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BY THE COMPTROLLER GENERAL

Report To The Congress

OF THE UNITED STATES

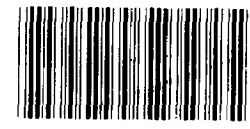
GAO

Hospice Care--A Growing Concept In The United States

Three Senators requested that GAO review hospices in the United States to determine their number and location, the number *planned within the next year*, the characteristics of their patients, State licensing and health planning requirements, and operating costs and sources of funds.

GAO found 59 organizations that consider themselves to be hospices, and 73 others being *planned*. These organizations provide various combinations of medical care and emotional and spiritual support services to terminally ill patients and their families.

Medicare, Medicaid, Social Services, and programs authorized under the Older Americans Act *do not cover hospice care as a distinct type of service*, but they pay for at least some services hospices provide. Laws governing the Federal programs would probably have to be amended to cover all services hospices provide, especially those provided to family members.



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Report

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*Nat. Cancer
Institute
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To the President of the Senate and the
Speaker of the House of Representatives

This report, which summarizes the results of our study of hospices in the United States, describes the basic principles of hospice care and the services hospices provide. It also discusses characteristics of hospice patients and services hospices provide that are presently covered and reimbursable under the Medicare, Medicaid, Social Services, and Older Americans Act programs. We are sending the report to the Congress because of the general interest in hospices as an alternate method of caring for the terminally ill.

We discussed the report with officials of the Department of Health, Education, and Welfare and considered their comments in preparing the report.

Our study was made at the request of Senators Abraham A. Ribicoff, Edward M. Kennedy, and Robert J. Dole.

We are sending copies of this report to the Director, Office of Management and Budget, and the Secretary of Health, Education, and Welfare.

Comptroller General
of the United States



D I G E S T

There is no standard definition of a hospice or of what services an organization must provide to be considered a hospice. However, in the United States, the hospice concept generally is considered to be a program that provides palliative care--medical relief of pain--and supportive services to terminally ill persons and assistance to their families in adjusting to the patient's illness and death.

Fifty-nine organizations in the United States consider themselves to be hospices. They provide many different combinations of medical and support services to terminally ill patients, most of whom suffer from cancer. Seventy-three other organizations plan to establish hospice care programs and also provide various mixes of services.

Hospices are a possible alternative to traditional care for the terminally ill patient. They claim to provide continuity of inpatient, outpatient, and home care for patients and continuity of care for family members before and after a patient's death.

In most States hospices are covered under licensing and certificate of need laws for the traditional levels of care they provide--inpatient hospital, skilled nursing facility, and home health care. (See pp. 12 and 13.)

The cost of establishing and operating a hospice appears to depend primarily on the type of facility, if any, used; the range of services provided; and the ratio of paid staff to volunteers. (See pp. 20 to 22.)

Most hospices depend heavily on volunteers for services, but normally have some paid staff to provide medical and professional health-related services. (See pp. 15 and 16.)

Medicare, Medicaid, Social Services, and programs authorized under the Older Americans Act can pay for at least some services provided by hospices, but laws governing these programs would probably have to be amended to cover all hospice services, especially those provided to families. (See pp. 23 to 27.)

Costs at the various levels of care (for example, home health care) should be relatively comparable between hospices and traditional providers; any savings from hospices would depend on their ability to care for patients at a lower level of care (skilled nursing or intermediate care instead of hospital, or home health instead of skilled nursing). (See p. 29.)

GAO discussed the report with officials of the Department of Health, Education, and Welfare and considered their comments in preparing the report.

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ABBREVIATIONS

GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
NCI	National Cancer Institute

CHAPTER 1

INTRODUCTION

On May 12, 1978, Senators Abraham A. Ribicoff, Edward M. Kennedy, and Robert J. Dole requested us to review hospices in the United States. Specifically, they asked us to (1) determine the number of operating hospices and their locations, (2) determine the number of hospices in the developmental stage that expect to become operational within a year, (3) describe the characteristics of the patients served by hospices, (4) review State licensure and health planning requirements for hospices, and (5) identify hospices' operating costs and sources of funds. They expressed particular interest in the potential for Medicare and Medicaid payments to hospices.

HOSPICE: A CONCEPT OF CARE FOR TERMINALLY ILL PATIENTS AND THEIR FAMILIES

There is no standard definition of what a hospice is or what services an organization must provide to be considered a hospice. However, it is generally agreed that the hospice concept in the United States is a program of care in which an organized interdisciplinary team systematically provides palliative care (medical relief of pain) and supportive services to patients dying from terminal illness. The team also assists the patient's family in making the necessary adjustments to the patient's illness and death. The program's objective is to make the patient's remaining days as comfortable and meaningful as possible and to help the family cope with the stress. Chapter 2 of this report details the principles of the hospice concept.

The concept had its origin in homes established by religious orders during the Middle Ages in Europe, where pilgrims received care and personal attention as they traveled to the Holy Land. Institutions of early medicine evolved from these homes and incorporated the hospice concept of providing personal attention and care for the sick and dying poor.

A group of Catholic widows established a hospice in Lyon, France, in 1842 for poor women with incurable and inoperable cancer. In the mid-1800s, the founder of the Irish Sisters of Charity established a hospice for the dying in Dublin, Ireland. About 50 years later in London, England, the Irish Sisters established St. Joseph's Hospice, while an Anglican Order and a Mission of the Methodist Church established two other hospices.

In addition to the nursing care, spriritual and emotional support, and home care that reportedly characterized the early European hospices, modern hospices focus on the management of the pain and symptoms associated with terminal illness. St. Christopher's Hospice in London and the Royal Victoria in Montreal, Canada, are two programs that have gained recognition in the United States for developing advanced techniques for managing such pain and symptoms. St. Christopher's is a freestanding facility with a home care program, while the program at the Royal Victoria is organized as a unit in a hospital also with a home care program. Most of the hospices operating and developing in the United States use the British and Canadian hospices as models.

Hospice, Inc.--founded in New Haven, Connecticut, in 1971--was the first formally organized hospice in this country. It operates as a home health organization and expects to provide inpatient care in its freestanding facility in the near future. A freestanding hospice in Tucson, Arizona, which opened in 1977, provides inpatient care and plans to develop a home care program. Both hospices modeled their programs after St. Christopher's.

Several hospitals have organized hospice programs as units in their hospitals similar to the Royal Victoria. Other U.S. hospices are organizing their programs as units in skilled nursing facilities, freestanding facilities with hospital affiliation, hospice teams in hospitals, home health care organizations, and all-volunteer organizations with no facilities. Some of these hospices, however, expect to have freestanding facilities in the future.

Each hospice determines the range of services it provides. Although a given hospice may not provide all of these services, the hospice concept includes the following types of care: inpatient skilled nursing care in a nursing home or hospital; physician services; home health care, including nursing and personal care services; physical, speech, and occupational therapy; pain relief treatment; emotional support services; and spiritual support.

FEDERALLY FUNDED PROGRAMS COVER SOME SERVICES PROVIDED BY HOSPICES

Four Federal programs--Medicare, Medicaid, Social Services, and Older Americans Act programs--are potential sources of funds on an ongoing basis for hospices. Each program will pay for some of the services provided by hospices; however, none specifically covers hospice care as a distinct type of service.

The Medicare and Medicaid programs

Medicare and Medicaid, established by titles XVIII and XIX of the Social Security Act, respectively, and administered by the Department of Health, Education, and Welfare's (HEW's) Health Care Financing Administration, help eligible persons meet the costs of health care services.

Medicare provides two basic types of protection:

- Hospital insurance benefits under part A (generally financed by special social security payroll taxes) cover inpatient hospital services and posthospital care in skilled nursing facilities and patients' homes.
- Supplementary medical insurance benefits under part B, a voluntary program financed by premiums of enrollees (currently \$8.20 per month) and general Federal contributions, cover physician services and many other medical services, including outpatient hospital and home health services.

Persons 65 years of age and older who are entitled to social security or railroad retirement or survivors' benefits, persons who have received social security disability benefits for at least 24 consecutive months, and most persons with end-stage renal disease qualify for part A coverage. All resident citizens and aliens with 5 years of continuous residence in the United States who are 65 or older as well as disabled persons with part A coverage are eligible for part B coverage.

Medicaid is a grant-in-aid program in which the Federal and State governments share the costs of providing medical services to eligible persons. It is administered by the States under HEW regulation. States with Medicaid programs must provide inpatient and outpatient hospital, skilled nursing facility, physician, laboratory and X-ray, home health, family planning, and preventive health care for children. States can also choose to cover any other medical or remedial services recognized under State law and approved by HEW. The specific scope and limitations on hospital, nursing home, home health, and other medical services covered under Medicaid vary from State to State.

Medicaid covers two groups of people: the categorically needy who receive or are eligible to receive cash assistance and the medically needy whose income is too high to qualify for cash assistance but too low to pay for medical care.

During fiscal year 1978, Medicare covered about 26 million people with total program costs of about \$25.7 billion (\$18.0 billion under part A and \$7.7 billion under part B). During the same period, Medicaid paid about \$19.1 billion (the Federal share was \$10.8 billion) for care provided to about 21 million recipients.

The title XX program

A variety of social services, including home-based services, can be covered and funded from State programs established under title XX of the Social Security Act, commonly known as the Social Services program. HEW's Office of Human Development Services is responsible for this program. The home-based services can include homemaker, home health aide, home management, and personal care. Although the covered services under title XX vary from State to State, at least one home-based service is included in each State program. Cash assistance recipients and other low-income persons are eligible for these services.

Of the \$3.7 billion in Social Services funds expended in fiscal year 1978, about \$572 million was used for homemaker/chore and health-related services.

Older Americans Act programs

The Older Americans Act of 1965, as amended, authorizes projects to help elderly Americans maintain a dignified and, to as great an extent as possible, independent lifestyle. Generally, persons age 60 and over are eligible for services under the Older Americans Act. Many of the projects contain home health components and other health-related features, including visiting nurses, home health services for the home-bound elderly, homemaker services, health education, immunization and screening programs, home repairs, and home-delivered meals.

The Older Americans Act also funds research and demonstration projects to develop models or alternatives for living and service delivery arrangements for older Americans who would otherwise require institutionalization.

Another part of the Older Americans Act is designed to improve the well-being of older persons through nutrition and social service programs. Meals and supportive services are provided in congregate settings, as well as in the home.

During fiscal year 1978, \$506 million (the Federal share) was obligated to the Older Americans Act programs. We were unable to determine the amount of obligations for the types of services hospices provide.

HEW DEMONSTRATION PROJECTS COVER THE FULL RANGE OF HOSPICE SERVICES

The National Cancer Institute (NCI) and the Health Care Financing Administration are funding projects providing the full range of hospice services under their research and demonstration programs. The NCI hospice demonstration projects are designed to evaluate hospice care for terminal cancer patients as a medical alternative to institutionalized care. In 1974, NCI awarded a \$790,000, 3-year contract to Hospice, Inc. (the first formally organized hospice in the United States). During fiscal years 1977 and 1978, NCI awarded 3-year demonstration project contracts totaling \$4.9 million to three other hospices. These projects are at Hillhaven Hospice in Tucson, Arizona; Riverside Hospice in Boonton, New Jersey; and Kaiser Permanente in Norwalk, California. NCI also plans to award some grants in fiscal year 1979 for the study of specific aspects of terminal care (such as bereavement) for which hospices and others may submit proposals. The amount of total Federal funding that will be awarded had not been determined as of January 1979.

The Health Care Financing Administration invited applications for participation in hospice demonstration projects on October 27, 1978. It expects to sign provider agreements with a few hospices during fiscal year 1979. These projects will permit reimbursement for all hospice services provided to Medicare and Medicaid beneficiaries. These projects are to help HEW evaluate the levels of hospice care, the range of services, and the costs of care and develop standards so that it can make policy decisions regarding Medicare and Medicaid coverage of hospice services.

SCOPE OF REVIEW

Between July and September 1978, we made a telephone survey (about 500 contacts) in an attempt to identify all operating and developing hospices. We started our survey using lists of possible hospice groups and interest groups obtained from the National Hospice Organization, an HEW consultant, and several other sources. During our survey, we gathered information on the organization, licensing, patients, services, and funding of operating hospices and on developing hospices' plans for operations. We also solicited names of additional hospices that were thought to be either operating or in the developmental stage.

In August 1978, we visited 16 operating hospices, all but 1 of which had provided services for a year or more. During these visits, we obtained more detailed information on the hospices' operations.

We also reviewed pertinent Federal laws and regulations, literature, and information on demonstration and research projects related to hospice care.

CHAPTER 2

WHAT IS A HOSPICE?

The hospice concept has four basic principles that, according to its advocates, distinguish it from the traditional health care system:

- The patient and his/her family, not just the patient, are considered the unit of care.
- An interdisciplinary team is used to assess the physical, psychological, and spiritual needs of the patient and family, develop an overall plan of care, and provide coordinated care.
- Pain and the collateral symptoms associated with the terminal illness and its previous treatment are controlled, but no heroic efforts are made to cure the patient.
- Bereavement followup is provided to the family to overcome their emotional suffering.

Programs operating under the hospice concept are caring almost exclusively for cancer patients whose attending physicians have determined that the disease has progressed to the point where curative and restorative treatment is no longer reasonable and prolonging life should no longer be the objective of medical care.

PATIENT AND FAMILY, THE UNIT OF CARE

Under the hospice concept, the aim is to keep the family involved in caring for the terminally ill patient and to provide the support necessary to help the family cope with the stress involved in caring for the patient and adjusting to life without the patient. Hospices consider the supportive care of family members to be a preventive measure. This view is based on studies showing that families have broken up as a result of the patient's illness and that family members without the necessary support have, after the patient's death, committed suicide, developed reactive depression, and had other serious medical or psychological problems.

THE INTERDISCIPLINARY TEAM INTEGRATES PATIENT AND FAMILY CARE

Hospices contend that care of the terminally ill requires an interdisciplinary team to be available to both

the patient and the family. The team--made up of paid and volunteer physicians, nurses, social workers, psychologists, clergy, and persons of various other backgrounds--is set up to ensure total, planned care to overcome the medical and psychological problems of the patient and the family. Hospices believe that care is often fragmented in the traditional health care system, especially as it relates to the patient's family.

Hospices begin their team approach by assessing the needs of the patient and the family. This includes determining

- the patient's physical needs,
- the patient's and the family members' emotional state and each person's ability to cope with problems and emotional stress,
- the family's financial needs, and
- the patient's and the family's spiritual needs or religious preferences.

A plan of care is developed which addresses the identified needs and concerns of the patient and the family.

The hospice team nurse or coordinator develops the initial plan of care (usually in accordance with the attending physician's orders and approval), which is reviewed and further developed by the team. The team reevaluates and updates the plan periodically, usually weekly, at patient conferences involving all team members. The problems associated with terminal illness are viewed as being so numerous and varied that no one individual is able to tackle them all effectively. The major benefit of the hospice team approach is viewed as a more concentrated, intensive effort to evaluate and pursue a plan of care that is tailored to meet the special needs of each terminally ill patient and family. This approach provides for continuity among inpatient, outpatient, and home elements of the patient's care and continuity of care for family members before and after the patient's death.

In addition to medical services, team members provide personal care to the patient (e.g., feeding, bathing, and hair grooming), homemaker services (e.g., scrubbing floors, caring for pets, grocery shopping, and food preparation), and transportation. Hospice team members provide these services to assure that the physical needs and need for self-esteem are met.

MANAGEMENT OF PAIN AND SYMPTOMS
TO PROVIDE COMFORT

Most hospices believe that helping the patient to meet death is impossible unless pain is controlled. Medical and nursing skills are used to assess the amount of pain the patient is undergoing and the amount of medication needed to maintain the patient in an alert but pain-free state until death. Usually a nonnarcotic or narcotic/nonnarcotic mixture of pain-killing drugs is given orally to the patient in sufficient quantity and at appropriate intervals to provide continuous relief. Hospices contend that their use of these drugs, as well as their approach to prescribing and administering them on a preventive schedule, is more effective in making the patient's remaining life comfortable than the "as needed" schedule used by traditional inpatient facilities and health professionals.

The medication used widely by U.S. hospices is a mixture containing a depressant drug (such as liquid morphine or methadone), ethyl alcohol, and a simple syrup or flavoring agent. Sometimes a narcotic stimulant (such as cocaine) is added to the mixture to stimulate alertness.

To determine the medication dosage needed to bring the patient's pain under control for a 4-hour period, medication is often prescribed and administered incrementally. An initial dosage is given and then adjusted upward or downward each time the pain gets out of control until the correct dosage for a 4-hour period is determined.

Additionally, palliative surgery and radiation are used in some rare cases of cancer to relieve the patient from chronic pain. These approaches to pain management are coordinated with acute care facilities which offer the necessary surgical and radiological expertise.

While more traditional health care providers normally focus on curing the patient of the illness and using rehabilitative measures to restore the patient's functional abilities, hospices focus on attacking the patient's symptoms rather than the disease. Hospices believe that it is this difference in approach--controlling symptoms to make the patient comfortable versus attempting to cure--that sets them apart from other kinds of health care providers.

The prolonged use of pain-killing drugs, as well as surgical, chemical, or radiation therapies associated with the treatment of terminal illness, can result in such adverse

side effects as constipation, nausea, and vomiting. Instead of trying to treat these problems, hospices usually only try to free the patient from the distress they cause. An example cited by several hospices relates to bowel obstruction, which is relatively common in patients with the various abdominal cancers. The hospices said that, in the acute care health system, the patient may be treated by such radical methods as surgery designed to remove bowel obstructions. In a hospice, however, both the health care professionals and the patient realize that death is imminent and that "curing" the obstruction through surgery, with its concomitant pain and discomfort, is futile. Instead, medication is used to control pain and nausea associated with the obstruction and thereby permit the patient to comfortably live out his/her remaining days.

BEREAVEMENT FOLLOWUP TO
HELP FAMILIES COPE WITH DEATH

Unlike the conventional health care settings, hospices provide bereavement followup--that is, assistance to family members after the patient's death to help them overcome psychological suffering. This assistance, in the form of telephone calls or home visits, is thought to give the survivors an opportunity to openly express their grief and discuss the illness and death. This helps mitigate the potential effects of bereavement, such as illness, alcoholism, and depression. Hospices believe that such assistance may have to be provided to the family for as long as a year after the patient's death. Hospices include bereavement followup in the plan of care discussed earlier in this chapter.

CHAPTER 3

HOW MANY HOSPICES ARE THERE

AND WHAT SERVICES ARE THEY PROVIDING?

We identified 59 organizations that consider themselves to be providing at least one service employing the hospice concept and 73 others that said they were planning or in the process of establishing hospices.

Hospices are operating and developing in every region of the United States. Most of the operating hospices are located on the east and west coasts, with about 37 percent located in California. (For detailed data on the locations of operating and developing hospices, see app. I.)

OPERATING HOSPICES ARE ORGANIZED IN VARIOUS WAYS

The 59 operating hospices either were located in hospitals, nursing homes, or freestanding facilities or were organized as home health agencies or volunteer agencies acting as resource referrers. All but four were nonprofit organizations. Fifty-four percent of the hospices were located in a hospital or other inpatient facility.

The following table shows the number of operating hospices and their tax status by type of inpatient facility.

<u>Type of facility</u>	<u>For-profit</u>	<u>Nonprofit corporation</u>	<u>Nonprofit not incorporated</u>	<u>Total</u>
Freestanding	-	a/3	b/2	5
Hospital	4	19	1	24
Skilled nursing facility	-	1	-	1
Health maintenance organization	-	-	2	2
No inpatient facility	-	26	1	27
Total	<u>4</u>	<u>49</u>	<u>6</u>	<u>59</u>

a/One of the three freestanding facilities was under construction at the time of our fieldwork.

b/One of these facilities is a joint venture between two hospitals, and the other is a State demonstration project.

Of the hospital hospice programs, 12 were organized as distinct units in the facility, while 11 were programs under a medical or support service department within the hospital, such as community medicine, home health care, nursing service, human support, community service, and chaplaincy departments. The distinct units ranged in size from 4 to 15 beds.

Most hospice programs reported to be providing or coordinating medical services had physicians who directed and supervised their clinical service activities. A few hospices had registered nurses or medical social workers who supervised these activities.

About half of the hospices had persons with professional backgrounds in administration to supervise their administrative operations. The others had registered nurses, social workers, physicians, clergy, or psychologists directing administrative activities.

OVER HALF OF THE OPERATING HOSPICES ARE LICENSED HEALTH CARE PROVIDERS

On January 18, 1979, Connecticut became the first State to have regulations governing the licensing of hospices. However, 31 (52 percent) of the hospices were licensed as hospitals, home health agencies, skilled nursing facilities, and/or psychiatric hospitals. The other 28 hospices held no licenses to provide health care services. Some of these non-licensed programs providing home health care services are located in States, such as Colorado and Connecticut, that do not license home health agencies. Other nonlicensed hospices did not provide services that required licensure. Three non-licensed hospice organizations told us that they contracted with the local Visiting Nurse Associations to provide home nursing care.

The following table lists the number of hospices by type of license, as of September 1978.

Licenses Held by 59 Operating Hospices

<u>License held</u>	<u>Number of hospices (note a)</u>
Hospital	24
Psychiatric hospital	2
Skilled nursing facility	5
Home health agency	19
No license held (note b)	28

a/Does not total 59 because some hospices hold multiple licenses.

b/These hospices provide no medical services that require licenses.

Additionally, seven of the hospices required certificates of need from their respective States before they could provide nursing and medical services--two for home health agencies, four for inpatient facilities, and one for capital expenditures for a hospital conversion.

Many of the hospices existed as other kinds of providers before they began providing hospice services and, therefore, did not require certificates of need when they added a hospice program. Under the National Health Planning and Resources Development Act of 1974, as amended, and regulations, States are required to have certificate of need programs covering the construction of or additions to hospitals and skilled nursing facilities, capital expenditures of over \$150,000 for adding service capabilities to facilities, and formation of new home health agencies. This provision would apply to hospices fitting one of these categories.

HOSPICES PROVIDE VARYING MIXES
OF MEDICAL AND SUPPORTIVE SERVICES

Most hospices provide home health, bereavement followup, and referral to other agencies for services, as well as various other medical and supportive services. We developed, based on the literature on hospices, a list of 10 medical services and 6 supportive services commonly provided by hospices. The 59 operating hospices we identified were asked to indicate services they provide and services for which they make referrals or coordinate. 1/ The following table shows the hospices' responses.

1/"Coordinating" involves working with another organization to integrate the services provided by that organization into the hospice's overall plan of care. "Referring" means merely sending the patient to another organization to obtain services.

Services Provided by
the 59 Operating Hospices

<u>Services</u>	<u>Percent of hospices that</u>		
	<u>Provide service</u>	<u>Coordinate or make referrals (note a)</u>	<u>Do not provide, refer, or coordinate service</u>
Medical services:			
Home health, skilled nursing care, and aide	68	20	12
Home visits by physicians	41	30	29
Psychiatric consultation	46	24	30
Pain control:			
Medication	63	22	15
Surgery (note b)	7	59	34
Radiation (note b)	7	66	27
Physical therapy	41	39	20
Occupational therapy	29	32	39
Inpatient care	30	36	34
Ambulatory services in an outpatient facility	19	30	51
Supportive services:			
Bereavement followup	93	2	5
Day care for patient	10	7	83
Homemaker services	30	48	22
Meal preparation at home	17	59	24
Respite care (note c)	63	5	32
Death education	61	3	36

a/Seventeen percent of the hospices do not make referrals to other agencies.

b/These services are rarely performed since they are normally not medically necessary to relieve terminally ill patients' pain.

c/The patient receives total care from hospice representatives in a facility or in the home so that family members or primary care givers in the home may have a couple of days or more of rest from the stress of caring for the patient.

Only 50 percent of the hospices provide 24-hour-a-day, 7-day-a-week home nursing care, which many individuals consider an essential element of hospice care. Such care was provided by licensed home health care agencies, hospitals with home health care agency licenses, hospitals (without a home health agency license) that have volunteer nurses to make home visits, and nonlicensed organizations.

Hospices that provide psychiatric consultation indicated that this service is primarily provided to the hospice staff rather than the patient and family. The psychiatrist gives the staff emotional support and helps the team determine how best to serve the patient and his/her family. A few hospices, however, indicated that the psychiatrist or a psychiatric nurse may have individual sessions with either the patient or family member.

Most hospices provide 7 to 12 of the services listed in the previous table. Some hospices provide more medical services, whereas others provide more supportive services. Only a few hospices provide either as many as 14 of the services or as few as 2 or 3.

Five hospices said they plan to expand their home care nursing programs to provide 24-hour-a-day, 7-day-a-week services. Several others indicated that they plan to upgrade services they presently provide. For example, some hospices plan to upgrade their bereavement followup service by making periodic home visits to the family members instead of just sending cards of condolence and making occasional telephone calls. Another example is a hospice that plans to expand its death education program from just orienting its volunteers to including training experiences for local physicians, nurses, and clergy.

About half the operating hospices plan to provide additional types of services. Most want inpatient facilities if they can obtain the necessary funds.

HOSPICES HAVE PAID, CONTRACT, AND VOLUNTEER WORKERS

During our telephone survey, we asked for information on the hospices' staffing patterns, including whether the staff was paid or volunteer. Of the 59 operating hospices, 53 gave us this data in some detail. Of these hospices 39 had paid staff and 14 had an all-volunteer staff. Five other hospices could not provide detailed staffing data because their staff was a part of the overall hospital staff

and records were not segregated. One other hospice said that all of its staff were volunteers, but it could not provide an accurate count of them. In addition, 12 of the 59 said that they contracted with another organization to obtain some of their staff.

Paid staff totaled about 340 full-time equivalents for the 39 hospices reporting paid staff, and volunteer staff totaled 2,251 persons for the 53 hospices that reported such data. Paid staff ranged from a low of 0.1 full-time equivalents to a high of 51.5 (a freestanding facility hospice), while active volunteer staff ranged from 1 to 160 persons. The ratio of paid to volunteer staff ranged from 1 full-time equivalent to 0.2 volunteers to 1 full-time equivalent to 134 volunteers.

Most paid staff were medical personnel (mainly nurses, with some physicians, therapists, and technicians); the rest were administrative and clerical staff. In contrast, most volunteers were persons trained by the hospices to provide personal care services and give emotional support to the patient and family.

The following table shows the number and percent of paid and volunteer staff by major occupational groups, as reported by 53 hospices.

<u>Occupational group</u>	<u>Paid workers</u>		<u>Volunteers</u>	
	<u>Number</u>	<u>Percent</u>	<u>Number</u>	<u>Percent</u>
Physicians	13.0	4	138	6
Nursing/aide staff	181.5	53	305	14
Therapists/ technicians	6.2	2	27	1
Social/psycho- logical staff	19.2	6	208	9
Personal care/ administra- tive/clerical staff	<u>120.8</u>	<u>35</u>	<u>1,573</u>	<u>70</u>
Total	<u>340.7</u>	<u>100</u>	<u>2,251</u>	<u>100</u>

DEVELOPING HOSPICES EXPECT TO
OPERATE SIMILARLY TO CURRENT HOSPICES

Seventy-three groups we spoke with expected to become operational hospices by July 1979. They expect to organize and operate similarly to currently operating hospices, and

they too intend to provide various mixes of services. All but one of the developing hospices were nonprofit organizations.

Thirty-three percent of the developing hospice programs expect to be located in either a hospital, skilled nursing, or freestanding facility. Of the developing hospices, 45 percent have no current plans to have an inpatient facility, and 22 percent are undecided about such plans. The following table shows the developing hospices' tax status by the planned type of inpatient facility, if any.

Tax Status of Developing Hospices, by Type of Facility

<u>Type of facility planned</u>	<u>For-profit</u>	<u>Nonprofit corporation</u>	<u>Nonprofit not incorporated</u>	<u>Total</u>
Freestanding	-	3	1	4
Hospital	-	12	5	17
Skilled nursing or intermediate care facility	-	2	1	3
No inpatient facility	-	32	1	33
Type of facility undecided	<u>1</u>	<u>14</u>	<u>1</u>	<u>16</u>
Total	<u>1</u>	<u>63</u>	<u>9</u>	<u>73</u>

CHAPTER 4

WHOM DO HOSPICES SERVE?

Hospices primarily serve terminal cancer patients and their families, cases in which it is relatively easy to tell when a patient becomes terminal. Hospices have served a few patients in the terminal stage of kidney failure and heart disease. For most hospice patients, life expectancy is 6 months or less and active treatment to cure the disease has been determined useless.

HOSPICES SERVE TERMINALLY ILL PATIENTS WHO SHARE OTHER CHARACTERISTICS

The National Cancer Institute reported that 387,430 persons died from cancer in 1977, 60 percent of whom were 65 years of age or older. ^{1/} Thus, since hospices were primarily serving cancer patients, the potential population that hospices could serve is about 400,000 persons per year. Also, since 60 percent were 65 years or older, potential Medicare eligibles who could use hospices would be about 250,000 persons per year.

Operating hospices served patients ranging from 12 to 80 years old. Although the average age of 2,980 patients served by the 56 operating hospices that maintained age data was 58 years, most of the hospice patients were between 60 and 70.

Fifty-two operating hospices were able to tell us the racial composition of the patients they served. The racial mixture of the patients served generally reflected the racial composition of the areas served. Most of the patients were caucasian, but some were black, Spanish surname, Asian American, and Native American.

Eleven hospices were able to tell us the sources from which their patients were referred. Of the 575 patients in these programs, 66 percent were referred by physicians, 10 percent by friends, 9 percent by nurses, 8 percent by social workers, and 7 percent by other sources (such as ministers and physical therapists).

^{1/}These figures were based on a 10-percent sample of the national population reported in "NCI Monograph No. 41."

Thirteen hospices were able to provide statistics on the patients' average length-of-participation in the program, which ranged from 13.9 to 105 days. ^{1/} For the 15 hospices with inpatient facilities that reported average length-of-inpatient-stay data, it averaged 20 days, ranging from 8.2 to 60 days. The hospice with the 60-day average length-of-stay told us that, once its patients are admitted to its inpatient facility, they usually remain until they die.

We attempted to determine the types and quantities of services a typical hospice patient would receive. However, most hospices did not have detailed data on the number of times they provided a particular service. Thus, we could not obtain such figures as average number of home health visits per patient or average number of emotional support sessions.

HOSPICES SERVE PATIENTS' FAMILIES

Hospices serve terminal patients' families by helping them make physical and emotional adjustments, offering support, and encouraging them to articulate and explore their feelings and fears. According to hospice staff, they operate as active listeners to help the patient and family cope with stress, maintain self-worth, and maintain some environmental control during the patient's illness. Hospices also provide bereavement followup after the patient's death to family members and persons emotionally close to the patient.

Hospices varied in their approaches to bereavement followup. Some hospices limited it to a telephone call or a note to the family about a week after the patient's death; others also made periodic home visits to the family for 6 months or more and attended widows' and widowers' groups.

^{1/}This figure does not mean average length-of-stay in an inpatient facility, but includes both home and inpatient care. It does not include the length-of-time patients' family members participate in the program after the patient's death.

CHAPTER 5

HOW ARE HOSPICES FUNDED AND HOW

MUCH DOES HOSPICE CARE COST?

The amount of funds needed to establish a hospice is related to the types of service provided--the highest need is associated with those providing inpatient services in new facilities; the second highest, with those providing inpatient services in converted facilities; and the lowest, with those providing only home-based services. Operating costs are similarly related to the types of service provided.

None of the hospices could provide us with detailed information on the number of services provided and their costs. Therefore, we were not able to compare the cost of hospice care with the cost of care in the traditional health delivery system.

REQUIREMENTS FOR INITIAL FUNDING DEPEND ON SERVICES PROVIDED

Forty-two hospices provided data on the sources and amount of funds needed to begin providing services. They said that initial funding, ranging from \$100 to \$3 million, came from five major sources--private donations; membership fees; hospital revenues that exceeded expenses; Federal, State, and local grants and contracts; and private grants. Private organizations providing grants to hospices included the American Cancer Society, the Kaiser Foundation, and churches. A few hospices said they received some Federal funds from NCI and the Comprehensive Employment and Training Act program.

The amount of initial funding needed to begin providing services depended on the mix of services provided. Generally, hospices that constructed a facility had the highest initial funding, followed by those who converted parts of existing facilities, and those not providing inpatient services. For example, one private freestanding facility with 39 beds told us it needed \$998,000 of initial funding to start its program. A skilled nursing facility said it used \$86,000 to convert part of its facility into a six-bed hospice unit. The highest level of initial funding that a non-facility-based hospice reported for its program was \$38,000. Most non-facility-based home health agencies needed initial funds of about \$5,000 to \$10,000 to establish their programs. Most non-facility-based hospices refer patients to facilities when inpatient services are needed.

HOSPICES' OPERATIONS ARE
FUNDED BY SEVERAL SOURCES

Nineteen hospices, which provided us relatively detailed data on the sources and amounts of operating funds, reported that they received revenue ranging from \$1,125 to \$302,610 from six major sources during varying periods of time between January 1977 and July 1978. The following table shows, by major source, the amount of revenue these hospices received and the number receiving operating funds from each source.

Sources and Amounts of Operating Funds
for 19 Hospices from
January 1977-July 1978 (note a)

<u>Source of operating funds</u>	<u>Amount of funds received</u>	<u>Number of hospices</u>
Medicare	\$160,685	2
Medicaid	2,650	1
Commercial insurance and self-paying patients	110,526	3
Contributions	95,075	16
Endowments, trusts, and memorials	10,452	4
Grants and contracts (note b)	157,800	12
Other	<u>101,180</u>	5
Total	<u>\$638,368</u>	

a/The hospices had been operating for various periods (1 month, 6 months, 12 months, etc.) and their financial reporting periods varied. The data in this table are provided on a total of 155 months of operation between January 1977 and July 1978.

b/This category includes Federal grants under the Comprehensive Employment and Training Act and Older Americans Act, Federal contracts with NCI, revenue sharing funds, State grants, and private grants.

All hospices that received payments from Medicare, commercial insurance, and self-paying patients were facility-based programs. Of the funds paid in these categories, 84 percent went to one freestanding facility-based hospice.

OPERATING COSTS DEPEND ON SERVICES
PROVIDED AND STAFFING PATTERN

Nineteen hospices provided us data on operating expenses for at least a 6-month period. The operating costs that a hospice has, like the level of initial funding it needs, depends on the services it provides and its staffing pattern. Those having inpatient facilities had relatively high costs compared to those providing only home-based services.

Two freestanding hospices had the highest operating expenses. 1/ Each provided most of the 16 medical and supportive services that are commonly performed by hospices, and each had a large paid staff. Their operating expenses totaled \$668,560 and \$550,000 for a year's period for serving 182 and 156 patients, respectively. Their paid staffs totaled 29.8 and 51.5 full-time equivalents, respectively, and their ratios of paid staff to volunteers were relatively small (1 full-time equivalent of paid staff to 3.1 volunteers for one hospice and 1 to 3.7 for the other).

One of the freestanding hospices, according to its unaudited Medicare cost report, had a cost per inpatient day of about \$140. This high cost was probably attributable to its low occupancy rate of 23 percent for its 39-bed facility. Of the inpatient days 75 percent (2,145 days) were for Medicare eligibles.

Non-facility-based programs, which provided a few medical and supportive services, used volunteers rather than paid staff to a greater extent than the facility-based programs and had lower operating costs. For example, one non-facility-based program with 30 volunteers and 3 part-time paid staff (2 nurses and 1 secretary) had operating expenses of \$17,202 to serve 171 patients during 1978. This hospice said that about \$190,000 worth of professional services had been donated.

1/One of these is a home health organization with a 44-bed facility under construction.

CHAPTER 6
EXISTING FEDERAL PROGRAMS AS
POTENTIAL FINANCING SOURCES
FOR HOSPICE SERVICES

Many of the services provided by hospices have the potential to be covered by the Medicare, Medicaid, Social Services, and Older Americans Act programs under the present law. Others probably cannot be covered. HEW and/or the States are responsible for determining whether specific services are covered under these programs, and they will have to make the final determinations. Also, it should be recognized that a number of people who are potential hospice patients are not eligible for any of the four programs. This chapter discusses the coverage potential and problems of various hospice services.

INPATIENT CARE

Both Medicare and Medicaid cover inpatient hospital and skilled nursing facility services. Medicaid also covers intermediate care facility services. If the inpatient care provided by a hospice meets the definition applicable to these levels of care, Medicare and Medicaid would pay for such services up to a beneficiary's maximum benefits. Medicare helps pay for 90 inpatient hospital days and 100 skilled nursing facility days per spell of illness. To be eligible for Medicare skilled nursing facility services, the patient must have been hospitalized for at least 3 days prior to admission to the facility. Medicaid limits on covered days vary by State.

For Medicare, an inpatient hospital is defined as a facility primarily engaged in providing to inpatients--by or under the supervision of a physician--diagnostic, therapeutic, and/or rehabilitative services for medical diagnosis, treatment, care, or rehabilitation of injured, disabled, or sick persons. To be covered as inpatient hospital services, it is required that the services be medically necessary and that it be necessary that the services be provided in a hospital and not at a lower level of care. Medicaid uses the same definition.

The main question that could arise concerning coverage of inpatient hospital services for hospice patients is whether

it is necessary for the patient to receive the service in a hospital. Of course, if the service could be adequately provided at a lower level of care, it should be.

For Medicare and Medicaid, the definition of skilled nursing facility is the same: a facility engaged primarily in providing skilled nursing care and related services or rehabilitation services to injured, disabled, or sick persons on a daily basis. Again, in order to be covered, it must be necessary to provide the services in the skilled nursing facility.

Assuming that the necessity requirement (and for Medicare the 3-day prior hospitalization requirement) is met, hospices should be able to obtain Medicare and Medicaid reimbursement for skilled nursing facility services they provide. In fact, Medicare presumes that a patient is eligible for 14 days of skilled nursing care after discharge from a hospital with a diagnosis of terminal cancer, the disease most hospice patients have. A potential problem with Medicare coverage is the requirement that a person be hospitalized for 3 consecutive days before admission to the skilled nursing facility. Some potential hospice patients may not meet this requirement.

Intermediate care facility services under Medicaid are health-related inpatient care and services provided to individuals who do not require the degree of care and treatment that a hospital or skilled nursing facility is designed to provide. Because of these individuals' mental or physical condition, they require care and services (above the level of room and board) that can be made available to them only through institutional facilities.

Normally, hospice patients in intermediate care facilities would meet coverage requirements if eligible for Medicaid.

PHYSICIAN SERVICES

Both Medicare and Medicaid pay for physician services. No problems should arise in hospices receiving payment for these services except in a few State Medicaid programs that severely restrict the number of physician visits allowed.

HOME HEALTH CARE SERVICES

Medicare, Medicaid, Social Services, and Older Americans Act programs all provide home health care services. Home health is covered under both parts A and B of Medicare, the primary difference being that, to be covered under part A, the patient must have been hospitalized for at least 3 consecutive days. 1/ Skilled nursing visits and home health aide visits, including personal care services if provided incidental to skilled nursing services, are covered.

Potential problems in obtaining Medicare payments for hospice home health services arise because of several Medicare requirements. One requirement is that the patient must be homebound; that is, unable to leave the home except for infrequent or brief absences to obtain the services in another setting. Many terminal cancer patients, who represent the vast majority of hospice patients, remain ambulatory and, thus, are not homebound until the very last days of life. However, hospices believe such patients should be cared for in the familiar setting of the home because this is the most psychologically comfortable setting for the patient. Unless the homebound requirement is eliminated, many hospice home health visits could not be covered by Medicare. The Health Care Financing Administration estimated that eliminating the homebound requirement for all Medicare beneficiaries, not just hospice patients, would increase Medicare home health costs by \$140 million during fiscal year 1979.

Another requirement which could pose problems is that the services provided by a nurse during a home health visit must involve skilled nursing care before a Medicare payment can be made. In other words, at least one service that meets the definition of skilled nursing care must be provided. Hospices told us that many home health visits are for observation. Such visits are not routinely covered by Medicare but can be if certain conditions, such as a probability of a change in the patient's condition, are met. Also, personal care services provided by home health aides are not covered unless they are provided in connection with skilled nursing care under an approved plan of care. Hospices told us that many of their home health aide visits would not meet the skilled nursing care requirement. The Health Care Financing Administration estimated that including coverage of

1/Bills to eliminate the 3-day hospitalization requirement were introduced in the 95th Congress but were not finally enacted before adjournment. H.R. 13097 was passed by the House; H.R. 5285 was passed by the House, then by the Senate in an amended form.

homemaker services for all beneficiaries, not just those served by hospices, would increase Medicare home health costs by \$300 million during fiscal year 1979.

Finally, Medicare requires that home health patients require intermittent skilled nursing care (for example, a few hours a day several times a week or once a month). Occasionally, more service (i.e., 8 hours) may be provided for a limited period when the physician recommends it. Medicare requires that the patient must be confined to his or her home and under the care of a physician who establishes the plan of treatment and certifies the necessity for home health services.

Under the Medicaid and Social Services programs, States are permitted great latitude in designing their home health care programs. The same is substantially true for grantee agencies under the Older Americans Act. Thus, the requirements for and limitations on reimbursement under these programs vary from State to State and from area to area. Some use Medicare requirements and limitations, while others are either more or less restrictive.

EMOTIONAL SUPPORT SERVICES

As part of its home health benefits, Medicare covers medical social services 1/ under the direction of a physician. Medicare, however, requires that these services be provided by a qualified psychiatric or medical social worker. At least four hospices told us that their staff involved in providing patient/family counseling and emotional support do not meet the Medicare requirements, which they believe are too stringent.

Although Federal law has no specific restrictions on mental health benefits under Medicaid, except for those in institutions, most States provide only limited Medicaid mental health benefits. Also, if mental health benefits are provided under a State's Social Services program or an agency's Older Americans Act program, they are usually quite limited.

1/Medical social services are services necessary to assist the patient and his family in adjusting to social and emotional conditions related to the patient's health problem.

PAIN CONTROL

Both Medicaid and Medicare will pay for pain control surgery and radiation treatments, both of which are rarely used by hospices. Medicare will pay for pain control drugs only if provided to an inpatient or if the drug cannot be self-administered. Drugs given by most hospices can be self-administered. All Medicaid programs except one State's cover inpatient and outpatient drugs.

PHYSICAL AND OCCUPATIONAL THERAPY

Medicare pays for these services if prescribed by a physician. Thirty-two jurisdictions cover these services under Medicaid.

HOMEMAKER SERVICES

Under Medicare the primary function of a home health aide is the personal care of a patient. However, the aides can perform incidental household services (homemaker services) intimately related to the patient's health care. Thus, the problem in obtaining reimbursement for hospice homemaker services under Medicare and Medicaid could be more severe than those previously discussed under home health service for home health aide visits.

Both the Social Services and Older Americans Act programs allow homemaker services to be covered. Many States and aging agencies do cover these services.

DEATH EDUCATION/BEREAVEMENT FOLLOWUP

Neither Medicare nor Medicaid specifically cover death education and bereavement followup services. These services could be covered and reimbursable under Medicare and Medicaid if they were demonstrated to be medically necessary. If so, family members receiving these services would have to be eligible for Medicare or Medicaid before hospices would be reimbursed by these programs.

Death education and bereavement followup services could probably be covered by States and aging agencies under the broad provisions of the authorizing legislation for the Social Services and Older Americans Act programs.

CHAPTER 7

CONCLUSIONS

There presently is no standard definition of what a hospice is or what services an organization must provide to be considered a hospice. However, the hospice concept is based on four generally accepted principles:

- The terminally ill patient and his/her family, not just the patient, are the unit of care.
- An interdisciplinary team is used to assess the total needs of patient and family and then provide coordinated services to meet these needs.
- Pain and collateral symptoms associated with the terminal illness are controlled, but no heroic efforts are made to cure the patient.
- Bereavement followup is provided to the family to overcome their emotional suffering.

The 59 operating organizations that considered themselves to be hospices provided greatly varying mixes of services; many organizations offered a broad mixture of medical and supportive services, while others primarily provided referral and coordination services. The 73 organizations we identified that are planning on developing hospice programs also intend to provide varying mixes of services.

As of January 31, 1979, only Connecticut had regulations that specifically dealt with hospice licensure. At least one other State was considering such a hospice licensure law. In most States hospices would be covered under the licensure laws for the levels of care they provide; that is, inpatient hospital, skilled nursing facility, and home health care. The same applies to certificate of need laws.

Most hospices depended heavily on volunteers to provide services, some almost exclusively. Hospices normally had paid staff and often contracted with other organizations to provide services.

Almost all of the patients being served by hospices suffered from cancer. In 1977, 387,430 people died from cancer, 60 percent of whom were 65 years of age or older. Thus, the

potential population that hospices could serve is about 400,000 per year, about 250,000 of which would be potential Medicare eligibles.

The costs of establishing and operating a hospice appear to primarily depend on the type of facility, if any, used to provide inpatient services. Costs also depend on the range of services provided and ratio of paid to volunteer staff.

We were unable to obtain detailed information on the quantity of services provided to the average patient and family or the costs of specific services. Thus, we could not determine what the cost of hospice care for a "typical" patient would be. However, because hospices provide the same types of service as traditional health care providers (inpatient hospital, skilled nursing facility, and home health care) with such additional services as death education and bereavement followup, costs at the same level of care (for example, home health care) should be roughly comparable between hospices and traditional providers. Any cost savings available from the hospice concept would appear to depend on the ability of hospices to care for patients at a lower level of care (home health instead of skilled nursing facility or skilled nursing facility instead of inpatient hospital). We were unable to obtain sufficient information on U.S. hospices to reach conclusions about whether hospices have this ability. HEW is in the process of funding experiments that should provide data on the relative costs of caring for terminally ill patients under the hospice and traditional modes of care.

Four existing Federal and Federal/State programs-- Medicare, Medicaid, Social Services, and Older Americans Act programs--can pay for at least some of the services provided by hospices. The laws governing these programs may have to be amended in order to cover all of the services hospices provide. Also, many citizens are ineligible for these programs. Private insurance companies have not become involved in hospice care to any great extent.

NUMBER OF DEVELOPING AND OPERATINGHOSPICES BY REGION AND STATEAS OF SEPTEMBER 30, 1978

<u>HEW region and State</u>	<u>Number of hospices in the developmental stage</u>	<u>Number of operating hospices</u>
Region I:		
Connecticut	0	1
Maine	1	1
Massachusetts	3	1
New Hampshire	<u>1</u>	<u>0</u>
	<u>5</u>	<u>3</u>
Region II:		
New Jersey	2	2
New York	<u>7</u>	<u>3</u>
	<u>9</u>	<u>5</u>
Region III:		
District of Columbia	1	1
Maryland	1	1
Pennsylvania	2	2
Virginia	1	2
West Virginia	<u>1</u>	<u>0</u>
	<u>6</u>	<u>6</u>
Region IV:		
Alabama	1	0
Florida	4	3
Georgia	1	1
Kentucky	1	2
North Carolina	<u>1</u>	<u>1</u>
	<u>8</u>	<u>7</u>

<u>HEW region and State</u>	<u>Number of hospices in the developmental stage</u>	<u>Number of operating hospices</u>
Region V:		
Illinois	5	2
Indiana	2	2
Michigan	3	0
Minnesota	2	1
Ohio	4	0
Wisconsin	<u>4</u>	<u>2</u>
	<u>20</u>	<u>7</u>
Region VI:		
Arkansas	1	0
New Mexico	0	1
Texas	<u>2</u>	<u>0</u>
	<u>3</u>	<u>1</u>
Region VII:		
Iowa	0	1
Missouri	<u>2</u>	<u>2</u>
	<u>2</u>	<u>3</u>
Region VIII:		
Colorado	1	2
North Dakota	<u>1</u>	<u>0</u>
	<u>2</u>	<u>2</u>
Region IX:		
Arizona	1	1
California	<u>a/16</u>	22
Hawaii	0	1
Nevada	<u>1</u>	<u>0</u>
	<u>18</u>	<u>24</u>
Region X:		
Washington	<u>0</u>	<u>1</u>
Total	<u>73</u>	<u>59</u>

a/One of the developing hospices, a pilot project of the Veterans Administration, became operational in November 1978.

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