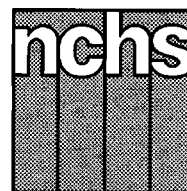


Advance Data



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Characteristics of Patients Receiving Hospice Care Services: United States, 1994

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Abstract

Objective—This report presents data on current hospice care patients. Numbers and percents are shown by selected characteristics of the agencies from which the patients received services, by selected patient characteristics, by services provided, by types of personnel that provided the services, and by diagnoses of these patients.

Methods—The data used for this report are from the National Center for Health Statistics' 1994 National Home and Hospice Care Survey. This is an annual survey through which data are collected on the use of hospices and home health care agencies in the United States.

Results—An estimated 61,000 patients were receiving hospice care services from 1,300 hospices and home health agencies in 1994. Fifty-five percent were women, 69 percent were 65 years of age and over, 81 percent were white patients, 48 percent were married, and 31 percent were widowed. Eighty-four percent were living in a private or semi-private residence, and 90 percent had a primary caregiver. Sixty percent received help from the agency with at least one activity of daily living (ADL), 46 percent with at least one instrumental activity of daily living (IADL), and 26 percent with walking. At admission, there was an average of 2.2 diagnoses per patient; 57 percent had a primary diagnosis of a malignant neoplasm and 9 percent had a primary diagnosis of heart disease.

Keywords: National Home and Hospice Care Survey • long-term care • functional status • malignant neoplasms

Introduction

This report presents statistics from the 1994 National Home and Hospice Care Survey (NHHCS), a segment of the long-term care component of the National Health Care Survey (1). The NHHCS, an annual survey operated by the National Center for Health Statistics (NCHS), collects data on the use of

hospices and home health care agencies in the United States. Information is collected about the agencies that provide hospice and home health care services, their current patients, and their discharges.

At the time of the survey, there were an estimated 10,900 hospices and home health care agencies providing

services to 1,950,300 patients in the United States—1,889,400 patients were receiving home health care services and 61,000 were receiving hospice care services (2). A report has been published presenting the characteristics of elderly home health care users in 1994 (3). This report, focusing on the patients who received hospice care services, provides 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 independence while minimizing the effects of disability and illness, including terminal illness. Hospice care is 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 (2). Although home health care agencies may provide hospice care as well as home health care, hospices generally provide only hospice care services.



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Hospice care in the United States began in the early 1970's and relied heavily on professional and lay volunteers. The movement has since grown into a more formal, regulated industry. Reimbursement for hospice care services is provided by many insurance programs, including Medicare and Medicaid. 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 (2,4–6).

Methods

Data collection for the 1994 NHHCS was conducted between August and December 1994. 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. A brief overview of the data collection methods and estimation and testing procedures for the NHHCS is in the [Technical notes](#). More detailed information has been published in other reports (2,7,8).

Statistics presented in this report are estimated numbers and percents of current hospice care patients 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 with at least one current hospice care patient at the time of the survey. A current patient is a patient who was on the rolls of the agency as of midnight on the day immediately before the date of the survey.

Agency characteristics examined include ownership, Medicare and Medicaid certification, affiliation, location, and size. 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. Two types of locations are reported: geographic region and metropolitan statistical area. Size was determined from the total number of patients receiving either hospice or home health care at the time of the survey. This number was obtained from the list of current patients that was used for patient sample selection and that was constructed at the time of the survey.

Patient information included in this report consists of demographic characteristics (sex, age, race, and marital status), living arrangements, primary caregiver status, and functional status of the patients. Information on functional status includes use of special aids and vision, hearing, and continence status. Statistics are also presented about the services provided to the patients (including assistance with activities of daily living, walking, and instrumental activities of daily living) and types of personnel providing the services. Activities of daily living include bathing, dressing, eating, transferring from a bed or a chair, and using the toilet room. Instrumental activities of daily living include doing light housework, managing money, shopping for groceries or clothes, using the telephone, preparing meals, and taking medications. Finally, diagnoses of the patients at admission and at the time of the survey are examined.

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 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

Agency characteristics

[Table 1](#) shows the number and percent of agencies providing care to hospice patients at the time of the survey in 1994 according to selected agency characteristics. The number and percent of current patients served by these agencies are also shown. An estimated 1,300 hospices and home health care agencies were providing hospice care services to 61,000 patients in the United States.

The vast majority of the facilities—1,100, or 87 percent—were voluntary nonprofit agencies. Seventy-nine percent were certified under Medicare and 70 percent were certified under Medicaid as hospices, while 45 percent and 44 percent were certified under Medicare and Medicaid, respectively, as home health agencies. Five hundred of the agencies, or 35 percent, were operated by a hospital, and 400, or 34 percent, were part of a group or chain of agencies.

Thirty-eight percent of the agencies providing hospice care services were in the Midwest region, 28 percent were in the South, 21 percent were in the Northeast, and 13 percent were in the West. Seven hundred (53 percent) of the agencies were located in a metropolitan statistical area (MSA).

Most of these agencies were relatively small. Over half (53 percent) had 30 or fewer hospice or home health care patients at the time of the survey, while only 20 percent were serving more than 100 patients.

The majority of the hospice care patients (52,600, or 86 percent) were receiving services from voluntary nonprofit hospices and home health agencies. Over 80 percent of the patients were being served by an agency that was certified under Medicare and/or Medicaid as a hospice, a home health agency, or both. Thirty-three percent of the patients received services from a hospital-affiliated agency, and 40 percent received services from an agency that was part of a group or chain of agencies.

Of the patients served, 34 percent were served by agencies in the South

Table 1. Number and percent of agencies with hospice care patients and hospice care patients by selected agency characteristics: United States, 1994

Agency characteristic	Agencies		Current patients	
	Number	Percent	Number	Percent
All agencies	1,300	100.0	61,000	100.0
Ownership				
Proprietary	*100	*9.1	6,700	11.0
Voluntary nonprofit	1,100	87.0	52,600	86.3
Government and other	*	*	*1,700	*2.7
Certification ¹				
Medicare:				
As hospice	1,000	78.8	51,400	84.3
As home health agency	600	44.9	32,300	52.9
Medicaid:				
As hospice	900	69.7	49,300	80.8
As home health agency	600	44.1	31,800	52.2
Affiliation ¹				
Operated by hospital	500	35.0	19,800	32.5
Part of a group	400	33.7	24,200	39.8
Geographic region				
Northeast	300	20.5	15,400	25.2
Midwest	500	37.8	14,300	23.4
South	400	28.3	20,800	34.2
West	200	13.4	10,500	17.2
Location of agency				
MSA ²	700	53.0	47,500	77.8
Non-MSA ²	*600	*47.0	13,500	22.2
Size of agency ³				
1–15 patients	*500	*35.3	*4,000	*6.5
16–30 patients	200	17.3	5,100	8.4
31–100 patients	400	27.2	17,000	27.8
101–300 patients	200	12.7	16,100	26.4
More than 300 patients	*100	*7.5	18,800	30.8

* Figure does not meet standard of reliability or precision.

¹Numbers may not add to total because not all agencies are certified or affiliated, and an agency may have more than one type of certification or affiliation.

²MSA is metropolitan statistical area.

³Size of agency is based on the total number of both hospice and home health care current patients at the time of the survey.

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

region, 25 percent in the Northeast, 23 percent in the Midwest, and 17 percent in the West. Although 53 percent of the agencies were located in an MSA, these agencies served 78 percent of the patients.

Not surprisingly, most of the patients were being served by larger agencies. The 700 agencies with 30 or fewer patients (53 percent of the agencies) were providing services to only 15 percent (9,100) of the current hospice care patients. In contrast, 57 percent (34,900) of the patients were receiving services from the 300 agencies (20 percent) that had more than 100 home and hospice care patients.

Patient characteristics

Table 2 shows the number and percent 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. Moreover, the women served were older than the men: 75 percent of the women were 65 years of age and over compared with 61 percent of the men.

Eighty-one percent of the patients were white and 8 percent were black and other races. Race was unknown for 11 percent of the patients. There was no significant difference in the number of

patients by sex within each race category.

Just under half (48 percent) of the 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 at the time of the survey than were women, whereas women were more likely to be widowed.

Most of the hospice care patients—84 percent—were living in a private or semi-private residence at the time of the survey, and about 11 percent were residents of an inpatient health facility (table 3). Of the

Table 2. Number and percent of current patients receiving hospice care by selected patient characteristics: United States, 1994

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female
	Number			Percent		
Total	61,000	27,200	33,700	100.0	100.0	100.0
Age at admission ¹						
Under 65 years	18,900	10,500	8,400	30.9	38.5	24.8
Under 45 years	5,200	3,700	*1,500	8.6	13.7	*4.4
45–64 years	13,600	6,800	6,900	22.4	24.8	20.4
65 years and over	41,900	16,700	25,200	68.8	61.4	74.7
65–69 years	5,800	2,100	3,700	9.5	7.8	10.9
70–74 years	8,400	4,600	3,800	13.8	16.9	11.4
75–79 years	7,500	3,200	4,300	12.3	11.8	12.7
80–84 years	10,000	3,400	6,600	16.5	12.6	19.6
85 years and over	10,100	3,400	6,800	16.6	12.3	20.1
Race						
White	49,300	22,500	26,800	80.8	82.6	79.3
Black and other ²	4,800	*2,700	2,100	7.9	*9.9	6.2
Black	4,400	*2,500	1,900	7.2	*9.2	5.6
Unknown	6,900	*2,000	4,900	11.4	*7.5	14.5
Current marital status						
Married	29,500	19,000	10,500	48.4	69.7	31.1
Not married ³	29,200	7,900	21,400	47.9	28.8	63.4
Widowed	18,600	2,700	15,900	30.6	10.1	47.1
Unknown	2,300	*	*1,900	3.7	*	*5.5

* Figure does not meet standard of reliability or precision.

¹Excludes unknown.

²Includes race other than white, black, or unknown.

³Includes separated.

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

noninstitutionalized patients, 73 percent lived with family members, 17 percent lived alone, and 7 percent lived only with nonfamily members. Men were more likely to be living in a private or semi-private residence than were women. On the other hand, a significantly larger percent of women than men were living in a health facility at the time of the survey. Of the noninstitutionalized patients, a larger percent of men than women lived with family members.

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. In addition, most of the patients with a primary caregiver lived with their caregiver. Again, there were differences in caregiver status between the two sexes. Men were more likely than were women both to have a caregiver and to live with their caregiver. Although the primary caregiver was most often a relative of

the patient, the type of relationship was 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.

The number and percent of current hospice care patients using selected aids at the time of the survey are shown in table 4. About half of the patients were using an aid to help with mobility—most commonly a walker or a wheelchair. Other aids used included eye glasses (43 percent), hospital bed (40 percent), supplemental oxygen (26 percent), and commode (25 percent). Twenty percent of the patients were using dentures, 12 percent used a shower chair, 5 percent had a hearing aid, and 4 percent used transfer equipment. Twenty-two percent of the patients used at least one other type of aid.

About a quarter of the current hospice care patients had an ostomy or an indwelling catheter at the time of the

survey (table 4). Excluding these patients, 16 percent had difficulty controlling their bladder and 15 percent had difficulty controlling their bowels.

Table 4 also shows that over half of the current patients did not have difficulty seeing or hearing (with the use of an aid if applicable). Twenty percent had some vision impairment and 16 percent had some hearing impairment, even with the use of aids. Note, however, that the vision or hearing status was unknown for over 25 percent of the patients.

Table 5 provides information on agency assistance with activities of daily living (ADL's), instrumental activities of daily living (IADL's), and walking, by sex and by whether the patient lived with his/her primary caregiver. As stated previously, patient information collected through the NHHCS is obtained from the medical records maintained by the agency. However, it has been found that functional problems are frequently underreported in medical records (9). Therefore, information on ADL's and

Table 3. Number and percent of current patients receiving hospice care by current residence, living arrangements, and primary caregiver status: United States, 1994

Patient characteristic	Both sexes			Both sexes		
	Male	Female	Both sexes	Male	Female	Both sexes
	Number			Percent		
Total	61,000	27,200	33,700	100.0	100.0	100.0
Current residence ¹						
Private or semiprivate residence ²	51,100	24,600	26,500	83.8	90.4	78.5
Board and care or residential care facility	2,100	*	*1,400	3.5	*	*4.1
Health facility (including mental health facility)	6,500	1,600	4,900	10.6	5.9	14.4
Living arrangements ³						
Noninstitutionalized patients ⁴	54,500	25,600	28,900	100.0	100.0	100.0
Lives with family members	39,500	22,400	17,100	72.5	87.2	59.4
Lives alone	9,200	*1,900	7,300	16.9	*7.4	25.3
Lives with only nonfamily members	3,700	*1,100	2,600	6.7	*4.3	8.9
Primary caregiver status						
Has no primary caregiver ⁵	6,200	1,500	4,800	10.2	5.3	14.1
Has primary caregiver	54,800	25,800	29,000	89.8	94.7	85.9
Patients with primary caregiver	54,800	25,800	29,000	100.0	100.0	100.0
Lives with primary caregiver	42,700	22,900	19,800	78.1	88.9	68.4
Relationship of primary caregiver to patient: ¹						
Spouse	25,600	17,200	8,400	46.8	66.8	29.0
Child/child-in-law	13,300	3,000	10,300	24.3	11.8	35.4
Other relative	9,800	3,800	*6,000	17.9	14.6	*20.8
Friend or neighbor	*1,300	*	*700	*2.3	*	*2.6

* Figure does not meet standard of reliability or precision.

¹Excludes other and unknown.

²Includes private residence, rented room, boarding house, and retirement home.

³Excludes those for whom living arrangements are unknown.

⁴Excludes those living in health facilities.

⁵Includes unknowns.

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

IADL's collected in the NHHCS was limited to identifying whether agency personnel provided help with each specific activity, rather than whether the patient needed help with the activity. Hence, measures of ADL's and IADL's obtained through the NHHCS serve more as indicators of services provided rather than as indicators of functional status. To the extent that hospice care patients receive help from other persons (such as their primary caregiver, family members, and friends), their need for help with these activities is underestimated by the NHHCS.

Sixty percent of all patients received help from the agency with at least one ADL, 46 percent received help with at least one IADL, and 26 percent received help with walking. With respect to specific ADL's, hospice care patients received agency help most often with bathing or showering (56 percent) and dressing (43 percent); for specific IADL's, the most common types of

assistance included taking medications (29 percent) and doing light housework (26 percent). Although a larger percent of women than men received help with each ADL, with doing light housework, with preparing meals, and with walking, the differences are not statistically significant.

Of the patients living with their primary caregiver, 58 percent received help from the agency with at least one ADL, 48 percent received help with at least one IADL, and 29 percent received help with walking. The comparable percents for patients not living with their primary caregiver were 66 percent, 40 percent, and 28 percent. Although none of the differences in percents are statistically significant, a larger percent of hospice care patients who did not live with their primary caregiver received help from the agencies with at least one ADL, specifically bathing and showering, dressing, or eating. On the other hand, of those who lived with

their primary caregiver, a larger percent received help with at least one IADL, especially doing light housework and taking medications.

Services and diagnoses

The number and percent of patients receiving services within the most recent billing period are shown in table 6. Virtually all of the patients had received at least one of the listed services within that time period. Of these, the majority (92 percent) received skilled nursing services. Over half received social services or personal care (60 percent and 52 percent, respectively), and about a third received medications (36 percent), spiritual care (34 percent), or counseling (33 percent). A significantly larger percent of women than men received personal care.

Table 6 also provides information on the type of service provider seen during the most recent billing period.

Table 4. Number and percent of current patients receiving hospice care by type of aids currently used and selected functional status characteristics: United States, 1994

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female
	Number			Percent		
All patients	61,000	27,200	33,700	100.0	100.0	100.0
Special aids						
Patients with at least one special aid ^{1,2}	51,700	23,100	28,600	84.8	84.8	84.8
Aids used:						
Mobility aids ¹	31,500	13,500	18,000	51.6	49.5	53.3
Wheelchair	18,200	7,800	10,400	29.9	28.8	30.7
Walker	16,400	7,000	9,400	26.8	25.6	27.8
Crutches, cane	7,500	2,900	*4,600	12.4	10.9	*13.7
Eye glasses	26,200	10,000	16,200	43.0	36.8	48.1
Hospital bed	24,300	10,400	13,900	39.8	38.1	41.2
Oxygen	15,900	7,700	8,100	26.0	28.4	24.2
Commode	15,000	6,600	8,400	24.7	24.3	25.0
Dentures	12,100	5,700	6,300	19.8	21.1	18.8
Shower chair	7,600	4,300	3,300	12.4	15.9	9.7
Hearing aid	3,300	*1,800	*1,500	5.3	*6.6	*4.3
Transfer equipment	2,100	*1,100	*1,100	3.5	*3.9	*3.2
All other aids	13,500	7,100	6,400	22.1	25.9	18.9
Has ostomy or indwelling catheter	15,900	7,500	8,400	26.0	27.4	24.9
Continence ³						
Difficulty controlling bladder	9,900	4,500	5,400	16.2	16.4	16.1
Difficulty controlling bowels	8,900	4,100	4,800	14.7	15.1	14.3
Vision						
Not impaired	32,100	15,200	16,900	52.6	55.7	50.1
Impaired	12,100	3,700	8,400	19.9	13.6	25.0
Unknown ⁴	16,700	8,400	8,400	27.5	30.7	24.9
Hearing						
Not impaired	35,600	15,400	20,100	58.3	56.6	59.7
Impaired	9,800	3,800	6,000	16.0	13.9	17.7
Unknown ⁴	15,700	8,000	7,600	25.7	29.5	22.6

* Figure does not meet standard of reliability or precision.

¹Numbers may add to more than total since a patient may use more than one type of aid.

²Excludes unknowns.

³Excludes those with an ostomy or indwelling catheter.

⁴Includes those for whom status cannot be determined (e.g., comatose patients, infants).

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

Again, virtually all of the patients had been seen by at least one type of provider. The type of provider seen reflects the services provided. The vast majority of patients (93 percent) had been seen by a registered nurse, 64 percent had been seen by a social worker, 45 percent had been seen by a home health aide, and 27 percent had been seen by a chaplain. About 30 percent of the patients had been seen by volunteers during the last billing period. A larger percent of women than men were seen by home health aides.

The number and percent of primary and all-listed diagnoses at admission and at the time of the survey are shown in [tables 7 and 8](#). There was an average of

2.2 diagnoses per patient at admission and 2.1 diagnoses per patient at the time of the survey. Overall, the current diagnosis (the diagnosis at the time of the survey) did not differ significantly from the diagnosis at admission for both the primary diagnosis and the all-listed diagnoses. At admission, most (57 percent) of the hospice care patients had a primary diagnosis of malignant neoplasm, and about 9 percent had a primary diagnosis of heart disease. Over 40 percent of the all-listed diagnoses was for a malignant neoplasm and about 11 percent was for some form of heart disease.

Information on the most common admission diagnoses for current hospice

care patients according to sex is shown in [tables 9–11](#). The number of diagnoses within every category shown in [table 9](#) was larger for women than for men except for the primary diagnosis of diseases of the circulatory system and heart disease. However, the differences are statistically significant only for all-listed diagnoses of chronic obstructive pulmonary disease. Over half of the patients—58 percent of the men and 56 percent of the women—had a primary diagnosis of malignant neoplasm; the comparable percents for all-listed diagnoses are 45 percent for men and 39 percent for women.

The most common malignant neoplasms at admission are shown in

Table 5. Number and percent of current patients receiving hospice care who receive help from the agency with activities of daily living, instrumental activities of daily living, and walking: United States, 1994

ADL's and IADL's	All patients	Sex		Lives with primary caregiver		
		Male	Female	Yes	No ¹	
		Number				
All patients	61,000	27,200	33,700	42,700	18,200	
Receives help from agency with ADL's						
Receives help with at least one ADL	36,500	14,900	21,700	24,600	12,000	
ADL's:						
Bathing or showering	33,900	13,900	20,000	23,300	10,600	
Dressing	26,000	10,300	15,700	17,500	8,500	
Eating	11,100	3,900	7,200	7,200	3,900	
Transferring in or out of beds or chairs	21,500	8,200	13,300	15,400	6,000	
Using the toilet room	17,200	6,500	10,700	12,900	4,300	
Receives help from agency with IADL's						
Receives help with at least one IADL	27,900	13,000	14,800	20,700	7,200	
IADL's:						
Doing light housework	16,100	7,000	9,200	12,100	4,100	
Managing money	1,100	*600	*500	*800	*	
Shopping for groceries or clothes	4,800	*2,100	2,600	3,300	*1,500	
Using the telephone	*2,300	*	*1,100	*1,400	*	
Preparing meals	8,800	3,100	5,700	6,000	2,800	
Taking medications	17,700	8,400	9,300	13,200	4,500	
Receives help from agency with walking	17,300	7,000	10,200	12,200	5,100	
		Percent				
All patients	100.0	100.0	100.0	100.0	100.0	
Receives help from agency with ADL's						
Receives help with at least one ADL	59.9	54.6	64.3	57.5	65.6	
ADL's:						
Bathing or showering	55.6	50.9	59.4	54.5	58.1	
Dressing	42.7	37.6	46.7	41.0	46.4	
Eating	18.1	14.1	21.4	16.8	21.3	
Transferring in or out of beds or chairs	35.2	29.9	39.5	36.1	33.1	
Using the toilet room	28.2	23.9	31.8	30.1	23.8	
Receives help from agency with IADL's						
Receives help with at least one IADL	45.8	47.8	44.1	48.4	39.7	
IADL's:						
Doing light housework	26.4	25.6	27.2	28.2	22.3	
Managing money	1.8	*2.1	*1.6	*1.7	*	
Shopping for groceries or clothes	7.8	*7.8	7.8	7.7	*8.2	
Using the telephone	*3.7	*	*3.3	*3.2	*	
Preparing meals	14.4	11.4	16.8	14.1	15.2	
Taking medications	29.0	30.9	27.5	30.9	24.6	
Receives help from agency with walking	25.8	25.8	30.4	28.6	27.8	

* Figure does not meet standard of reliability or precision.

¹Includes unknown and patients that have no primary caregiver.

NOTES: Numbers may add to more than totals because a patient may receive help with more than one type of ADL or IADL. ADL is activities of daily living, and IADL is instrumental activities of daily living. Percents are based on the unrounded figures.

table 10 for men and table 11 for women. For men, the most common primary malignant neoplasms involved the prostate; the trachea, bronchus, and lung; and the large intestine and rectum. Women most often had a primary malignant neoplasm of the trachea, bronchus, and lung; the large intestine and rectum; the breast; or the female genital organs. When looking at

all-listed diagnoses, malignant neoplasms of the brain and spinal cord, the liver and intrahepatic bile ducts, and the bone also frequently occurred for both men and women.

Summary and discussion

This report presents data on characteristics of patients receiving

hospice care services in 1994. Overall, 61,000 patients were receiving hospice care services from 1,300 hospices and home health care agencies in the United States. Most of the patients were served by voluntary nonprofit organizations and by agencies that were Medicare and/or Medicaid certified.

Fifty-five percent of the hospice care patients were women and four out

Table 6. Number and percent of current patients receiving hospice care by services received and type of provider seen during last billing period, according to sex: United States, 1994

Patient characteristic	Both sexes			Both sexes		
	Male	Female	Both sexes	Male	Female	Both sexes
	Number			Percent		
All patients	61,000	27,200	33,700	100.0	100.0	100.0
Services received ¹						
Received at least one service during the last billing period ²	60,700	27,200	33,500	99.6	99.9	99.3
Patients who received at least one service	60,700	27,200	33,500	100.0	100.0	100.0
Skilled nursing services	55,700	24,700	31,000	91.7	90.6	92.6
Social services	36,600	16,900	19,700	60.3	62.1	58.9
Personal care	31,600	11,500	20,200	52.1	42.1	60.2
Medications	22,000	9,800	12,200	36.3	36.0	36.5
Spiritual care	20,700	7,900	12,800	34.1	29.0	38.1
Counseling	19,700	9,000	10,700	32.5	33.2	31.9
Volunteers	18,100	7,900	10,200	29.8	29.0	30.4
Durable medical equipment and supplies	16,400	6,900	9,500	27.1	25.5	28.4
Physician services	7,800	3,200	4,600	12.9	11.9	13.7
Homemaker and/or companion services	7,600	3,300	4,200	12.5	12.3	12.7
Respite care	*4,100	*2,700	1,500	*6.8	*9.8	4.4
High tech services including enterostomal therapy	3,900	*2,700	*1,200	6.4	*9.8	*3.7
Referral services	3,200	1,300	1,900	5.3	4.8	5.7
Dietary and nutritional services	2,900	*1,400	1,500	4.8	*5.1	4.6
Continuous home care	2,200	*1,000	*1,200	3.6	*3.8	*3.5
All other services	7,300	2,400	4,900	12.0	8.6	14.6
Service provider ¹						
At least one provider seen during the last billing period ²	60,400	27,100	33,400	99.1	99.4	98.9
Patients who saw at least one provider	60,400	27,100	33,400	100.0	100.0	100.0
Registered nurses	56,400	25,400	31,000	93.2	93.7	92.9
Social workers	38,700	18,300	20,400	64.0	67.4	61.3
Home health aides	27,100	10,300	16,800	44.8	38.1	50.3
Volunteers	18,200	8,200	10,000	30.1	30.3	29.9
Chaplains	16,600	6,200	10,300	27.4	23.1	30.9
Nursing aides and attendants	7,100	2,400	4,800	11.8	8.8	14.3
Licensed practical or vocational nurses	6,500	3,400	3,100	10.7	12.5	9.3
Physicians	5,700	2,500	3,200	9.4	9.4	9.5
Homemakers and/or personal caretakers	4,300	*2,000	2,300	7.1	*7.5	6.8
All other providers	7,900	2,900	5,000	13.0	10.5	15.0

* Figure does not meet standard of reliability or precision.

¹Numbers may add to more than total since a patient may be listed in more than one category.

²Excludes unknowns.

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

of five patients were white. Overall, two-thirds of the patients were 65 years of age and over when they were admitted to the agency. At the time of the survey, about half were married, a third were widowed, and four out of five were living in a private or semi-private residence. Most of the patients had a primary caregiver. Of the patients with a primary caregiver, most were related to and lived with their caregiver.

Men tended to be younger, married, living in a private or semi-private residence, and living with family members. Women tended to be older and widowed. Although most of the

women also lived in a private or semi-private residence and lived with family members, a larger proportion of women than men lived in an inpatient health facility or lived alone.

A larger proportion of men than women had a primary caregiver. Of those with a primary caregiver, men were more likely to live with their caregiver than were women. Consistent with the patterns of age, marital status, and living arrangements, the primary caregiver of most of the men was their spouse. On the other hand, the primary caregiver of most of the women was

another relative, most often a child or child-in-law.

Sixty percent of all patients received help from the agency with at least one ADL, about half received help with at least one IADL, and one quarter received help with walking. Although the differences are not statistically significant, a higher proportion of women than of men received help with all of the ADL's listed, with walking, with doing light housework, and with preparing meals. Again, this pattern is consistent with the previous pattern noted of a larger proportion of women than men being older, widowed, living

Table 7. Number of current patients receiving hospice care services by primary diagnosis and all-listed diagnoses at admission and at time of survey: United States, 1994

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis		All-listed diagnoses	
	At admission	At time of survey	At admission	At time of survey
All diagnoses	61,000	61,000	132,600	126,300
Infectious and parasitic diseases001-139	1,900	1,900	*3,900	*4,000
Auto-Immune Deficiency Syndrome (AIDS) or Human Immunodeficiency Virus (HIV)042-044	1,900	1,900	1,900	1,900
Neoplasms140-239	35,800	34,000	56,200	54,200
Malignant neoplasms140-208,230-234	34,700	33,000	55,100	53,100
Malignant neoplasm of large intestine and rectum153-154,197.5	4,900	4,800	5,400	5,400
Malignant neoplasm of liver and intrahepatic bile ducts155,198.7	*1,000	*1,000	4,300	4,200
Malignant neoplasm of pancreas157	1,800	1,700	1,800	1,700
Malignant neoplasm of trachea, bronchus, and lung162,197.0,197.3	7,600	7,200	9,500	9,200
Malignant neoplasm of bone170,198.5	*	*	4,000	4,000
Malignant neoplasm of breast174-175,198.81	2,900	2,900	3,200	3,100
Malignant neoplasm of female genital organs179-184,198.6	2,100	2,100	*2,100	*2,100
Malignant neoplasm of prostate185	3,600	*3,600	3,900	3,900
Malignant neoplasm of brain and spinal cord191,192.2,198.3	*1,800	*1,800	3,600	3,600
Malignant neoplasm of lymphatic and hematopoietic tissue200-208	1,500	1,400	2,700	2,600
Malignant neoplasm of other specified sites140-152,156,158-161, 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	6,200	5,300	9,600	8,600
Malignant neoplasm, disseminated or without specification of site199	*1,100	*1,100	4,900	4,600
Endocrine, nutritional, and metabolic diseases and immunity disorders240-279	*	*	5,400	5,500
Diabetes mellitus250	*	*	3,300	3,300
Mental disorders290-319	*	*	*4,100	*3,600
Diseases of the nervous system and sense organs320-389	4,100	3,800	7,200	6,900
Alzheimer's disease331.0	*1,400	*1,200	*1,800	*1,600
Other hereditary and degenerative diseases of the central nervous system330,331.1-337	*2,600	*2,500	*3,800	*3,700
Diseases of the circulatory system390-459	7,800	7,700	23,600	22,200
Essential hypertension401	*	*	*4,500	*4,600
Heart disease391-392.0,393-398,402,404,410-416,420-429	5,600	5,500	14,200	12,700
Ischemic heart disease410-414	*	*	2,400	2,300
Congestive heart failure428.0	3,600	3,500	7,000	5,800
Cerebrovascular disease430-438	*1,300	*1,300	2,700	2,700
Diseases of the respiratory system460-519	4,000	3,000	7,000	6,000
Chronic obstructive pulmonary disease and allied conditions490-496	3,600	2,600	5,700	4,500
Diseases of the digestive system520-579	*	*	3,400	3,300
Diseases of the musculoskeletal system and connective tissue710-739	*	*	*6,200	*4,400
Symptoms, signs, and ill-defined conditions780-799	*	*	4,300	4,900
Supplementary classificationsV01-V82	*	*	*3,400	*3,400
Posthospital aftercareV42-V46,V52,V53.3-V53.7,V54-V58	*	-	*2,300	*2,400
All other diagnoses	*2,000	*1,500	7,900	8,000
No or unknown diagnosis	*	*3,700

* Figure does not meet standard of reliability or precision.

- Quantity zero.

... Category not applicable

¹Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).

NOTE: Numbers may not add to totals because of rounding.

alone, and not having or not living with their primary caregiver.

Although the differences are not statistically significant, a larger

proportion of patients not living with their primary caregiver received agency help with three of the five ADL's listed. In contrast, agency help was received

with at least one IADL for a smaller, rather than a larger, proportion of patients who were not living with their primary caregiver. One explanation for

Table 8. Percent distribution of current patients receiving hospice care services by diagnostic category, according to primary diagnosis and all-listed diagnoses at admission and at time of survey: United States, 1994

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis		All-listed diagnoses	
	At admission	At time of survey	At admission	At time of survey
All diagnoses	100.0	100.0	100.0	100.0
Infectious and parasitic diseases 001-139	3.1	3.1	*3.0	*3.2
Auto-Immune Deficiency Syndrome (AIDS) or Human Immunodeficiency Virus (HIV) 042-044	3.1	3.1	1.5	1.5
Neoplasms 140-239	58.6	55.8	42.4	42.9
Malignant neoplasms 140-208,230-234	56.9	54.1	41.5	42.0
Malignant neoplasm of large intestine and rectum 153-154,197.5	8.0	7.9	4.1	4.3
Malignant neoplasm of liver and intrahepatic bile ducts 155,197.7	*1.6	*1.6	3.2	3.3
Malignant neoplasm of pancreas 157	2.9	2.8	1.4	1.4
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	12.5	11.8	7.2	7.3
Malignant neoplasm of bone 170,198.5	*	*	3.0	3.2
Malignant neoplasm of breast 174-175,198.81	4.7	4.7	2.4	2.5
Malignant neoplasm of female genital organs 179-184,198.6	3.4	3.4	*1.6	*1.6
Malignant neoplasm of prostate 185	5.9	*5.8	3.0	3.1
Malignant neoplasm of brain and spinal cord 191,192.2,198.3	*3.0	*3.0	2.7	2.8
Malignant neoplasm of lymphatic and hematopoietic tissue 200-208	2.5	2.2	2.0	2.0
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	10.2	8.6	7.2	6.8
Malignant neoplasm, disseminated or without specification of site 199	*1.8	*1.8	3.7	3.7
Endocrine, nutritional, and metabolic diseases and immunity disorders 240-279	*	*	4.1	4.3
Diabetes mellitus 250	*	*	2.5	2.6
Mental disorders 290-319	*	*	*3.1	*2.9
Diseases of the nervous system and sense organs 320-389	6.7	6.3	5.4	5.4
Alzheimer's disease 331.0	*2.2	*2.0	*1.3	*1.3
Other hereditary and degenerative diseases of the central nervous system 330,331.1-337	*4.2	*4.1	*2.9	*2.9
Diseases of the circulatory system 390-459	12.7	12.6	17.8	17.6
Essential hypertension 401	*	*	*3.4	*3.6
Heart disease 391-392.0,393-398,402,404,410-416,420-429	9.3	9.1	10.7	10.1
Ischemic heart disease 410-414	*	*	1.8	1.8
Congestive heart failure 428.0	5.9	5.8	5.3	4.6
Cerebrovascular disease 430-438	*2.1	*2.1	2.1	2.1
Diseases of the respiratory system 460-519	6.6	4.9	5.3	4.8
Chronic obstructive pulmonary disease and allied conditions 490-496	6.0	4.2	4.3	3.5
Diseases of the digestive system 520-579	*	*	2.5	2.6
Diseases of the musculoskeletal system and connective tissue 710-739	*	*	*4.7	*3.5
Symptoms, signs, and ill-defined conditions 780-799	*	*	3.3	3.8
Supplementary classifications V01-V82	*	*	*2.5	*2.7
Posthospital aftercare V42-V46,V52,V53.3-V53.7,V54-V58	*	-	*1.8	*1.9
All other diagnoses	*3.2	*2.4	5.9	6.4
No or unknown diagnosis	*	*6.1

* Figure does not meet standard of reliability or precision.

- Quantity zero.

... Category not applicable

¹Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).

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

these results concerns the patterns of marital status, living arrangements, and primary caregiver status already noted. That is, men tended to be married and living with their primary caregiver who was most often their spouse. Although the men served by these agencies tended to be younger than the women served,

the majority of the men were 65 years of age or older. This implies that their spouses (who were frequently their caregivers), were also elderly. The wives probably needed help caring for their spouses, especially with the more physical activities such as transferring in or out of beds or chairs, using the toilet

room, and light housekeeping.

Regarding services provided, a significantly larger percent of women than men received personal care services, which is consistent with the patterns of marital status, living arrangements, and caretaker status of women. Similarly, a larger percent of

Table 9. Number and percent of current patients receiving hospice care services by diagnostic category, according to selected primary and all-listed diagnoses at admission and sex: United States, 1994

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis			All-listed diagnoses		
	Both sexes	Male	Female	Both sexes	Male	Female
	Number of diagnoses					
All diagnoses	61,000	27,200	33,700	132,600	57,200	75,400
Neoplasms 140-239	35,800	16,000	19,800	56,200	25,700	30,500
Malignant neoplasms 140-208,230-234	34,700	15,700	19,000	55,100	25,500	29,600
Diseases of the circulatory system 390-459	7,800	4,100	3,700	23,600	10,500	13,100
Heart disease 391-392.0,393-398,402,404,410-416,420-429	5,600	3,000	2,700	14,200	6,700	7,500
Diseases of the respiratory system 460-519	4,000	*1,100	2,900	7,000	2,700	*4,300
Chronic obstructive pulmonary disease and allied conditions 490-496	3,600	*1,000	*2,600	5,700	2,100	*3,600
	Percent					
All diagnoses	100.0	100.0	100.0	100.0	100.0	100.0
Neoplasms 140-239	58.6	58.6	58.7	42.4	44.9	40.5
Malignant neoplasms 140-208,230-234	56.9	57.7	56.2	41.5	44.5	39.3
Diseases of the circulatory system 390-459	12.7	14.9	11.0	17.8	18.3	17.4
Heart disease 391-392.0,393-398,402,404,410-416,420-429	9.3	10.8	8.0	10.7	11.7	9.9
Diseases of the respiratory system 460-519	6.6	*3.9	8.7	5.3	4.7	*5.7
Chronic obstructive pulmonary disease and allied conditions 490-496	6.0	*3.9	*7.7	4.3	3.7	*4.7

* Figure does not meet standard of reliability or precision.
¹Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9CM) (12).
 NOTES: Numbers may not add to totals because of rounding. Percents are based on unrounded numbers.

Table 10. Number and percent of men receiving hospice care services by diagnostic category and selected diagnoses at admission for malignant neoplasms: United States, 1994

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis	All-listed diagnosis	Primary diagnosis	All-listed diagnosis
	Number	Number	Percent	Percent
Malignant neoplasms 140-208,230-234	15,700	25,500	100.0	100.0
Malignant neoplasm of prostate 185	3,500	3,900	22.5	15.1
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	3,400	4,200	21.5	16.4
Malignant neoplasm of large intestine and rectum 153-154,197.5	1,900	2,100	12.0	8.1
Malignant neoplasm of brain and spinal cord 191,192.2,198.3	*	*1,200	*	*4.8
Malignant neoplasm of liver and intrahepatic bile ducts 155,197.7	*	1,500	*	6.0
Malignant neoplasm of bone 170,198.5	*	2,400	*	9.4

* Figure does not meet standard of reliability or precision.
¹Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).
 NOTES: Numbers may not add to totals because of rounding. Percents are based on unrounded numbers.

women than men were seen by home health aides—the type of staff member that frequently provides personal care.

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Table 11. Number and percent of women receiving hospice care services by diagnostic category and selected diagnoses at admission for malignant neoplasms: United States, 1994

<i>Diagnostic category and ICD-9-CM code¹</i>	<i>Primary diagnosis</i>	<i>All-listed diagnoses</i>	<i>Primary diagnosis</i>	<i>All-listed diagnoses</i>
	Number		Percent	
Malignant neoplasms 140-208,230-234	19,000	29,600	100.0	100.0
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	4,200	5,400	22.3	18.1
Malignant neoplasm of large intestine and rectum 153-154,197.5	*3,000	*3,400	*15.8	*11.4
Malignant neoplasm of breast 174-175,198.81	2,700	3,000	14.3	10.2
Malignant neoplasm of female genital organs 179-184,198.6	2,100	*2,100	11.0	*7.1
Malignant neoplasm of brain and spinal cord 191,192.2,198.3	*	*2,300	*	*7.9
Malignant neoplasm of liver and intrahepatic bile ducts 155,197.7	*	2,700	*	9.3
Malignant neoplasm of bone 170,198.5	*	1,600	*	5.5

* Figure does not meet standard of reliability or precision.

¹Based on the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) (12).

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

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Technical notes

Following is a brief overview of the data collection methods and estimation procedures for the 1994 NHHCS. More detailed information has been published (2,6,7).

Sampling design

The sampling frame for the 1994 NHHCS consists of all hospices and home health care agencies identified through the 1991 National Health Provider Inventory (NHPI) (10) or that had opened for business after the 1991 NHPI and before December 1994, as identified through the Agency Reporting System (ARS) (11). The NHPI is a comprehensive census of nursing and related care homes, residential care homes, home health care agencies, and hospices. It is conducted periodically by NCHS.

The sample design for the 1994 NHHCS was a stratified three-stage probability design. The first stage consisted of the selection of geographic areas called primary sampling units (PSU's)—counties, groups of counties, county equivalents, or towns and townships—throughout the United States. At the second stage, a stratified sample of hospices and home health agencies was selected within the PSU's. Each agency was placed into one of six strata based on type of agency (hospice versus home health and mixed agencies), type of PSU (self-representing versus all others), and metropolitan statistical area (MSA) status (MSA versus non-MSA). Self-representing PSU's are the largest PSU's in the United States and were selected with certainty (probability of 1). The other PSU's were not selected with certainty (probability less than 1). MSA is defined by the U.S. Office of Management and Budget on the basis of the 1980 Census. Within these sampling strata, agencies were arrayed by four regions (Northeast, Midwest, South, and West), five types of ownership (for profit, nonprofit, State or local government, Federal government, and other), two types of certification status (Medicare and Medicaid), and size (number of current patients). These

categories were based on information from the NHPI and the ARS.

The sample for the 1994 NHHCS consisted of 1,510 agencies. Of these, 1,450 were in scope for the survey. Out of scope agencies were those that were closed, were not providing hospice or home health care services to patients at the time of the survey, or were duplicates of or had merged with other sampled agencies. Of the 1,450 in scope agencies, 53 refused to participate and 4 could not be located. Ninety-six percent, or 1,393 agencies, agreed to participate.

The third stage of sample selection, sampling of six current patients and six discharges within each agency, was done using a sample selection table to obtain systematic probability samples of current patients and of discharges. The patients and discharges were selected from lists constructed for each agency at the time of the interview. Current patients were defined as those patients who were on the rolls of the agency as of midnight on the day immediately before the date of the survey. Discharges referred to those patients who were discharged from care by the hospice or home health agency during a designated month between October 1993 and September 1994.

Data collection and processing

Data collection for the 1994 NHHCS began with a letter sent to all sampled agencies informing the administrator of the authorizing legislation, purpose, and content of the survey. Each agency was then contacted by an interviewer to discuss the survey and to arrange an appointment with the administrator. During the appointment, some information about the agency was collected, as well as detailed information about the current patients and discharges for patients who received hospice and home health care services from the agency. All information was obtained by personal interview with the administrator or person designated by the administrator; the respondent referred to medical and other records as necessary. No patient was interviewed directly.

After the data had been collected and converted into machine-readable

form, extensive editing was conducted by computer to ensure that all responses were accurate, consistent, logical, and complete. The medical information recorded on the patient questionnaires was coded by NCHS staff according to the *International Classification of Diseases, 9th Revision, Clinical Modification* (12). Up to 12 diagnostic codes were assigned for each sample patient (a maximum of 6 at admission, and a maximum of 6 at time of survey or discharge).

Estimation procedures

Statistics presented in this report were derived by a multistage estimation procedure (13) 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. This component consists of the inverse of the probability of selecting (a) the PSU, (b) the agency, and (c) the patient or discharge within each agency. The second component, which consists of an 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 and tests of significance

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 (14). Exact SE estimates were used in tests of significance in this report.

The relative standard error (RSE) of an estimate is obtained by dividing the SE by the estimate itself. The result is expressed as a percent of the estimate. SE's and RSE's for aggregate estimates of patients presented in this report may be estimated using the following general formula, where X is the estimate in thousands:

$$\text{RSE}(X) = \sqrt{0.009611 + \frac{26.195620}{X}}$$

Because of the relationship between the RSE and the estimate, the SE of an estimate can be obtained by multiplying the estimate by its RSE.

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). If the sample size is less than 30, the value of the estimate is not reported. If the sample size is 30–59, or 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.

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