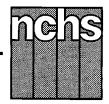
<u>Advance</u> Data



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Characteristics of Hospice Care Discharges: United States, 1993–94

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Abstract

Objective— This report presents data on hospice care discharges. Numbers and percents of discharges are shown by selected characteristics of the agencies from which the patients were discharged, by selected patient characteristics, by services provided, by types of personnel that provided the services, and by diagnoses of these discharged 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—There were an estimated 328,000 discharges from hospice care from 1,300 hospices and home health agencies in 1993–94. Death was the reason for discharge for 88 percent of the discharges. Fifty-two percent of the discharges were for men, 73 percent were for patients 65 years of age and over, 79 percent were white, 49 percent were married, and 30 percent were widowed. Eighty-three percent of the discharged patients were living in a private or semiprivate residence during their care and 95 percent had a primary caregiver. During the last time service was provided prior to discharge, 67 percent received help from the agency with at least one activity of daily living (ADL), 53 percent with at least one instrumental activity of daily living (IADL), and 30 percent with walking. These discharges had an average of 2.2 diagnoses at admission; 69 percent had a primary diagnosis of a malignant neoplasm; and 8 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 (NHCS), 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.

During the year prior to the survey, there were an estimated 5,600,200 discharges from 10,900 hospices and home health care agencies in the United States; 5,272,200 of the discharges were from home health care and 328,000 were from hospice care (2). A report has been published presenting characteristics of current hospice care patients served in 1994 (3). This report, focusing on hospice care discharges, provides statistics on the complete episode of care of this 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 primary 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 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 (2).

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 cope 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 (2-6).

Methods

Data collection for the 1994
NHHCS was conducted between
September and December 1994. Data
were collected on a sample of current
patients and of discharges from a
representative sample of hospices and
home health care agencies. Patient data
were obtained from the medical records
of the sampled patients and discharges.
A brief overview of the data collection
methods and estimation procedures for
the 1994 NHHCS is in the Technical
notes. More detailed information is
published in other reports (2,7,8).

Statistics presented in this report are estimated numbers and percents of hospice care discharges by various items of interest. A limited amount of information about the agencies that provided the services is also given. For this report, agencies that provided hospice care services are limited to those agencies with at least one discharge from hospice care during a designated month prior to the time 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 location are reported: geographic region and metropolitan statistical area. Size was determined from the total number of both hospice and home health care discharges that occurred during a specified month during the 12 months prior to the time of the survey. This number was obtained from the list of discharges that was used for 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), reason for discharge, living arrangements, primary caregiver status, and functional status. Information on functional status includes use of special aids, vision, hearing, and continence status. Statistics are also presented about the services provided to the discharged patients (including assistance with activities of daily living, walking, and instrumental activities of daily living) and types of personnel that provided 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 at admission and at discharge 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 that had hospice care discharges according to agency characteristics. The number and percent of discharges from these agencies are also shown. An estimated 1,300 hospices and home health care agencies in the United States had 328,000 hospice care discharges during 1993–94.

The vast majority of the facilities—1,100, or 84 percent—were voluntary nonprofit agencies. Seventy-four percent were certified under Medicare and 67 percent were certified under Medicaid as hospices, while 42 percent and 43 percent were certified under Medicare and Medicaid, respectively, as home health agencies. Four hundred of the agencies, or 36 percent, were operated by a hospital, and 500, or 42 percent, were part of a group or chain of agencies.

Thirty-five percent of the agencies with hospice care discharges were in the South, 26 percent were in the Midwest, 25 percent were in the Northeast, and 14 percent were in the West. Eight hundred (61 percent) of the agencies were located in a metropolitan statistical area (MSA).

Most of these agencies were relatively small. Almost half (48 percent) had 15 or fewer discharges from hospice or home health care during a given month prior to the survey, 19 percent had 16–30 discharges, and 32 percent had more than 30 discharges.

The majority of the hospice care discharges (285,300, or 87 percent) were from voluntary nonprofit hospices and home health agencies. Over 85 percent were from an agency that was certified under Medicare and/or Medicaid as a hospice, a home health agency, or both. Twenty-eight percent of the discharges were from a hospital-affiliated agency and 48 percent were from an agency that was part of a group or chain of agencies.

Of all the hospice care discharges, 34 percent were from agencies in the

Table 1. Number and percent distribution of agencies with hospice care discharges and hospice care discharges by selected agency characteristics: United States, 1993–94

	Ag	encies	Discharges		
Agency characteristic	Number	Percent distribution	Number	Percent distribution	
All agencies	1,300	100.0	328,000	100.0	
Ownership					
Proprietary	*100	*9.4	33,300	10.2	
Voluntary nonprofit	1,100	83.8	285,300	87.0	
Government and other	*	*	*9,300	*2.8	
Certification ¹					
Medicare:					
As hospice	900	74.2	287,400	87.6	
As home health agency	500	41.9	180,300	55.0	
Medicaid:					
As hospice	800	67.2	279,700	85.3	
As home health agency	500	43.4	181,300	55.3	
Affiliation ¹					
Operated by hospital	400	35.5	93,200	28.4	
Part of a group	500	41.5	155,700	47.5	
Geographic region					
Northeast	300	24.8	109,800	33.5	
Midwest	300	26.4	73,600	22.4	
South	400	34.8	97,900	29.8	
West	200	14.0	46,800	14.3	
Location of agency					
MSA ²	800	61.0	272,200	83.0	
Non-MSA ²	*500	*39.0	55,800	17.0	
Size of agency ³					
1–6 discharges	*300	*23.0	16,300	5.0	
7–15 discharges	300	25.2	42,800	13.0	
16–30 discharges	200	19.4	50,200	15.3	
31–100 discharges	300	22.8	103,900	31.7	
More than 100 discharges	*100	*9.6	114,900	35.0	

^{*} Figure does not meet standard of reliability or precision.

Northeast, 30 percent from agencies in the South, 22 percent from agencies in the Midwest, and 14 percent from agencies in the West. Although 61 percent of the agencies were located in an MSA, these agencies had 83 percent of the discharges.

Not surprisingly, most of the discharges were from larger agencies. The 600 agencies with 15 or fewer monthly discharges (48 percent of the agencies) had only 18 percent (59,100) of the hospice care discharges. In contrast, 67 percent (218,800) of the hospice care discharges were from the 400 agencies (32 percent) that had more

than 30 home and hospice care discharges during any given month.

Discharge characteristics

Table 2 shows the number and percent of hospice care discharges by selected demographic characteristics and reason for discharge. Although a larger percent of the discharges were male (52 percent were for men compared with 48 percent for women), the difference is not statistically significant. The majority of the discharges—73 percent—were for patients 65 years of age and over. The percent of discharges for each age group

did not differ significantly between the two sexes.

Seventy-nine percent of the discharges were white and 8 percent were black and other races. Race was unknown for 13 percent of the discharges. There was no significant difference in the percent of discharges by sex within each race category.

Just under half (49 percent) of the discharges were married at the time of discharge. Of those who were not married, the majority (67 percent) were widowed. The marital status of male discharges, however, was quite different than that of female discharges. Males were more likely to be married at the time of discharge and females were more likely to be widowed.

The most common reason for discharge was death of the patient (88 percent of all discharges were deceased). Four percent of the discharges occurred because the patient was admitted to an inpatient health care facility—most often a hospital.

Most of the discharged hospice patients—83 percent—were living in a private or semiprivate residence during their episode of care, and about 11 percent were residents of an inpatient health facility (table 3). Of the discharges for noninstitutionalized patients, 80 percent lived with family members, 10 percent lived alone, and 9 percent lived with nonfamily members. Men were more likely to be living in a private or semiprivate residence than were women. Although a larger percent of women than of men were living in a health facility during their episode of care, the difference was not statistically significant. Of the discharges for noninstitutionalized patients, a larger percent of men than of women lived with family members.

The majority of the discharged patients had a primary caregiver, that is, an individual or organization responsible for providing personal care assistance, companionship, and/or supervision of the patient. In addition, most of the discharged patients with a primary caregiver lived with their caregiver. Men were more likely than were women to live with their caregiver. Although the primary caregiver was most often a relative, the type of relationship was

¹Numbers may not add to total since 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 discharges for a specified month.

Table 2. Number and percent distribution of hospice care discharges by selected patient characteristics, according to sex: United States, 1993–94

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female
		Number		Perc	ent distri	bution
All discharges	328,000	171,500	156,500	100.0	100.0	100.0
Age at admission ¹						
Under 65 years	88,400	45,700	42,800	27.0	26.6	27.3
Under 45 years	18,600	12,200	*6,400	5.7	7.1	*4.1
45–64 years	69,900	33,500	36,300	21.3	19.5	23.2
65 years and over	239,100	125,800	113,300	72.9	73.4	72.4
65–69 years	38,000	24,400	13,600	11.6	14.2	8.7
70–74 years	53,200	32,400	20,800	16.2	18.9	13.3
75–79 years	50,700	23,900	26,800	15.5	13.9	17.1
80-84 years	40,700	19,200	21,500	12.4	11.2	13.8
85 years and over	56,500	25,900	30,600	17.2	15.1	19.6
Race						
White	260,400	142,500	117,900	79.4	83.1	75.3
Black and other ²	25,600	12,700	12,900	7.8	7.4	8.3
Black	24,000	11,800	12,200	7.3	6.9	7.8
Unknown	42,000	16,300	25,700	12.8	9.5	16.4
Marital status at discharge						
Married	160,300	108,700	51,600	48.9	63.4	33.0
Not married ³	145,600	58,100	87,500	44.4	33.9	55.9
Widowed	97,300	32,900	64,400	29.7	19.2	41.1
Unknown	*22,200	*	*17,400	*6.8	*	*11.1
Reason for discharge ¹						
Deceased	288,000	150,600	137,400	87.8	87.8	87.8
Admitted to inpatient facility	13,000	*	*5,800	4.0	*	*3.7
Admitted to hospital	*10,200	*	*	*3.1	*	*
Other reason for discharge	26,300	*13,700	*12,600	8.0	*8.0	*8.1

^{*} Figure does not meet standard of reliability or precision.

different 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.

The number and percent of hospice care discharges by selected aids used the last time service was provided are shown in table 4. Ninety percent of the discharged patients used at least one aid. Over one-half (54 percent) were using a hospital bed and 43 percent were using something to help with mobility—most often a wheelchair or a walker. Other aids used included eye glasses (37 percent), commode (31 percent), supplemental oxygen (29 percent), and dentures (20 percent).

Thirty percent of the hospice care discharges had an ostomy or an indwelling catheter the last time service was provided prior to discharge (table 4). Excluding these discharges, 27 percent had difficulty controlling their bladder and 22 percent had difficulty controlling their bowels.

Table 4 also shows that over one-half of the discharged patients did not have difficulty seeing or hearing (with the use of an aid if applicable). Seventeen percent had some vision impairment and 15 percent had some hearing impairment, even with the use of aids. Note, however, that the vision or hearing status was unknown for some 30 percent of the discharges.

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 discharged patient lived with his or 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 IADL's collected in the NHHCS is 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, members of their family, and friends), their need for help with these activities is underestimated by the NHHCS.

The last time service was provided before discharge, 67 percent of all discharges received agency help with at least one ADL, 53 percent received help with at least one IADL, and 30 percent received help with walking. With respect to specific ADL's, agency help was received most often with bathing or showering (64 percent), dressing (51 percent), and transferring in or out of beds or chairs (42 percent). For specific IADL's, the most common types of assistance included taking medications (37 percent) and doing light housework (29 percent). Although a larger percent of men than of women received help with each ADL, with preparing meals, and with walking, the differences are not statistically significant.

Of the discharged patients who lived with their primary caregiver during their episode of care, a larger percent received agency help with at least one ADL or IADL—specifically, with bathing or showering, dressing, transferring in or out of beds or chairs, and taking medications. The differences were significant, however, only for help with at least one ADL and for help with bathing or showering.

Services and diagnoses

The number and percent of discharges for whom a service was

¹Excludes unknown.

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

³Includes separated.

Table 3. Number and percent distribution of hospice care discharges by residence, primary caregiver status, and living arrangements during care, according to sex: United States, 1993–94

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female
		Number		Perd	ent distr	ibution
All discharges	328,000	171,500	156,500	100.0	100.0	100.0
Residence during care ¹						
Private or semiprivate residence ²	271,000 *17,500	148,700	122,300	82.6 *5.3	86.7	78.2
Health facility (including mental health facility)	36,900	17,400	19,500	11.3	10.2	12.5
Primary caregiver status						
Had no primary caregiver ³	16,100	*5,700	*10,300	4.9	*3.4	*6.6
Had primary caregiver	311,900	165,800	146,200	95.1	96.6	93.4
Living arrangements ⁴						
Noninstitutionalized patients ⁵	291,100	154,100	137,000	100.0	100.0	100.0
Lived with family members	231,700	133,100	98,600	79.6	86.4	72.0
Lived alone	30,200	*9,800	20,400	10.4	*6.3	14.9
Lived with only nonfamily members	24,900	*9,500	*15,400	8.6	*6.1	*11.3
Patients with primary caregiver						
Total with caregiver	311,900	165,800	146,200	100.0	100.0	100.0
Lived with primary caregiver	241,100	144,100	97,000	77.3	86.9	66.4
Relationship of primary caregiver to patient ¹						
Spouse	139,800	98,600	41,300	44.8	59.5	28.2
Child and/or child-in-law	99,500	35,900	63,600	31.9	21.7	43.5
Other relative	43,000	18,900	24,100	13.8	11.4	16.5
Friend or neighbor	*7,200	*5,400	*	*2.3	*3.2	*

^{*} Figure does not meet standard of reliability or precision.

provided during the 30 days prior to discharge are shown in table 6. Virtually all of the discharges had received at least one of the listed services within that time period. Of these, the vast majority (91 percent) received skilled nursing services. Over one-half received social services or personal care (62 percent and 61 percent, respectively), 41 percent received spiritual care, and about a third received medications (37 percent), volunteer services (35 percent), counseling (32 percent), or durable medical equipment or supplies (30 percent). A significantly larger percent of women than of men received continuous home care; other differences noted are not statistically significant.

Table 6 also provides information on the type of service provider seen during the 30 days prior to discharge.

Again, virtually all of the discharges had been seen by at least one type of provider. The type of provider seen reflects the services provided. The vast majority of discharged patients (92 percent) had been seen by a registered nurse, 65 percent had been seen by a social worker, 55 percent had been seen by a home health aide, 33 percent had been seen by volunteers, and 33 percent had been seen by a chaplain.

The number and percent of primary and all-listed diagnoses at admission and at discharge are shown in tables 7 and 8. There was an average of 2.2 diagnoses per discharge at admission and 2.1 diagnoses at discharge. Overall, the discharge diagnosis did not differ significantly from the diagnosis at admission for both the primary diagnosis and the all-listed diagnoses. At

admission, most (69 percent) of the hospice care discharges had a primary diagnosis of malignant neoplasm, and about 8 percent had a primary diagnosis of heart disease. Fifty percent of the all-listed diagnoses were for a malignant neoplasm and about 9 percent were for some form of heart disease.

Information on the most common admission diagnoses for hospice care discharges according to sex is shown in tables 9–11. Over two-thirds of the discharges—68 percent of the men and 70 percent of the women—had a primary diagnosis of malignant neoplasm; the comparable percents for all-listed diagnoses are 50 percent for both men and women.

The most common malignant neoplasms at admission are shown in table 10 for male discharges and table 11 for female discharges. For men, the most common primary malignant neoplasms involved the trachea, bronchus, and lung; the prostate; and the large intestine and rectum. Women most often had a primary malignant neoplasm of the large intestine and rectum; the trachea, bronchus, and lung; or the breast. 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.

Summary and discussion

This report presents data on characteristics of discharges from hospice care services during 1993–94. Overall, there were 328,000 hospice care discharges from 1,300 hospices and home health care agencies in the United States. Most of the discharges were from voluntary nonprofit organizations and from agencies that were Medicare and/or Medicaid certified.

Nine out of 10 hospice care discharges occurred because the patient died. Fifty-two percent of the discharges were male and 4 out of 5 were white patients. Overall, almost three-fourths of the discharged patients were 65 years of age and over when they were admitted to the agency; at the time of discharge, about half were married, almost a third were widowed, and 4 out of every 5 were living in a private or semiprivate residence. Most of the discharges had a

¹Excludes other and unknown.

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

³Includes unknowns.

⁴Excludes those for whom living arrangements are unknown.

⁵Excludes those living in health facilities.

Table 4. Number and percent distribution of hospice care discharges by type of aids used and functional status the last time service was provided, according to sex: United States, 1993–94

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female
		Number		Perd	cent distri	bution
Total	328,000	171,500	156,500	100.0	100.0	100.0
Special aids						
Discharges with at least one special $\operatorname{aid}^{1,2}$ Aids used:	293,900	152,700	141,200	89.6	89.1	90.2
Hospital bed	175,800	91,100	84,700	53.6	53.1	54.1
Mobility aids ¹	140,000	76,400	63,600	42.7	44.5	40.6
Wheelchair	96,100	46,500	49,700	29.3	27.1	31.7
Walker	54,200	33,500	20,800	16.5	19.5	13.3
Crutches, cane	25,500	19,700	*5,800	7.8	11.5	*3.7
Eye glasses	122,600	68,700	54,000	37.4	40.0	34.5
Commode	100,400	50,900	49,500	30.6	29.7	31.6
Oxygen	94,000	48,600	45,400	28.7	28.3	29.0
Dentures	64,400	30,500	33,800	19.6	17.8	21.6
Shower chair	27,300	17,600	9,700	8.3	10.3	6.2
Hearing aid	*20,900	*7,500	*13,400	*6.4	*4.4	*8.5
Transfer equipment	*12,500	*9,100	*3,400	*3.8	*5.3	*2.2
All other aids	75,000	38,300	36,700	22.9	22.3	23.4
Had ostomy or indwelling catheter	98,000	52,900	45,100	29.9	30.9	28.8
Continence ³						
Difficulty controlling bladder	88,400	43,500	44,900	27.0	25.4	28.7
Difficulty controlling bowels	73,100	34,600	38,500	22.3	20.2	24.6
Vision						
Not impaired	166,500	84,800	81,700	50.8	49.4	52.2
Impaired	56,200	31,800	24,400	17.1	18.6	15.6
Unknown ⁴	105,300	54,900	50,400	32.1	32.0	32.2
Hearing						
Not impaired	182,300	94,300	88,000	55.6	55.0	56.2
Impaired	48,300	28,200	20,100	14.7	16.4	12.9
Unknown ⁴	97,400	49,000	48,400	29.7	28.6	30.9

^{*} Figure does not meet standard of reliability or precision.

primary caregiver. Of those with a primary caregiver, most were related to and lived with their caregiver.

Discharged men tended to be married, living in a private or semiprivate residence, and living with family members. Women tended to be widowed. Although most of the discharged women also lived in a private or semiprivate residence and lived with family members, a larger proportion of women than men lived in an inpatient health facility or lived alone.

Of the discharged patients with a primary caregiver, men were more likely

to live with their caregiver than were women. Consistent with the patterns of marital status and living arrangements, the primary caregiver of most of the men was their spouse. The primary caregiver of most of the women, on the other hand, was another relative, most often a child or child-in-law.

Two-thirds of all discharges received help from the agency with at least one ADL, over half received help with at least one IADL, and 3 out of 10 received help with walking. A significantly larger proportion of discharged patients who lived with their primary caregiver received agency help

with at least one of the five ADL's listed and with bathing or showering. Because this help was received within the 30 days prior to the patient's discharge (almost always due to their death), these patients were probably quite debilitated and required more care than the primary caregiver was able to provide alone. It is speculated that patients who were not living with or had no primary caregiver but who were also very debilitated were already living in or had been discharged to an inpatient health facility (tables 2 and 3).

Regarding services provided, a significantly larger percent of women than of men received continuous home care within the 30 days prior to their discharge. Again, this is consistent with the patterns of marital status, living arrangements, and caretaker status of women.

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¹Numbers may add to more than total since more than one type of aid may have been used.

²Excludes unknowns.

³Excludes those with an ostomy or indwelling catheter.

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

Table 5. Number and percent distribution of hospice care discharges who received help from the agency with activities of daily living, instrumental activities of daily living, and walking the last time service was provided, according to sex: United States, 1993–94

	All	S	Sex		l with caregiver
ADL's and IADL's	All discharges	Male	Female	Yes	No ¹
			Number		
All discharges	328,000	171,500	156,500	241,100	86,900
Received help from agency with ADL's					
Received help with at least one ADL ADL's:	219,700	121,100	98,600	170,900	48,800
Bathing or showering	211,400	117,900	93,600	164,300	47,200
Dressing	165,800	92,200	73,600	127,400	38,400
Eating	90,100	47,800	42,400	61,000	29,100
Transferring in or out of beds or chairs	137,200	72,500	64,700	106,200	31,000
Using the toilet room	104,000	56,500	47,500	76,500	27,500
Received help from agency with IADL's					
Received help with at least one IADL IADL's:	172,100	87,100	85,100	130,000	42,100
Doing light housework	96,300	46,900	49,400	71,700	24,600
Managing money	*5,000	*	*	*	*
Shopping for groceries or clothes	24,700	*12,800	*12,000	14,000	*10,700
Using the telephone	*14,800	*6,500	*	*4,600	*
Preparing meals	52,300	28,800	23,400	32,400	19,900
Taking medications	119,700	59,400	60,300	94,500	25,300
Received help from the agency with walking	97,000	54,800	42,300	70,500	26,500
		Perc	ent distributi	on	
All discharges	100.0	100.0	100.0	100.0	100.0
Received help from agency with ADL's					
Received help with at least one ADL ADL's:	67.0	70.6	63.0	70.9	56.2
Bathing or showering	64.5	68.7	59.8	68.1	54.3
Dressing	50.6	53.8	47.1	52.8	44.2
Eating	27.5	27.9	27.1	25.3	33.5
Transferring in or out of beds or chairs	41.8	42.3	41.3	44.0	35.7
Using the toilet room	31.7	32.9	30.3	31.7	31.6
Received help from agency with IADL's					
Received help with at least one IADL IADL's:	52.5	50.8	54.3	53.9	48.5
Doing light housework	29.4	27.3	31.6	29.7	28.3
Managing money	*1.5	*7.4	*7.0	 F 0	*40.4
Shopping for groceries or clothes	7.5 *4.5	^7.4 *3.8	*7.6 *	5.8 *1.9	*12.4
Using the telephone	4.5 15.9	3.6 16.8	15.0	13.4	22.9
Taking medications	36.5	34.6	38.5	39.2	22.9
Received help from the agency with walking	29.6	31.9	27.0	29.2	30.5

^{*} Figure does not meet standard of reliability or precision.

NOTES: Numbers may add to more than totals because help may have been received 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.

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¹Includes unknowns and discharges with no primary caregiver.

Table 6. Number and percent distribution of hospice care discharges by services received and type of provider seen during the 30 days prior to discharge, according to sex: United States, 1993–94

Patient characteristic	Both sexes	Male	Female	Both sexes	Male	Female	
	Number			Percent distribution			
All discharges	328,000	171,500	156,500	100.0	100.0	100.0	
Services received ¹							
Received at least one service during the 30 days prior to discharge	317,400	169,800	147,700	96.8	99.0	94.4	
Discharges with at least one service ²	317,400	169,800	147,700	100.0	100.0	100.0	
Skilled nursing services	290,100	157,100	133,100	91.4	92.5	90.1	
Social services	195,700	106,700	89,000	61.6	62.8	60.3	
Personal care	194,300	103,400	90,900	61.2	60.9	61.6	
Spiritual care	128,700	65,700	62,900	40.5	38.7	42.6	
Medications	117,000	60,000	57,000	36.9	35.3	38.6	
Volunteer services	111,400	55,900	55,500	35.1	32.9	37.6	
Counseling	101,300	57,300	43,900	31.9	33.8	29.7	
Durable medical equipment and medical supplies	95,600	47,300	48,300	30.1	27.9	32.7	
Physician services	56,000	33,100	23,000	17.7	19.5	15.6	
Homemaker/Companion services	54,700	35,200	19,500	17.2	20.7	13.2	
Dietary and nutritional services	32,600	*25,400	*7,200	10.3	15.0	*4.9	
Referral services	30,600	17,100	*13,400	9.6	10.1	*9.1	
High tech care including enterostomal therapy	*25,900	*18,600	*7,400	*8.2	*10.9	*5.0	
Continuous home care	24,200	7,900	16,300	7.6	4.6	11.1	
Inpatient respite care	*22,100	*12,400	*9,700	*6.9	*7.3	*6.6	
Oral hygiene/Prevention services	16,400	*11,600	*4,600	5.2	*6.8	*3.3	
All other services	26,500	14,500	12,000	8.4	8.5	8.1	
Service provider ¹							
At least one provider seen during the 30 days prior to discharge	316,700	169,300	147,300	96.5	98.7	94.1	
Discharges with at least one provider ²	316,700	169,300	147,300	100.0	100.0	100.0	
Registered nurses	290,200	153,900	136,300	91.6	90.9	92.5	
Social workers	205,900	113,900	92,000	65.0	67.3	62.4	
Home health aides	173,400	92,200	81,200	54.8	54.4	55.1	
Volunteers	104,800	50,600	54,200	33.1	29.9	36.8	
Chaplain	102,800	51,000	51,700	32.5	30.1	35.1	
Physicians	45,100	27,500	17,600	14.2	16.3	11.9	
Nursing aides and attendants	44,300	27,800	16,500	14.0	16.4	11.2	
Licensed practical or vocational nurses	34,800	19,000	15,800	11.0	11.2	10.7	
Homemakers/Personal caretakers	16,700	*8,600	*8,100	5.3	*5.1	*5.5	
All other providers	38,600	24,200	14,500	12.2	14.3	9.8	

^{*} Figure does not meet standard of reliability or precision.

¹Numbers may add to more than total since more than one service may have been received or more than one provider may have been seen.

²Excludes unknowns

Table 7. Number of hospice care discharges by diagnostic category of primary and all-listed diagnoses at admission and at discharge: United States, 1993–94

	Primary	diagnosis	All-listed diagnoses		
Diagnostic category and ICD-9-CM code ¹	At admission	At discharge	At admission	At discharge	
All diagnoses	328,000	328,000	708,000	695,500	
Infectious and parasitic diseases	9,900 8,300	9,500 8,300	14,700 10,900	14,300 10,700	
Neoplasms. .140–239 Malignant neoplasms .140–208,230–234 Malignant neoplasm of large intestine and rectum .153–154,197.5 Malignant neoplasm of liver and intrahepatic bile ducts .155,197.7	232,300 226,300 37,300 *7,800	226,800 220,900 35,800 *7,800	359,200 351,200 40,700 31,700	352,600 344,600 39,100 30,700	
Malignant neoplasm of pancreas	*14,100 45,500	*13,600 46,100	*15,200 59,500	*14,700 58,600	
Malignant neoplasm of bone	17,000 *7,800 17,100	16,600 *7,800 16,900	23,700 17,900 8,300 18,300	23,500 17,400 8,300 19,500	
Malignant neoplasm of brain and spinal cord	*7,600 14,600	*7,500 14,300	21,900 18,000	21,300 17,700	
197.6,197.8,198.0–198.2,198.4,198.7,198.82–198.89,230–234 Malignant neoplasm, disseminated or without specification of site 199	43,200 11,700	43,000 11,400	60,000 36,000	59,900 36,900	
Endocrine, nutritional, and metabolic diseases and immunity disorders	*	*	38,700 17,200	38,600 16,700	
Mental disorders	*	*	8,100	7,600	
Diseases of the nervous system and sense organs	*8,300	*8,300 * *	27,300 *4,800 *6,200	26,400 *4,700 *6,000	
Diseases of the circulatory system	36,000	36,100	104,000 17,300	100,600 *17,800	
Heart disease .391–392.0,393–398,402,404,410–416,420–429 Ischemic heart disease .410–414 Congestive heart failure .428.0 Cerebrovascular disease .430–438	25,800 * *10,800 *7,400	25,400 * *10,200 *7,500	63,300 *11,200 22,800 16,900	59,300 *9,300 21,100 16,800	
Diseases of the respiratory system	7,200 *6,000	7,300 *5,900	35,600 19,300	34,700 18,400	
Diseases of the digestive system	*	*	*24,700 *14,400	*24,700 *14,800	
Diseases of the genitourinary system	*10,600 *10,500	*10,700 *10,600	*14,900 *12,600	*14,900 *12,700	
Symptoms, signs, and ill-defined conditions	*	*	26,700	27,800	
Supplementary classifications	*	*	*20,500 *15,300	*18,600 *14,900	
All other diagnoses	*	*	33,700	34,700	
No or unknown diagnosis.	*	*6,600			

 $^{^{\}star}$ Figure does not meet standard of reliability or precision.

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

^{...} Category not applicable.

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

Table 8. Percent distribution of hospice care discharges by diagnostic category of primary and all-listed diagnoses at admission and at discharge: United States, 1993–94

	Primary	diagnosis	All-listed diagnoses		
Diagnostic category and ICD-9-CM code ¹		At discharge	At admission	At discharge	
All diagnoses	100.0	100.0	100.0	100.0	
Infectious and parasitic diseases	3.0 2.5	2.9 2.5	2.1 1.5	2.1 1.5	
Neoplasms.	70.8 69.0	69.2 67.3	50.7 49.6	50.7 49.5	
Malignant neoplasm of large intestine and rectum	11.4 *2.4	10.9 *2.4	5.7 4.5	5.6 4.4	
Malignant neoplasm of pancreas	*4.3	*4.1	*2.1	*2.1	
Malignant neoplasm of trachea, bronchus, and lung	13.9	14.0	8.4 3.4	8.0 3.4	
Malignant neoplasm of breast	5.2 *2.4	5.0 *2.4	2.5 1.2	2.5 1.2	
Malignant neoplasm of prostate	5.2	5.2	2.6	2.8	
Malignant neoplasm of brain and spinal cord	*2.3 4.4	*2.3 4.3	3.1 2.5	3.1 2.5	
197.4,197.6,197.8,198.0–198.2,198.4,198.7,198.82–198.89,230–234 Malignant neoplasm, disseminated or without specification of site 199	13.2 3.6	13.1 3.5	8.5 5.1	8.6 5.3	
Endocrine, nutritional, and metabolic diseases and immunity disorders	*	*	5.5	5.5	
Diabetes mellitus	*	*	2.4 1.1	2.4 1.1	
Diseases of the nervous system and sense organs	*2.5 *	*2.5	3.9 *0.7	3.8 *0.7	
Other hereditary and degenerative diseases of the central nervous system 330,331.1–337	*	*	*0.9	*0.9	
Diseases of the circulatory system	11.0	11.0	14.7 2.4	14.5 *2.6	
Heart disease	7.9	7.8	8.9 *1.6	8.5 *1.3	
Congestive heart failure	*3.3 *2.3	*3.1 *2.3	3.2 2.4	3.0 2.4	
Diseases of the respiratory system	2.2 *1.8	2.2 *1.8	5.0 2.7	5.0 2.6	
Diseases of the digestive system	*	*	*3.5 *2.0	*3.6 *2.1	
viseases of the genitourinary system	*3.2 *3.2	*3.3 *3.2	*2.1 *1.8	*2.1 *1.8	
symptoms, signs, and ill-defined conditions	*	*	3.8	4.0	
Supplementary classifications	*	*	*2.9 *2.2	*2.7 *2.1	
Postnospital aftercare	*	*	4.8	5.1	
No or unknown diagnosis	*	*2.0			

 $^{^{\}star}$ Figure does not meet standard of reliability or precision.

^{. .} Category not applicable.

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

Table 9. Number and percent distribution of hospice care discharges by diagnostic category of primary and all-listed diagnoses at admission, according to sex: United States, 1994

	Pri	mary diagn	osis	All-listed diagnoses		
Diagnostic category and ICD-9-CM code ¹	Both sexes	Male	Female	Both sexes	Male	Female
			Number of	diagnoses		
All diagnoses	328,000	171,500	156,500	708,000	361,000	347,000
Infectious and parasitic diseases	9,900 8,300	8,400 7,500	*	14,700 10,900	12,500 9,700	*
Neoplasms. 140–239 Malignant neoplasms. 140–208,230–234	232,300 226,300	119,200 116,200	113,100 110,100	359,200 351,200	184,000 179,100	175,200 172,100
Endocrine, nutritional, and metabolic diseases and immunity disorders	*	*	*	38,700 17,200	12,900 *7,100	*25,800 *10,100
Diseases of the circulatory system 390–459 Heart disease 391–392.0,393–398,402,404,410–416,420–429	36,000 25,800	23,700 *17,400	12,300 *8,400	104,000 63,300	56,900 *39,300	47,100 24,000
Diseases of the respiratory system	7,200 *6,000	*4,400 *3,700	*	35,600 19,300	25,500 13,000	10,100 *6,300
			Percent d	listribution		
All diagnoses	100.0	100.0	100.0	100.0	100.0	100.0
Infectious and parasitic diseases	3.0 2.5	4.9 4.4	*	2.1 1.5	3.4 2.7	*
Neoplasms. 140–239 Malignant neoplasms. 140–208,230–234	70.8 69.0	69.5 67.8	72.2 70.3	50.7 49.6	51.0 49.6	50.5 49.6
Endocrine, nutritional, and metabolic diseases and immunity disorders	*	*	*	5.5 2.4	3.6 *2.0	*7.4 *2.9
Diseases of the circulatory system	11.0 7.9	13.8 *10.1	7.8 *5.4	14.7 8.9	15.8 *10.9	13.6 6.9
Diseases of the respiratory system	2.2 *1.8	*2.6 *2.1	*	5.0 2.7	7.1 3.6	2.9 *1.8

^{*} Figure does not meet standard of reliability or precision.

NOTES: Figures will not add to totals because not all diagnoses are shown. Percents are based on unrounded numbers.

Table 10. Number and percent distribution of men with malignant neoplasms discharged from hospice care by diagnostic category of primary and all-listed diagnoses at admission: United States, 1993–94

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis	All-listed diagnoses	Primary diagnosis	All-listed diagnoses
	Nu	mber	Percent distr	
- Malignant neoplasms	116,200	179,100	100.0	100.0
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	25,900	32,800	22.3	18.3
Malignant neoplasm of prostate	17,100	18,300	14.7	10.2
Malignant neoplasm of large intestine and rectum 153–154,197.5	16,600	18,400	14.3	10.3
Malignant neoplasm of pancreas	*	*9,500	*	*5.3
Malignant neoplasm of lymphatic and hematopoietic tissue 200–208	*7,700	*10,300	*6.6	*5.7
Malignant neoplasm of brain and spinal cord 191,192.2,198.3	*	13,600	*	7.6
Malignant neoplasm of liver and intrahepatic bile ducts 155,197.7	*	15,100	*	8.4
Malignant neoplasm of bone	*	12,600	*	7.0

^{*} Figure does not meet standard of reliability or precision.

NOTES: Figures will not add to totals because not all diagnoses are shown. Percents are based on unrounded numbers.

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

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

Table 11. Number and percent distribution of women with malignant neoplasms discharged from hospice care by diagnostic category of primary and all-listed diagnoses at admission: United States, 1993-94

Diagnostic category and ICD-9-CM code ¹	Primary diagnosis	All-listed diagnoses	Primary diagnosis	All-listed diagnoses
_	Number Pero		Percent of	distribution
alignant neoplasms	110,100	172,100	100.0	100.0
Malignant neoplasm of large intestine and rectum 153–154,197.5	*20,700	*22,300	*18.8	*13.0
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	19,500	26,700	17.7	15.5
Malignant neoplasm of breast	16,800	17,700	15.3	10.3
Malignant neoplasm of female genital organs 179–184,198.6	*7,700	8,200	*7.0	4.8
Malignant neoplasm of lymphatic and hematopoietic tissue 200–208	*6,900	*9,400	*6.3	*5.5
Malignant neoplasm of pancreas	*5,300	*5,700	*4.8	*3.3
Malignant neoplasm of liver and intrahepatic bile ducts 155,197.7	*	16,600	*	9.6
Malignant neoplasm of brain and spinal cord 191,192.2,198.3	*	8,300	*	4.8
Malignant neoplasm of bone	*	*11,200	*	*6.5

NOTES: Figures will not add to totals because not all diagnoses are shown. Percents are based on unrounded numbers.

^{*} Figure does not meet standard of reliability or precision.

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

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 (7,8).

Sampling design

The sampling frame for the 1994 NHHCS consisted of all hospices and home health care agencies that were 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 found to be 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 patient 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 discharges presented in this report may be estimated using the following general formula, where *X* is the estimate in thousands:

$$RSE(X) = \sqrt{0.007581 + \frac{208.593103}{X}}$$

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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