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Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Data From the National
Health Care Survey

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

Hyattsville, Maryland
August 2003
DHHS Publication No. (PHS) 2003-1725

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Cooperation of the U.S. Census Bureau

Under the legislation establishing the National Health Survey, the Public Health Service is authorized to use, insofar as possible, the services or facilities of other Federal, State, or private agencies.

In accordance with specifications established by the National Center for Health Statistics, the U.S. Census Bureau, under a contractual arrangement, participated in planning the surveys and collecting the data for the National Home and Hospice Care Survey.

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Abstract

Objective

To obtain the maximum benefit from hospice, a person should receive hospice services for at least 30 days. For many Americans, this goal is not being met. This report presents data on hospice care discharges for 2000. Selected trend data are also presented.

Methods

Data are from the National Home and Hospice Care Survey. The data presented are numbers and percents by selected discharge characteristics. Length of service measures include average and median length of service and length of service intervals.

Results and Conclusions

There were 621,100 discharges from hospice care in 2000. The typical discharge was elderly, white, lived in a private or semiprivate residence with a caregiver to whom they were related, and died while in hospice care. The primary source of payment was Medicare. Most received three or more services, were seen by three or more service providers, received help from the hospice with at least one activity of daily living (ADL), were incontinent, and had mobility limitation. Cancer is the most common primary admission diagnosis, but the proportion decreased from 75 percent in 1992 to 58 percent in 2000.

Most of the discharges did not receive timely care. Sixty-three percent of discharges received hospice care for less than 30 days. The average length of service was 46.9 days, and the median length of service was 15.6 days. Shorter lengths of service occurred for those who were living in institutions, did not receive help from the agency with ADLs, had a lower level of mobility limitation, and had a primary admission diagnosis of cerebrovascular disease. Of the noninstitutionalized discharges, those whose primary caregiver was a spouse had shorter lengths of service than those who were cared for by a child.

Keywords: National Home and Hospice Care Survey • long-term care • hospice discharges • length of service

Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000

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

Highlights

- There were 621,100 discharges from hospice care in 2000. Most were elderly, white, and lived in a private or semiprivate residence. There was no significant difference among discharges by sex, and they were equally likely to be married or unmarried. Most of them had a primary caregiver who was a relative and with whom they lived.
- The majority of hospice care discharges in 2000 did not receive timely care. Sixty-three percent of discharges received hospice care for less than 30 days. The average length of service was 46.9 days (down from 84.0 days in 1994), and the median length of service was 15.6 days (down from 27.4 days in 1994).
- Cancer remains the most common primary admission diagnosis for hospice discharges, but the proportion decreased from 75 percent in 1992 to 58 percent in 2000. Other primary admission diagnoses included heart disease, dementia, cerebrovascular disease, and chronic obstructive pulmonary disease and allied conditions.
- Eighty-five percent of the discharges received three or more services, and 75 percent were seen by three or more service providers during the 30 days prior to discharge.
- Seventy-one percent received help from the hospice with at least one activity of daily living (ADL), 71 percent were incontinent, 82 percent had mobility limitation, 70 percent used a hospital bed, and 51 percent used oxygen.

- Shorter lengths of service occurred for discharges who were living in institutions, did not receive help from the agency with ADLs, had a lower level of mobility limitation, and had a primary admission diagnosis of cerebrovascular disease.

Introduction

End-of-life or hospice care has been available in the United States since the early 1970s. At that time, hospice care relied heavily on professional and lay volunteers. Although volunteers are still an important component of hospice, the movement has grown into a more formalized, regulated industry. The use of hospice care services in the United States also increased during the latter part of the 20th century, primarily as a result of the availability of the Medicare Hospice Benefit, which began in 1983. Medicaid reimbursement for hospice care became available in 1986 as an optional service; this coverage is currently available in 43 States and the District of Columbia. Many private health insurance companies also include hospice care as one of their covered services (1–4).

Hospice care services are provided by home health care agencies as well as by hospices. These agencies are usually defined by the focus 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. Home health agencies often provide hospice care as well as home health care, but hospices generally provide only hospice care services. Although hospice services are available in inpatient settings, most of these services are provided in the patient's home or usual residence.

The eligibility requirements for hospice care vary depending on who is providing the service. The requirements for most programs are based on those of the Medicare Hospice Benefit (MHB), but many hospices have broader eligibility criteria so persons not eligible for the MHB can be admitted for care. The MHB can be used by persons who are certified by a physician as having a terminal illness (that is, a life expectancy of 6 months or less). Because predicting life expectancy is an inexact science, a person may be re-certified for the MHB indefinitely as long as he/she meets the Medicare eligibility criteria (2,4–7).

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 cope with the approaching death. 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. Studies demonstrate that those who receive hospice care are very satisfied with the care received and indicate that this care meets the needs of both the patients and their families (3,7). To obtain the maximum benefit from hospice, a person should receive services in a timely manner. However, a widely accepted definition of “timely” is lacking. Some experts suggest that hospice care services should be received for at least 30 days before death (8); others recommend 60 days as the minimum (9). The MHB originally assumed that the average length of service in hospice care would be 70 days, and that the services provided and their cost would be spread over that time period (3).

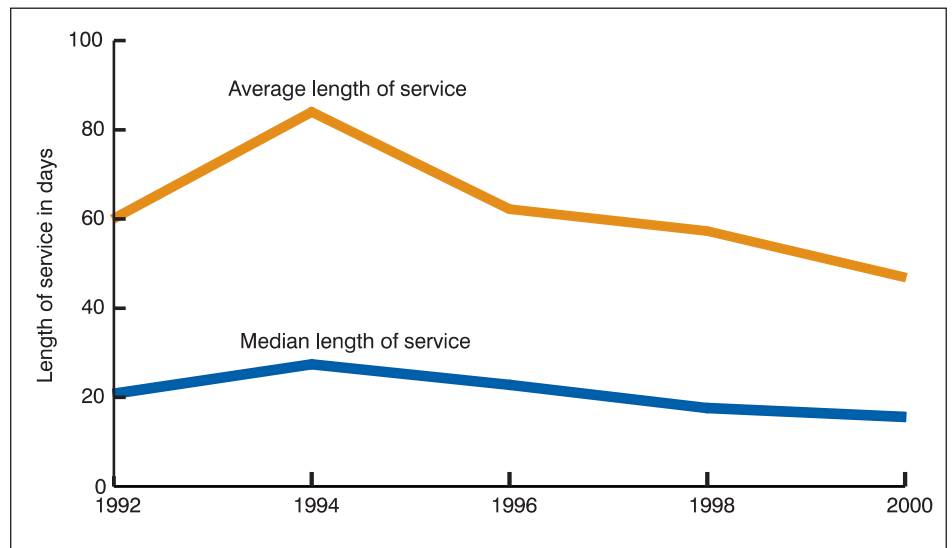


Figure 1. Average and median length of service for hospice care discharges: United States, selected years 1992–2000

Regardless of the definition used, the goal of timely hospice care is not being met for many Americans. Various studies indicate that both the average and median lengths of service in hospice declined during the 1990s (3,7,10–11). Data from the National Home and Hospice Care Survey support this observation (figure 1). Both the average and median lengths of service declined steadily from 1994 to 2000—the average from 84.0 to 46.9 days and the median from 27.4 to 15.6 days. Reasons offered for this failure to provide timely care include a lack of knowledge (in both the medical community and the general American public) of the availability and benefits of hospice care. Restrictive eligibility requirements of funding sources—either perceived or actual—have also been suggested as a reason for late referrals to hospice. In addition, many eligible persons do not receive hospice care until they are very close to death because of an unwillingness on their part, their caregiver's part, and/or their physician's part, to accept and discuss end-of-life care (3,5–12).

This report examines hospice care discharges by length of service. The results include a description of discharge characteristics, followed by an analysis of how these characteristics differ by length of service.

Methods

Data analyzed in this report are from the 2000 National Home and Hospice Care Survey (NHHCS), a nationwide sample survey that was first conducted by the National Center for Health Statistics in 1992 (13). The NHHCS, a segment of the long-term care component of the National Health Care Survey (14), collects information about agencies that provide home health and hospice care services, their current patients, and their discharges.

A brief overview of the survey methodology is presented here. More detailed information about the data collection methods and estimation and testing procedures for the NHHCS, as well as definitions of selected terms used in this report, are in [Appendix I](#).

The sampling frame for the 2000 NHHCS consisted of 15,451 agencies classified as agencies providing home health and hospice care. The universe of home health agencies and hospices was obtained from various national organizations and other sources. The sample consisted of 1,800 agencies selected from this universe.

Data collection for the 2000 NHHCS occurred from August through December 2000. The survey was conducted using a combination of personal interview with hospice staff

and review of patients' medical records. Data on agency characteristics were obtained by personal interview with the administrator. Patient and discharge data were obtained by interviewing a staff person most familiar with the medical records.

Statistics presented in this report are estimated numbers and percents of hospice care discharges and length of service by various items of interest. Discharge data are used because these data represent a complete episode of care. Discharges refer to patients who were removed from the agency rolls (including those who died) during a designated month (October 1999–September 2000) that was randomly selected for each agency. The data are weighted to represent the number of discharges that occurred during the 12-month period, October 1999–September 2000. The estimates are based on a sample of 2,327 discharges. The data collection instrument used, the Discharged Patient Questionnaire, is shown in “Appendix II.”

Characteristics examined include demographics (sex, age, race, and marital status), primary source of payment, discharge status (alive and deceased), living arrangements, caregiver status, services received, service providers seen, functional status, and diagnoses at admission. Age and marital status refer to the status at the time of discharge. Primary source of payment is the source that paid the greatest amount of charges for care. For those discharged alive, discharge status is further subdivided into those who no longer needed hospice care, those who were transferred to inpatient care, and those who were discharged for some other reason. Living arrangements refer to where and with whom the discharge lived during the episode of care. Caregiver status refers to whether the discharge had a primary caregiver and, for those with a caregiver, whether the discharge lived with the caregiver and the relationship of the discharge to the caregiver. Services received and service providers seen refer to what occurred during the 30 days prior to discharge.

Measures of functional status include activities of daily living (ADLs), continence status, mobility status, and

use of selected aids or devices. Five ADLs are examined (bathing, dressing, eating, transferring in or out of beds or chairs, and using the toilet room) and refer to whether the discharge received personal help from the agency in performing any ADLs. Incontinence is defined as the discharge having an indwelling urinary catheter or urostomy, a colostomy or ileostomy, or difficulty controlling the bladder or bowels. Mobility status is broadly defined to refer to both upper and lower body facility of movement. Mobility limitation is defined as receiving personal help from the agency with selected ADLs (bathing, dressing, transferring in or out of beds or chairs, and using the toilet room), walking, or regularly using selected aids or devices. Three levels of mobility limitation are examined. Severe mobility limitation refers to discharges who received personal help from the agency with at least one of the following: transferring in or out of beds or chairs, walking, or using the toilet room. Moderate limitation refers to discharges not included above, but who used at least one of the following aids: cane or crutches; geri-chairs, lift chairs, or other specialized chairs; transfer equipment; walker; or wheelchair (manual or motorized). Mild limitation refers to discharges not included in the previous levels, but who received personal help from the agency in bathing or dressing or used at least one of the following aids: bedside commode, elevated or raised toilet seat, grab bars, or shower chair or bath bench. For both ADLs and mobility status, an unknown number of discharges who were bedbound or received help only from nonagency persons are excluded from these measures because this information was not collected. Finally, the use of the following four special aids or devices is examined: hospital bed, oxygen, IV therapy equipment, and enteral feeding equipment.

One primary and up to five secondary admission diagnoses are recorded for each discharge. The primary diagnosis is the diagnosis most responsible for the discharge's admission to hospice care. All diagnoses are coded according to the *International*

Classification of Diseases, 9th Revision, Clinical Modification (15).

The following three measures of length of service are used: average and median length of service and length of service intervals (less than 30 days and 30 days or more). For this report, discharges received services in a timely manner if they received hospice care for 30 days or more.

Average length of service is computed by summing the number of days of service and dividing the result by the number of discharges within the particular category of interest. This statistic is very sensitive to extremes (very low or very high values) and is, therefore, best used with data that are symmetrically distributed.

Median length of service is determined by identifying the midpoint of the distribution (the point at which 50 percent of the cases are below it and 50 percent are above it). As such, it is insensitive to extremes and is therefore often used with skewed or asymmetrical distributions.

Average length of service has traditionally been analyzed in the past and is presented in this report to maintain continuity. Median length of service, however, gives a more accurate picture of hospice use since the length of service of hospice patients is skewed toward the shorter lengths of service.

Two types of tests of significance are used in this report. The Bonferroni multiple comparisons test is used for testing comparisons—for example, differences between average lengths of service for discharges by diagnosis. Tests of trends—such as changes of length of service over time—are done using a weighted least squares regression method (16). Both types of tests are based on the two-sided z -test with an overall 0.05 level of significance. A critical value of 1.96 was used for the trend tests. Critical values for the Bonferroni test vary depending on the possible number of comparisons that can be made (16). The standard errors were approximated using SUDAAN software, which takes into account the complex sample design of the survey. A description of the software and the approach it uses is published

elsewhere (17). Standard errors of the estimates are included in “Appendix I.”

Results

Patient Characteristics

During 2000, there were 621,100 discharges from hospice care (table 1). There was no significant difference by sex. The majority (80 percent) were elderly (65 years of age and over). Eighty-four percent of the discharges were white and 10 percent were black or African American or other races. About one-half (47 percent) were married at the time of discharge. Of those who were not married, the majority was widowed.

Medicare was the primary source of payment for most (79 percent) of the discharges. Private sources of payment, such as private insurance, own income, or family support, accounted for an additional 13 percent, and Medicaid was the primary payer for 5 percent.

The most common reason for discharge was death (86 percent). Eight percent were discharged because they no longer needed services—for example, their condition stabilized or they were no longer eligible for hospice care. Only 2 percent of the discharges occurred because the patient was transferred to inpatient care, including care provided in a hospital or nursing home.

Most of the discharges (61 percent) lived in a private or semiprivate residence during their episode of care, and about 35 percent were already residents of an inpatient health facility (table 2). Of the noninstitutionalized discharges (those not living in a health facility), 81 percent lived with family members, 8 percent lived with only nonfamily members, and 9 percent lived alone.

Information about the caregiver status of hospice discharges is shown in table 3. Ninety-two percent of the discharges had a primary caregiver, that is, an individual who was responsible for providing personal care assistance, companionship, and/or supervision to the patient. This caregiver was not a staff member of the agency providing

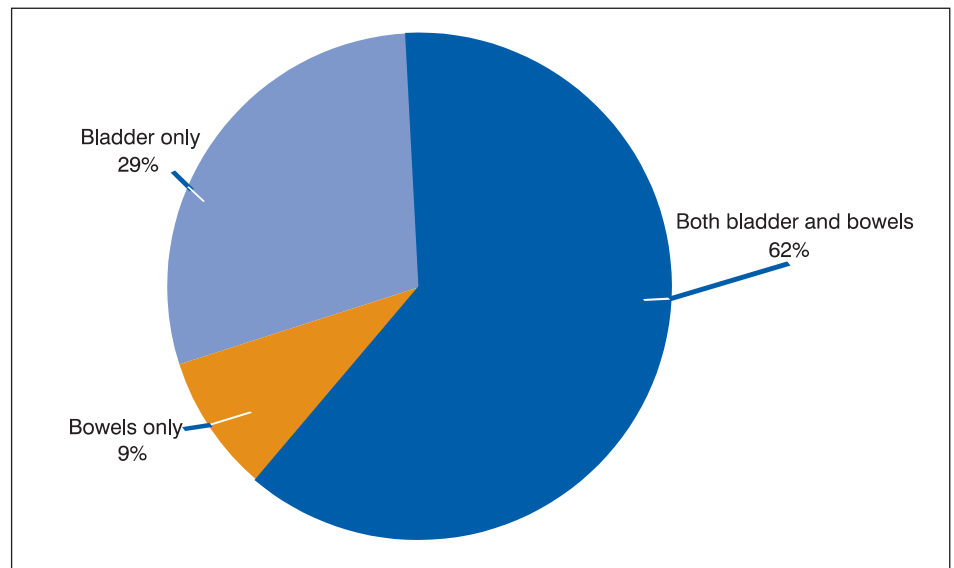


Figure 2. Percent distribution of incontinent hospice care discharges by type of incontinence: United States, 2000

hospice care. For 61 percent of the institutionalized discharges (those living in a health facility) the primary caregiver was a relative, and for 39 percent, the primary caregiver was someone hired by the discharged person or a member of the staff of the facility where the person resided. Ninety percent of the noninstitutionalized discharges were related to their primary caregiver; for most of these, the caregiver was their spouse.

Services and Service Providers

Information on services received and type of service provider seen is shown in tables 4 and 5. Most discharges (92 percent) received skilled nursing services. Other frequently received services were referral or social services (72 percent), homemaker-household or personal care services (62 percent), prescription medications (59 percent), and pastoral or spiritual care (59 percent). The type of service provider usually mirrors the services provided. Most discharges were seen by a nurse (96 percent). A social worker or mental health specialist (76 percent), a home health or nursing aide (69 percent), or a chaplain (53 percent) was also frequently seen. Although 62 percent of the discharges received homemaker-household or personal care

services, only 7 percent were seen by a homemaker or personal caretaker. Other types of staff such as home health aides or nursing aides and attendants provide much of this type of care. The majority of hospice discharges received multiple services provided by several types of providers. Eighty-five percent received three or more different types of services and 75 percent were seen by three or more types of providers.

Functional Status

Table 6 provides information on the following measures of functional status for hospice care discharges: help with ADLs, continence, mobility, and use of selected aids or devices.

Seventy-one percent of the discharges received personal help from the agency with at least one ADL. Most of the discharges received help with bathing or showering (70 percent) or with dressing (59 percent), and almost half (48 percent) received help with transferring in or out of beds or chairs.

The majority (71 percent) of the discharges had a problem with continence, defined as having an indwelling urinary catheter or urostomy, a colostomy or ileostomy, or difficulty controlling their bladder or bowels. Of the incontinent discharges, 62 percent had both bladder and bowel incontinence and 29 percent had only bladder incontinence (figure 2).

Eighty-two percent of the discharges had limited mobility. Seventeen percent had a mild limitation, that is, they received personal help from the agency only with bathing, showering, dressing, or used aids such as an elevated toilet seat or a shower chair to help with nonambulatory types of mobility limitation. An additional 15 percent did not receive personal help from the agency with getting around, but used an aid or device such as a cane, transfer equipment, or a wheelchair, for transferring, walking, or otherwise ambulating (moderate limitation). One-half had severe mobility limitation and received help from agency personnel with transferring in or out of beds or chairs, walking, or using the toilet room. Of the remaining 18 percent, some may have had mobility limitations, but are not included above because they were bedbound, infants, or received help only from persons not associated with the hospice. This information is not collected in the NHHCS.

The use of a hospital bed, oxygen (including oxygen concentrator), intravenous (IV) therapy equipment, and enteral feeding equipment was also examined. Eighty-two percent of the discharges used one or more of these aids or devices. Most (70 percent) had a hospital bed, and 51 percent used oxygen.

Diagnoses

One primary and up to five secondary admission diagnoses were recorded for each discharge. The primary admission diagnosis for 58 percent of the hospice care discharges, as shown in [table 7](#), was a malignant neoplasm. Common noncancer primary diagnoses included heart disease (7 percent), dementia (6 percent), cerebrovascular disease (5 percent), and chronic obstructive pulmonary disease (COPD) and allied conditions (4 percent).

Sixty-two percent of the hospice discharges had multiple diagnoses. Of the secondary diagnoses, 29 percent were malignant neoplasms, 8 percent were heart disease, 7 percent were cerebrovascular disease, and 6 percent

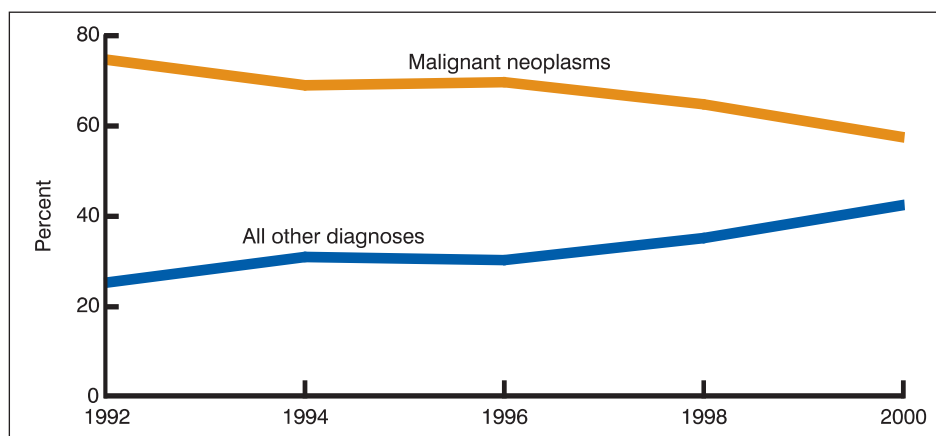


Figure 3. Percent of hospice care discharges by primary admission diagnosis: United States, selected years 1992–2000

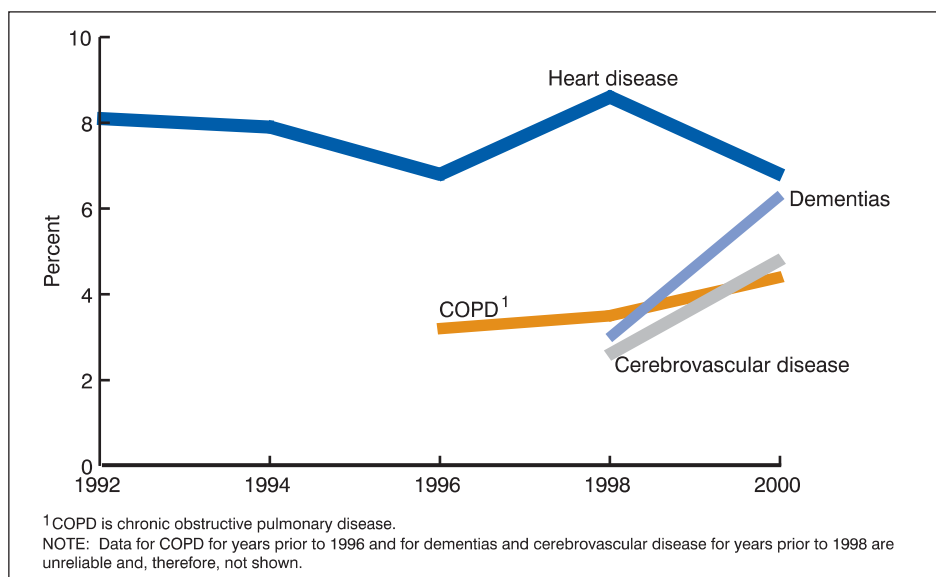


Figure 4. Percent of hospice care discharges by primary noncancer admission diagnosis: United States, selected years 1992–2000

were diabetes mellitus. Malignant neoplasms were more likely to be primary diagnoses, and diabetes mellitus was almost always a secondary diagnosis. The other diagnoses listed were equally likely to be primary or secondary.

Hospice patients are predominantly cancer patients. Prognosis is relatively easy to determine for many cancer diagnoses—much easier than for other, more chronic but equally fatal diseases such as heart disease or COPD. In recent years, hospice care has become more available to persons with diseases other than cancer. Data from the NHHCS reflect this trend ([table 8](#), [figure 3](#)). The percent of hospice discharges with a primary diagnosis of

malignant neoplasm has been steadily declining since 1992, from 75 percent in 1992 to 58 percent in 2000. As shown in [figure 4](#), the proportion of heart disease diagnoses has remained steady over this time at 7–8 percent. Noncancer diagnoses that are being reported in recent years include dementias, cerebrovascular disease, and COPD.

Length-of-Service Measures

Hospice care should be provided for 30 days or more to receive maximum benefit from the care (8). During 2000, only 37 percent of the discharges fell into this category. The average length of service for hospice discharges was 46.9

days, and the median length of service was 15.6 days (table 1).

Length-of-service measures did not differ significantly for the demographic characteristics studied. The average length of service, however, was longer for Medicare than for Medicaid discharges (48.1 days compared with 24.3 days).

Differences were seen for length-of-service measures by reason for discharge. The average length of service was longer for those discharged alive (73.1 days) than for discharges who died (42.4 days), and a larger proportion of those who were discharged alive (61 percent) than deceased (33 percent) received services for 30 days or more.

As shown in table 2, median length of service was shorter for discharges living in a health facility during their episode of care (6.4 days) compared with those who did not live in a health facility (20.6 days) or who lived in a private or semiprivate residence (19.9 days).

Table 9 shows length-of-service measures by caregiver characteristics for noninstitutionalized discharges. For these discharges, the median length of service was shorter for those whose primary caregiver was a spouse (14.9 days) than for those whose caregiver was a child or child-in-law (35.4 days). Consistent with this, discharges whose primary caregiver was a spouse were less likely to receive services for 30 days or more (33 percent) than those whose primary caregiver was a child or child-in-law (56 percent).

Some differences occurred for length-of-service measures by various types of functional status (table 6). Discharges who received help with more ADLs had a longer average length of service, as illustrated in figure 5. This trend is significant at the 0.05 level. Discharges receiving help from the agency with one or more ADLs were more likely to receive hospice care for 30 days or more than those who received no help from the agency in ADLs (42 percent compared with 27 percent).

As mentioned previously, discharges with mobility limitation are those receiving personal help from the agency with selected ADLs, walking, or

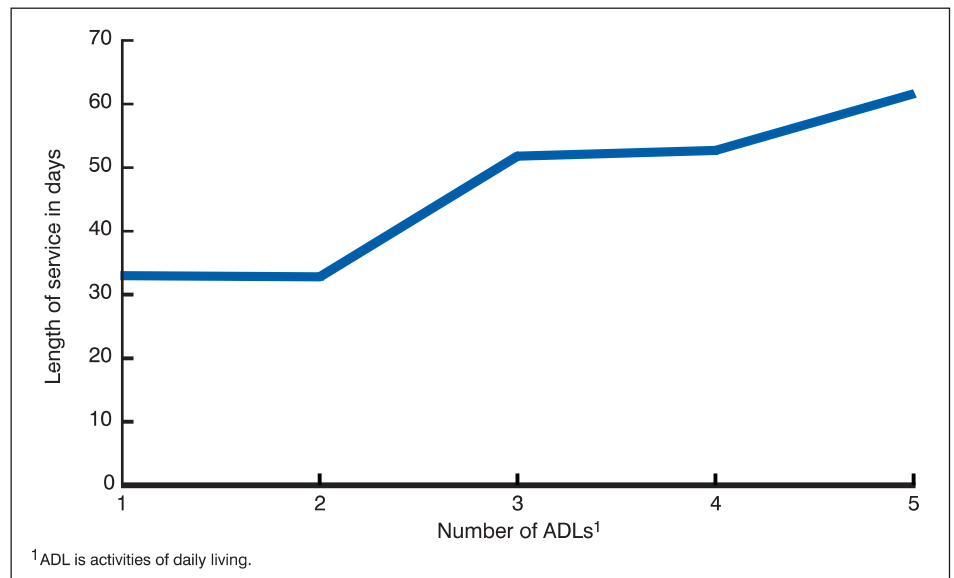


Figure 5. Average length of service by number of ADLs for hospice care discharges: United States, 2000

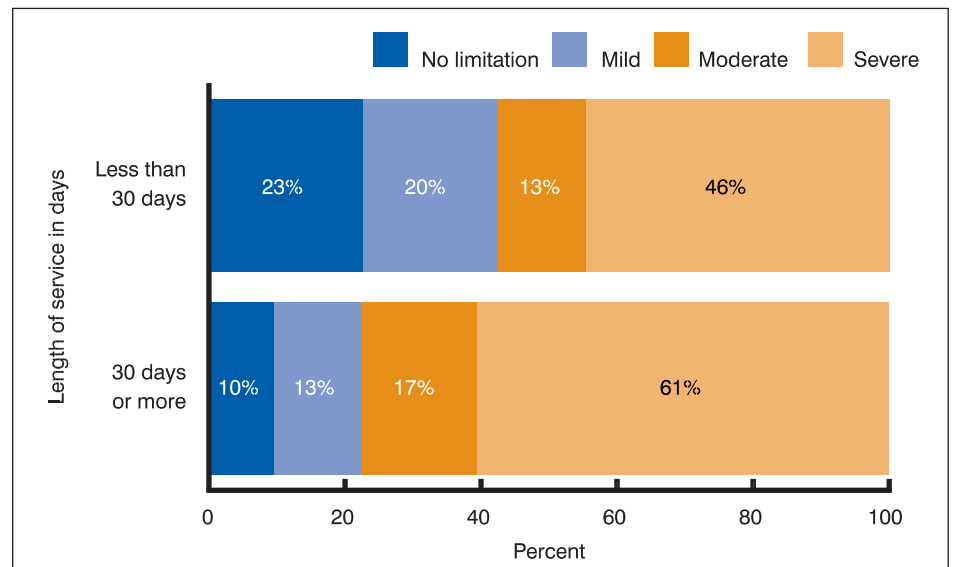


Figure 6. Percent distribution of hospice discharges by mobility limitation, according to length of service: United States, 2000

regularly using mobility aids or devices. Those with a mild limitation had a shorter average length of service than those with severe limitation, 29.4 days compared with 56.7 days. Figure 6 shows the percent distribution of discharges by mobility limitation according to length-of-service interval. A higher percent of discharges who received hospice care for 30 days or more (90 percent) than those who received care for less than 30 days (77 percent) had a mobility limitation. Moreover, those who received care for 30 days or more were more likely to be severely limited than those who received

care for less than 30 days (61 percent compared with 45 percent).

Finally, discharges using one or more of the following aids—hospital bed, oxygen, IV therapy equipment, and enteral feeding equipment—had a shorter median length of service (13.3 days) than those who used none of these aids (27.0 days).

Data on length of service by primary diagnosis are shown in table 10. Both the average and median lengths of service for discharges with cerebrovascular disease (16.2 days and 3.8 days, respectively) were shorter than those for discharges with malignant

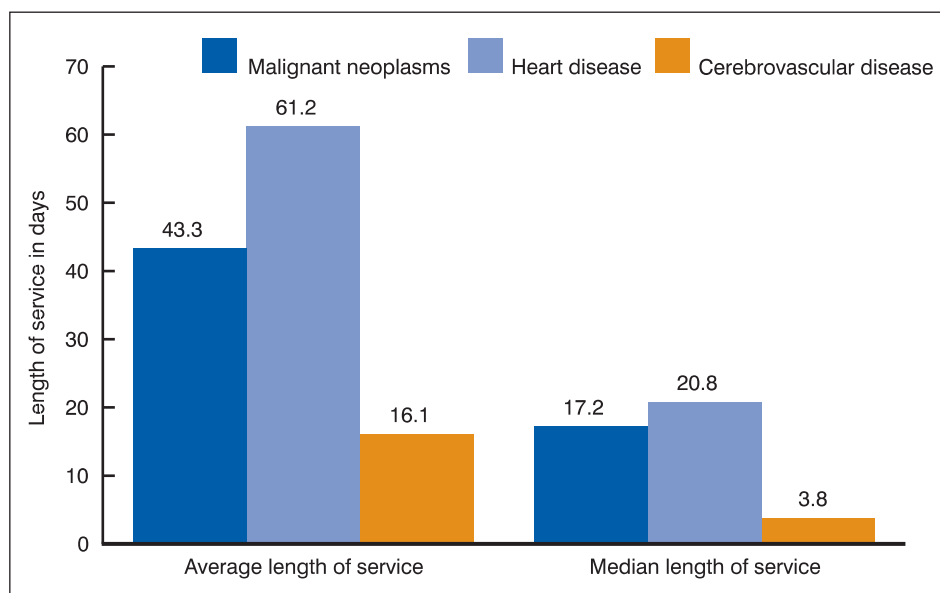


Figure 7. Average and median length of service for selected primary admission diagnoses for hospice care discharges: United States, 2000

neoplasms (43.3 days and 17.2 days) or heart disease (61.2 days and 20.8 days). This is illustrated in [figure 7](#). Almost 90 percent of the discharges with a primary diagnosis of cerebrovascular disease received hospice care for less than 30 days. This is greater than the proportion of discharges with a primary diagnosis of cancer (62 percent) or heart disease (56 percent).

Summary and Discussion

In 2000, there were 621,100 discharges from hospice care in the United States. The typical discharge was elderly, white, lived in a private or semiprivate residence with family members, lived with and was related to their primary caregiver, and was discharged because of death. The primary source of payment for hospice care was Medicare. There was no significant difference among hospice discharges by sex, and they were equally likely to be married or unmarried.

Most hospice discharges received three or more services from three or more service providers. Most often the services provided were skilled nursing services, referral or social services,

homemaker-household or personal care services, and pastoral or spiritual care. Nurses, social workers or mental health specialists, home health or nursing aides, and chaplains most frequently provided the services.

The majority of discharges had one or more of the following types of functional limitation: received help from the agency with at least one ADL; were incontinent (bladder and/or bowels); had mobility limitation; and used a hospital bed, oxygen, IV therapy equipment, or enteral feeding equipment.

Cancer remains the primary admission diagnosis, although the proportion decreased from 75 percent in 1992 to 58 percent in 2000. Other admission diagnoses included heart disease, dementia, cerebrovascular disease, and chronic obstructive pulmonary disease. A major reason for the decline in malignant neoplasms as a primary diagnosis involves the easing of the regulations for the Medicare Hospice Benefit in the Balanced Budget Act of 1997. As a result, persons may now be re-certified as eligible for hospice care an indefinite number of times as long as their life expectancy is 6 months or less. The hospice industry has actively worked to make hospice available to persons with diseases other than cancer by educating both the public and the medical community about the availability of hospice care, the

applicability of this care for diseases other than cancer, and the importance of enrolling in hospice earlier in the disease process than has occurred in the past (2,4–7,9).

Three length-of-service measures were examined—average, median, and length-of-service intervals (less than 30 days and 30 days or more). Average length of service has traditionally been analyzed in the past and is presented in this report to maintain continuity. Median length of service, however, gives a more accurate picture of hospice use since the length of service of hospice patients is skewed toward the shorter end of the spectrum. The average length of service for hospice discharges was 46.9 days in 2000, a steady decline from 84.0 days in 1994. A similar decline occurred for median length of service, from 27.4 days in 1994 to 15.6 days in 2000. This pattern has also been reported elsewhere and is believed to be an indication of a decreasing ability of the U.S. health care system to provide timely hospice care to those who need and desire it (3,7,10–11). In 2000, only 37 percent of the discharges received hospice care for at least 30 days.

Some differences in discharge characteristics by the various length of service measures occurred. Medicaid discharges had a shorter average length of service than Medicare discharges. Institutionalized discharges (those living in a health facility during their hospice care) had a shorter median length of service than those who lived elsewhere. Institutionalized discharges may be at a more critical stage in their illness than those living in private homes or their caregivers may be less able to care for them at home as their illness progresses. Discharges living in nursing homes may have a shorter length of service in hospice care because the nursing home may use hospice services only as a late-stage resource. Noninstitutionalized discharges whose primary caregiver was their spouse had shorter lengths of service (as measured by median length of service and length of service intervals) than those whose primary caregiver was a child or child-in-law. Perhaps it is easier to accept the presence of a terminal illness in a parent

than in a spouse. Children may also be less able (because of other obligations) to bear the entire burden of caregiving for a terminal patient and seek formal hospice care earlier in the disease process. Discharges with a primary admission diagnosis of cerebrovascular disease (stroke) had a shorter length of service for all three length of service measures than did those whose diagnosis was cancer or heart disease. Those with stroke may have been referred to hospice care at a more acute or advanced stage in their illness and died sooner than discharges with cancer or heart disease. The time from onset of a diagnosis of stroke to death may also be shorter for some cases.

Some significant differences occurred for length of service measures by discharge status. A greater proportion of those discharged alive compared with those who were discharged because of death received services for 30 days or more. Those who were discharged alive also had a longer average length of service than those who were deceased.

The use of selected aids or devices (hospital bed, oxygen, IV therapy equipment, and enteral feeding equipment) was negatively associated with median length of service, while help with ADLs and mobility limitation was positively associated with average length of service and length of service intervals. Discharges using the aids listed may be admitted in a more critical state of health resulting in a more rapid death than those not using these types of aids or those receiving agency help with ADLs.

Several strengths and weaknesses of the data presented here should be kept in mind. Data collected through the NHHCS are representative of hospice care provided throughout the United States regardless of the funding status of the agency providing the care, so agencies not certified by Medicare or Medicaid are included in the sample. However, because the data are based on a sample, there may not be a sufficient number of cases to provide reliable estimates for relatively rare events.

The data were collected from the medical records of the discharges. Although this results in better accuracy and more completeness of medical data,

some information, such as functional status or help with ADLs by nonagency persons, is not always available in medical records (19). Mobility limitation, for example, may be underestimated in this report because this variable is based on the discharge receiving personal help from the agency with ADLs or walking rather than a direct assessment of functional level. ADLs are often provided to persons with chronic conditions (19) and are frequently provided by informal caregivers (18,20). Some discharges may have received help with ADLs from their primary caregiver and not agency personnel; others did not receive help with ADLs (especially those related to mobility) because they were bedbound (and bedbound status is not known). For these reasons mobility limitation for some discharges may not be known.

The use of discharge data, rather than data on current patients, allows the analysis of a complete episode of care. Discharge data, however, may tend to underestimate those patients who receive care for long periods of time because the likelihood of being included in a sample of discharges is greater for those whose lengths of service is relatively short. This report, therefore, may overestimate the proportion of discharges who received hospice care for less than 30 days. The average and median lengths of service reported here may also be shorter than the true estimates. A sample of current patients is more likely to provide information on long-term users of care because these patients are more likely to be enrolled with the agency on the day that the data were collected. However, data on current patients does not provide information about a complete episode of care. A cohort of hospice patients, followed from admission to discharge, would provide the most appropriate information on length of service.

In summary, there were 621,100 discharges from hospice care in 2000. Most discharges were elderly, white, noninstitutionalized, and had a primary caregiver with whom they lived and to whom they were related. Most required help with ADLs, were incontinent, and had a mobility limitation. The majority

of hospice care discharges did not receive timely care in 2000. Sixty-three percent received hospice care for less than 30 days. The average length of service was 46.9 days (down from 84.0 days in 1994), and the median length of service was 15.6 days (down from 27.4 days in 1994). Shorter lengths of service occurred for discharges who were institutionalized, did not receive help from the agency with ADLs, had mild mobility limitation, and had a primary admission diagnosis of cerebrovascular disease. Of the noninstitutionalized discharges, those whose primary caregiver was a spouse had shorter lengths of service than those who were cared for by a child.

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Table 1. Number and percent distribution of hospice care discharges by length of service, according to selected patient characteristics: United States, 2000

Discharge characteristic	Length of service in days							
	Discharges		Percent distribution				Average length of service	Median length of service
	Number	Percent distribution	Total	Less than 30 days	30 days or more			
Total	621,100	100.0	100.0	62.8	37.2	46.9	15.6	
Sex								
Male	309,300	49.8	100.0	66.7	33.3	42.8	14.5	
Female	311,800	50.2	100.0	58.9	41.1	50.9	18.1	
Age at discharge								
Under 65 years	126,900	20.4	100.0	64.1	35.9	43.9	15.0	
65 years and over	494,300	79.6	100.0	62.4	37.6	47.7	16.3	
65–74 years	153,100	24.7	100.0	65.0	35.0	41.2	16.4	
75–84 years	176,400	28.4	100.0	62.3	37.7	50.6	16.5	
85 years and over	164,800	26.5	100.0	60.2	39.8	50.5	*15.9	
Race ¹								
White	522,500	84.1	100.0	62.6	37.4	46.7	14.8	
Black or African American and other races	64,300	10.3	100.0	68.5	31.5	*53.6	15.8	
Black or African American	50,100	8.1	100.0	66.8	33.2	*61.1	*14.9	
Unknown	34,400	5.5	100.0	55.5	*44.5	36.7	*26.8	
Marital status at discharge								
Married	293,400	47.2	100.0	67.5	32.5	40.0	11.7	
Not married	289,500	46.6	100.0	58.8	41.2	54.1	18.5	
Widowed	206,400	33.2	100.0	58.7	41.3	53.5	*18.4	
Divorced or separated	35,200	5.7	100.0	63.1	36.9	*74.8	*14.3	
Single or never married	47,900	7.7	100.0	56.3	43.7	41.5	*19.5	
Unknown	38,300	6.2	100.0	*56.4	*43.6	45.3	*24.2	
Primary source of payment								
Medicare	488,000	78.6	100.0	61.5	38.5	48.1	16.7	
All other sources	133,200	21.4	100.0	67.6	32.4	42.4	*10.3	
Medicaid	31,400	5.1	100.0	73.7	*26.3	24.3	*5.4	
Private ²	80,600	13.0	100.0	64.4	35.6	*49.4	*11.0	
Other ³	21,100	3.4	100.0	70.9	*29.1	42.5	*7.0	
Reason for discharge								
Died	531,000	85.5	100.0	66.7	33.3	42.4	13.6	
Did not die	90,200	14.5	100.0	39.5	60.5	73.1	*43.6	
Services no longer needed from agency ⁴	49,000	7.9	100.0	*29.2	70.8	86.2	64.7	
Transferred to inpatient care ⁵	14,500	2.3	100.0	*	*63.9	81.7	71.0	
Other and unknown	26,700	4.3	100.0	*60.2	*39.8	44.4	*10.0	

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Prior to 1998, only one race was recorded. Since 1998, more than one race may be recorded. The categories "White" and "Black or African American" include only those discharges for whom that one race was reported. Discharges for whom more than one race was reported are included in "Black or African American and other races."

²Includes private insurance, own income, family support, Social Security benefits, retirement funds, and welfare.

³Includes unknown source and no charge for care.

⁴Includes recovered, stabilized, treatment plan completed, no longer eligible for hospice care, and insurance coverage no longer available.

⁵Includes transferred to hospital, nursing home, or other inpatient or residential care.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 2. Number and percent distribution of hospice care discharges by length of service, according to residence and living arrangements: United States, 2000

Discharge characteristic	Length of service in days							
	Discharges		Percent distribution				Average length of service	Median length of service
	Number	Percent distribution	Total	Less than 30 days	30 days or more			
Total	621,100	100.0	100.0	62.8	37.2	46.9	15.6	
Residence during care								
Private or semiprivate residence ¹	379,900	61.2	100.0	59.7	40.3	49.7	19.9	
Board and care, assisted living, or residential care facility	21,600	3.5	100.0	*45.7	*54.3	71.6	*38.9	
Health facility (including mental health facility)	217,000	34.9	100.0	69.9	30.1	39.7	6.4	
Unknown	*	*	*	*	*	*	*	
Living arrangements of discharges not in a health facility ²								
Total	404,200	100.0	100.0	58.9	41.1	50.7	20.6	
Lived alone	36,000	8.9	100.0	*47.2	52.8	67.0	*38.8	
Lived with someone	358,900	88.8	100.0	59.4	40.6	49.9	20.4	
Lived with family members	326,900	80.9	100.0	59.4	40.6	49.8	18.9	
Lived only with nonfamily members	32,000	7.9	100.0	59.1	*40.9	50.3	*24.4	

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Includes private residence, rented room, boarding house, and retirement home.

²Excludes those for whom living arrangements are unknown.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 3. Number and percent distribution of hospice care discharges by type of residence, according to caregiver status: United States, 2000

Discharge characteristic	Type of residence			Type of residence		
	Total	Health facility	All other and unknown type	Total	Health facility	All other and unknown type
	Number			Percent distribution		
All discharges	621,100	217,000	404,200	100.0	100.0	100.0
Primary caregiver status						
Primary caregiver	569,000	189,300	379,700	91.6	87.2	94.0
No primary caregiver or unknown	52,100	27,700	24,400	8.4	*12.8	6.0
Discharges with primary caregiver	569,000	189,300	379,700	100.0	100.0	100.0
Lived with primary caregiver						
Yes	434,300	96,400	337,900	76.3	50.9	89.0
No or unknown	134,700	92,900	41,800	23.7	49.1	11.0
Relationship of primary caregiver to discharge						
Relative	458,700	116,100	342,600	80.6	61.3	90.2
Spouse	238,200	52,200	186,000	41.9	27.6	49.0
Child/child-in-law	167,600	53,100	114,500	29.5	28.0	30.2
Other relative	52,900	*10,900	42,000	9.3	*5.7	11.1
Nonrelative	110,300	73,200	37,100	19.4	38.7	9.8
Hired by discharge/staff of residential facility	81,300	66,800	*14,500	14.3	35.3	*3.8
Other nonrelative or unknown	29,000	*	22,700	5.1	*	6.0

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

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

Table 4. Number and percent of hospice care discharges and percent distribution by length of service, according to services received during the 30 days prior to discharge: United States, 2000

Service received ¹	Discharges		Length of service in days				
	Number	Percent	Percent distribution				
			Total	Less than 30 days	30 days or more	Average length of service	Median length of service
All discharges	621,100	...	100.0	62.8	37.2	46.9	15.6
Medical and skilled nursing							
Skilled nursing	570,400	91.8	100.0	62.7	37.3	46.7	16.0
Physician	186,900	30.1	100.0	64.2	35.8	42.5	14.9
Equipment and medication							
Medications	367,100	59.1	100.0	61.8	38.2	51.0	15.4
Durable medical equipment and supplies	279,600	45.0	100.0	59.7	40.3	49.0	18.5
Personal care							
Homemaker-household or personal care ²	387,100	62.3	100.0	58.2	41.8	51.1	20.9
Companion or volunteer ²	195,300	31.5	100.0	51.5	48.5	63.6	26.9
Continuous home care	23,800	3.8	100.0	47.5	52.5	68.3	42.1
Psychosocial							
Referral or social ²	446,300	71.9	100.0	61.6	38.4	47.4	16.9
Pastoral or spiritual care ²	366,200	59.0	100.0	62.8	37.2	46.3	15.7
Counseling or psychological ²	194,400	31.3	100.0	57.9	42.1	49.5	20.7
Respite care	43,400	7.0	100.0	*54.2	45.8	62.6	*23.6
Other							
High-tech care ^{2,3}	127,500	20.5	100.0	58.8	41.2	64.5	*15.1
Other ^{2,4}	164,100	26.4	100.0	55.5	44.5	35.8	*15.6
Number of services received							
0–2 ⁵	96,100	15.5	100.0	77.0	23.0	29.1	*3.1
3–5	237,900	38.3	100.0	59.2	40.8	51.0	17.2
6–8	185,500	29.9	100.0	61.8	38.2	51.4	19.3
9 or more	101,500	16.4	100.0	59.5	40.5	46.0	*16.7

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.

²A discharge is counted only once even though it may have received more than one type of service in this category.

³Includes enterostomal therapy, IV therapy, respiratory therapy, and other high-tech care such as enteral nutrition or dialysis.

⁴Includes dental treatment services, dietary and/or nutritional services, Meals on Wheels, occupational therapy, physical therapy, speech therapy and/or audiology, transportation, vocational therapy, and other services.

⁵Includes a small number of discharges for whom no services were reported.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 5. Number and percent of hospice care discharges and percent distribution by length of service, according to service providers seen during the 30 days prior to discharge: United States, 2000

Provider seen	Length of service in days							
	Discharges		Percent distribution				Average length of service	Median length of service
	Number	Percent	Total	Less than 30 days	30 days or more			
All discharges	621,100	...	100.0	62.8	37.2	46.9	15.6	
Type of provider ¹								
Nurses ^{2,3}	598,700	96.4	100.0	63.5	36.5	45.8	15.2	
Social workers/mental health specialists ²	470,700	75.8	100.0	61.0	39.0	45.6	18.1	
Home health aides/nursing aides/attendants ²	427,500	68.8	100.0	58.5	41.5	49.7	20.4	
Chaplains	328,400	52.9	100.0	64.5	35.5	43.2	14.9	
Volunteers	192,900	31.1	100.0	50.4	49.6	64.2	28.2	
Physicians	153,000	24.6	100.0	69.0	31.0	37.3	*10.2	
Homemakers/personal caretakers	40,900	6.6	100.0	58.3	41.7	77.4	*18.8	
Other ^{2,4}	116,700	18.8	100.0	60.7	39.3	40.8	*20.9	
Number of providers seen								
0-1 ⁵	65,500	10.6	100.0	76.0	*24.0	*47.4	*2.0	
2	91,900	14.8	100.0	67.5	32.5	33.1	*6.0	
3	120,300	19.4	100.0	60.3	39.7	50.5	19.0	
4	118,600	19.1	100.0	54.7	45.3	55.9	26.1	
5 or more	224,800	36.2	100.0	62.6	37.4	45.7	16.1	

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.

²A discharge is counted only once even though it may have been seen by more than one type of provider in this category.

³Includes registered, licensed practical, and vocational nurses.

⁴Includes dietitians or nutritionists, occupational therapists, physical therapists, respiratory therapists, speech pathologists or audiologists, and other providers.

⁵Includes a small number of discharges for whom no providers were reported.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 6. Number and percent of hospice care discharges and percent distribution by length of service, according to selected types of functional status: United States, 2000

Functional status	Length of service in days						
	Discharges		Percent distribution				
	Number	Percent	Total	Less than 30 days	30 days or more	Average length of service	Median length of service
All discharges	621,100	...	100.0	62.8	37.2	46.9	15.6
Received help from agency with ADLs ^{1,2}							
Bathing or showering	431,800	69.5	100.0	58.0	42.0	50.4	20.0
Dressing	364,700	58.7	100.0	57.8	42.2	53.1	20.7
Eating	218,300	35.1	100.0	61.9	38.1	52.7	15.7
Transferring in or out of beds or chairs	294,900	47.5	100.0	55.8	44.2	56.9	24.1
Using the toilet room	236,400	38.1	100.0	54.0	46.0	58.6	23.9
Functional status in ADLs ²							
Received no help from agency with ADLs ³	179,800	29.0	100.0	73.5	26.5	39.4	*5.2
Received help from agency with 1 or more ADLs	441,300	71.1	100.0	58.4	41.6	49.9	19.5
Received help with:							
1 ADL	31,800	5.1	100.0	57.7	42.3	33.0	*16.8
2 ADLs	87,200	14.0	100.0	67.3	32.7	32.8	*10.4
3 ADLs	86,300	13.9	100.0	55.5	44.5	51.8	*24.9
4 ADLs	99,400	16.0	100.0	55.0	45.0	52.7	23.8
5 ADLs	136,700	22.0	100.0	57.2	42.8	61.6	*19.8
Continence status							
Continent	181,300	29.2	100.0	58.9	41.1	50.2	18.9
Incontinent ⁴	439,800	70.8	100.0	64.4	35.6	45.5	14.6
Only bladder incontinence or device ⁵	126,700	20.4	100.0	57.3	42.7	51.9	*16.6
Only bowel incontinence or device ⁶	40,700	6.6	100.0	*59.4	*40.6	37.9	26.1
Both bladder and bowel incontinence or device ^{5,6}	272,500	43.9	100.0	68.4	31.6	43.7	12.0
Mobility status							
No mobility limitation ³	110,700	17.8	100.0	79.8	20.2	*34.0	*2.0
Mobility limitation	510,400	82.2	100.0	59.1	40.9	49.7	18.7
Limitation level:							
Mild	106,800	17.2	100.0	72.7	27.3	29.4	*5.9
Moderate	89,900	14.5	100.0	55.9	44.1	49.3	20.9
Severe	313,700	50.5	100.0	55.4	44.6	56.7	24.5
Use of selected aids or devices							
No aids or devices	114,700	18.5	100.0	52.0	48.0	54.8	27.0
Aids or devices ¹	506,400	81.5	100.0	65.2	34.8	45.1	13.3
Hospital bed	435,000	70.0	100.0	65.9	34.1	44.2	11.8
Oxygen	313,500	50.5	100.0	68.7	31.3	39.3	11.7
IV therapy equipment	46,700	7.5	100.0	63.6	*36.4	*66.1	*9.8
Enteral feeding equipment	19,200	3.1	100.0	*21.0	*79.0	69.2	*53.9

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.²ADL is activity of daily living.³Includes an unknown number of discharges who were bedbound or received help only from nonagency persons.⁴Includes an indwelling urinary catheter or urostomy, a colostomy or ileostomy, or difficulty controlling the bladder or bowels.⁵Bladder incontinence or device includes an indwelling urinary catheter or urostomy or difficulty controlling the bladder.⁶Bowel incontinence or device includes a colostomy, ileostomy, or difficulty controlling the bowels.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 7. Number and percent distribution of diagnoses for hospice care discharges by primary or secondary diagnosis, according to diagnostic category: United States, 2000

Diagnostic category and ICD-9-CM code ¹	All diagnoses	Type of diagnosis ²		All diagnoses	Type of diagnosis ²	
		Primary	Secondary		Primary	Secondary
		Number			Percent distribution	
All diagnoses ³	1,437,500	621,100	820,500	100.0	100.0	100.0
Malignant neoplasms	592,100	357,000	235,100	41.2	57.5	28.7
Malignant neoplasm of large intestine and rectum	60,000	51,500	*	4.2	8.3	*
Malignant neoplasm of trachea, bronchus, and lung	146,100	120,500	25,600	10.2	19.4	*3.1
All other diagnoses	845,500	264,200	585,200	58.8	42.5	71.3
Diabetes mellitus	47,100	*	46,300	3.3	*	5.6
Dementias	72,000	39,400	32,600	5.0	6.3	4.0
Heart disease	109,200	42,500	66,700	7.6	6.8	8.1
Congestive heart failure	49,700	23,500	26,200	3.5	3.8	3.2
Cerebrovascular disease	83,900	29,600	54,400	5.8	4.8	6.6
Chronic obstructive pulmonary disease and allied conditions	65,800	27,600	38,200	4.6	4.4	4.7

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

²The primary diagnosis is the diagnosis most responsible for the discharge's admission to hospice care. All other diagnoses are secondary diagnoses.

³Includes a small number of discharges for which the primary diagnosis is unknown.

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

Table 8. Number and percent distribution of hospice care discharges by primary admission diagnosis: United States, selected years 1992-2000

Diagnostic category and ICD-9-CM code ¹	1992	1994	1996	1998	2000
	Number				
All discharges	219,300	328,000	393,200	496,000	621,100
	Percent distribution				
All discharges	100.0	100.0	100.0	100.0	100.0
Malignant neoplasms	74.7	69.0	69.7	64.8	57.5
Malignant neoplasm of large intestine and rectum	6.3	11.4	8.7	7.9	8.3
Malignant neoplasm of trachea, bronchus, and lung	19.1	13.9	21.9	15.2	19.4
All other diagnoses	25.3	31.0	30.3	35.2	42.5
Dementias	*	*	*2.9	3.0	6.3
Heart disease	8.1	7.9	6.8	8.6	6.8
Congestive heart failure	*3.2	*3.3	3.0	4.4	3.8
Cerebrovascular disease	*	*2.3	*2.2	2.6	4.8
Chronic obstructive pulmonary disease and allied conditions	*2.3	*1.8	3.2	3.5	4.4

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

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

Table 9. Number and percent distribution of hospice care discharges not living in a health facility by length of service, according to caregiver status: United States, 2000

Discharge characteristic	Number of discharges	Length of service in days				
		Percent distribution			Average length of service	Median length of service
		Total	Less than 30 days	30 days or more		
All discharges	404,200	100.0	58.9	41.1	50.7	20.6
Primary caregiver status						
Had primary caregiver	379,700	100.0	57.9	42.1	51.0	21.8
Had no primary caregiver or unknown	24,400	100.0	*74.3	*	*47.0	*7.0
Lived with primary caregiver ¹						
Lived with caregiver	337,900	100.0	58.8	41.2	50.5	20.3
Did not live with caregiver or unknown	41,800	100.0	51.2	48.8	54.5	*28.1
Relationship of primary caregiver to discharge ¹						
Relative	342,600	100.0	57.6	42.4	51.3	20.5
Spouse	186,000	100.0	66.7	33.3	41.7	14.9
Child/child-in-law	114,500	100.0	43.9	56.1	70.2	35.4
Other relative	42,000	100.0	54.3	45.7	42.1	*18.7
Nonrelative	37,100	100.0	61.5	38.5	48.1	23.8

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Includes only discharges with a primary caregiver.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Table 10. Number and percent distribution of hospice care discharges by length of service, according to primary admission diagnosis: United States, 2000

Diagnostic category and ICD–9–CM code ¹	Number of discharges	Length of service in days					
		Percent distribution			Average length of service	Median length of service	
		Total	Less than 30 days	30 days or more			
Total ²	621,100	100.0	62.8	37.2	46.9	15.6	
Malignant neoplasms	140–208,230–234	357,000	100.0	62.2	37.8	43.3	17.2
Malignant neoplasm of large intestine and rectum	153–154,197.5	51,500	100.0	64.0	*36.0	32.9	*16.2
Malignant neoplasm of trachea, bronchus, and lung	162,197.0,197.3	120,500	100.0	59.3	40.7	39.4	*18.6
All other diagnoses	264,200	100.0	63.6	36.4	51.8	*12.2	
Dementias	290,294,331.0	39,400	100.0	70.8	*29.2	44.9	*6.8
Heart disease	391–392.0,393–398,402,404,410–416,420–429	42,500	100.0	55.7	44.3	61.2	20.8
Congestive heart failure	428.0	23,500	100.0	64.4	35.6	57.8	*14.6
Cerebrovascular disease	430–438	29,600	100.0	89.0	*11.0	16.1	3.8
Chronic obstructive pulmonary disease and allied conditions	490–496	27,600	100.0	72.4	*27.6	*68.7	*14.4

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

²Includes unknown diagnosis.

NOTES: Numbers may not add to totals because of rounding. Percents and average and median lengths of service are based on the unrounded figures.

Appendix I

Technical Notes

Data in this report are from the 2000 National Home and Hospice Care Survey (NHHCS), the sixth in a series of surveys that was first conducted by the National Center for Health Statistics (NCHS) in 1992 (13). Other surveys were done in 1993, 1994, 1996, and 1998. The NHHCS, a segment of the long-term care component of the National Health Care Survey (14), collects information about agencies that provide home health and hospice care services, their current patients, and their discharges.

Scope of the Survey

The sampling frame for the NHHCS consists of agencies classified as providing home health or hospice care. These agencies were originally identified through the 1991 National Health Provider Inventory (NHPI). The NHPI is a comprehensive census of nursing and related care homes, residential care homes, home health agencies, and hospices and has been conducted periodically by NCHS (21,22). For the 1992, 1994, and 1996 surveys, the NHPI was updated using the Agency Reporting System. This system consisted primarily of lists or directories of facilities from State agencies, Federal agencies, and national voluntary organizations (22–24).

Starting with the 1998 NHHCS, the universe of home health agencies and hospices was obtained from various national organizations and other sources. The sampling frame for the 2000 NHHCS consisted of 15,451 agencies and was obtained from two sources, the SMG Home Healthcare Market Database and the mailing list of members of the National Hospice and Palliative Care Organization (25,26). The methodology used to create the SMG file was similar to that used for the NHPI (obtaining lists of agencies directly from States). The SMG file may include agencies that provide both home health and hospice care, but does not include agencies that provide only

hospice care. The agencies within these two sources were unduplicated prior to sample selection. The sample consisted of 1,800 agencies selected from this frame.

Only agencies providing home health or hospice care services to patients at the time of the survey are eligible to participate in the NHHCS. Of the 1,800 agencies in the 2000 sample, 1,478 (82 percent) were considered in scope for the survey. Of the 322 out-of-scope agencies, 286 were not providing home health or hospice care services to patients at the time of the survey and 36 were duplicates of, or had merged with, other sampled agencies. Of the in-scope agencies, 1,425 (96 percent) agreed to participate and 53 (4 percent) refused.

Sample Design

The sample design for the 2000 NHHCS was a stratified two-stage probability design (27). The first stage consisted of the selection of a stratified sample of agencies. Each agency was placed into 1 of 24 strata based on type of agency (home health agencies, hospices, and mixed agencies), metropolitan statistical area (MSA) status (has an MSA code versus no code), and region (Northeast, Midwest, South, and West). 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 types of ownership (for profit, nonprofit, government, and unknown), three types of certification status (certified by Medicare and/or Medicaid, not certified, and unknown), State, MSA code, county, ZIP code, and size (number of current patients).

The second 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 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 home health agency or hospice during a designated month between October 1999 and September 2000. Discharges that occurred because of the patient's death were included.

Data Collection and Processing

Data collection for the 2000 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. Three questionnaires and two sampling lists were used to collect the data. The Agency Questionnaire was completed with the administrator or a person designated by the administrator. The interviewer then constructed the Current Patient Sampling List and the Discharged Patient Sampling List. These lists were used to select the sample patients and discharges. Sampling was accomplished by using tables showing sets of sample line numbers for each possible count of current patients and discharges in the agency. Up to six current patients and up to six discharges were selected.

After the samples had been selected, the Current Patient Questionnaires and the Discharged Patient Questionnaires were completed for each sampled person by interviewing the staff member most familiar with the care provided to the patient. The respondent referred to patient medical and other records as necessary. No patient was interviewed directly. After the data had been collected, they were converted into machine-readable form. Extensive editing was then conducted by computer to ensure that all responses were accurate, consistent, logical, and complete. The medical information recorded on the patient questionnaires was coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification* (15). Up to 12 diagnostic codes (a maximum of 6 at admission, and 6 at the time of survey or discharge) and up to 2

procedure codes were assigned for each sample patient or discharge.

Estimation Procedure

Statistics presented in this report were derived by a multistage estimation procedure (28) that produces essentially unbiased national estimates and has the following three principal components: (a) inflation by the reciprocals of the probabilities of sample selection, (b) adjustment for nonresponse, and (c) ratio adjustment to fixed totals.

Inflation by the reciprocals of the probabilities of sample selection—There is a probability for each stage of sampling: (a) the probability of selecting the agency, and (b) the probability of selecting the patient or discharge within each agency. For example, the probability of selecting a discharge within an agency is the number of discharges selected divided by the total number of discharges from the agency within the designated month. The overall probability of selection is the product of the probabilities at each stage. This component is the inverse of the overall selection probability and is the basic inflation weight.

Adjustment for nonresponse—NHHCS data were adjusted for three types of nonresponse. The first type occurred when an in-scope (NHHCS eligible) sample agency did not respond. The second type occurred when an agency did not complete the sampling lists used to select the patient or discharge samples. The third type occurred when the agency did not complete the questionnaire for a sample patient or discharge. The nonresponse adjustment brings estimates based only on the responding cases up to the level that would have been achieved if all eligible cases had responded.

Ratio adjustment to fixed totals—Adjustments were made within each of four groups defined by region to adjust for over- or undersampling of agencies reported in the sampling frame. This adjustment is a multiplicative factor whose numerator was the number of agencies in the sampling frame within each region and whose denominator was the estimated number of agencies for that same group.

Reliability of Estimates

Because the statistics presented here are based on a sample, they will differ somewhat from values that would have been obtained if a complete census had been taken using the same schedules, instructions, and procedures. As in any sample survey, the results are subject to both sampling and nonsampling errors. To the extent possible, the latter types of errors are kept to a minimum by methods built into survey procedures. Because survey results are subject to both sampling and nonsampling errors, the total error is larger than errors from sampling variability alone.

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, SEs typically underestimate the true errors of the statistics because they reflect only errors resulting from sampling.

Standard errors in this report were approximated using SUDAAN software and are shown in [tables I–X](#). SUDAAN computes SEs 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 (17).

Presentation of Estimates

NCHS bases publication of estimates for the NHHCS on the relative standard error (RSE) of the estimate and the number of sample records on which the estimate is based (referred to as the sample size). The RSE is another measure of variability and is calculated by dividing the SE of an estimate by the estimate itself. The result is then converted into a percent by multiplying it by 100. Estimates are not presented in NCHS reports unless a reasonable assumption regarding the probability distribution of the sampling error is

possible. Because of the complex sample design of the NHHCS, the following guidelines are used:

- If the sample size is less than 30, the value of the estimate is not reported. This is indicated with an asterisk (*).
- If the sample size is 30–59 or if the sample is 60 or more and the RSE is 30 percent or more, the estimate is reported, but should not be assumed reliable. This is indicated with an asterisk (*) preceding the figure 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.

Definitions of Selected Terms

Activities of daily living (ADLs)—refers to a set of basic activities that a person must be able to perform to care for him/herself. The five ADLs used in this report are bathing, dressing, getting to and from and using the toilet room, transferring in and out of beds or chairs, and eating.

Age—is the discharge's age at the time of discharge and is calculated as the difference in years between the date of birth and the date of discharge.

Continence status—refers to the ability to control one's bladder or bowels.

Incontinence—refers to discharges who are unable to control their bladder or bowels, and, for this report, had an indwelling urinary catheter or urostomy or a colostomy or ileostomy.

Length of service—is the period of time from the date of the most recent admission to the date of discharge.

Marital status—is the marital status at the time of discharge.

Single—includes discharges who were not married, but it is unknown if the discharge was widowed, divorced, separated, or never married.

Mobility status—is broadly defined to refer to both upper and lower body

facility of movement. Discharges with mobility limitation may also receive help with one or more ADLs and are categorized into one of three levels.

Severe limitation—refers to discharges who received personal help from the agency with at least one of the following: transferring in or out of beds or chairs, walking, or using the toilet room.

Moderate limitation—refers to discharges not included above, but who used at least one of the following aids: cane or crutches; geri-chairs, lift chairs, or other specialized chairs; transfer equipment; walker; or wheelchair (manual or motorized).

Mild limitation—refers to discharges not included in the previous two levels, but who received personal help from the agency with bathing, showering, or dressing. It also includes discharges who used at least one of the following aids: bedside commode, elevated or raised toilet seat, grab bars, or shower chair or bath bench.

Primary caregiver—is an individual who was responsible for providing personal care assistance, companionship, and/or supervision to the discharge.

Primary source of payment—is the one payment source that paid the greatest amount of the discharge's charge.

Race—refers to the discharge's racial background as reported by agency staff. Prior to 1998, only one race was recorded. Since 1998, more than one race may be recorded. In the tables in this report, the categories "White" and "Black or African American" include only those discharges for whom that one race was reported. Discharges for whom more than one race was reported are included in the "all other races" category and are included in the category "Black or African American and all other races" in the tables.

Reason for discharge—is the reason the patient was discharged from hospice care.

Services no longer needed from agency—includes recovered,

stabilized, treatment plan completed, no longer eligible for hospice care, and insurance no longer available.

Transferred to inpatient care—includes transferred to hospital, nursing home, or other inpatient or residential care.

Other—includes family or friends resumed care, transferred to another form of outpatient care, and moved out of area.

Residence—is where the discharge was living during the episode of care before discharge.

Private or semiprivate residence—includes private residence (house or apartment, rented or owned), rented room or boarding house (open to anyone as defined by the landlord for rental payment), and retirement home (a facility that provides room and board to elderly or impaired persons).

Board and care, assisted living, or residential care facility—includes a facility that has three beds or more and that provides personal care or supervision to its residents, not just room and board. Includes group home, foster home, rest home, congregate living, and adult foster care.

Health facility—includes nursing home, hospital, mental health facility, or other facility or institution that provides lodging, board, and social and physical care including the recording of health information, dietary supervision, and supervised hygienic services for three or more patients not related to the operator.

Table I. Standard errors for number and percent distribution of hospice care discharges by length of service, according to selected patient characteristics: United States, 2000

Discharge characteristic	Length of service in days					
	Discharges		Percent distribution			
	Number	Percent distribution	Less than 30 days	30 days or more	Average length of service	Median length of service
Total	45,700	—	2.6	2.6	4.3	2.3
Sex						
Male	28,700	2.5	3.4	3.4	4.7	3.0
Female	25,800	2.5	3.6	3.6	6.3	3.9
Age at discharge						
Under 65 years	16,500	2.1	6.0	6.0	12.1	4.3
65 years and over	37,000	2.1	2.8	2.8	4.4	3.0
65–74 years	15,500	2.1	4.6	4.6	6.3	4.5
75–84 years	17,700	2.3	4.9	4.9	7.2	4.2
85 years and over	19,400	2.4	5.6	5.6	6.6	*6.1
Race ¹						
White	39,700	2.0	2.8	2.8	4.2	2.6
Black or African American and other races	11,300	1.7	7.8	7.8	*22.3	3.7
Black or African American	9,900	1.5	9.3	9.3	*28.0	*5.8
Unknown	7,200	1.2	10.2	*10.2	5.8	*9.4
Marital status at discharge						
Married	26,900	2.8	3.3	3.3	4.4	2.7
Not married	26,700	2.7	4.3	4.3	7.6	4.3
Widowed	21,800	2.5	5.1	5.1	7.8	*6.0
Divorced or separated	7,200	1.2	10.5	10.5	*37.9	*11.9
Single or never married	7,900	1.3	8.6	8.6	6.6	*5.9
Unknown	9,200	1.5	*9.2	*9.2	9.2	*14.9
Primary source of payment						
Medicare	37,100	2.3	2.9	2.9	4.4	3.0
All other sources	17,100	2.3	5.8	5.8	11.9	*3.9
Medicaid	7,200	1.1	8.1	*8.1	4.7	*4.3
Private ²	13,200	1.9	8.2	8.2	*18.7	*6.5
Other ³	4,500	0.8	7.9	*7.9	10.9	*4.6
Reason for discharge						
Died	41,900	2.1	2.5	2.5	4.5	1.9
Did not die	13,500	2.1	8.1	8.1	10.3	*17.9
Services no longer needed from agency ⁴	11,000	1.8	*12.5	12.5	16.3	16.9
Transferred to inpatient care ⁵	3,800	0.6	*	*12.6	20.1	20.2
Other and unknown	6,500	1.1	*11.7	*11.7	12.5	*9.5

— Quantity zero.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Prior to 1998 only one race was recorded. Since 1998, more than one race may be recorded. The categories "White" and "Black or African American" include only those discharges for whom that one race was reported. Discharges for whom more than one race was reported are included in "Black or African American and other races."²Includes private insurance, own income, family support, Social Security benefits, retirement funds, and welfare.³Includes unknown source and no charge for care.⁴Includes recovered, stabilized, treatment plan completed, no longer eligible for hospice care, or insurance coverage no longer available.⁵Includes transferred to hospital, nursing home, or other inpatient or residential care.

NOTE: The standard error of 100.0 percent is zero.

Table II. Standard errors for number and percent distribution of hospice care discharges by length of service, according to residence and living arrangements: United States, 2000

Discharge characteristic	Length of service in days					
	Discharges		Percent distribution			
	Number	Percent distribution	Less than 30 days	30 days or more	Average length of service	Median length of service
Total	45,700	—	2.6	2.6	4.3	2.3
Residence during care						
Private or semiprivate residence ¹	27,200	3.9	3.2	3.2	5.7	2.6
Board and care, assisted living, or residential care facility	5,500	0.9	*13.2	*13.2	15.8	*21.8
Health facility (including mental health facility)	34,100	4.1	4.4	4.4	6.0	1.6
Unknown	*	*	*	*	*	*
Living arrangements of discharges not in a health facility ²						
Total	28,500	—	3.0	3.0	5.5	2.6
Lived alone	7,300	1.8	*10.9	10.9	13.6	*14.1
Lived with someone	26,600	2.0	3.2	3.2	6.1	2.6
Lived with family members	25,600	2.5	3.4	3.4	6.5	3.1
Lived only with nonfamily members	6,000	1.5	10.1	*10.1	9.1	*9.1

— Quantity zero.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Includes private residence, rented room, boarding house, and retirement home.²Excludes those for whom living arrangements are unknown.

NOTE: The standard error of 100.0 percent is zero.

Table III. Standard errors for number and percent distribution of hospice care discharges by type of residence, according to caregiver status: United States, 2000

Discharge characteristic	Type of residence			Type of residence		
	Total	Health facility	All other and unknown type	Total	Health facility	All other and unknown type
All discharges	45,700	34,100	28,500	—	—	—
Primary caregiver status						
Primary caregiver	44,100	33,200	27,600	1.8	4.1	1.7
No primary caregiver or unknown	10,800	8,100	6,700	1.8	*4.1	1.7
Discharges with primary caregiver	44,100	33,200	27,600	—	—	—
Lived with primary caregiver						
Yes	31,600	18,100	26,200	3.5	7.4	2.0
No or unknown	24,600	23,700	7,300	3.5	7.4	2.0
Relationship of primary caregiver to discharge						
Relative	41,100	29,400	26,700	2.6	7.3	1.9
Spouse	24,000	14,600	18,100	2.7	4.6	3.3
Child/child-in-law	20,100	14,800	13,600	2.4	4.6	3.0
Other relative	9,600	*3,900	8,800	1.6	*1.9	2.3
Nonrelative	14,200	12,400	6,900	2.6	7.3	1.9
Hired by discharge/staff of residential facility	12,600	11,900	*4,300	2.3	7.7	*1.2
Other nonrelative or unknown	6,600	*	5,500	1.2	*	1.6

— Quantity zero.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

Table IV. Standard errors for number and percent of hospice care discharges and percent distribution by length of service, according to services received during the 30 days prior to discharge: United States, 2000

Service received ¹	Discharges		Length of service in days			
	Number	Percent	Percent distribution		Average length of service	Median length of service
			Less than 30 days	30 days or more		
All discharges	45,700	...	2.6	2.6	4.3	2.3
Medical and skilled nursing						
Skilled nursing	43,500	1.5	2.8	2.8	4.6	2.7
Physician	30,700	4.0	5.3	5.3	5.3	4.0
Equipment and medication						
Medications	36,400	3.5	3.2	3.2	6.3	2.8
Durable medical equipment and supplies	26,000	3.0	3.3	3.3	4.2	3.3
Personal care						
Homemaker-household or personal care ²	35,300	3.1	3.3	3.3	4.8	2.8
Companion or volunteer ²	22,100	2.9	4.9	4.9	7.9	7.7
Continuous home care	4,800	0.9	9.6	9.6	9.4	12.2
Psychosocial						
Referral or social ²	40,900	2.9	3.3	3.3	4.3	3.1
Pastoral or spiritual care ²	38,300	3.5	3.7	3.7	4.6	3.5
Counseling or psychological ²	19,400	3.3	4.0	4.0	5.3	4.0
Respite care	9,900	1.7	*9.8	9.8	17.6	*11.2
Other						
High-tech care ^{2,3}	19,000	2.6	6.8	6.8	14.5	*7.3
Other ^{2,4}	25,000	3.1	6.0	6.0	7.2	*10.1
Number of services received						
0-2 ⁵	14,400	2.2	5.8	5.8	6.1	*1.6
3-5	24,600	3.2	4.4	4.4	8.9	4.2
6-8	18,500	2.5	4.4	4.4	5.6	2.9
9 or more	19,200	2.7	7.3	7.3	6.6	*8.7

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.

²A discharge is counted only once even though it may have received more than one type of service in this category.

³Includes enterostomal therapy, IV therapy, respiratory therapy, and other high-tech care such as enteral nutrition or dialysis.

⁴Includes dental treatment services, dietary and/or nutritional services, Meals on Wheels, occupational therapy, physical therapy, speech therapy and/or audiology, transportation, vocational therapy, and other services.

⁵Includes a small number of discharges for whom no services were reported.

NOTE: The standard error of 100.0 percent is zero.

Table V. Standard errors for number and percent of hospice care discharges and percent distribution by length of service, according to service providers seen during the 30 days prior to discharge: United States, 2000

Provider seen	Discharges		Length of service in days			
			Percent distribution		Average length of service	Median length of service
	Number	Percent	Less than 30 days	30 days or more		
All discharges	45,700	...	2.6	2.6	4.3	2.3
Type of provider ¹						
Nurses ^{2,3}	45,700	0.9	2.6	2.6	4.4	2.6
Social workers/mental health specialists ²	40,900	2.8	2.9	2.9	3.6	2.8
Home health aides/nursing aides/attendants ²	38,900	3.0	3.4	3.4	4.7	3.1
Chaplains	37,000	3.6	3.8	3.8	4.5	3.6
Volunteers	23,000	3.0	5.3	5.3	8.2	7.9
Physicians	32,600	4.5	5.4	5.4	5.5	*3.5
Homemakers/personal caretakers	6,800	1.2	5.8	5.8	17.0	*6.0
Other ^{2,4}	22,300	3.0	7.6	7.6	6.5	*7.0
Number of providers seen						
0-1 ⁵	11,900	2.0	7.2	*7.2	*22.5	*4.0
2	12,900	2.1	6.8	6.8	6.4	*3.6
3	16,300	2.5	6.0	6.0	11.3	5.3
4	13,100	2.1	5.8	5.8	6.9	7.1
5 or more	33,100	4.0	5.0	5.0	5.8	4.4

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.

²A discharge is counted only once even though it may have been seen by more than one type of provider in this category.

³ Includes registered, licensed practical, and vocational nurses.

⁴Includes dietitians or nutritionists, occupational therapists, physical therapists, respiratory therapists, speech pathologists or audiologists, and other providers.

⁵Includes a small number of discharges for whom no providers were reported.

NOTE: The standard error of 100.0 percent is zero.

Table VI. Standard errors for number and percent of hospice care discharges and percent distribution by length of service, according to selected types of functional status: United States, 2000

Functional status	Length of service in days					
	Discharges		Percent distribution			
	Number	Percent	Less than 30 days	30 days or more	Average length of service	Median length of service
All discharges	45,700	...	2.6	2.6	4.3	2.3
Received help from agency with ADLs ^{1,2}						
Bathing or showering	35,700	2.6	3.3	3.3	4.5	3.1
Dressing	32,500	3.0	3.4	3.4	5.2	3.0
Eating	26,600	3.5	5.2	5.2	7.8	4.2
Transferring in or out of beds or chairs	27,800	2.8	3.4	3.4	5.9	3.6
Using the toilet room	23,300	2.9	4.3	4.3	7.3	4.5
Functional status in ADLs ²						
Received no help from agency with ADLs ³	20,100	2.7	4.4	4.4	9.6	*2.2
Received help from agency with 1 or more ADLs	36,500	2.7	3.2	3.2	4.4	3.0
Received help with:						
1 ADL	6,900	1.2	11.4	11.4	6.8	*12.3
2 ADLs	15,900	2.5	8.9	8.9	7.0	*6.8
3 ADLs	13,800	1.8	6.8	6.8	6.8	*7.7
4 ADLs	13,400	2.0	5.4	5.4	9.0	3.8
5 ADLs	18,300	2.7	5.8	5.8	10.8	*7.3
Continence status						
Continent	21,600	2.7	4.1	4.1	6.2	4.8
Incontinent ⁴	34,400	2.7	2.9	2.9	5.0	2.5
Only bladder incontinence or device ⁵	18,700	2.8	6.2	6.2	8.5	*6.1
Only bowel incontinence or device ⁶	9,600	1.5	*10.3	*10.3	5.9	7.3
Both bladder and bowel incontinence or device ^{5,6}	24,700	3.1	3.6	3.6	6.8	2.8
Mobility status						
No mobility limitation ³	17,900	2.6	5.5	5.5	*14.1	*1.7
Mobility limitation	39,100	2.6	3.0	3.0	4.2	3.2
Limitation level:						
Mild	17,700	2.5	7.7	7.7	6.2	*2.3
Moderate	9,800	1.8	6.0	6.0	7.5	5.4
Severe	28,300	2.8	3.3	3.3	5.6	3.4
Use of selected aids or devices						
No aids or devices	12,900	2.1	5.8	5.8	7.8	5.8
Aids or devices ¹	42,200	2.1	2.8	2.8	4.7	2.3
Hospital bed	39,200	2.6	3.2	3.2	5.1	2.4
Oxygen	29,100	2.9	3.2	3.2	3.9	3.0
IV therapy equipment	11,500	1.7	12.3	*12.3	*31.6	*14.7
Enteral feeding equipment	4,500	0.8	*6.2	*6.2	10.7	*22.9

... Category not applicable.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹A discharge may be included in more than one category.²ADL is activity of daily living.³Includes an unknown number of discharges who were bedbound or received help only from nonagency persons.⁴Includes an indwelling urinary catheter or urostomy, a colostomy or ileostomy, or difficulty controlling the bladder or bowels.⁵Bladder incontinence or device includes an indwelling urinary catheter or urostomy or difficulty controlling the bladder.⁶Bowel incontinence or device includes a colostomy or ileostomy or difficulty controlling the bowels.

NOTE: The standard error of 100.0 percent is zero.

Table VII. Standard errors for number and percent distribution of diagnoses for hospice care discharges by primary or secondary diagnosis, according to diagnostic category: United States, 2000

Diagnostic category and ICD-9CM code ¹	All diagnoses	Type of diagnosis ²		All diagnoses	Type of diagnosis ²	
		Primary	Secondary		Primary	Secondary
		Number			Percent distribution	
All diagnoses ³	145,100	45,700	104,900	—	—	—
Malignant neoplasms 140-208,230-234	58,500	29,600	33,400	2.6	2.5	2.9
Malignant neoplasm of large intestine and rectum 153-154,197.5	14,300	11,200	*	0.9	1.7	*
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	19,200	13,700	11,000	0.9	1.8	*1.2
All other diagnoses	104,400	25,000	84,200	2.6	2.5	2.9
Diabetes mellitus 250	11,800	*	11,800	0.7	*	1.2
Dementias 290,294,331.0	13,500	9,100	9,600	0.8	1.5	1.1
Heart disease 391-392.0,393-398,402,404,410-416,420-429	14,900	6,200	13,200	0.9	1.1	1.5
Congestive heart failure 428.0	8,200	4,200	6,800	0.5	0.7	0.8
Cerebrovascular disease 430-438	21,500	8,500	18,900	1.2	1.4	1.9
Chronic obstructive pulmonary disease and allied conditions 490-496	12,400	6,500	10,400	0.7	1.0	1.1

— Quantity zero.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

²The primary diagnosis is the diagnosis most responsible for the discharge's admission to hospice care. All other diagnoses are secondary diagnoses.

³Includes a small number of discharges for which the primary diagnosis is unknown.

Table VIII. Standard errors for number and percent distribution of hospice care discharges by primary admission diagnosis: United States, selected years 1992-2000

Diagnostic category and ICD-9-CM code ¹	1992	1994	1996	1998	2000
	Number				
All discharges	15,100	22,300	31,700	43,400	45,700
	Percent distribution				
All discharges	—	—	—	—	—
Malignant neoplasms 140-208,230-234	2.1	2.4	2.4	2.5	2.5
Malignant neoplasm of large intestine and rectum 153-154,197.5	0.9	2.3	1.7	1.5	1.7
Malignant neoplasm of trachea, bronchus, and lung 162,197.0,197.3	2.3	1.4	2.1	1.5	1.8
All other diagnoses	2.1	2.4	2.4	2.5	2.5
Dementias 290,294,331.0	*	*	*1.2	0.6	1.5
Heart disease 391-392.0,393-398,402,404,410-416,420-429	1.6	1.8	1.3	1.6	1.1
Congestive heart failure 428.0	*0.9	*0.9	0.8	1.3	0.7
Cerebrovascular disease 430-438	*	*0.8	*0.6	0.6	1.4
Chronic obstructive pulmonary disease and allied conditions 490-496	*0.7	*0.4	0.9	0.9	1.0

— Quantity zero.

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30-59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

Table IX. Standard errors for number and percent distribution of hospice care discharges not living in a health facility by length of service, according to caregiver status: United States, 2000

Discharge characteristic	Number of discharges	Length of service in days			
		Percent distribution		Average length of service	Median length of service
		Less than 30 days	30 days or more		
All discharges	28,500	3.0	3.0	5.5	2.6
Primary caregiver status					
Had primary caregiver	27,600	3.1	3.1	5.7	2.7
Had no primary caregiver or unknown	6,700	*8.8	*	*16.9	*5.9
Lived with primary caregiver ¹					
Lived with caregiver	26,200	3.4	3.4	6.4	2.9
Did not live with caregiver or unknown	7,300	9.5	9.5	8.6	*11.3
Relationship of primary caregiver to discharge ¹					
Relative	26,700	3.3	3.3	6.2	3.3
Spouse	18,100	4.2	4.2	5.6	2.9
Child/child-in-law	13,600	5.9	5.9	15.0	6.4
Other relative	8,800	9.6	9.6	8.1	*13.8
Nonrelative	6,900	9.6	9.6	8.8	5.5

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹ Includes only discharges with a primary caregiver.

NOTE: The standard error of 100.0 percent is zero.

Table X. Standard errors for number and percent distribution of hospice care discharges by length of service, according to primary admission diagnosis: United States, 2000

Diagnostic category and ICD–9–CM ¹	Number of discharges	Length of service in days				
		Percent distribution		Average length of service	Median length of service	
		Less than 30 days	30 days or more			
Total ²	45,700	2.6	2.6	4.3	2.3	
Malignant neoplasms	140–208,230–234	29,600	3.2	3.2	4.1	2.5
Malignant neoplasm of large intestine and rectum	153–154,197.5	11,200	10.9	*10.9	6.3	*9.4
Malignant neoplasm of trachea, bronchus, and lung	162,197.0,197.3	13,700	5.9	5.9	4.7	*6.6
All other diagnoses	25,000	4.3	4.3	7.5	*4.5	
Dementias	290,294,331.0	9,100	8.8	*8.8	12.9	*5.9
Heart disease	391–392.0,393–398,402,404,410–416,420–429	6,200	7.7	7.7	10.7	5.9
Congestive heart failure	428.0	4,200	7.9	7.9	13.6	*6.8
Cerebrovascular disease	430–438	8,500	4.4	*4.4	4.7	1.0
Chronic obstructive pulmonary disease and allied conditions	490–496	6,500	9.1	*9.1	*22.4	*7.2

* Data do not meet standard of reliability or precision (sample size is less than 30) and are, therefore, not reported. If shown with a number, data should not be assumed reliable because the sample size is 30–59 or is greater than 59, but has a relative standard error of 30 percent or more.

¹Based on the *International Classification of Diseases, 9th Revision, Clinical Modification* (15).

²Includes unknown diagnosis.

NOTE: The standard error of 100.0 percent is zero.

Appendix II

Discharged Patient Questionnaire

OMB No. 0920-0298; Approval Expires 03/31/2001

<p>FORM HHCS-5 (3-27-2000)</p> <p>U.S. DEPARTMENT OF COMMERCE Economics and Statistics Administration U.S. CENSUS BUREAU</p> <p>ACTING AS COLLECTING AGENT FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES U.S. PUBLIC HEALTH SERVICE CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS</p> <p style="text-align: center;">DISCHARGED PATIENT QUESTIONNAIRE</p> <p style="text-align: center;">2000 NATIONAL HOME AND HOSPICE CARE SURVEY</p>	<p>NOTICE – Public reporting burden for this collection of information is estimated to average 10 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; Paperwork Reduction Project (0920-0298) 1600 Clifton Road, MSD-24, Atlanta, GA 30333. Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).</p>
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Section A – ADMINISTRATIVE INFORMATION

1. Field representative name	2. FR code	3. Date of interview						
		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <th style="width: 33%;">Month</th> <th style="width: 33%;">Day</th> <th style="width: 33%;">Year</th> </tr> <tr> <td> </td> <td> </td> <td> </td> </tr> </table>	Month	Day	Year			
Month	Day	Year						

Section B – PATIENT INFORMATION

1. Discharged patient line number →		2. Date of Discharge						
		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <th style="width: 33%;">Month</th> <th style="width: 33%;">Day</th> <th style="width: 33%;">Year</th> </tr> <tr> <td> </td> <td> </td> <td> </td> </tr> </table>	Month	Day	Year			
Month	Day	Year						

Section C – STATUS OF INTERVIEW

01 Complete
 02 Partial
 03 Patient included in sampling list in error – **Explain in NOTES section.**
 04 Incorrect sample line number selected
 05 Refused
 06 Assessment only
 07 Unable to locate record – **Explain in NOTES section.**
 08 Less than 6 discharges selected
 09 Other noninterview – **Explain in NOTES section.**
 10 No discharges

NOTES

01 Mark (X) this box if comments are written in this section or any other place on this questionnaire.

Read to each new respondent.

In order to obtain national level data about patients who are discharged from hospices and home health agencies such as this one, we are collecting information about a sample of discharges. I will be asking questions about the background, health status, treatment, social contacts, and billing information for each sampled discharge.

The information you provide will be held in strict confidence and will be used ONLY by persons involved in the survey and only for the purposes of the survey.

In answering these questions, it is especially important to locate the information in the patient's medical record. Do you have the medical file(s) and record(s) for the selected discharged patient(s)?

If not, ask the respondent to get it/them prior to beginning the interview. Fill sections A and B on the front of all the discharged patient forms while the respondent gets the records. If no record is available for a patient, try to obtain as much information as possible from whatever administrative records are available and/or from the respondent's memory.

<p>1. What was this patient's sex?</p>	<p>01 <input type="checkbox"/> Male 02 <input type="checkbox"/> Female</p>														
<p>2. What was her/his date of birth?</p>	<p style="text-align: right;">Age (at discharge)</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="width: 20px;">Month</td> <td style="width: 20px;">Day</td> <td style="width: 40px;">Year</td> <td style="width: 20px;">OR</td> <td style="width: 40px;">Years</td> <td style="width: 20px;">OR</td> <td style="width: 40px;">Months</td> </tr> <tr> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td style="height: 20px;"></td> <td></td> <td style="height: 20px;"></td> <td></td> <td style="height: 20px;"></td> </tr> </table>	Month	Day	Year	OR	Years	OR	Months							
Month	Day	Year	OR	Years	OR	Months									
<p>3a. Was she/he of Hispanic or Latino origin?</p>	<p>01 <input type="checkbox"/> Yes 02 <input type="checkbox"/> No 03 <input type="checkbox"/> Don't know</p>														
<p><i>HAND FLASHCARD 1.</i></p> <p>b. Which of these best described her/his race?</p> <p><i>Mark (X) all that apply.</i></p> <p>PROBE: Any others?</p>	<p>01 <input type="checkbox"/> American Indian or Alaska Native 02 <input type="checkbox"/> Asian 03 <input type="checkbox"/> Black or African American 04 <input type="checkbox"/> Native Hawaiian or other Pacific Islander 05 <input type="checkbox"/> White 06 <input type="checkbox"/> Other - <i>Specify</i> <input checked="" type="checkbox"/></p> <hr style="width: 100%;"/> <p style="text-align: center;">NOTE - Hispanic is NOT a race.</p> <p>07 <input type="checkbox"/> Don't know</p>														
<p>4. What was her/his marital status at the time of discharge?</p> <p><i>Mark (X) only one box.</i></p>	<p>01 <input type="checkbox"/> Married 02 <input type="checkbox"/> Widowed 03 <input type="checkbox"/> Divorced 04 <input type="checkbox"/> Separated 05 <input type="checkbox"/> Never married 06 <input type="checkbox"/> Single 07 <input type="checkbox"/> Don't know</p>														
<p><i>HAND FLASHCARD 2.</i></p> <p>5a. During the episode of care that ended on (date of discharge), where was she/he living?</p> <p><i>Mark (X) only one box.</i></p>	<p>01 <input type="checkbox"/> Private residence (house or apartment) 02 <input type="checkbox"/> Rented room, boarding house 03 <input type="checkbox"/> Retirement home or apartment, including elderly housing 04 <input type="checkbox"/> Board and care, assisted living, or residential care facility 05 <input type="checkbox"/> Nursing home, hospital, or other inpatient health facility (including mental health facility) - <i>SKIP to item 6 Introduction</i> 06 <input type="checkbox"/> Other - <i>Specify</i> <input checked="" type="checkbox"/></p> <hr style="width: 100%;"/>														
<p>b. Was she/he living with family members, nonfamily members, both family and nonfamily members, or alone?</p>	<p>01 <input type="checkbox"/> With family members 02 <input type="checkbox"/> With nonfamily members 03 <input type="checkbox"/> With both family members and nonfamily members 04 <input type="checkbox"/> Alone 05 <input type="checkbox"/> Don't know</p>														

<p><i>HAND FLASHCARD 3.</i></p> <p>6. Who referred her/him to this agency?</p> <p><i>Mark (X) all that apply.</i></p> <p>PROBE: Any other sources?</p>	<p>01 <input type="checkbox"/> Self/Family</p> <p>02 <input type="checkbox"/> Nursing home</p> <p>03 <input type="checkbox"/> Hospital</p> <p>04 <input type="checkbox"/> Physician</p> <p>05 <input type="checkbox"/> Health department</p> <p>06 <input type="checkbox"/> Social service agency</p> <p>07 <input type="checkbox"/> Home health agency</p> <p>08 <input type="checkbox"/> Hospice</p> <p>09 <input type="checkbox"/> Religious organization</p> <p>10 <input type="checkbox"/> Health maintenance organization</p> <p>11 <input type="checkbox"/> Friend/Neighbor</p> <p>12 <input type="checkbox"/> Other – <i>Specify</i> _____</p> <p>_____</p> <p>13 <input type="checkbox"/> Don't know</p>						
<p>7. What was the date of her/his admission for the period of care which ended on (Date of discharge)?</p>	<table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <thead> <tr> <th style="width: 25%;">Month</th> <th style="width: 25%;">Day</th> <th style="width: 50%;">Year</th> </tr> </thead> <tbody> <tr> <td style="height: 20px;"> </td> <td style="height: 20px;"> </td> <td style="height: 20px;"> </td> </tr> </tbody> </table> <p style="text-align: right;">00 <input type="checkbox"/> Only an assessment was done for this patient (patient was not provided services by this agency)</p>	Month	Day	Year			
Month	Day	Year					
<p>8a. According to the medical record, what were the primary and other diagnoses at the time of her/his admission that ended with this (discharge/assessment)?</p> <p>PROBE: Any other diagnoses?</p>	<p>01 <input type="checkbox"/> No diagnosis</p> <p>02 <input type="checkbox"/> Admission diagnoses unknown</p> <p>Primary: 1 _____</p> <p>Others: 2 _____</p> <p>3 _____</p> <p>4 _____</p> <p>5 _____</p> <p>6 _____</p>						
<p><i>Refer to Q7. If ONLY an assessment was done for this patient, END THE INTERVIEW AND MARK STATUS CODE "06" IN SECTION C ON THE COVER. THEN GO TO the next discharged patient questionnaire.</i></p> <p><i>If the patient was admitted to the agency and provided services by the agency, CONTINUE this interview.</i></p> <p>b. According to the medical records, what were her/his primary and other diagnoses at the time of discharge – that is, on (Date of discharge)?</p> <p>PROBE: Any other diagnoses?</p>	<p>01 <input type="checkbox"/> No diagnosis</p> <p>02 <input type="checkbox"/> Same as 8a</p> <p>03 <input type="checkbox"/> Discharge diagnoses unknown</p> <p>Primary: 1 _____</p> <p>Others: 2 _____</p> <p>3 _____</p> <p>4 _____</p> <p>5 _____</p> <p>6 _____</p>						
<p>c. According to the medical record, did she/he have any diagnostic or surgical procedures that were related to her/his admission to this agency?</p>	<p>01 <input type="checkbox"/> Yes</p> <p>1 _____</p> <p>2 _____</p> <p>02 <input type="checkbox"/> No procedures</p>						

<p>HAND FLASHCARD 4.</p> <p>8d. Why was she/he discharged?</p> <p>Mark (X) only one box.</p>	<p>01 <input type="checkbox"/> Recovered</p> <p>02 <input type="checkbox"/> Stabilized</p> <p>03 <input type="checkbox"/> Family/friends resumed care</p> <p>04 <input type="checkbox"/> Services no longer needed, treatment plan completed</p> <p>05 <input type="checkbox"/> No longer eligible for service/no longer home bound</p> <p>Transferred to inpatient care</p> <p>06 <input type="checkbox"/> Hospital</p> <p>07 <input type="checkbox"/> Nursing home</p> <p>08 <input type="checkbox"/> Other inpatient or residential care – <i>Specify</i> ↘</p> <p>_____</p> <p>09 <input type="checkbox"/> Transferred to another form of outpatient or home care – <i>Specify</i> ↘</p> <p>_____</p> <p>10 <input type="checkbox"/> Moved out of area</p> <p>11 <input type="checkbox"/> Deceased</p> <p>12 <input type="checkbox"/> Other – <i>Specify</i> ↘</p> <p>_____</p> <p>13 <input type="checkbox"/> Don't know</p>
<p>9. What type of care was she/he receiving at the time of discharge? Was it home health care, home care, or hospice care?</p>	<p>01 <input type="checkbox"/> Home health care or home care</p> <p>02 <input type="checkbox"/> Hospice care</p> <p>02a <input type="checkbox"/> In the home or usual place of residence</p> <p>02b <input type="checkbox"/> Inpatient</p>
<p>10a. Did she/he have a primary caregiver outside of this agency?</p>	<p>01 <input type="checkbox"/> Yes</p> <p>02 <input type="checkbox"/> No } <i>SKIP to item 11</i></p> <p>03 <input type="checkbox"/> Don't know</p>
<p>b. Did she/he usually live with (her/his) primary caregiver?</p>	<p>01 <input type="checkbox"/> Yes</p> <p>02 <input type="checkbox"/> No</p> <p>03 <input type="checkbox"/> Don't know</p>
<p>HAND FLASHCARD 5.</p> <p>c. What was the relationship of the primary caregiver to the patient?</p> <p>Mark (X) only one box.</p>	<p>01 <input type="checkbox"/> Spouse</p> <p>02 <input type="checkbox"/> Parent</p> <p>03 <input type="checkbox"/> Child, including daughter- or son-in-law</p> <p>04 <input type="checkbox"/> Sister or brother, including sister- or brother-in-law</p> <p>05 <input type="checkbox"/> Other relative – <i>Specify</i> ↘</p> <p>_____</p> <p>06 <input type="checkbox"/> Friend or neighbor</p> <p>07 <input type="checkbox"/> Paid help or staff of facility where patient resides</p> <p>08 <input type="checkbox"/> Other – <i>Specify</i> ↘</p> <p>_____</p> <p>09 <input type="checkbox"/> Don't know</p>

HAND FLASHCARD 6.

11. During the 30 days prior to (discharge/death), which of these aids or special devices did she/he regularly use?

Mark (X) all that apply.

PROBE: Any other aids?

- 00 No aids used
- 01 Bedside commode
- 02 Blood glucose monitor
- 03 Cane, crutches
- 04 Dentures (full or partial)
- 05 Elevated/raised toilet seat
- 06 Enteral feeding equipment
- 07 Eyeglasses (including contact lenses)
- 08 Geri-chairs, lift chairs, other specialized chairs
- 09 Grab bars
- 10 Hearing aid
- 11 Hospital bed
- 12 IV therapy equipment
- 13 Mattress, special (eggcrate, foam, air, gel, etc.)
- 14 Orthotics, including braces
- 15 Overbed table
- Respiratory therapy equipment
- 16 Oxygen (including oxygen concentrator)
- 17 Other respiratory therapy equipment
- 18 Shower chair/Bath bench
- 19 Transfer equipment
- 20 Walker
- 21 Wheel chair – Manually operated
- 22 Wheel chair – Motorized (including scooter)
- 23 Other – Specify

INSTRUCTION BOX For items 12 through 17, use the phrase "AT THE TIME OF DISCHARGE ON (date of discharge)" if the patient was discharged alive. Use the phrase "IMMEDIATELY PRIOR TO DEATH" if the patient was discharged dead.

For items 12a–13b, refer to item 11.

12a. (At the time of discharge on (date of discharge)/ Immediately prior to death), did she/he have any difficulty in seeing (when wearing glasses)?

- 01 Yes
- 02 No.
- 03 Not applicable (e.g., comatose) } **SKIP to item 13a**
- 04 Don't know

HAND FLASHCARD 7.

b. Was her/his sight (when wearing glasses) partially, severely, or completely impaired as defined on this card?

- 01 Partially impaired
- 02 Severely impaired
- 03 Completely lost, blind
- 04 Don't know

13a. (At the time of discharge on (date of discharge)/ Immediately prior to death), did she/he have any difficulty in hearing (when wearing a hearing aid)?

- 01 Yes
- 02 No.
- 03 Not applicable (e.g., comatose) } **SKIP to item 14a**
- 04 Don't know

HAND FLASHCARD 8.

b. Was her/his hearing (when wearing a hearing aid) partially, severely, or completely impaired, as defined on this card?

- 01 Partially impaired
- 02 Severely impaired
- 03 Completely lost, deaf
- 04 Don't know

14a. (At the time of discharge on (date of discharge)/ Immediately prior to death), did she/he have an indwelling urinary catheter or urostomy?

- 01 Yes
- 02 No.
- 03 Don't know } **SKIP to item 15**

b. Did she/he receive assistance from your agency staff in caring for this device?

- 01 Yes
- 02 No.
- 03 Don't know } **SKIP to item 16a**

15. (At the time of discharge on (date of discharge) immediately prior to death), did she/he have any difficulty in controlling (his/her) bladder?	01 <input type="checkbox"/> Yes 02 <input type="checkbox"/> No 03 <input type="checkbox"/> Infant 04 <input type="checkbox"/> Don't know																																			
16a. (At the time of discharge on (date of discharge) immediately prior to death), did she/he have a colostomy or ileostomy?	01 <input type="checkbox"/> Yes 02 <input type="checkbox"/> No 03 <input type="checkbox"/> Don't know } SKIP to item 17																																			
b. Did she/he receive assistance from your agency staff in caring for this device?	01 <input type="checkbox"/> Yes 02 <input type="checkbox"/> No 03 <input type="checkbox"/> Don't know } SKIP to item 18																																			
17. (At the time of discharge on (date of discharge) immediately prior to death), did she/he have any difficulty in controlling (his/her) bowels?	01 <input type="checkbox"/> Yes 02 <input type="checkbox"/> No 03 <input type="checkbox"/> Infant 04 <input type="checkbox"/> Don't know																																			
HAND FLASHCARD 9. 18. During the 30 days prior to (discharge/death), did she/he receive personal help from this agency in any of the following activities as defined on this card - Mark (X) one box for each activity.	<table border="1" style="width:100%; border-collapse: collapse; text-align: center;"> <thead> <tr> <th style="width:45%;"></th> <th style="width:15%;">Yes</th> <th style="width:15%;">No</th> <th style="width:15%;">Don't know</th> <th style="width:15%;">Not applicable (e.g., patient was bedfast)</th> </tr> </thead> <tbody> <tr> <td>a. Bathing or showering?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>b. Dressing?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>c. Eating?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>d. Transferring in or out of beds or chairs?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>e. Walking?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>f. Using the toilet room?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> </tbody> </table>		Yes	No	Don't know	Not applicable (e.g., patient was bedfast)	a. Bathing or showering?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	b. Dressing?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	c. Eating?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	d. Transferring in or out of beds or chairs?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	e. Walking?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	f. Using the toilet room?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>
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HAND FLASHCARD 10. 19. During the 30 days prior to (discharge/death), did she/he receive personal help from your agency in any of the following activities as defined on this card - Mark (X) one box for each activity.	<table border="1" style="width:100%; border-collapse: collapse; text-align: center;"> <thead> <tr> <th style="width:45%;"></th> <th style="width:15%;">Yes</th> <th style="width:15%;">No</th> <th style="width:15%;">Don't know</th> <th style="width:15%;">Not applicable (e.g., patient was bedfast)</th> </tr> </thead> <tbody> <tr> <td>a. Doing light housework?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>b. Managing money?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>c. Shopping for groceries or clothes?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>d. Using the telephone (dialing or receiving calls)?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>e. Preparing meals?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> <tr> <td>f. Taking medications?</td> <td>01 <input type="checkbox"/></td> <td>02 <input type="checkbox"/></td> <td>03 <input type="checkbox"/></td> <td>04 <input type="checkbox"/></td> </tr> </tbody> </table>		Yes	No	Don't know	Not applicable (e.g., patient was bedfast)	a. Doing light housework?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	b. Managing money?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	c. Shopping for groceries or clothes?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	d. Using the telephone (dialing or receiving calls)?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	e. Preparing meals?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>	f. Taking medications?	01 <input type="checkbox"/>	02 <input type="checkbox"/>	03 <input type="checkbox"/>	04 <input type="checkbox"/>
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NOTES																																				

HAND FLASHCARD 11.

20a. During the 30 days prior to (discharge/death), which of these services were provided to her/him BY YOUR AGENCY?

Mark (X) all that apply.

PROBE: Any other services?

- | | |
|--|--|
| 00 <input type="checkbox"/> None | 16 <input type="checkbox"/> Physician services |
| 01 <input type="checkbox"/> Companion services | 17 <input type="checkbox"/> Psychological services |
| 02 <input type="checkbox"/> Continuous home care | 18 <input type="checkbox"/> Referral services |
| 03 <input type="checkbox"/> Counseling | 19 <input type="checkbox"/> Respiratory therapy |
| 04 <input type="checkbox"/> Dental treatment services | 20 <input type="checkbox"/> Respite care |
| 05 <input type="checkbox"/> Dietary/nutritional services | 21 <input type="checkbox"/> Skilled nursing services |
| 06 <input type="checkbox"/> Durable medical equipment and supplies | 22 <input type="checkbox"/> Social services |
| 07 <input type="checkbox"/> Enterostomal therapy | 23 <input type="checkbox"/> Speech therapy/Audiology |
| 08 <input type="checkbox"/> Homemaker-household services | 24 <input type="checkbox"/> Spiritual care |
| 09 <input type="checkbox"/> IV therapy | 25 <input type="checkbox"/> Transportation |
| 10 <input type="checkbox"/> Meals on Wheels | 26 <input type="checkbox"/> Vocational therapy |
| 11 <input type="checkbox"/> Medications | 27 <input type="checkbox"/> Volunteer services |
| 12 <input type="checkbox"/> Occupational therapy | 28 <input type="checkbox"/> Other high tech care (e.g., enteral nutrition, dialysis) |
| 13 <input type="checkbox"/> Pastoral care | 29 <input type="checkbox"/> Other services – <i>Specify</i> ↘ |
| 14 <input type="checkbox"/> Personal care | |
| 15 <input type="checkbox"/> Physical therapy | |

HAND FLASHCARD 12.

b. During the 30 days prior to (discharge/death), which of these service providers FROM YOUR AGENCY visited her/him?

Mark (X) all that apply.

PROBE: Any other providers?

- | | |
|---|--|
| 00 <input type="checkbox"/> None | 09 <input type="checkbox"/> Physical therapists |
| 01 <input type="checkbox"/> Chaplain | 10 <input type="checkbox"/> Physicians |
| 02 <input type="checkbox"/> Dietitians/Nutritionists | 11 <input type="checkbox"/> Registered nurses |
| 03 <input type="checkbox"/> Home health aides | 12 <input type="checkbox"/> Respiratory therapists |
| 04 <input type="checkbox"/> Homemakers/Personal caretakers | 13 <input type="checkbox"/> Social workers |
| 05 <input type="checkbox"/> Licensed practical or vocational nurses | 14 <input type="checkbox"/> Speech pathologists/Audiologists |
| 06 <input type="checkbox"/> Mental health specialists | 15 <input type="checkbox"/> Volunteers |
| 07 <input type="checkbox"/> Nursing aides and attendants | 16 <input type="checkbox"/> Other providers – <i>Specify</i> ↘ |
| 08 <input type="checkbox"/> Occupational therapists | |

NOTES

HAND FLASHCARD 13.

21. What was the PRIMARY expected source of payment for her/his entire episode of care?

Mark (X) only one source.

For the source of payment ask:
Is the (source of payment) for home health care or hospice care?

	Home Health Care	Hospice Care
01 <input type="checkbox"/> Medicare	01 <input type="checkbox"/>	01 <input type="checkbox"/>
a. Fee-for-service Medicare	01a <input type="checkbox"/>	01a <input type="checkbox"/>
b. Medicare HMO	01b <input type="checkbox"/>	01b <input type="checkbox"/>
02 <input type="checkbox"/> Medicaid	02 <input type="checkbox"/>	02 <input type="checkbox"/>
a. Fee-for-service or traditional Medicaid	02a <input type="checkbox"/>	02a <input type="checkbox"/>
b. Privately insured through Medicaid	02b <input type="checkbox"/>	02b <input type="checkbox"/>
03 <input type="checkbox"/> Other government medical assistance	03 <input type="checkbox"/>	03 <input type="checkbox"/>
04 <input type="checkbox"/> Private insurance	04 <input type="checkbox"/>	04 <input type="checkbox"/>
a. HMO or IPA	04a <input type="checkbox"/>	04a <input type="checkbox"/>
b. Indemnity plan or PPO	04b <input type="checkbox"/>	04b <input type="checkbox"/>
c. Other – Specify ↴		
	04c <input type="checkbox"/>	04c <input type="checkbox"/>
05 <input type="checkbox"/> Own income, family support, Social Security benefits, retirement funds, or welfare	05 <input type="checkbox"/>	05 <input type="checkbox"/>
06 <input type="checkbox"/> Supplemental Security Income (SSI)	06 <input type="checkbox"/>	06 <input type="checkbox"/>
07 <input type="checkbox"/> Religious organizations, foundations, agencies	07 <input type="checkbox"/>	07 <input type="checkbox"/>
08 <input type="checkbox"/> Veterans Administration	08 <input type="checkbox"/>	08 <input type="checkbox"/>
09 <input type="checkbox"/> CHAMPVA/CHAMPUS	09 <input type="checkbox"/>	09 <input type="checkbox"/>
10 <input type="checkbox"/> Other military medicine	10 <input type="checkbox"/>	10 <input type="checkbox"/>
11 <input type="checkbox"/> Other – Specify ↴		
	11 <input type="checkbox"/>	11 <input type="checkbox"/>
12 <input type="checkbox"/> Payment source not yet determined	SKIP to item 24	
13 <input type="checkbox"/> No charge made for care	SKIP to item 25	

NOTES

HAND FLASHCARD 13.

22. What were ALL the secondary sources of payment for her/his entire episode of care?

Mark (X) all that apply.

PROBE: Any other sources of payment?

For the source of payment ask:
Was the (source of payment) for home health care or hospice care?

	Home Health Care	Hospice Care
00 <input type="checkbox"/> No secondary sources		
01 <input type="checkbox"/> Medicare	01 <input type="checkbox"/>	01 <input type="checkbox"/>
a. Fee-for-service Medicare	01a <input type="checkbox"/>	01a <input type="checkbox"/>
b. Medicare HMO	01b <input type="checkbox"/>	01b <input type="checkbox"/>
02 <input type="checkbox"/> Medicaid	02 <input type="checkbox"/>	02 <input type="checkbox"/>
a. Fee-for-service or traditional Medicaid	02a <input type="checkbox"/>	02a <input type="checkbox"/>
b. Privately insured through Medicaid	02b <input type="checkbox"/>	02b <input type="checkbox"/>
03 <input type="checkbox"/> Other government medical assistance	03 <input type="checkbox"/>	03 <input type="checkbox"/>
04 <input type="checkbox"/> Private insurance	04 <input type="checkbox"/>	04 <input type="checkbox"/>
a. HMO or IPA	04a <input type="checkbox"/>	04a <input type="checkbox"/>
b. Indemnity plan or PPO	04b <input type="checkbox"/>	04b <input type="checkbox"/>
c. Other - Specify _____	04c <input type="checkbox"/>	04c <input type="checkbox"/>
05 <input type="checkbox"/> Own income, family support, Social Security benefits, retirement funds, or welfare	05 <input type="checkbox"/>	05 <input type="checkbox"/>
06 <input type="checkbox"/> Supplemental Security Income (SSI)	06 <input type="checkbox"/>	06 <input type="checkbox"/>
07 <input type="checkbox"/> Religious organizations, foundations, agencies	07 <input type="checkbox"/>	07 <input type="checkbox"/>
08 <input type="checkbox"/> Veterans Administration	08 <input type="checkbox"/>	08 <input type="checkbox"/>
09 <input type="checkbox"/> CHAMPVA/CHAMPUS	09 <input type="checkbox"/>	09 <input type="checkbox"/>
10 <input type="checkbox"/> Other military medicine	10 <input type="checkbox"/>	10 <input type="checkbox"/>
11 <input type="checkbox"/> Other - Specify _____	11 <input type="checkbox"/>	11 <input type="checkbox"/>

23a. What was the last amount billed for her/his care, including all charges for services, drugs, special medical supplies, etc., before discounts or adjustments?

Total amount

\$ _____ .00

01 Don't know } *SKIP to item 24*
 02 Not billed yet }

b. What dates are covered by the amount billed?

Month	Day	Year	to	Month	Day	Year

24. Which best describes the way this agency (was/will be) reimbursed for the total charges?

01 Based on services provided
 02 Capitation (services provided under a capitation agreement or by salaried staff in an HMO)
 03 Don't know

25. When was the last time service was provided to this patient for the period of care that ended (date of discharge)?

Month	Day	Year

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For answers to questions about this report or for a list of reports published in these series, contact:

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(301) 458-4636
E-mail: nchsquery@cdc.gov
Internet: www.cdc.gov/nchs

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