

**FINAL REPORT BY THE
DEPARTMENT OF HEALTH
IN CONJUNCTION WITH THE
HOSPICE ADVISORY COMMITTEE**

TO

THE GOVERNOR

AND

THE GENERAL ASSEMBLY OF VIRGINIA



HOUSE DOCUMENT NO. 15

**COMMONWEALTH OF VIRGINIA
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Report by the
Department of Health
In Conjunction with the
Hospice Advisory Committee
to The Governor and the General Assembly of Virginia
Richmond, Virginia
October, 1980

To: The Honorable John N. Dalton, Governor of Virginia
And the General Assembly of Virginia

The Virginia Department of Health has completed its Evaluative Study of hospice programs in the Commonwealth pursuant to House Joint Resolution No. 252 of the 1979 Session of the General Assembly. The Resolution follows:

HOUSE JOINT RESOLUTION NO. 252

Requesting the Department of Health to study hospice programs and to apply for the waiver of necessary Medicaid requirements to facilitate the study.

WHEREAS, "hospice" is a coordinated program of home and inpatient care which treats the terminally ill patient and family as a unit, employing an interdisciplinary team acting under the direction of an autonomous hospice administration; in addition, the program provides palliative and supportive care to meet the physical, psychological, social, economic and other special needs which are experienced during the final stages of illness, and during dying and bereavement; and

WHEREAS, the Joint Subcommittee to study Hospice has concluded that further study of hospice programs throughout the Commonwealth is needed to provide reliable data regarding standards of care, criteria for licensure, reimbursement policies and the appropriateness of various hospice programs; and

WHEREAS, the United States Department of Health, Education and Welfare is administering a similar nationwide study of hospice programs and, upon requests from the states, has agreed to waive certain Medicaid requirements perceived to hinder the provision of hospice care; Now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Health is requested to conduct an evaluative study of hospice programs in Virginia and to make recommendations regarding standards for the quality of care, criteria for licensure, and reimbursement of both the home care and in-patient components of hospice programs provided in a variety of health care settings and geographic areas of the State. The Department of Health is encouraged to coordinate its study with the evaluation being administered by the United States Department of Health, Education and Welfare; and, be it

RESOLVED FURTHER, That the Department of Health is requested to apply for the waiver of necessary Medicaid requirements by the United States Department of Health, Education and Welfare to assist hospice programs in providing services to Medicaid eligible patients.

The Department of Health is requested to present an interim report to the Governor and to the nineteen hundred eighty Session of the General Assembly and a final report to the Governor and the nineteen hundred eighty-one Session of the General Assembly.

EXECUTIVE SUMMARY

Legislative Mandate

The 1979 Virginia General Assembly directed the Virginia Department of Health to conduct a two-year evaluative study of hospice and to make "recommendations regarding standards for the quality of care and criteria for licensure and reimbursement of both the home care and inpatient components of hospice programs provided in a variety of health-care settings and geographic areas of the state." To conduct this study, the Department of Health appointed a Hospice Advisory Committee in order to draw on relevant expertise of various individuals across the State.

Hospice Concept

Hospice programs of care have evolved in recognition of the unique needs of the dying patient for comfort, contact with family and friends, freedom from pain, and a preference for care at home. The hospice movement attempts to offer an alternative to the 20th century emphasis upon the institution rather than the home as the principal place for dying. The term "hospice" refers to a philosophy and concept of care for terminally ill patients and families, and not to a building or site from which hospice care is delivered. A hospice program provides palliative and supportive care for terminally ill patients and their families in both home and inpatient settings, depending on the individual needs of the patient and family. Hospice care may not be appropriate for all terminal patients and families, and should be viewed as an alternative care system which should be available as an option for those patients and families who choose palliative treatment modalities. Hospice utilizes an interdisciplinary team approach to care. In addition to health professionals, the team includes two groups unique to hospice, the patient and his family, and trained volunteers. The hospice concept emphasizes care at home with inpatient backup, continuity of care and caregivers, control of symptoms, and bereavement services.

Contents of Report

This report contains an introduction to the hospice concept, a description of hospice program development in Virginia, a description of the legislative history of hospice, an overview of the evaluative study design, a discussion of significant accomplishments, and a listing of conclusions and recommendations requiring legislative action.

Conclusions and Legislative Recommendation

A. Continuation of the evaluative study is recommended, with particular efforts directed to data collection and analysis for an additional one to two year period in order to track the continuing evolution of the hospice concept and how it is being applied in Virginia. The continued monitoring of cost, utilization, and reimbursement experience will assure that any changes in the statutes or policies of the Commonwealth of Virginia related to hospice will be based on valid, comprehensive information.

B. The Department of Health in conjunction with the Hospice Advisory Committee has concluded that licensure of hospice programs is necessary to insure consumer protection, to preserve the integrity of the hospice concept, and to assure quality hospice program development.

I. LEGISLATIVE HISTORY AND BACKGROUND INFORMATION

In response to the growing interest and public support for the hospice concept in Virginia, the 1978 Virginia General Assembly passed House Resolution No. 84, which requested a Joint Subcommittee of the Committee on Health, Welfare and Institutions and the Committee on Corporations, Insurance and Banking of the House of Delegates "to study the necessary changes in State laws and regulations to establish hospices in Virginia." The Final Report of that Subcommittee (House Document No. 36, 1979) recommended that:

...the Department of Health conduct a two-year evaluative study of hospice programs throughout Virginia to provide data and to make recommendations to the General Assembly regarding the legislative action to facilitate the provision of hospice services in the Commonwealth. Criteria for standards defining appropriateness and quality of care and for licensure of hospice programs including both the home care and inpatient components should be investigated. Reliable cost data regarding reimbursement for hospice services which are not covered under third-party reimbursement policies, in addition to alternative reimbursement methods should be examined in the study. Comparisons of various health-care settings of hospice and the appropriateness of services provided to the patient and his family should be reviewed. The Department of Health is encouraged to coordinate its study of hospice with the evaluation being conducted under the direction of the United States Department of Health, Education, and Welfare and to encourage providers of hospice programs throughout the Commonwealth to apply with HEW for participation as demonstration projects.

This legislative request for an Evaluative Study of hospice programs proved most timely. The information obtained in the study is critical to promoting quality hospice program development in the Commonwealth. Although there are not yet nationally accepted standards of care or regulatory mechanisms to insure quality care and to facilitate reimbursement, research and demonstration projects have been funded by the Department of Health and Human Services (formerly DHEW), the National Cancer Institute, individual states, and local Blue Cross/Blue Shield Plans. In addition, employers are beginning to request inclusion of hospice care in their medical insurance benefit packages, in response to desires expressed by employee groups. Insurance carriers are also beginning to offer coverage for hospice care on a limited basis. However, insurers are concerned about the lack of systematic definitions of hospice care, and about the quality of services being offered. Overall it is estimated that over 500 institutions, groups, and/or agencies are engaged in the planning for or operation of hospice programs across the country. These factors reflect the importance of developing quality care standards, quality assurance mechanisms, and provider reimbursement mechanisms.

In response to the legislative mandate from the General Assembly, the Office of Health Planning and Resources Development of the Virginia Department of Health initiated an Evaluative Study of hospice programs in April 1979. As a first step, the Hospice Advisory Committee was formed in order to draw on the expertise of those individuals and groups most

knowledgeable regarding the hospice concept. This broadly-based technical group assisted the Department in examining and resolving issues surrounding hospice and its development in the Commonwealth.

The Advisory Committee is composed of representatives of all hospice programs in Virginia with Certificates of Need, third-party payers, regional health planning agencies, nursing homes, hospitals, the Virginia Medical Assistance Program, and the Bureau of Medical Facilities Services of the Virginia Department of Health. A detailed listing of the individual members of the Hospice Advisory Committee is provided as Appendix A.

II. INTRODUCTION TO THE HOSPICE CONCEPT

Originally, hospice was a medieval name for way stations for pilgrims and travelers where they could be replenished, refreshed, and cared for. As religious organizations became skilled in the care of the sick, the hospices evolved into hospitals. Hospices disappeared as such until the mid-nineteenth century when the Irish sisters of Charity formed hospice units, one being at Harold's Cross in Dublin. The first modern hospice, St. Christopher's, was developed in Syderham near London in 1962, after thirteen years of work and study by Dr. Cecily Saunders. The British model of hospice care is primarily institution-based, although in several presentations in this country Dr. Saunders has lauded the American innovation of home health care to the hospice concept.

During the past five years, hospice care has emerged as a growing mode of delivering health care services across the United States. Although most of the principles embodied in the hospice concept are not new to health care professionals, the application of the principles of hospice care in an organized, comprehensive fashion, which is responsive to the needs of the terminally ill and their families, is new.

The goal and objectives of an organized system of hospice care have been defined by the Hospice Advisory Committee to meet the needs of the terminally ill in the 1980's.

Goal:

To provide support and care for terminally ill patients and their families as they go through the traumatic life experience of progressive disease and ultimately reach the final stage of death.

Objectives:

- 1) To assist the terminally ill patient to live as fully as possible with the assistance of a dependable support system including the family and an interdisciplinary team.
- 2) To focus the coordinated efforts of a hospice trained interdisciplinary team (including patient and family) on the alleviation of physical, mental, emotional, and spiritual symptoms and to foster self-management, maximum comfort, optimal living, peaceful death, and resolution of loss.

- 3) To provide appropriate and cost effective alternatives to prolonged acute care hospital stays through appropriate home health services and flexible back-up inpatient services.
- 4) To supplement, not duplicate, existing services.
- 5) To educate health professionals and lay persons about hospice care for the terminally ill patient and family.

Within a health care delivery system that has stressed cure, rapid rehabilitation, and sophisticated technology, it is apparent that helping a patient and family achieve maximum comfort and a peaceful dying process represents a new emphasis. Prior to the widespread availability of hospitals and sophisticated life-saving technology, most people died at home, cared for principally by members of their extended family.

The hospice movement attempts to offer an alternative to the twentieth century reliance upon the institution rather than the home as the principal place for dying. With the centralization of effective medical technologies in hospitals, and the consequent transfer of seriously ill patients from home to a hospital or nursing home, family responsibility for and participation in the process of dying has gradually diminished. Instead, the care of dying patients has become the responsibility of hospital and nursing home staffs and subject to institutional priorities. In 1978, 75% of all recorded deaths in Virginia occurred in a hospital or nursing home where institutional regulations, procedures, and personnel resources govern the normal process of acute care. That process generally does not adequately address the psychosocial, spiritual, and palliative needs of the terminally ill or their families. The hospice concept of care has evolved in recognition of the unique needs of the dying patient for comfort, contact with family and friends, freedom from pain, and care at home.

Hospice is more than a concept. Hospice is a program that provides palliative and supportive care for terminally ill patients and their families in both home and inpatient settings, depending on the individual needs of the patient and family. Hospice care is not necessarily appropriate for all terminal patients and families, and should be viewed as an alternative care system which should be available as an option for those patients and families who choose palliative treatment modalities.

The Hospice Advisory Committee has adopted the following definition which captures the unique aspects of the hospice philosophy:

Hospice shall mean a coordinated program of home and inpatient care, under the direction of an identifiable hospice administration, providing palliative and supportive medical and other health services to terminally ill patients and their families. Hospice shall utilize a medically directed interdisciplinary team. A hospice program of care shall provide services to meet the physical, psychological, social, spiritual and other special needs which are experienced during the final

stages of illness and during dying and bereavement. Care should be available 24 hours a day, seven days a week.

Though diverse in organization, facilities, and personnel, hospices share similar components which are defined by six essential characteristics. First, the patient and family are considered the unit of care. Second, the team's commitment is to maximize patient comfort by symptom control, both physical and psychological. Third, there is a commitment to combining multidisciplinary professional resources so that support for patient and family is available 24 hours a day. Fourth, emphasis is placed on home care; if inpatient care is required, there is continuity of care, and care given is provided in a home-like atmosphere. Fifth, bereavement counseling and support are available to the family prior to and after the death of the patient. Sixth, specially trained volunteer workers are an intricate part of the effort to supplement the efforts of technically trained staff.

The first American hospice program was Connecticut Hospice, Inc., which began providing home care services in 1974. Through experience in the delivery of hospice home health services, Connecticut Hospice, Inc. identified a need for a back-up inpatient component of the hospice program. Such factors as preserving the integrity of the hospice concept and assuring continuity of care influenced the decision to construct an inpatient facility.

Generally, the hospice program models in the United States can be categorized in one of the following classes: community-based freestanding programs, institution-based or home health-agency based, depending on where the administrative responsibility for the program is located. Within each of the models, there are organizational variations.

Community-based freestanding hospice programs have developed where existing or new community organizations, not tied to another health organization, initiate and administer hospice services. Nationally the best known community-based model is Connecticut Hospice, Inc. Hillhaven Hospice in Tucson, Arizona, is another example of a freestanding hospice program. Initially, Hillhaven offered only inpatient hospice services but experience gained with their inpatient component identified a need for a home emphasis; therefore, a coordinated home and inpatient program was developed.

Institutional-based programs are administered by existing health care facilities, such as hospitals and nursing homes. Often an existing unit of a facility is remodeled to accommodate the unique requirements of hospice patients. Such a unit generally functions as part of the hospital or nursing home but has its own staff, which has been specially trained to care for the dying and their families. Additionally, institutional policies and procedures are relaxed in order to accommodate the special needs of the population. St. Luke's Hospital Center in New York in 1975 was one of the first hospitals to initiate such a hospice program, initially providing only inpatient care, but linkages with home health care are currently being explored.

The last type of hospice model is one sponsored by a home health agency. Hospice of Marin in San Rafael, California, is one example of this type. In order to assure continuity between inpatient and home care service, the hospice program has developed service agreements and/or contracts with local hospitals for the provision of inpatient care.

Generally, the model upon which a specific hospice is based reflects the special circumstances and resources of its individual community and state. The importance of allowing for flexibility, innovation, and local autonomy must be balanced with the importance of assuring the development of quality hospice programs.

III. HOSPICE PROGRAM DEVELOPMENT IN VIRGINIA

In Virginia, the hospice philosophy has stimulated interest in the development of hospice programs. As of October 1, 1980, there were three operational hospice programs in Virginia. In April 1979, Riverside Hospital in Newport News, Virginia, was granted a Certificate of Need to operate a demonstration hospice program. The Riverside program includes a seven-bed inpatient component and home health-care services provided in cooperation with the local health department in the Peninsula Health District.

Hospice of Northern Virginia, Inc. has been delivering hospice home health services since March 1978, first under arrangement with the Visiting Nurse Association of Northern Virginia, and since February 1980, as a licensed home health agency. In June 1979, this group received a Certificate of Need to renovate the Woodlawn School in Arlington to provide facilities for a 15-bed inpatient component and a base of operation for the home health-care component and other hospice staff. Completion of the renovation is expected in 1981.

In April 1980, Roanoke Memorial Hospitals in Roanoke, Virginia, began operation of a coordinated hospice program. The program has a ten-bed inpatient unit and home health services are being delivered in cooperation with the Roanoke-Salem Health Department.

In addition to the currently operational hospice programs in Virginia, a number of institutions and community groups have made formal contact with the Virginia Department of Health about the establishment of programs for the terminally ill. These groups are located in the following areas of the State: Norfolk, Suffolk, Winchester, Charlottesville, Fredericksburg, and Richmond. Many of these groups have sought technical and planning guidance from the Department of Health and the Hospice Advisory Committee. The Evaluative Study has provided important information for these groups to utilize in their planning efforts. The continued use of the Evaluative Study results will contribute to the orderly development of quality hospice programs in the Commonwealth.

Federal initiatives with hospice have also occurred in Virginia. In October 1979, the U. S. Department of Health, Education, and Welfare (now the Department of Health and Human Services) announced that 26 hospice programs were selected from 226 applicants as demonstration sites for an evaluation of hospice care. Two of the 26 programs selected are located

in Virginia: Hospice of Northern Virginia, Inc., and the Medical College of Virginia Cancer Rehabilitation and Continuing Care Program. The Medical College of Virginia Cancer Rehabilitation and Continuing Care Program is a certified home health program that offers nursing, occupational therapy, physical therapy, and speech therapy to cancer patients. The demonstration was initiated on October 1, 1980, and will be in effect for two years. An additional year will be required for the evaluation of the demonstration results.

This National study represents a strong commitment at the Federal level to evaluate the claims that hospice is a more appropriate system of care for terminally ill patients in terms of providing both humane care and cost-effective care. Specifically, the study will obtain policy-relevant information about the probable demand for, costs of, and appropriateness of Titles XVIII and XIX (Medicare and Medicaid) reimbursement for hospice services. The study will attempt to answer the following fundamental questions:

- 1) How do costs of care provided to the terminally ill through hospices compare with that provided through the "traditional" care setting, and what is the likely demand for such hospice care?
- 2) Are hospice care and its costs additional to, or in lieu of that provided the terminally ill outside the hospice -- would total costs of serving the terminally ill through hospice care be more or less expensive than such service through traditional, non-hospice care?
- 3) How does the quality of, and satisfaction of the patient, and family, with care provided in the hospice setting compare with that provided outside the hospice?
- 4) What would be the likely consequences for hospices, hospice care, and demand for such care of a decision to reimburse for hospice services through Titles XVIII and XIX or other third-party payers?¹

In addition to evaluating these four questions, the demonstration projects will be reimbursed for providing selected services, such as bereavement, home health aides, continuous care nursing, and respite care which are not currently reimbursable under Medicare legislation.

At the request of the General Assembly, the Department of Health, the Virginia Medical Assistance Program, also filed an application with the Department of Health, Education, and Welfare for waivers of Medicaid restrictions on reimbursement for hospice services. The Medicaid proposal also would allow for reimbursement of hospice services which are not currently covered in the Virginia Plan for Medical Assistance. The Department of Health was officially notified on September 29, 1980, that the Virginia Medical Assistance Program will be participating in the demonstration effort.

¹National Hospice Study, Solicitation for Grant Applications, sponsored by the Health Care Financing Administration, the Robert Wood Johnson Foundation and the John A. Hartford Foundation, May 1, 1980.

It should be stressed that whereas House Joint Resolution No. 252 encouraged coordination of the Federal Department of Health and Human Services (formerly DHEW) Demonstration and the Virginia Evaluative Study, this coordination has not occurred due to significant time delays in the selection of the Federal demonstration sites, the development of service definitions at the Federal level, and the start-up date. It is unfortunate that the potential benefits of such a coordinated study were lost. However, the Virginia Department of Health and the Hospice Advisory Committee have monitored closely the Federal efforts. Copies of the Evaluative Study documents have been forwarded to the Department of Health and Human Services, Health Care Financing Administration, for consideration in planning for the demonstration projects.

IV. STUDY DESIGN OF HOSPICE EVALUATIVE STUDY

At its first meeting in April 1979, the Hospice Advisory Committee assisted the Department of Health in drafting the following specific study objectives to guide the two-year Evaluative Study.

STUDY OBJECTIVES:

- 1) To identify the types of patients served, range of services provided, and utilization of those services in the home and inpatient settings;
- 2) To describe and evaluate hospice in various settings as an alternative service and delivery system for the care of the terminally ill;
- 3) To consider and evaluate the comparative costs of hospice services provided in different settings and varying hospice modes;
- 4) To develop standards regarding appropriateness and quality of care;
- 5) To determine the extent of need for hospice programs and to develop comprehensive planning standards and criteria for hospice program development;
- 6) To determine the most appropriate quality assurance mechanism for hospice programs;
- 7) To identify alternative reimbursement mechanisms;
- 8) To compare and assess hospice services relative to services to terminally ill patients provided in hospitals and skilled nursing facilities;
- 9) To consider the effect of hospice services on reimbursable and non-reimbursable costs;
- 10) To determine changes necessary to Titles XVIII and XIX (Medicare and Medicaid) and other sources of third-party payment to accommodate the provisions of hospice care.

In order to accomplish these objectives, the Department of Health with the assistance of the Hospice Advisory Committee set out to complete

the following major tasks:

- 1) Development of a working definition of a hospice program and its program components;
- 2) Development of planning guidelines which would provide the basis for both determining the need for hospice programs and establishing the quality components of such programs;
- 3) Collection of pertinent data from operational hospice programs in Virginia;
- 4) Investigation of the alternative mechanisms for quality assurance;
- 5) Identification and study of the limitations of current reimbursement for the full range of hospice service.

The Hospice Advisory Committee has met at least monthly since April 1979. The primary goal of the Department and the Committee in conducting the Evaluative Study has been to develop a coherent State policy which would provide for the orderly development of quality hospice programs in the Commonwealth. The Hospice Advisory Committee recognized that the uniqueness of the hospice concept and the newness of hospice programs tend to cause confusion among lay persons and health care professionals regarding appropriate standards of care, quality assurance mechanisms, reimbursement, and health planning. However, through discussion and study of these issues, significant progress has been made. It is believed that the open dialogue among providers, third-party payers, planners, and regulators should continue. Towards that end, the Hospice Advisory Committee has agreed to continue its work to assist the Department of Health with the further examination of hospice programs in the Commonwealth.

V. SIGNIFICANT ACCOMPLISHMENTS

As reported in Section IV, ten specific objectives were developed for the Hospice Evaluative Study. The results of the tasks associated with the study objectives are presented in this section of the report. Each objective is identified, and activity relating to the objective is then discussed.

A. STUDY OBJECTIVE #1

To identify the types of patients served, the range of services offered, and the utilization of services provided by hospice in the home and inpatient settings

1. Discussion

As stated in the Interim Report (House Document No. 9, 1980), study of the operational programs in Virginia was a priority activity for the second year of the Evaluative Study. The Hospice Advisory Committee advised the Department of Health in selecting those data elements which would assist the Commit-

tee in achieving the study objectives. A copy of the data collection instruments is included as Appendix B.

Representatives from Certificate-of-Need approved hospice programs (i.e. the three hospice providers represented on the Advisory Committee) agreed to participate in the data collection effort. However, the ability to collect data has been limited for several reasons. It was initially anticipated that data could be obtained from the three approved comprehensive programs (i.e. home health and inpatient care). However, Roanoke Memorial Hospitals Hospice Program did not begin operation until April 1980, and Hospice of Northern Virginia, Inc. has not opened its inpatient unit. Additionally, all hospice programs are still in a developmental phase, and, therefore, the data generally reflect the "newness" of the programs. Nevertheless, preliminary program and patient demographic data have been collected from Hospice of Northern Virginia, Inc. and Riverside Hospice for the period January 1, 1980 through June 30, 1980.

Information collected from these two programs which has aided in the achievement of the first objective is presented below. The types of patients served, the range of services offered, and the utilization of services provided are described first for Hospice of Northern Virginia, Inc., and then for Riverside Hospice.

2. Hospice of Northern Virginia, Inc. (HNV) Home Care Program

Information was obtained from discharge abstracts for patients admitted between January 1, 1980, and June 30, 1980, who died prior to July 12, 1980.

a. Types of Patients Served

Statistics on age, sex, diagnosis, responsible caregiver, and referral source for the 73 (one male was of unknown age) patients served are presented below:

(1) Age

	<u>All Patients</u>	<u>Male</u>	<u>Female</u>
Mean	63.375	61.744	65.793

(2) Age Distribution

<u>Age</u>	<u>Frequency</u>
Less than 45 years	4
45 - 54 years	13
55 - 64 years	19
65 - 74 years	19
75 - 84 years	15

<u>Age</u>	<u>Frequency</u>
84 years and over	<u>2</u>
Total	<u>72</u>

(3) Sex

Male	44
Female	<u>29</u>
Total	<u>73</u>

(4) Most Frequently Named Diagnostic Categories

<u>Diagnosis</u>	<u>Number of Patients</u>	<u>Percentage</u>
Cancer of the Lung	18	24.66
Cancer of the Colon	12	16.44
Cancer of the Breast	6	8.22
Cancer of the Pancreas	4	5.48
Cancer of the Bladder	3	4.11
Cancer of the Prostate	3	4.11
Other Cancer Diagnoses	26	1.36
Other Diagnoses	<u>1</u>	<u>35.61</u>
Total	<u>73</u>	<u>100.00</u>

All but one of the 73 patients were cancer victims. That one individual was diagnosed as having congestive heart failure with additional complications.

(5) Most Frequently Named as Responsible Caregiver

<u>Responsible Caregiver</u>	<u>Number of Times Quoted</u>
Wife	31
Daughter	12
Husband	11
Son	4
Son and Wife	3

(6) Most Frequently Named Referral Source

<u>Referral Source</u>	<u>Number of Patients</u>	<u>Percentage</u>
Physician	20	27.40
Home Health Agency	19	26.02
Family	17	23.29
Hospital	9	12.33
Friend	3	4.11
Other	<u>5</u>	<u>6.85</u>
Total	<u>73</u>	<u>100.00</u>

b. Range of Services Offered

Both patient care services in the home and bereavement services were provided by Hospice of Northern Virginia, Inc.

(1) Patient Care Services

During the reporting period, Hospice of Northern Virginia directly provided physician services, skilled nursing services, social work services, and volunteer services. In addition, the program contracted for skilled nursing (prior to licensing as a home health agency), home health aides, physical therapy, occupational therapy, and psychologist services.

Since the complete program was recently initiated, the sample size was small. Therefore, a presentation of more detailed data on patient-care services, such as average number of services provided per patient, is not believed to be meaningful. Data efforts will be continued for a minimum of the period July 1, 1980, to December 31, 1980. This additional information should allow for a more detailed analysis and evaluation.

Additionally, these data collection efforts may allow for an analysis to determine possible correlations between the following variables:

- 1) Number of type of services and age.
- 2) Number of type of services and length of stay.
- 3) Number or type of services and diagnoses.
- 4) Length of stay and diagnosis.

(2) Bereavement Services

Bereavement services have also been provided by Hospice of Northern Virginia. Information was received on 44 hospice patients who died between January and July, 1980. A total of 111 visits were made, or an average of 2.52 visits per patient. No services were provided to five families either because of discontinued contact after patient death or because alternative means of support were determined to be available (e.g. hospital staff or community provided adequate support, etc).

A review of the data collection forms indicates that the spouse or client group (family) were the most frequent recipients of bereavement services. The

majority of visits involved a one-to-one contact between the client and the provider of the services. The provider was most often either a volunteer or a nurse (R.N.) and the service was most often provided either at the client's home or in staff initiated telephone conversation. The majority of the bereavement contacts were made for support and assessment of the client.

c. Utilization of Services

As previously noted, at this time it is difficult to present a meaningful analysis of the number of visits received per patient. However, the length of stay in the program can provide some insight into the utilization of services.

An average length of stay of 24.82 days was calculated on a total of 71 patients. The information recorded on discharge abstracts of the two remaining patients did not allow for a clear determination of length of stay in the program. The percentage breakdown of the 71 patients reveals the distribution of the length of stay.

Cumulative Percentage of Patients Discharged
by Length of Stay:

	Cumulative %			
	50%	75%	90%	95%
Length of Stay	18 days	37.5 days	61.8 days	76.45 days

3. Riverside Hospice Program

Riverside Hospital's Hospice Program has been in operation since April of 1979, and consists of both inpatient and home health care. The information presented here was obtained from discharge abstracts for the 52 patients in the program during the first six months of 1980 (17 of these patients were first admitted to the program between June and December, 1979).

a. Types of Patients Served

Statistics on age, sex, diagnosis, responsible caregiver, and referral source for the 52 (one female was of unknown age) patients served are as follows:

(1) Age

	<u>All Patients</u>	<u>Male</u>	<u>Female</u>
Mean	65.02	65.64	64.55

(2) Age Distribution

<u>Age</u>	<u>Frequency</u>
Less than 45 years	5
45 - 54 years	7
55 - 64 years	7
65 - 74 years	20
75 - 84 years	8
84 years and over	<u>4</u>
Total	51

(3) Sex

Male	22
Female	<u>30</u>
Total	52

(4) Most frequently Named Diagnostic Categories

<u>Diagnosis</u>	<u>Number of Patients</u>	<u>Percentage</u>
Cancer of the Lung	14	26.92
Cancer of the Colon	6	11.54
Cancer of the Breast	4	7.69
Cancer of the Neck	4	7.69
Metastatic Cancer - Primary Location Unspecified	4	7.69
Other Cancer Diagnoses	18	34.62
Other Diagnoses	<u>2</u>	<u>3.85</u>
Total	52	100.00

All but two of the 52 patients were diagnosed as having cancer. Of those two patients, one had an unknown diagnosis and the other was diagnosed as having MS/ALS (Multiple Sclerosis/Amyotrophic Lateral Sclerosis).

(5) Most Frequently Named as Responsible Caregiver

<u>Responsible Caregiver</u>	<u>Number of Times Quoted</u>
Daughter	13
Wife	12
Husband	12
Son(s)	4
Unknown	4

(6) Most Frequently Named Referral Source

<u>Referral Source</u>	<u>Number of Patients</u>	<u>Percentage</u>
Physician	43	82.69
Family and Physician	8	15.39
Unknown	1	1.92
Total	52	100.00

b. Range of Services Offered

Summaries of both patient care services and bereavement services are presented below.

(1) Patient Care Services

(a) Inpatient

During the reporting period, Riverside Hospice directly provided physician, skilled nursing, social work, physical therapy, occupational therapy, psychological, volunteer services, and chaplains' services to their patients.

(b) Home Health

Riverside contracted with the Peninsula Health Department for skilled nursing and home health aide services. The Hospice directly provided psychologist, volunteer, and chaplains' services.

As discussed previously, since the program was recently initiated, the sample size is limited and a presentation of the number of services provided per patient would not be meaningful at this time. Continued data collection will serve to allow for such an analysis in the future.

(2) Bereavement Services

Bereavement service information was provided on 51 hospice patients. A total of 140 visits were made, or an average of 2.745 visits per patient. No information was provided for one patient. In four cases no bereavement services were provided either because the intended client did not desire bereavement follow-up or because of discontinued contact with family members.

A review of the data collection forms indicates that the spouse or a child were the most frequent

recipients of bereavement services. The services were provided most often by registered nurses and volunteers and most frequently involved support and/or funeral attendance. Approximately one-third of the services were provided through staff initiated telephone contact.

c. Utilization of Services

An average length of stay of 56.298 days was calculated for 47 patients. Five patients' lengths of stay could not be determined from information recorded. Additional analysis reveals that a few patients had exceptionally long stays in the program. This caused the relatively high average length of stay.

Cumulative Percentage of Patients Discharged
by Length of Stay:

Length of Stay	Cumulative %			
	50%	75%	90%	95%
	18.5 days	60.5 days	175 days	201.3 days

The type of care received by these 47 patients is shown as follows:

	Number of Patients	% of Patients	Days of Care	% of Total Days of Care	ALOS
Received Inpatient Care Only	25	53.19	250	9.45	10.0
Received both Inpatient and Home Health Care	20	42.55	2295	86.73	114.75
Received Home Health Care Only	2	4.26	101	3.82	50.5
Total	47	100.00	2646	100.00	

Most of the 20 patients who received both inpatient care and home health care during their stay in the program spent a greater amount of time as home health patients than as inpatients.

	Days of Care	% of Total Days of Care	ALOS
Inpatient Portion	941	35.56	47.05
Home Health Portion	1354	51.17	67.7

B. STUDY OBJECTIVE #2

To describe and evaluate hospice in various settings as an alternative service and delivery system for the care of the terminally ill

Discussion

The achievement of this objective is based upon study of the two operational programs in Virginia.

The information presently available, which will be presented below, allows for an initial comparison of the two programs. However, for a meaningful evaluation to be possible, data must be collected for a longer period of time, and additional analysis performed by the Hospice Advisory Committee and the Department of Health.

Comparison of the program data submitted by Hospice of Northern Virginia, Inc., and Riverside Hospital reflects the following differences and similarities between the two programs:

1) The two programs operate different models of hospice programs; one is a freestanding organization and the other is a hospital-based program; 2) Hospice of Northern Virginia, Inc. offers only home health care services at the present time; 3) both the programs are relatively new; 4) the services offered by the programs are basically the same.

A brief comparison of the data submitted by the two programs reveals the following points:

- The mean age of the patients served by both programs has been similar and, as predicted, most patients have been 65 years of age or older.
- Total patients served for the time period January 1, 1980, to June 30, 1980, were 52 for Riverside and 73 for Northern Virginia.
- For both programs the most frequently named referral source was the physician.
- For both programs the three most frequent diagnostic categories were cancer of the lung, cancer of the colon, and cancer of the breast. Of the total of 125 patients served by both programs, only three patients did not have a diagnosis of cancer.
- The three most frequently named responsible caregivers for both programs were daughter, wife, and husband. However, for Hospice of Northern Virginia, Inc. the wife was most frequently named, while for Riverside Hospice the daughter was most frequently named.
- The average length of stay statistic also merits comment. It is not possible to determine at this point an accurate analysis of the average length of stay, because those patients admitted to the program during the six months period but who were still alive on June 30, 1980 were not reported. It is apparent that Hospice of Northern Virginia receives referrals towards the end of the terminal phase, as shown by a mean length of stay of 26.7

days. Patients who are referred towards the end of the terminal phase may not receive as much benefit from the total plan of care. A study by the National Hospice Organization in 1979 revealed a similar length of stay for 20 hospice programs across the country.² However, the literature reveals that as health professionals, particularly physicians, and consumers become more educated to the hospice program, earlier referrals are received and the average length of stay increased. It appears from the Riverside length of stay statistic (56.29 days) that referrals are received earlier in the terminal phase than are referrals received by Hospice of Northern Virginia. Nevertheless, a terminal patient has been defined as a person with a life expectancy of six months or less. One prominent reason for the selection of the "six months or less" was the belief that appropriate palliative and supportive care plans took time to establish, and that the true benefits of hospice care could not be realized in a relatively short period of time. The average length of stay statistic should be monitored as knowledge of the hospice concept increases.

As the Advisory Committee continues its efforts, similarities and differences between the two program models will be evaluated. Issues to be examined in the future monitoring of these hospice programs include: Will the length of stay in the home care component of a program increase as patients, families, and physicians become more knowledgeable about care at home and are helped by the hospice team to overcome fears? Will home visitation by a physician increase the likelihood of being able to die at home? Is the volunteer component linked to the likelihood of being able to die at home? What effect does the particular organizational model have on the utilization of the various services? These and other questions underscore the need for continued evaluation.

C. STUDY OBJECTIVE #3

To consider and evaluate the comparative costs of hospice services provided in different settings and varying hospice modes

Discussion

The Hospice Advisory Committee attempted to evaluate the comparative costs of hospice services provided through varying organizational models. The two operational programs, Hospice of Northern Virginia, Inc. and Riverside Hospice, were requested to submit extensive financial data including total operating costs for both home health and inpatient care, total revenue by source, patient and insurance revenue by service and source, services billed vs. services reimbursed, and non-reimbursable services. This information has been collected for the period January 1, 1980, to June 30, 1980, from the two operational programs. However, the Department of Health agrees

²Delivery and Payment of Hospice Services: Investigative Study, National Hospice Organization, Final Report, September 1979.

with the Hospice Advisory Committee that the data are incomplete and do not reflect an accurate presentation of costs. The reasons include the following: the two programs are still in developmental stages; Hospice of Northern Virginia does not yet provide an inpatient component; the patient sample size is too small; and record-keeping systems require revision in order to allow for accurate reporting of the information. Additional experience with, and a longer period of time for, the collection of financial information will contribute to more meaningful data presentation and analysis.

The issue of cost effectiveness was also addressed. There is a close relationship between the issues of cost effectiveness and the potential for third-party payment. Contentions surrounding cost effectiveness cover a wide range. Some believe that hospice care is an additional layer of service and will, therefore, add to the total cost of care. Others view hospice care as either a substitution for services currently available which will cost less than traditional services, or as a reallocation of services that will lead to no net change in the overall cost of care. It is too early to resolve some of the primary cost effectiveness issues based on the data received to date on Virginia hospice programs. Nevertheless, four out of five reimbursement policy issues identified by a National Hospice Organization Study have been answered. These issues are: 1) What is hospice care and how does it differ from benefits currently offered? 2) Is there a demand for hospice care services? 3) Is there a community need for hospice care services? 4) Does payment for hospice care offer potential cost savings, cost substitution, or cost addition? 5) What is the capability of the delivery system to provide quality hospice services?

The definitions of hospice programs and their essential components have been formulated; acceptable planning guidelines which project need for hospice programs have been drafted and will be incorporated into basic State policy documents (refer to Study Objective #4); demand for payments for hospice services is being made by group accounts, subscribers and providers of care; and the capability of the delivery system to provide quality service will be monitored through an appropriate quality assurance mechanism. (Refer to discussion under Objective #6.) The issue of cost savings or cost substitution is not answerable at the present time. After two years of study in Virginia, however, more is known about patients who typically use hospice care services, service definitions have been formulated, and policies regarding integration of hospice services and quality control have been drafted. These accomplishments represent important first steps toward resolution of reimbursement issues. Tasks which remain are resolution of additional reimbursement issues such as 1) Which hospice services should be covered? 2) Should payment continue to be provided under existing benefits through selected modifications to benefits, or by developing a new and distinct hospice benefit? 3) What changes in eligibility requirements will be needed if existing benefits are used? 4) What are appropriate rates to pay for hospice services? 5) What is the appropriate provider payment mechanism to encourage cost efficiencies without jeopardizing quality? 6) Are new provider agreements neces-

sary for hospice care if an arrangement currently exists with the provider for the provision of other services? 7) What are the components of utilization review criteria designed to monitor appropriate use of the hospice services? 8) How can the impact of paying for hospice services be evaluated?

D. STUDY OBJECTIVE #4

To develop standards regarding appropriateness and quality of care

Discussion

The Hospice Advisory Committee determined that the first step in achieving this objective was the formulation of definitions of service. The Committee drafted a definition of a hospice program, goals and objectives of a hospice program and components of a program which must be in place for there to be a quality program. These definitions are as follows:

Definition of Hospice

"Hospice shall mean a coordinated program of home and inpatient care under the direction of an identifiable Hospice Administration providing palliative and supportive medical and other health services to terminally ill patients and their families. Hospice shall utilize a medically directed interdisciplinary team. A Hospice Program of Care shall provide care to meet the physical, psychological, social, spiritual and other special needs which are experienced during the final stages of illness, and during dying and bereavement. The care shall be available 24 hours a day, seven days a week."

Definition of Terms

1) "Hospice patient" shall mean a terminally ill patient, with a life expectancy of six months or less, who, alone or in conjunction with designated family member(s), has voluntarily requested admission and been accepted into a hospice program for which the Department of Health has issued an operating Certificate of Need.

2) "Hospice patient's family" shall mean the hospice patient's immediate relations, including a spouse, brother, sister, child or parent. In addition, other relations and individuals with significant personal ties to the hospice patient may be designated as members of the hospice patient's family by mutual agreement among the hospice patient, the relation or individual, and the hospice team.

3) "Identifiable hospice administration" shall mean an administrative group, individual or legal entity that has a distinct organizational structure, accountable to the governing authority. This administration shall be responsible for the management of all aspects of the program.

4) "Interdisciplinary team" shall mean the patient and the patient's family, the attending physician, and the following hospice personnel: hospice physician, nurse, social worker, and trained volunteer. Providers of special services, such as clergy, mental health, and pharmacy, and any other appropriate allied health service shall also be included on the team as the needs of the patient dictate.

5) "Bereavement service" shall include counseling and support services to be offered during the bereavement period, which is that period of time after the death of a loved one.

6) "Palliative care" shall mean that treatment directed at controlling pain, relieving other symptoms, and focusing on the special needs of the patient and family as they experience the stress of the dying process, rather than the treatment aimed at investigation and intervention for the purpose of cure or prolongation of life.

A review of the literature, experience or programs in Virginia, and discussion among experts in planning and reimbursement were among the steps taken to formulate a basic description of a quality hospice program. Once this activity was completed, it was possible to devise planning guidelines and standards/criteria by which to evaluate potential providers of hospice care. The Committee is currently working on specific standards for operational hospice programs. These will become the substance of regulations for quality assurance. (See Study Objective #6)

E. STUDY OBJECTIVE #5

To determine the extent of need for hospice programs and to develop comprehensive planning standards and criteria for hospice program development

Discussion

The issues of quality program standards and criteria for licensure are inextricably linked with the development of comprehensive planning standards and criteria. Criteria are those measurable characteristics of the health systems which serve as analytic tools on which evaluations and judgments may be based. Standards are desired levels or values of criteria which may be expressed in terms of the presence or absence of certain characteristics or degrees of conformance with an ideal. Standards and criteria are utilized in the Certificate of Public Need review process. Therefore, planning standards and criteria relative to availability, accessibility, continuity, cost and quality of proposed programs provide valuable tools for planning and development of hospice programs. The Department of Health with the assistance of the Hospice Advisory Committee has drafted standards and criteria for hospice programs. These are included as Appendix C. These guidelines will be incorporated into the proposed State Medical Facilities Plan to be reviewed by the public and adopted by the State Board of Health in early 1981 under the provisions of the Administrative Process Act. Such guidelines will enable potential hospice providers to plan for the provision of

certain minimum program components. Additionally, the use of these guidelines in the Certificate of Public Need process will insure that potential providers will be evaluated based on objective measures. These planning guidelines are designed to preserve the unique aspects of hospice programs at the "front end" of the development process.

A secondary benefit of these standards and criteria is that they form the basis for quality program standards, which can be incorporated into licensure standards with minimal modification. Thus, there will be consistency within State policy towards the development and monitoring of the quality of hospice programs. Formulation of such guidelines is never an easy task. However, the Department of Health and the Hospice Advisory Committee are confident that each guideline has been thoroughly assessed. The result is a strong consensus among knowledgeable persons and a set of meaningful guidelines.

F. STUDY OBJECTIVE #6

To determine the most appropriate quality assurance mechanism for hospice programs.

Discussion

Throughout the Evaluative Study, the Department of Health and the Hospice Advisory Committee have worked toward the goal of developing policy which will foster quality hospice program development. The Department of Health and the Hospice Advisory Committee have noted the growing interest across the State and country in the hospice concept. It is also recognized that the relatively few hospice programs across the country which have been operating for a significant period of time are operated by highly motivated, competent and compassionate groups. These groups have been the innovators as well as standard setters. The successes of these early programs have sparked the interest and enthusiasm of other community groups and existing health care facilities. As a result, concern has been expressed nationally and at the State level that new programs should be required to function at the same high level of competence.

Discussion of the manner in which that requirement can be enforced has consumed a major portion of the study effort. It is recognized that hospice is and should remain a flexible, innovative program, since it is necessary to promote new ideas and approaches to the care of terminally ill patients; at the same time, the basic integrity of the hospice concept must be preserved, and the health-care consumer must be protected.

Various quality assurance mechanisms, such as licensure, certification, and accreditation were explored during the past year. Particular attention was paid to striking a balance between needed regulation and promotion of flexibility. The Department of Health and the Hospice Advisory Committee believe that regulatory activity directed at hospice programs should have three purposes: protection of the consumer, preservation of the unique aspects of hospice, and

establishment of minimum standards of quality programs. These three purposes are discussed in further detail below:

1) Protection of the Consumer - Although the term "hospice" has gained notoriety and publicity, quality hospice programs were not well defined prior to this study. The public is not well informed as to the services that should be essential to a quality hospice program. Unless appropriate standards of quality care are developed and the mechanisms for regulating the maintenance of quality are in place, the public may be at risk. This is especially important since this is a particularly vulnerable time for terminally ill patients. The public should be assured that, at a minimum, a hospice program is administered properly, employs qualified personnel, offers services which reflect the hospice concept, and establishes effective internal quality assurance programs.

2) Preservation of the Unique Aspects of Hospice - Hospice care is different from traditional terminal care, provided in an institutional setting where the emphasis is appropriately placed on cure and rehabilitation. The unique aspects of hospice, such as the patient and family as the unit of care, emphasis on home care, palliative and supportive care, use of an interdisciplinary team, continuity of care (both service and personnel), bereavement services, continuous availability of care (24 hours a day, seven days a week), and structured support services for the staff, should be preserved through a distinct regulatory activity. There are different regulatory procedures for inpatient and home care providers. As hospice care combines both modes of care, hospice cannot be simply categorized either as inpatient or home care providers for the purpose of licensure. The ongoing program operation should be monitored as a whole with particular attention given to those unique aspects of hospice care.

3) Monitoring of Quality Program Standards - Quality program standards are directly linked to the issue of reimbursement. The Hospice Advisory Committee has established minimum quality program standards through formulation of the planning guidelines for hospice programs. Some of the services considered to be integral to a total hospice program are not reimbursable under existing third-party coverage. However, in spite of the current financial disincentive to offer these services, it is essential that they be provided. Minimum program standards are helpful in two respects: 1) third-party payers are able to evaluate an individual program against these standards, and, 2) a third-party payer, as well as the general public, can identify those providers who meet these standards and are capable of delivering high-quality hospice services.

The Department of Health and the Hospice Advisory Committee have determined that licensure would be an appropriate mechanism for quality assurance. First, licensure provides a formal process for monitoring and evaluating the competence of all providers of a given service, and, therefore, it provides an accurate measurement of essential program components. Secondly, the administrative mechanism for licensure is currently in place within the Department of Health. Third, the majority of third-party payment contracts contain a phrase

that care must be provided by "licensed facilities or services." These reasons, coupled with the need to protect the consumer, the need to preserve the unique aspects of hospice and the need to monitor quality care standards, support the conclusion that regulation through licensure is the most appropriate quality assurance mechanism.

Should licensing authority be granted, the Department of Health intends to request the continued advice of the Hospice Advisory Committee in the implementation of the licensure function.

G. STUDY OBJECTIVE #7

To identify alternative reimbursement methods

Discussion

It had been the intent of the Hospice Advisory Committee to draw upon the national effort in order to assess alternative reimbursement methods. However, due to the delay in the initiation of the demonstration, projections upon which the analysis was to be based have not taken place. The Hospice Advisory Committee and the Department of Health intend to continue the collection of cost and reimbursement data in an effort to evaluate possible alternative reimbursement methods for implementation in Virginia.

H. STUDY OBJECTIVE #8

To compare and assess a hospice program of care with services to terminally ill patients provided in hospitals and skilled nursing facilities

I. STUDY OBJECTIVE #9

To consider the effect of hospice on reimbursable and non-reimbursable costs

Discussion

These objectives were to be analyzed on the basis of the Department of Health and Human Services demonstration effort. The resources assigned to implement the evaluative study of hospices by the Department of Health were insufficient to allow for completion of these study objectives. The Hospice Advisory Committee acknowledges the importance of these particular objectives to the resolution of reimbursement policy issues, and the contention of hospice advocates that hospice care is more appropriate; however, such an objective is beyond the scope of this study. The DHSS, through the Health Care Financing Administration, has designed their evaluation study of hospices to include matching samples of patients in both hospice programs and conventional care settings, such as hospitals. Within the DHHS study activity, fulltime data collectors will be assigned to each hospice site as well as to the control sample in the conventional care settings. The results of the DHHS study will be assessed by

the Department of Health for future consideration. These results, when available, will be shared with the Governor and the General Assembly.

J. STUDY OBJECTIVE #10

To determine changes necessary to Titles XVIII and XIX (Medicare and Medicaid) and other sources of third-party payment to accommodate the provisions of hospice care

Discussion

This objective was to be evaluated on the basis of the results of the Department of Health and Human Services Demonstration Projects. Changes in Medicare and Medicaid policies must take place at the Federal level. The demonstration projects were established specifically to identify changes in certain Medicare/Medicaid policies which hinder the provision of total hospice care and to determine what fiscal impact there would be if changes are made permanently. Certain unique aspects of hospice care are at variance with current third-party payment structures and policies. Current reimbursement policies emphasize cure and rehabilitation. The unit of care is the patient, not the patient and family. Such services as bereavement care, social work services, and spiritual counseling are not typically reimbursable. Additionally, certain restrictions on eligibility for receipt of services through Medicare and other sources of third-party payment compound the problem. Examples of these restrictions include: the requirement that a patient be homebound to be eligible for home health care; limits on the total number of home visits; requirement for skilled nursing care services to be given during any visit; and the requirement that a patient must have been hospitalized for at least three days to be eligible for reimbursement for home health care. These restrictions among others will be "waived" during the DHHS Demonstration effort. As described earlier, the Department of Health will be monitoring the results of these demonstration efforts through the Virginia Medical Assistance Program participation in the waiver program.

VI. SUMMARY AND CONCLUSIONS

House Joint Resolution No. 252 requested the Department of Health to "conduct an Evaluative Study of hospice programs in Virginia and to make recommendations regarding standards for the quality of care, criteria for licensure, and reimbursement of both the home care and inpatient components of hospice programs provided in a variety of health care settings and geographic areas of the State."

The Department of Health and the Hospice Advisory Committee believe that significant progress has been made in the priority areas identified for study by the General Assembly.

The findings and conclusions may be summarized as follows:

- The Department of Health and the Hospice Advisory Committee have drafted definitions of a hospice program and its care components. These definitions provide an excellent foundation for quality program standards, licensure, planning guidelines, and the appropriateness of hospice programs.
- The Department of Health and the Hospice Advisory Committee have developed planning guidelines relating to availability, accessibility, quality, continuity and cost. The guidelines answer the questions of the total need for hospice programs in the State, and of program components which should be planned in order to have a quality hospice program.
- The Department of Health, with the cooperation and assistance of hospice providers of care, have collected and summarized preliminary program and patient demographic data. It is the consensus of the Department of Health and the Hospice Advisory Committee that continued collection and monitoring of data are necessary. For a thorough and careful evaluation of both utilization of services and cost data to be possible, more data must be collected over an extended period of time. The estimate of additional time needed to complete the data effort is one to two years. The Department of Health and the Hospice Advisory Committee believe that the continued data collection and detailed analysis will result in sound State policy for hospice program development.
- The Department of Health and the Hospice Advisory Committee recommend that quality care assurance through the licensure mechanism be instituted as soon as possible. Standards which can form the basis for licensure criteria have been formulated. Licensure is a necessary regulatory activity for the following reasons: need for consumer protection; need to preserve the unique aspects of the hospice concept; and third-party payment issues. The philosophy underlying such a licensure requirement would be to allow for quality hospice program development, to be sufficiently flexible in order to promote innovation, to be nonduplicative of other licensure requirements and to preserve the integrity of the hospice concept and its application in Virginia.
- The Department of Health and the Hospice Advisory Committee recommend that the question of reimbursement for hospice services remain open at this time. It is the consensus of the Department and the Committee that until licensure standards have been enacted and are in place, and until sufficient cost and utilization data on appropriate hospice services are made available, it would be premature to make any recommendation for legislative action on reimbursement. However, the Department of Health and the Hospice Advisory Committee do recommend the continued monitoring of cost, utilization, and reimbursement data with the understanding that the Department, in conjunction with the Hospice Advisory Committee, would propose legislative action should it be necessary at a later time. In the interim, the Department of Health and the Hospice Advisory Committee strongly encourage all third-party payers to continue to explore and establish both pilot programs and new benefit packages relating to hospice care.

- The Virginia Department of Health and the Hospice Advisory Committee recommend the continuation of the evaluative study of hospice programs in order to complete specific study objectives still in progress. To allow for the continuation of the evaluation, a Study Resolution is required.

VII. LEGISLATIVE COORDINATION

As required by Senate Joint Resolution No. 80, the Hospice Advisory Committee of the Department of Health is working cooperatively with a Subcommittee of the Senate Committee on Education and Health, and the House of Delegates Committee on Health, Welfare, and Institutions in developing a legislative proposal for licensure of hospice care in the Commonwealth. This subcommittee will report their findings and recommendations to the Governor and the 1981 Session of the General Assembly.

Respectfully Submitted,



James B. Kenley, M.D.
State Health Commissioner

APPENDIX A
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PATIENT DISCHARGE FORM

Hospice Program _____

Date Completed _____

Patient Number _____

A. Demographic Data

County/City of residency _____

Date of Birth _____

Sex _____ Race _____

Zip Code _____

Specialty of patient's physician _____

Diagnosis (ICDA-9-CM) _____

Prognosis _____

Responsible Caregiver

Family Member (specify) Relationship _____

Friend _____ None _____

Type of residence

House _____ Apartment _____ Nursing Home _____ Domiciliary care home _____

Other (specify) _____

B. Admission/Discharge Data

Date Admitted to Program _____ Date Discharged _____

Reason for discharge _____ Length of stay (days) _____

Date admitted to inpatient care _____ Date Discharged _____

Length of stay (days) _____

Date readmitted to inpatient care _____ Date Discharged _____

Length of stay (days) _____

Date readmitted to inpatient care _____ Date Discharged _____

Length of stay (days) _____

Place of death _____ Home _____ Inpatient Hospice Unit _____ Hospital _____ Nursing Home

_____ Other (specify) _____

Referral Source

Family _____

Physician _____

Self _____

Hospital _____

Home Health Agency _____

Health Department _____

Nursing Home _____

Other (Specify) _____

C. Services Provided

Total number of visits or inpatient encounters

Personnel	Home	Inpatient
Physician (not incl. psychiatrist)		
Skilled Nursing		NA
Home Health Aide		NA
Homemaker		NA
Social Work		
Physical Therapy		
Occupational Therapy		
Psychologist		
Psychiatrist		
Volunteer		
Clergy		
Other (specify)		

Drugs Prescribed _____

Birthdate (Month, Day, Year): _____

Date of Death: _____

BEREAVEMENT FORM

Patient Number: _____

Date: _____

Initials: _____

Hospice Program: _____

CODES

MONTH/DAY	CLIENT	TYPE OF VISIT	PROVIDER	ADDITIONAL PROVIDER (if any)	LOCATION	SERVICE	TIME OF DAY

- CLIENT**
1. Spouse
 2. Child
 3. Parent
 4. Other Family Member
 5. Significant Other
 6. Client Group
 7. Other

- ADDITIONAL PROVIDER**
0. None (Code same as Provider)

- LOCATION**
1. Telephone, Client Initiated
 2. Telephone, Staff Initiated
 3. Home
 4. Funeral Parlor
 5. Church
 6. Memorial Home
 7. Restaurant
 8. Office
 9. Other

- TYPE OF VISIT**
1. One-to-one contact
 2. Staff Conference
 3. Group Session
 4. Social Occasion
 5. Other

- PROVIDER**
1. Nurse, R.N.
 2. LVN
 3. Hospice M.D.
 4. Social Worker, MSW
 5. Social Worker, BA
 6. Home Health Aide
 7. Nurse's Aide
 8. Psychologist
 9. Psychiatrist
 10. Marriage, Family Counselor
 11. Other Counselor
 12. Clergy
 13. Home Care Volunteer
 14. Bereavement Volunteer
 15. Volunteer
 16. Interdisciplinary Team
 17. PMD
 18. Other

- SERVICE**
1. Assessment
 2. Counseling
 3. Referral
 4. Support
 5. Attend Funeral
 6. Practical Assistance
 7. Socialization
 8. Other

- TIME OF DAY**
1. Standard Working Hours (8-5, Mon-Fri)
 2. Other than Standard Working Hours

Other relevant information: _____

HOSPICE PROGRAM
Annual Report

Hospice Program _____
Date Completed _____
Reporting Period _____

A. Program Description

1. Services (check services provided)

Services	Home	Inpatient	Direct	Contracted
Physician				
Skilled Nursing				
Home Health Aide				
Homemaker				
Social Work				
Physical Therapy				
Occupational Therapy				
Psychologist				
Psychiatrist				
Volunteer				
Clergy				
Other (specify)				

2. Population of service area _____

B. Utilization

1. Home Care

Number of patients admitted _____
Number of patients served _____
Average caseload per month _____
Average length of stay _____

2. Inpatient Care

Number of bed days available _____
Number of bed days used _____
Annual Occupancy rate _____
Number of patients admitted _____
Number of patients served _____
Average length of stay _____

C. Revenues

1. Total revenues by source

Donations _____
 Memorials _____
 Grants _____
 Patient/insurance payments _____
 Workshops and Miscellaneous _____
 TOTAL _____

2. Patient and Insurance Revenue by Service and Source

	Home Care	Inpatient Care
Medicare		
Medicaid		
Blue Cross		
Other Insurance		
Self		

3. Services Billed vs. Services Reimbursed by Payer

	Home Care		Inpatient Care	
	Billed	Received	Billed	Received
Medicare				
Medicaid				
Blue Cross				
Other Insurance				
Self				

D. Costs

1. Home Care Total Operating Costs (see Home Health Agency Medicare Cost Report)

Salary Costs \$ _____
 Transportation Cost _____
 Contract Services _____
 Medical and Nursing Supplies _____
 Space Occupancy Costs _____
 Office Costs _____
 Other General Costs _____
 Cost not included above _____
 TOTAL \$ _____

2. Inpatient Care Total Operating Costs (See Hospital Medicare Cost Report)

_____ \$ _____
 _____ _____
 _____ _____

2. Continued

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
	\$ _____

3. Other Program Operating Costs (List Other Programs and Total Costs)

_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
_____	\$ _____
	\$ _____

4. Costs by Unit of Home Care Service

Home Care Service	Cost	Charge
Nursing		
Physician		
Social Work		
Home Health Aide		
Occupational Therapy		
Physical Therapy		
Homemaker		
Bereavement		
Cost per home care day	\$ _____	
Cost per length of stay	\$ _____	

5. Cost by Unit of Inpatient Service

Inpatient Service Unit	Cost
Nursing Services	
Social Services	
Physical Therapy	
Occupational Therapy	
Pharmacy	

5. Continued

Inpatient Service Unit	Cost
Food Services	
Laundry	

Cost per inpatient day \$ _____
 Charge per inpatient day \$ _____
 Cost per length of stay \$ _____

6. Non-reimbursable Services (List services provided and associated costs for which there is no reimbursement).

Services	Total Costs

Service Characteristics	Issue	Guidelines
Availability	1. Definition of Hospice Population	<p>Hospice Care is not appropriate for all terminal patients. Hospice care is appropriate for those terminally ill patients who choose palliative treatment modalities. The life expectancy of Hospice patients should be less than six months. Current Hospice programs estimate that approximately 90% of the hospice population has a diagnosis of cancer* and 10% of the served population has other diagnoses. Although patients afflicted with other terminal diseases could utilize hospice services, cancer is more predictable than most disease in terms of progression of disease and expected life span. Therefore, as a basis for computation of potential hospice population, the cancer population, plus 10%, will be utilized. Although death by cancer, per year, represents a specific population with a potential use for hospice services, the number of deaths does not reflect the actual demand for hospice programs. The demand for hospice services is dependent on a number of variables, including but not limited to, attitude of family, patient and physician, amount of medical information provided the patient/family, the level of awareness of hospice services in the community, the relationship established by the Hospice program with hospitals and other health care agencies. It is estimated that approximately 25% of cancer patients reach a point in treatment before death when cure is no longer anticipated and physician, patient, and family come to know that the appropriate goal is now palliative rather than curative care.</p>
	2. Admission Criteria	<p>1. Admission is limited to patients in the terminal state of illness, (survival expected to be less than six months), when the patient is no longer receiving treatment for cure, and the physician and patient agree that palliative care is appropriate, and the patient chooses Hospice care.</p>

* Cancer patients are the most likely hospice population as cancer diagnoses are more predictable than most in terms of progression of disease and expected life span.

Service Characteristics	Issue	Guidelines
Availability	2. Admission Criteria (Cont'd.)	<p>2. Admission is limited to those patients who have a family member, friend or relative available who is able and willing to assume the role of primary care giver. It may also be appropriate for the Hospice Team members to make available a volunteer or other community resource to assume the role of care giver for those patients without family.</p> <p>3. Admission will be denied to those patients in a comatose condition which is diagnosed as probably irreversible or when death is expected within hours.</p> <p>4. Patients whose condition has changed will be assured of admission or readmission to the Hospice inpatient unit as deemed appropriate by the Hospice Team.</p> <p>5. Priority for admission to the inpatient component will be given to those patients most difficult to manage due to poorly controlled physical symptoms or difficult psychosocial situations.</p>
	3. Service Capability in State	<p>Since the primary emphasis of a Hospice program is on Home Care, home care services must be available and accessible to the hospice population. The basis for determination of the number of patients in need of home care services should be 100%. One method of determining the inpatient component is:</p> <p>1. National data gathered from Riverside, Hillhaven, Bethesda Lutheran, and Bellin Memorial hospice programs indicate that the average daily census in an inpatient hospice unit is about .5 (.502) per 100 cancer deaths in the area by the hospice program.</p> <p>2. The equation used to convert this figure into beds is as follows:</p> <p>.502 (average daily census) divided by 100 multiplied by number of cancer deaths (in 1978 and 1985) = the average daily census in a given health service area. Divide this</p>

Service Characteristics	Issue	Guidelines
Availability	3. Service Capability in State (Cont.)	<p>figure by .9 (90 percent, adjustment factor for diagnoses other than cancer), then divide the result by .8 (80 percent occupancy) to get number of beds needed in a health service area.</p>

The results of these calculations for each of the five health service areas in the State and for the State as a whole for 1978 and 1985 are displayed in the table below.

Number of Beds Needed		
Health Service Area	1978	1985*
I	8	8
II	8	9
III	14	15
IV	11	12
V	15	16
TOTAL	56	60

*1985 data based on 7 percent increase in cancer mortality from 1978 to 1985, based on projections made for Northern Virginia of 1970-78 cancer mortality rates

Availability	4. Scope of Services Offered	<p>The Hospice System of Care should provide:</p> <ul style="list-style-type: none"> a. Coordinated in- and out-patient services, primary emphasis on home care. Back-up inpatient services should only be utilized when home care is not feasible. b. Care which includes working with the patient, family and/or primary care giver. c. Palliative care which is that treatment directed at controlling pain, relieving other symptoms and focusing on the special needs
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Service Characteristics	Issue	Guidelines
Availability	4. Scope of Services Offered (Cont.)	<p>of the patient and family as they experience the stress of the dying process, rather than the treatment aimed at investigation and intervention for the purposes of cure or prolongation of life.</p> <p>d. Interdisciplinary care provided by:</p> <ol style="list-style-type: none"> 1. physicians 2. nurses 3. social workers 4. physical therapists, occupational therapists, and other therapists 5. clergy, where desired 6. homemaker/home health aides 7. consultants, such as nutritional, pharmaceutical, psychiatric, psychological, radiologic, pediatric, oncologic, etc. 8. volunteers, specially selected and extensively trained to augment staff in the following areas: <ol style="list-style-type: none"> a. support; b. companionship; c. recreation; d. transportation; e. household chores 9. Other care givers as may be appropriate. <p>e. A mechanism for team planning of care, coordination of that care and team communication should be documented.</p> <p>f. Physician directed medical care and/or provision for medical direction.</p> <p>g. Bereavement follow-up services extended to the family and significant others during the period of grieving.</p> <p>h. Seven days-a-week, 24 hours-a-day services availability with</p>

Service Characteristics	Issue	Guidelines
Availability	4. Scope of Services Offered (Cont.)	<p>linkages to other program resources as necessary; such as pharmacy, lab, x-ray, physician services.</p> <p>i. Staff support and communication providing channels for staff (and volunteer) discussion, support and mutual evaluation.</p>
Accessibility	1. Travel Time	Hospice program should make hospice services accessible within a reasonable travel time.
	2. Accessibility to home care	Home health services must be available to all patients who reside in the service area of the hospice, either through direct provision of the service or through a contractual arrangement.
	3. Hours of operation	Hospice services should be available 24 hours a day, 7 days a week.
	4. Indigent Care	<p>a. The hospice care program should be accessible to all who need it regardless of ability to pay for the services, within pre-determined financial constraints set by the governing body of Hospice Program.</p> <p>b. The hospice care program should have written policies governing provision of services without charge.</p> <p>c. The hospice care program should have plans for working with social service agencies and refer appropriate patients to such organizations for financial assistance.</p>
	5. Accessible facility design	<p>The institution providing hospice services should promote accessibility by the handicapped through:</p> <p>a. ramps, walks and doorways that allow easy access by wheelchair;</p> <p>b. public toilets that accommodate wheelchairs;</p> <p>c. water fountains, telephones, foods that are accessible to persons in wheelchairs;</p>

Service Characteristics	Issue	Guidelines
Accessibility	5. Accessible facility design (Cont.)	d. special parking places for the handicapped.
	6. Public Education	a. The hospice should have an ongoing program for informing the general public and other health care providers of hospice service availability and charges. b. Estimates of charges for hospice services should be available to all consumers.
	7. Patient Mix	Hospice providers should provide services to all patients regardless of race, color, creed, age, or ethnicity.
	8. Accessibility by Visitors	a. The inpatient portion of the hospice program should have a written policy concerning visitation. b. The written policy concerning visitation should be as flexible as possible to accommodate patient's needs.
Continuity	1. Coordination of Services	a. All involved disciplines should work together as a team with a holistic approach, treating the whole person, not just physical symptoms. Interdisciplinary care should be carefully planned and should involve professionals, family, friends and volunteers. b. The hospice service should have written procedures and policies to assure coordination of services and periodically evaluate their effectiveness. c. Referring physicians should to the fullest extent possible, participate in the hospice program and in the diagnosis and management of problems.

Service Characteristics	Issue	Guidelines
Continuity	1. Coordination of Services	d. All levels of hospice services should have written guidelines for referrals to and from the service, and to and from components within the service as well as procedures for carrying out referrals.
	2. Admission-Discharge	a. Initial admission should include all necessary information.
		b. Subsequent readmission should rely on the initial information and should be a simple process.
		c. The service should have written policies and procedures regarding discharge planning for the improved patient and to assure adequate follow-up care.
	3. Bereavement Care	a. The hospice program should have a bereavement follow-up plan to support the family after the death of the patient.
b. The bereavement follow-up should be planned on an individual basis, according to the situation.		
Quality	1. Medical Record	a. Medical record must be maintained for each patient.
		b. Policies and procedures must be developed for safeguarding confidentiality of the medical records and patient information.
	2. Audits & Reviews	a. The hospice service should have a written plan for reviewing patient cases. This plan for reviewing patient care should include both in-patient care and home health care recipients.
		b. Program should have a written quality assurance plan which includes the review of patient care by an established set of criteria and standards for assessing the quality of patient care.
	3. Staff Requirements	The minimum staff for the interdisciplinary team must include: - Physicians

Service Characteristics	Issue	Guidelines
Quality	3. Staff Requirements	<ul style="list-style-type: none"> - Registered nurses - Social worker - Volunteers <p>The following other disciplines should be available for consultation or direct service on an as needed or desired basis:</p> <ul style="list-style-type: none"> - Registered dietician - Physical therapist - Occupational therapist - Speech therapist - Pharmacist - Psychologist - Psychiatrist - Pastoral counselor - Medical record consultant
	4. Hospice Administration	<p>Staff of the hospice program of care shall meet appropriate State requirements for licensure plus training in care for the terminally ill.</p> <p>There should be an identifiable administrative group, that has a distinct organizational structure, accountable to the governing authority, either directly or through the governing authority's chief executive officer, for all aspects of the program.</p>
	5. Staff Education	<ul style="list-style-type: none"> a. The staff should document that they have had some education and/or experience in the treatment of the terminally ill. Additionally, all hospice care programs must have channels for staff communication for mutual support and expression of manual and appropriate emotional response to human sorrow. b. All hospice care programs shall have an orientation and continuing education program for staff and volunteers to include at least basic hospice philosophy, symptom control, communication skills and bereavement counseling.
	6. Facility Components	<p>Whenever possible, the hospice inpatient component should avoid an institutional atmosphere and should provide those facilities and</p>

Service Characteristics	Issue	Guidelines
Quality	6. Facility Components	services which enhance the home like atmosphere of the inpatient component, e.g., family lounge, area for food preparation by the family, family sleeping area.
	7. Infection Control	The inpatient program should have a written program and policies for controlling infection consistent with JCAH standards.
	8. Safety Program	<p>The inpatient program should have written policies and procedures to assure the safety of patients, staff and visitors including:</p> <ul style="list-style-type: none"> a. a written, tested disaster plan consistent with JCAH standards b. a documented fire and safety plan, including procedure for fire drills and storage of oxygen c. specified written plans for maintenance of equipment
	9. Patient Satisfaction	<p>The service should have appropriate channels for:</p> <ul style="list-style-type: none"> a. customer participation b. patient complaints c. patient Bill of Rights
10. Hospice Compliance	a. The hospice should be in compliance with appropriate State licensing requirements.	
Cost	1. Cost/Charges	a. Prospective reimbursement schedules will be encouraged for all hospice care.

Service Characteristics	Issue	Guidelines
Cost	1. Cost/Charges	<p>b. The charge to the patient should be made in an equitable manner and be related to cost.</p> <p>c. Hospice care cost should be comparable to the cost of services provided by similar programs, e.g. home health agencies.</p>
	2. Financial Viability of the Organization	<p>a. The institution providing hospice services should be able to demonstrate effective systems of the management and control of cost within the facility.</p> <p>b. The current ratio (ratio of all current assets to current liabilities) should be such that the institution providing hospice services can meet its short term obligations with highly liquid assets.</p> <p>c. The ratio of net income after all expenses and taxes to total revenue should be large enough to cover current operations and future capital needs.</p>
	3. Rates of Service Utilization	<p>An optimal occupancy standard has not been determined. However, for planning purposes, the utilization of inpatient services should be at a reasonable level commensurate with the size of the inpatient unit before additional hospice programs are considered for approval.</p>
	4. Availability of Less Costly Alternatives	<p>a. Hospice services should be offered at the least intensive level which is consistent with the patient needs.</p> <p>b. Coordination and further development of existing health care providers should be encouraged whenever possible.</p> <p>c. Existing excess acute care capacity should be considered for conversion to inpatient hospice care before free standing construction is considered.</p>

OTHER STATES TAKING LEGISLATIVE ACTION
RELATING TO HOSPICE CARE

<u>State</u>	<u>Licensure</u>	<u>Category</u>	<u>Regulations</u>
Florida	Yes	Licensed as a Separate Program	Yes - Effective July 1, 1980
Kentucky	Yes	Licensed as a Separate Program	Being Developed
Nevada	Yes	Licensed as Home Health Agencies	Licensure Regulations for Separate Hospice Programs are Being Developed
Connecticut	Yes	Licensed as Free-standing Hospice and Hospice-Hospital Based Programs	Yes - Effective January 18, 1980
Arizona	Yes	Licensed as Hospital Hospice Programs	Yes - Effective January 28, 1980
New York	Yes	New Hospice Facilities and Units are Licensed only for Demonstration Projects	Yes - Effective June 14, 1979
California	Use Existing Regulations Primarily Home Health Agencies	Not applicable	No Regulations Developed due to Funding Restrictions