), medications (56 percent), and counseling (53 percent). Other commonly received services were volunteer services, homemaker-household services, and physician services. The type of service provider seen reflected the services provided. The vast majority of patients had been seen by a registered nurse (91 percent), followed by a social worker (78 percent) and home health aide (55 percent). Volunteers and chaplains were also frequent service providers.

Information on primary and all-listed diagnoses for current patients is shown in table 9. These patients had

an average of 2.5 diagnoses at admission. The primary diagnosis for most of the hospice care patients was a malignant neoplasm (58 percent). Heart disease (8 percent) and chronic obstructive pulmonary disease and allied conditions (COPD) (7 percent) were other common primary diagnoses. Almost 40 percent of the all-listed diagnoses were malignant neoplasms, 11 percent were heart disease, and 5 percent were COPD.

Twenty-three percent (13,600) of the current patients had one or more diagnostic or surgical procedures that were related to their admission for hospice care services. As shown in table 10, most (64 percent) of the procedures were diagnostic and miscellaneous therapeutic procedures

**Table 6. Number and percent distribution of hospice care discharges by residence during care and number and percent distribution of noninstitutionalized hospice care discharges by living arrangements, according to sex: United States, 1995–96**

Characteristic	Sex					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
All discharges . . . . .	393,200	197,700	195,500	100.0	100.0	100.0
Residence during care <sup>1</sup>						
Private or semiprivate residence <sup>2</sup> . . . . .	291,200	155,600	135,500	74.0	78.7	69.3
Board and care or residential care facility . . . . .	14,300	*6,200	*8,200	3.6	*3.1	*4.2
Health facility (including mental health facility) . . . . .	82,100	35,500	46,600	20.9	18.0	23.8
Living arrangements <sup>3</sup>						
Noninstitutionalized discharges . . . . .	291,200	155,600	135,500	100.0	100.0	100.0
Lived with family members . . . . .	244,000	139,800	104,200	83.8	89.8	76.9
Lived alone . . . . .	27,400	*8,800	18,600	9.4	*5.7	13.7
Lived with only nonfamily members . . . . .	11,000	*	6,800	3.8	*	5.0

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes other and unknown.

<sup>2</sup>Includes private residence, rented room, boarding house, and retirement home.

<sup>3</sup>Excludes those for whom living arrangements are unknown.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

**Table 7. Number and percent distribution of hospice care discharges by primary caregiver status and relationship to primary caregiver, according to sex: United States, 1995–96**

Characteristic	Sex					
	Total	Male	Female	Total	Male	Female
	Number			Percent distribution		
All discharges . . . . .	393,200	197,700	195,500	100.0	100.0	100.0
Primary caregiver status						
Had no primary caregiver or status unknown . . . . .	36,100	11,800	24,300	9.2	6.0	12.4
Had primary caregiver . . . . .	357,200	185,900	171,200	90.8	94.0	87.6
Lived with primary caregiver . . . . .	273,800	158,400	115,400	69.6	80.1	59.0
Relationship of primary caregiver to patient						
Discharges with primary caregiver . . . . .	357,200	185,900	171,200	100.0	100.0	100.0
Spouse . . . . .	165,800	114,800	51,000	46.4	61.7	29.8
Child/child-in-law . . . . .	92,100	31,600	60,500	25.8	17.0	35.3
Sister or brother <sup>1</sup> . . . . .	22,400	*7,000	*15,300	6.3	*3.8	*9.0
Other relative . . . . .	42,200	24,300	*17,900	11.8	13.1	*10.4
Friend or neighbor . . . . .	*9,600	*	*	*2.7	*	*
Hired help or staff of residential facility . . . . .	13,900	*4,700	9,100	3.9	*2.6	5.3
Other nonrelative or unknown . . . . .	*11,300	*	*	*3.2	*	*

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Includes sister- or brother-in-law.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

such as biopsies, radiology (x rays), microscopic examination of tissue (laboratory tests), chemotherapy, and radiation therapy. Surgical procedures on the digestive system were also fairly common.

The patterns for services received, types of service provider seen, diagnoses, and procedures for hospice care discharges are similar to those for

current patients (tables 11–13). Most of the discharges received skilled nursing services (96 percent), social services (76 percent), and medications (50 percent). Other commonly received services were counseling, volunteer services, homemaker-household services, and physician services. As with current patients, the type of service provider seen reflected the services provided. The

majority had been seen by a registered nurse (92 percent), a social worker (66 percent), and a home health aide (55 percent). Chaplains and volunteers were also frequent service providers.

The number and percent distribution of primary and all-listed diagnoses at admission are shown in table 12. Discharges had an average of 2.2 diagnoses at admission. As with current



**Table 8. Number and percent of hospice care current patients by services received, type of provider seen during the last 30 days, and sex: United States, 1996**

Characteristic	Sex <sup>1</sup>					
	Total	Male	Female	Total	Male	Female
	Number			Percent		
All current patients . . . . .	59,400	26,600	32,700	100.0	100.0	100.0
Services received <sup>2</sup>						
Nursing services . . . . .	55,400	25,200	30,200	93.3	94.6	92.3
Social services . . . . .	46,700	21,500	25,200	77.8	80.9	77.0
Medications . . . . .	33,400	15,000	18,300	56.2	56.4	56.1
Counseling . . . . .	31,200	14,400	16,800	52.6	54.2	51.3
Volunteers . . . . .	23,000	11,200	11,800	38.8	42.1	36.0
Homemaker-household services . . . . .	17,000	6,700	10,200	28.6	25.3	31.2
Physician services . . . . .	15,200	7,200	8,000	25.6	27.1	24.4
Mental health services . . . . .	7,200	3,400	3,800	12.1	12.8	11.5
Nutritionist services . . . . .	5,800	*2,300	*3,500	9.8	*8.5	*10.8
Continuous home care . . . . .	*3,700	*1,900	*1,800	*6.2	*7.1	*5.4
Spiritual care . . . . .	2,900	*1,100	1,800	4.8	*4.0	5.5
Transportation . . . . .	2,300	*1,000	*1,300	3.9	*3.7	*4.1
All other services . . . . .	6,900	2,600	4,300	11.6	9.7	13.1
Service provider <sup>1,2</sup>						
Registered nurse . . . . .	54,100	24,100	30,000	91.2	90.5	91.8
Social worker . . . . .	46,100	20,100	26,000	77.6	75.4	79.3
Home health aide . . . . .	32,400	13,400	18,900	54.5	50.4	57.9
Volunteer . . . . .	18,400	9,000	9,400	30.9	33.8	28.6
Chaplain . . . . .	18,100	8,500	9,600	30.5	31.9	29.4
Nursing aide or attendant . . . . .	10,000	4,500	5,500	16.8	16.8	16.8
Physician . . . . .	8,200	3,000	5,100	13.7	11.3	15.7
Licensed practical or vocational nurse . . . . .	8,100	3,600	4,500	13.7	13.7	13.6
Homemaker/personal caretaker . . . . .	6,800	3,300	3,500	11.4	12.3	10.6
Dietician/nutritionist . . . . .	4,000	*1,100	*2,900	6.7	*4.1	*8.9
All other providers . . . . .	4,700	*1,700	*3,000	7.8	*6.3	*9.0

\* Figure does not meet standard of reliability or precision and should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Excludes unknowns.

<sup>2</sup>Numbers may add to more than totals since a patient may be listed in more than one category.

NOTES: Numbers may add to more than totals because of rounding. Percents are based on the unrounded figures.

patients, the primary diagnosis for most of the discharges was a malignant neoplasm (70 percent). Heart disease (7 percent) and COPD (3 percent) were other common primary diagnoses. Almost 50 percent of the all-listed diagnoses were malignant neoplasms, 9 percent were heart disease, and 3 percent were COPD.

Twenty-one percent (84,300) of the discharges had one or more diagnostic or surgical procedures that were related to their admission for hospice care services. As shown in table 13, over half (54 percent) were diagnostic and miscellaneous therapeutic procedures. As with the current patients, surgical procedures on the digestive system were also fairly common.

### Summary and discussion

This report presents data on characteristics of hospice care current

patients and discharges from the 1996 National Home and Hospice Care Survey. At the time of the survey in 1996, an estimated 59,400 patients were receiving hospice care from 1,800 hospices and home health care agencies in the United States. These agencies had 393,200 discharges from hospice care during the year prior to the survey. Most of the patients and discharges were served by voluntary nonprofit organizations and from agencies that were Medicare and/or Medicaid certified.

Fifty-five percent of the current patients and 50 percent of the discharges were women. The majority of both current patients and discharges were elderly (65 years of age and over), white, lived in a private or semiprivate residence with family members, and had a primary caregiver. Two-thirds of the

men— both current patients and discharges—were married. Most of the women, on the other hand, were widowed. The difference in marital status of the two sexes was reflected in both their living arrangements and in their relationship to the primary caregiver. Most of the men were cared for by their spouse, and a significantly larger proportion of men than of women lived with family members and had a primary caregiver with whom they lived. In contrast, women were more likely to live alone and/or with nonfamily members. The primary caregiver of most of the women was a relative other than a spouse, most often a child or child-in-law. Four out of five of the hospice care discharges occurred because of the death of the patient.

A major goal of hospice care is to provide care for terminally ill patients. It

**Table 9. Number and percent distribution of current hospice care patients by diagnostic category, according to primary diagnosis and all-listed diagnoses at admission: United States, 1996**

Diagnostic category and ICD-9-CM code <sup>1</sup>	Primary diagnosis		All-listed diagnoses	
	Number	Percent distribution	Number	Percent distribution
All diagnoses . . . . .	59,400	100.0	146,900	100.0
Infectious and parasitic diseases . . . . . 001-139	*2,100	*3.5	4,500	3.1
Human immunodeficiency virus (HIV) . . . . . 042	*2,000	*3.3	*2,000	*1.4
Neoplasms . . . . . 140-239	35,400	59.6	56,500	38.4
Malignant neoplasms . . . . . 140-208,230-234	34,600	58.3	55,300	37.6
Malignant neoplasm of large intestine and rectum . . . . . 153-154, 197.5	2,400	4.0	3,700	2.5
Malignant neoplasm of liver and intrahepatic bile ducts . . . . . 155,197.7	*1,500	*2.6	5,100	3.4
Malignant neoplasm of pancreas . . . . . 157	*1,100	*1.9	*1,200	*0.8
Malignant neoplasm of trachea, bronchus, and lung . . . . . 162,197.0,197.3	9,400	15.8	11,600	7.9
Malignant neoplasm of bone . . . . . 170,198.5	*	*	4,700	3.2
Malignant neoplasm of breast . . . . . 174-175,198.81	3,700	6.2	3,900	2.7
Malignant neoplasm of female genital organs . . . . . 179-184,198.6	*1,900	*3.1	*2,800	*1.9
Malignant neoplasm of prostate . . . . . 185	3,900	6.6	4,300	2.9
Malignant neoplasm of brain and spinal cord . . . . . 191,192.2,198.3	*1,000	*1.7	2,600	1.8
Malignant neoplasm of lymphatic and hematopoietic tissue . . . . . 200-208	2,300	3.8	2,700	1.8
Malignant neoplasm of other specified sites . . . . . 140-152,156,158-161, 163-165,171-173,176,186-190,192.0-192.1,192.3-195,197.1-197.2, 197.4,197.6,197.8,198.0-198.2,198.4,198.7,198.82-198.89,230-234	5,500	9.3	7,800	5.3
Malignant neoplasm, disseminated or without specification of site . . . . . 199	*1,700	*2.9	4,900	3.3
Endocrine, nutritional, and metabolic diseases and immunity disorders . . . . . 240-279	*	*	7,300	5.0
Diabetes mellitus . . . . . 250	*	*	3,200	2.2
Mental disorders . . . . . 290-319	*	*	5,400	3.7
Diseases of the nervous system and sense organs . . . . . 320-389	4,800	8.1	8,800	6.0
Alzheimer's disease . . . . . 331.0	*2,800	*4.7	4,000	2.8
Other hereditary and degenerative diseases of the central nervous system . . . . . 330,331.1-337	*1,600	*2.7	2,300	1.5
Diseases of the circulatory system . . . . . 390-459	7,300	12.3	28,600	19.4
Essential hypertension . . . . . 401	*	*	4,200	2.9
Heart disease . . . . . 391-392.0,393-398,402,404,410-416,420-429	4,900	8.3	16,000	10.9
Ischemic heart disease . . . . . 410-414	*	*	3,400	2.3
Congestive heart failure . . . . . 428.0	3,000	5.0	5,600	3.8
Cerebrovascular disease . . . . . 430-438	*1,500	*2.5	4,700	3.2
Diseases of the respiratory system . . . . . 460-519	4,400	7.3	9,800	6.7
Chronic obstructive pulmonary disease and allied conditions . . . . . 490-496	4,000	6.8	7,300	5.0
Diseases of the digestive system . . . . . 520-579	*1,500	*2.5	4,500	3.1
Nonalcoholic disorders of the liver and biliary tract . . . . . 570,571.4-576	*	*	*1,000	*0.7
Diseases of the genitourinary system . . . . . 580-629	*	*	*2,400	*1.6
Renal failure . . . . . 584-586	*	*	*1,600	*1.1
Diseases of the musculoskeletal system and connective tissue . . . . . 710-739	*	*	4,300	2.9
Symptoms, signs, and ill-defined conditions . . . . . 780-799	*1,300	*2.2	5,900	4.0
Supplementary classifications . . . . . V01-V82	*	*	5,300	3.6
Posthospital aftercare . . . . . V42-V46,V52,V53.3-V53.7,V54-V58	*	*	*3,400	*2.3
All other diagnoses . . . . .	*	*	*3,600	*2.5

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30-59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

is, therefore, not surprising that malignant neoplasms were the most common diagnosis of hospice care patients and discharges. Other frequently occurring diagnoses were heart disease and chronic obstructive pulmonary disease and allied conditions.

Because the NHHCS is a sample survey, the estimates obtained through it are subject to some variability and will, therefore, differ from figures obtained

from a complete count (see the [Technical notes](#)). Other organizations collect similar data, but use different definitions and data collection methodologies. For example, the Health Care Financing Administration (HCFA) administers the Medicare and Medicaid programs. Most of the data collected and published by HCFA concern Medicare- and/or Medicaid-certified agencies and persons whose care is

provided through Medicare and/or Medicaid programs (10).

The National Association for Home Care (NAHC), a nationwide association of home care agencies, organizations, and hospices (12), provides information about both home health care and hospice care. Much of the statistical information published by NAHC, including that on hospice care, is

**Table 10. Number and percent distribution of all-listed procedures related to admission for current hospice care patients by type of procedure: United States, 1996**

Procedure and ICD-9-CM code <sup>1</sup>	Number	Percent distribution
All procedures . . . . .	18,200	100.0
Diagnostic and miscellaneous therapeutic procedures <sup>2</sup> . . . . .	11,600	63.7
Biopsies <sup>3</sup> . . . . .	*700	*4.1
Diagnostic radiology and related techniques and radioisotope scan and function study . . . . . 87-88,92.0-92.1	*5,300	*29.0
Microscopic examination (laboratory tests) . . . . . 90-91	*1,200	*6.3
Therapeutic radiology and chemotherapy . . . . . 92.2,99.25	1,900	10.4
Surgical procedures on the digestive system <sup>4</sup> . . . . .	1,900	10.7
All other procedures . . . . .	4,700	25.6

\* Figure does not meet standard of reliability or precision and should not be assumed reliable because the sample size is between 30-59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

<sup>2</sup>Includes surgical diagnostic procedures included in codes 01-86 of the procedure classification of the ICD-9-CM and miscellaneous diagnostic and therapeutic procedures (87-99). See the [Technical notes](#) for a list of codes used.

<sup>3</sup>Includes biopsies included in codes 01-86 of the ICD-9-CM. See the [Technical notes](#) for a list of codes used.

<sup>4</sup>Excludes surgical diagnostic procedures included in codes 42-54 of the procedure classification of the ICD-9-CM. See the [Technical notes](#) for a list of codes used.

NOTES: Figures may add to more than totals because of rounding and because a patient may have had more than one procedure. Percents are based on the unrounded numbers.

**Table 11. Number and percent of hospice care discharges by services received, type of provider seen during the 30 days prior to discharge, and sex: United States, 1995-96**

Characteristic	Sex					
	Total	Male	Female	Total	Male	Female
	Number			Percent		
All discharges . . . . .	393,200	197,700	195,500	100.0	100.0	100.0
Services received <sup>1</sup>						
Nursing services . . . . .	379,200	188,500	190,700	96.4	95.3	97.5
Social services . . . . .	299,300	151,200	148,000	76.1	76.5	75.7
Medications . . . . .	197,500	92,500	105,000	50.2	46.8	53.7
Counseling . . . . .	171,400	80,100	91,300	43.6	40.5	46.7
Volunteers . . . . .	119,600	59,600	59,900	30.4	30.2	30.7
Homemaker-household services . . . . .	100,400	46,400	54,000	25.5	23.5	27.6
Physician services . . . . .	97,100	49,300	47,800	24.7	25.0	24.4
Continuous home care . . . . .	47,300	24,000	23,100	12.0	12.2	11.8
Mental health services . . . . .	38,900	18,600	*20,200	9.9	9.4	*10.3
Spiritual care . . . . .	20,800	*8,600	*12,100	5.3	*4.4	*6.2
Nutritionist services . . . . .	18,700	*9,600	*9,100	4.8	*4.9	*4.7
Transportation . . . . .	17,000	*8,700	*	4.3	*4.4	*
All other services . . . . .	51,500	27,600	24,000	13.1	13.9	12.3
Service provider <sup>1</sup>						
Registered nurse . . . . .	360,300	180,400	179,900	91.6	91.3	92.0
Social worker . . . . .	260,700	134,800	125,900	66.3	68.2	64.4
Home health aide . . . . .	217,500	104,200	113,300	55.3	52.7	57.9
Chaplain . . . . .	127,500	58,600	68,900	32.4	29.6	35.2
Volunteer . . . . .	123,400	59,700	63,700	31.4	30.2	32.6
Physician . . . . .	65,200	34,900	30,300	16.6	17.6	15.5
Licensed practical or vocational nurse . . . . .	62,900	33,000	29,900	16.0	16.7	15.3
Nursing aide or attendant . . . . .	62,200	33,700	28,500	15.8	17.1	14.6
Homemaker/personal caretaker . . . . .	31,600	18,400	13,200	8.0	9.3	6.7
Dietician/nutritionist . . . . .	*14,900	*9,800	*	*3.8	*4.9	*
All other providers . . . . .	49,600	26,300	*23,400	12.6	13.3	*11.9

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30-59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Numbers may add to more than totals since a patient may be listed in more than one category.

NOTES: Numbers may add to more than totals because of rounding. Percents are based on the unrounded figures.

**Table 12. Number and percent distribution of hospice care discharges by diagnostic category, according to primary and all-listed diagnoses at admission: United States, 1995–96**

Diagnostic category and ICD-9-CM code <sup>1</sup>	Primary diagnosis		All-listed diagnoses	
	Number	Percent distribution	Number	Percent distribution
All diagnoses . . . . .	393,200	100.0	864,800	100.0
Infectious and parasitic diseases . . . . . 001–139	*15,200	*3.9	*23,200	*2.7
Human immunodeficiency virus (HIV) . . . . . 042	*11,500	*2.9	*13,800	*1.6
Neoplasms . . . . . 140–239	277,500	70.6	432,500	50.0
Malignant neoplasms . . . . . 140–208,230–234	274,000	69.7	428,900	49.6
Malignant neoplasm of large intestine and rectum . . . . . 153–154,197.5	34,000	8.6	36,600	4.2
Malignant neoplasm of liver and intrahepatic bile ducts . . . . . 155,197.7	*	*	39,300	4.5
Malignant neoplasm of pancreas . . . . . 157	11,800	3.0	11,800	1.4
Malignant neoplasm of trachea, bronchus, and lung . . . . . 162,197.0,197.3	86,000	21.9	103,800	12.0
Malignant neoplasm of bone . . . . . 170,198.5	*	*	32,600	3.8
Malignant neoplasm of breast . . . . . 174–175,198.81	17,300	4.4	18,700	2.2
Malignant neoplasm of female genital organs . . . . . 179–184,198.6	*10,100	*2.6	12,000	1.4
Malignant neoplasm of prostate . . . . . 185	12,900	3.3	15,000	1.7
Malignant neoplasm of brain and spinal cord . . . . . 191,192.2,198.3	*14,200	*3.6	34,900	4.0
Malignant neoplasm of lymphatic and hematopoietic tissue . . . . . 200–208	19,900	5.1	24,600	2.8
Malignant neoplasm of other specified sites . . . . . 140–152,156,158–161,163–165,171–173,176,186–190,192.0–192.1,192.3–195,197.1–197.2,194.4,197.6,197.8,198.0–198.2,198.4,198.7,198.82–198.89,230–234	48,500	12.3	76,600	8.9
Malignant neoplasm, disseminated or without specification of site . . . . . 199	*10,600	*2.7	22,800	2.6
Endocrine, nutritional, and metabolic diseases and immunity disorders . . . . . 240–279	*	*	27,600	3.2
Diabetes mellitus . . . . . 250	*	*	14,800	1.7
Mental disorders . . . . . 290–319	*	*	21,400	2.5
Diseases of the nervous system and sense organs . . . . . 320–389	*12,500	*3.2	34,500	4.0
Alzheimer's disease . . . . . 331.0	*	*	*10,800	*1.2
Other hereditary and degenerative diseases of the central nervous system . . . . . 330,331.1–337	*	*	*14,800	*1.7
Diseases of the circulatory system . . . . . 390–459	37,600	9.6	148,300	17.1
Essential hypertension . . . . . 401	*	*	25,800	3.0
Heart disease . . . . . 391–392.0,393–398,402,404,410–416,420–429	26,900	6.8	74,100	8.6
Ischemic heart disease . . . . . 410–414	*	*	*18,300	*2.1
Congestive heart failure . . . . . 428.0	11,900	3.0	35,500	4.1
Cerebrovascular disease . . . . . 430–438	*8,700	*2.2	32,700	3.8
Diseases of the respiratory system . . . . . 460–519	20,500	5.2	53,600	6.2
Chronic obstructive pulmonary disease and allied conditions . . . . . 490–496	12,700	3.2	29,700	3.4
Diseases of the digestive system . . . . . 520–579	*	*	15,500	1.8
Nonalcoholic disorders of the liver and biliary tract . . . . . 570,571.4–576	*	*	*6,300	*0.7
Diseases of the genitourinary system . . . . . 580–629	*9,300	*2.4	18,500	2.1
Renal failure . . . . . 584–586	*8,800	*2.2	12,600	1.5
Diseases of the musculoskeletal system and connective tissue . . . . . 710–739	*	*	*16,800	*1.9
Symptoms, signs, and ill-defined conditions . . . . . 780–799	*	*	39,000	4.5
Supplementary classifications . . . . . V01–V82	*	*	13,100	1.5
Posthospital aftercare . . . . . V42–V46,V52,V53.3–V53.7,V54–V58	*	*	9,100	1.0
All other diagnoses <sup>2</sup> . . . . .	*	*	20,800	2.4

\* Figure does not meet standard of reliability or precision (sample size is less than 30) and is therefore not reported. If shown with a number, it should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

<sup>2</sup>Includes no or unknown diagnosis.

NOTES: Numbers may not add to totals because of rounding. Percents are based on the unrounded figures.

summaries and analyses of data collected from other sources (13).

The National Hospice Organization (NHO) is a nonprofit organization concerned only with hospice care (14). Statistics on hospice care available from the NHO are gathered primarily from its members. The NHO also publishes some information obtained from secondary sources (15).

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**Table 13. Number and percent distribution of all-listed procedures related to admission for hospice care discharges by type of procedure: United States, 1995–96**

Procedure and ICD–9–CM code <sup>1</sup>	Number	Percent distribution
All procedures . . . . .	113,500	100.0
Diagnostic and miscellaneous therapeutic procedures <sup>2</sup> . . . . .	61,500	54.2
Biopsies <sup>3</sup> . . . . .	*5,000	*4.4
Diagnostic radiology and related techniques and radioisotope scan and function study . . . . 87–88,92.0–92.1	*19,300	*17.0
Microscopic examination (laboratory tests) . . . . . 90–91	*17,700	*15.6
Therapeutic radiology and chemotherapy . . . . . 92.2,99.25	*4,000	*3.6
Surgical procedures on the digestive system <sup>4</sup> . . . . .	12,700	11.2
All other procedures . . . . .	39,300	34.6

\* Figure does not meet standard of reliability or precision and should not be assumed reliable because the sample size is between 30–59 or the sample size is greater than 59 but has a relative standard error over 30 percent.

<sup>1</sup>Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

<sup>2</sup>Includes surgical diagnostic procedures included in codes 01–86 of the procedure classification of the ICD–9–CM and miscellaneous diagnostic and therapeutic procedures (87–99). See the [Technical notes](#) for a list of codes used.

<sup>3</sup>Includes biopsies included in codes 01–86 of the ICD–9–CM. See the [Technical notes](#) for a list of codes used.

<sup>4</sup>Excludes surgical diagnostic procedures included in codes 42–54 of the procedure classification of the ICD–9–CM. See the [Technical notes](#) for a list of codes used.

NOTES: Figures may add to more than totals because of rounding and because a discharge may have had more than one procedure. Percents are based on the unrounded numbers.

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## Technical notes

Following is a brief description of the technical aspects of the National Home and Hospice Care Survey. A detailed report about the development and conduct of the survey has been published (1). However, some aspects of the survey have changed. In 1996, the sample design was changed to a two-stage design from the three-stage design that was used during 1992–94. In addition, the data collection forms have been slightly modified each year. Copies of the data collection forms and a more detailed description of the 1996 NHHCS are included in other reports (6, 16).

### Data collection procedures

The sample for the 1996 National Home and Hospice Care Survey (NHHCS) consisted of 1,200 agencies that were selected from a universe of 16,700 agencies identified as providing home health and hospice care (17–19). Of the 1,200 agencies in the sample, 1,091 were considered in scope of the survey, 89 were not providing home health or hospice care services to patients at the time of the survey, and 20 were duplicates of or had merged with other sampled agencies. Of the in-scope agencies, 1,053 (97 percent) agreed to participate in the 1996 NHHCS, 34 refused to participate, and 3 could not be located.

The sample design for the 1996 NHHCS was a stratified two-stage probability design (20). At the first stage, a sample of agencies, stratified by type of agency (home health agency, hospice, and mixed agency) and geographic location, was selected. At the second stage, a systematic sample of current patients and discharges was selected within each agency.

Three questionnaires and two sampling lists were used to collect the data. The agency questionnaire was completed by interviewing the administrator of each agency. The interviewer then constructed a current patient sampling list and a discharged patient sampling list. These lists were used to select the sample patients and discharges. Up to six current patients and up to six discharges were selected.

The current patient questionnaires and the discharged patient questionnaires were then completed for each sampled person by interviewing the staff member most familiar with the care provided to the patient. The respondent referred to patient medical and other records as necessary. No patient was interviewed directly.

After the data had been collected, they were converted into machine-readable form by NCHS. Extensive computer and manual editing was conducted to ensure that all responses were accurate, consistent, logical, and complete. Diagnoses and procedures were coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification* (11). Up to 12 diagnostic codes (a maximum of 6 at admission and a maximum of 6 at the time of survey or discharge) and up to 2 procedure codes were assigned for each sample patient or discharge.

### Estimation procedures

Statistics presented in this report were derived by a multistage estimation procedure (21) that produces essentially unbiased national estimates and has three principal components. The first component, inflation by the reciprocals of the probabilities of sample selection, is the basic inflation weight. The second component, adjustment for nonresponse, brings estimates based only on the responding cases up to the level that would have been achieved if all eligible cases had responded. The third component, ratio adjustment to fixed totals, adjusts for over- or undersampling of agencies reported in the sampling frame.

### Reliability of estimates

Because the statistics presented in this report are based on a sample, they will differ somewhat from figures that would have been obtained if a complete census had been taken using the same schedules, instructions, and procedures. The standard error (SE) is primarily a measure of the variability that occurs by chance because a sample, rather than the entire universe, is surveyed. The SE also reflects part of the measurement error,

but it does not measure any systematic biases in the data. The chances are about 95 in 100 that an estimate from the sample differs from the value that would be obtained from a complete census by less than twice the SE. However, SE's typically underestimate the true errors of the statistics because they reflect only errors due to sampling.

The SE's used in this report were approximated using SUDAAN software. SUDAAN computes SE's by using a first-order Taylor approximation of the deviation of estimates from their expected values. A description of the software and the approach it uses has been published (22). Although exact SE estimates were used in tests of significance in this report, SE's for aggregate estimates presented may be estimated using the general formula:

$$SE(X) = X \cdot RSE(X)$$

where  $X$  is the estimate and  $RSE(X)$  is the relative standard error of the estimate. The relative standard error ( $RSE(X)$ ) may be estimated using the following general formula (23):

$$RSE(X) = \sqrt{\frac{B}{A + X}}$$

where  $X$  is the estimate and  $A$  and  $B$  are the appropriate parameters from [table I](#).

To approximate the relative standard error ( $RSE(p)$ ) and the standard error ( $SE(p)$ ) of a percent  $p$ , the appropriate values of parameter  $B$  from [table I](#) are used in the following equations:

$$RSE(p) = \sqrt{\frac{B \cdot (100 - p)}{p \cdot Y}}$$

and

$$SE(p) = p \cdot RSE(p)$$

where  $p = 100 \cdot X/Y$ ,  $X$  = the numerator of the estimated percent, and  $Y$  = the denominator of the estimated percent.

The standard error of a percent is valid only when one of the following conditions is satisfied: the relative standard error of the denominator is 5 percent or less (24) or the relative standard errors of the numerator and the denominator are both 10 percent or less (25).



**Presentation of estimates**

Publication of estimates for the NHHCS is based on the RSE of the estimate and the number of sample records on which the estimate is based (referred to as the sample size). Estimates are not presented unless a reasonable assumption regarding the probability distribution of the sampling error is possible.

Because of the complex sample design of the NHHCS, the following guidelines are used for presenting the estimates:

If the sample size is less than 30, the value of the estimate is not reported.

If the sample size is 30–59, or if the sample is 60 or more and the RSE is 30 percent or more, the estimate is reported but should not be assumed reliable. This is indicated by an asterisk (\*) in the tables.

If the sample size is 60 or more and the RSE is less than 30 percent, the estimate is reported and is considered reliable.

**Selected definitions**

**Terms relating to agencies**

*Agencies providing hospice care services*—are agencies that had at least one current hospice care patient at the time of the survey or had at least one discharge from hospice care during a designated month from October 1995 through September 1996.

*Region*—refers to the four geographic regions of the United States that correspond to those used by the U.S. Bureau of the Census (see [table II](#)).

**Terms relating to patients and discharges**

*Current patient*—is a patient on the agency’s roster as of midnight on the night before the survey.

*Discharge*—is a patient formally discharged from care by the agency. A patient can be counted more than once if the patient was discharged more than once during the reference period.

*Primary caregiver*—is an individual or organization that is responsible for providing personal care assistance, companionship, and/or supervision to

**Table I. Parameters used to compute relative standard error of numbers by type of estimate**

Type of estimate	Parameters	
	A	B
Agency . . . . .	0.019261	4.425270
Current patient . . . . .	0.018098	97.086178
Discharge . . . . .	0.026362	432.006607

**Table II. Geographic regions of the United States as used by the U.S. Bureau of the Census**

Region	States included
Northeast . . . . .	Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont
Midwest . . . . .	Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin
South . . . . .	Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia
West . . . . .	Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, New Mexico, Nevada, Oregon, Utah, Washington, Wyoming

the patient. The relationship of the primary caregiver to the patient is presented in this report. The following categories include answers that were originally listed in the “Other, specify” category: sister or brother, friend or neighbor, hired help or staff of residential care facility (includes staff of health facility).

*Residence*—is where the patient or discharge was living. Private or semiprivate residence includes private residence, rented room, boarding house, and retirement home. Health facility includes some answers that were originally listed in the “Other, specify” category.

*Reason for discharge*—is why the patient was discharged from care. Services provided from another source include family and/or friends resumed care, admitted to hospital, admitted to nursing home, and transferred to another agency.

*Services received*—The following categories include answers that were originally listed in the “Other, specify” category: continuous home care, counseling, nursing services, spiritual care. The category “All other services” is an unduplicated count—that is, if patients and/or discharges received more than one type of service that is not

listed separately in this report, they are counted only once in this category.

*Service provider*—The category “Chaplain” includes answers that were originally listed in the “Other, specify” category. The category “All other providers” is an unduplicated count—that is, if patients and/or discharges were seen by more than one type of service provider that is not listed separately in this report, they are counted only once in this category.

*Procedure categories*—See [table III](#) for the ICD–9–CM codes for the procedure categories shown in text [tables 10](#) and [13](#) in this report.

Table III. ICD-9-CM procedure codes used for categories shown in text tables 10 and 13

Category	ICD-9-CM codes <sup>1</sup>
Diagnostic and miscellaneous therapeutic procedures . . . . .	01.1,03.3,04.1,05.1,06.1,07.1,08.1,09.1,10.2,11.2,12.2,14.1,15.0,16.2,18.1,20.3,21.2,22.1,24.1,25.0,26.1,27.2,28.2,29.1,31.4,33.2,34.2,37.2,38.2,40.1,41.3,42.2,44.1,45.1-45.2,48.2,49.2,50.1,51.1,52.1,54.2,55.2,56.3,57.3,58.2,59.2,60.1,61.1,62.1,63.1,64.1,65.1,66.1,67.1,68.1,69.09,70.2,71.1,75.1,75.3,76.1,77.4,80.2,80.3,83.2,85.1,86.1
Biopsies . . . . .	01.11-01.15,13.32,04.11-04.12,05.11,06.11-06.13,07.11-07.17,08.11,09.11-09.12,10.21,11.22,12.22,15.01,16.23,18.12,20.32,21.22,22.11-22.12,24.11-24.12,25.01-25.02,26.11-26.12,27.21-27.24,28.11,29.12,31.43-31.45,33.24-33.28,34.23-34.27,37.24-37.25,38.21,40.11,41.31-41.33,42.24-42.25,44.14-44.15,45.14-45.16,45.25-45.27,48.24-48.26,49.22-49.23,50.11-50.12,51.12-51.14,52.11-52.12,52.14,54.22-54.24,55.23-55.24,56.32-56.34,57.33-57.34,58.23-58.24,59.21,60.11-60.15,61.11,62.11-62.12,63.01,64.11,65.11-65.12,66.11,67.11-67.12,68.13-68.16,70.23-70.24,71.11,76.11,77.4,80.3,83.21,85.11-85.12,86.11
Surgical procedures on the digestive system . . . . .	42.0-42.1,42.3-44.0,44.2-45.0,45.3-48.1,48.3-49.1,49.3-50.0,50.2-51.0,51.2-52.0,52.2-54.1,54.3-54.9

<sup>1</sup>Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (11).

**Suggested citation**

Haupt BJ. Characteristics of hospice care users: Data from the 1996 National Home and Hospice Care Survey. Advance data from vital and health statistics; no. 299. Hyattsville, Maryland: National Center for Health Statistics. 1998.

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**National Center for Health Statistics**

Director  
Edward J. Sondik, Ph.D.  
  
Deputy Director  
Jack R. Anderson

DEPARTMENT OF  
HEALTH & HUMAN SERVICES

Centers for Disease Control and Prevention  
National Center for Health Statistics  
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DHHS Publication No. (PHS) 98-1250  
8-0674 (8/98)