S. HRG. 98-1171

IMPLEMENTATION OF THE MEDICARE HOSPICE BENEFIT

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

SECOND SESSION

SEPTEMBER 17, 1984

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CONTENTS

ADMINISTRATION WITNESSES

PUBLIC WITNESSES

ADDITIONAL INFORMATION

Prepared statement of—Continued

COMMUNICATIONS

IMPLEMENTATION OF THE MEDICARE HOSPICE BENEFIT

MONDAY, SEPTEMBER 17, 1984

U.S. SENATE,
SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON FINANCE,
Washington, DC.

The committee met, pursuant to notice, at 2:05 p.m. in room SD-215, Dirksen Senate Office Building, Hon. David Durenberger (chairman) presiding.

Present: Senators Durenberger, Dole, Heinz, and Baucus.

[The press release announcing the hearing, the prepared statement of Senators Dole, Bentsen, and Baucus, and a background paper by the committee staff follow:]

[Press release No. 84-171, Aug. 28, 1984]

SENATE FINANCE SUBCOMMITTEE ON HEALTH SETS HEARING ON THE IMPLEMENTATION OF THE MEDICARE HOSPICE BENEFIT

Senator Dave Durenberger, Chairman of the Subcommittee on Health of the Senate Committee on Finance, announced today that the Subcommittee will hold a hearing on the status of the implementation of the medicare hospice benefit enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA).

The hearing will be held on Monday, September 17, 1984, beginning at 2:00 p.m. in Room SD-215 of the Dirksen Senate Office Building.

In announcing the hearing, Senator Durenberger noted that "final regulations implementing the medicare hospice benefit were published on December 16, 1983. Prior to that time, a hearing was held by this Subcommittee to obtain public comment on the proposed regulations and to learn the results of the Administration's hospice demonstration projects that were then nearing completion. That hearing was held on September 13, 1983.

"Subsequent to publication of the final regulations, questions have been raised regarding the progress in the actual implementation of the hospice benefit. Concerns have been voiced over the small number of hospices actually participating in the medicare program and the resulting small number of patients being cared for by these agencies. Additionally, it has been suggested that the current payment rates, particularly for home visits, may be insufficient. Lastly, the final report on the hospice demonstration projects has not as yet been forwarded to the Congress. The Subcommittee believes the information contained in this final report is necessary, particularly at this time, so we can fairly evaluate the currently established rates for the hospice benefit."

Senator Durenberger further stated that "the Subcommittee is interested in hearing from the Administration with respect to an overview of the current status of implemention, and with regard to the final timing and content of the report on the hospice demonstrations. In addition, the Subcommittee would also be interested in hearing from representatives of the hospice industry and others who have information on the current provision of hospice benefits in this country."

STATEMENT OF SENATOR BOB DOLE, IMPLEMENTATION OF THE HOSPICE BENEFIT, SEPTEMBER 17, 1984

Based on legislation I introduced in 1981 (S. 1958), the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) was used to create a hospice care benefit for medicare beneficiaries.

Enactment of the hospice provision was possible because many believe, as I do, that it is less costly to care for a patient at home, foregoing expensive hospital treatment. But more importantly, hospice care is more humanitarian. Rather than being in an institution alone much of the time, hospice care will allow an individual to remain at home, surrounded by family and friends.

We were here almost one year ago to the day, on September 15, 1983, examining the administration's regulatory efforts to implement the hospice provision. We had purposely delayed implementation of the hospice benefit until November of that year, 1983. The delay was intended to allow the administration an opportunity to reflect the results of a number of hospice demonstrations in its proposed regulations. Today we find that we are still facing problems with implementation. It will be repeated frequently here today that there are only 119 hospices certified under the program. Clearly this is not enough if we are really to make this benefit available to those medicare beneficiaries who need it. Something would appear to be amiss and I, like you, am anxious to determine what it is and how we might correct it.

Congressional support for hospice has not waned. In fact, as recently as August 10, 1984 the Senate passed a resolution designating November as national hospice month, the House passed a comparable resolution September 12, to recognize the contributions made by those involved in providing hospice services and the advancement of the movement itself. Because of this continuing commitment to the program, we are particularly concerned with what appears to be a very hesitant response from the hospice industry.

We knew when the benefit was first enacted that changes might be necessary. The amendment which was included in the 1984 deficit reduction act, providing some relief to the rural hospices, is an example of this philosophy. Some additional changes may still be necessary and we count on you to help us identify these areas.

It is my understanding that the most frequently mentioned area of concern is the payment level for home care. In addition, it has been suggested that the core service requirement continues to be a problem for a great number of hospices, many of which are located in rural areas.

Because the benefit sunsets in two years, we are anxious to learn as much as we can during this period of time. It is only in this fashion that we can hope to truly evaluate the success of the program in meeting the needs of those who choose the hospice option. It is for this reason that I am pleased that the subcommittee has chosen to hold a hearing at this time. Because of the strong position in favor of hospice care taken in the Republican platform statement, I know this administration is as anxious as we are to see this benefit made available. They are also, I am sure, just as anxious to make sure that every effort is made to gather together the necessary information to evaluate the successes and the problems being experienced by hospices nationwide.

In a letter I sent to Secretary Heckler August 28, 1984, I made clear my concern regarding the hospice study and the collection of cost information. I am hopeful that these issues along with many others will be addressed today.

I look forward to hearing from each of our witnesses.

STATEMENT OF SENATOR LLOYD BENTSEN

Mr. Chairman, I am encouraged that this hearing has been scheduled to afford those of us who are concerned about low participation rates in the hospice program an opportunity to learn more about the Department's intentions to develop reasonable rate schedules for hospice care. As a long time supporter of the hospice movement, I look forward to the time when all medicare beneficiaries can be assured that in their community, quality health care in those final days of terminal illness can be provided at home in a setting which allows families to remain together.

In 1982, when Congress opened the Medicare Program to hospice, it was estimated by the Congressional Budget Office that millions of dollars in savings could accrue to the medicare trust fund if only some individuals with a need for care chose hospice rather than traditional hospital services. I am aware that those projections were disputed by the Office of Management and Budget, but I am also aware that the OMB projections of program use were well above what has actually occurred. (OMB said 31,000 would use the benefit in 1984, only 5% of that have done so) in any case, the Department of Health and Human Services reports that through September 7, of the approximately 1,500 hospices nationwide, only 119 have received medicare certification and 47 are in the process of applying for certification. Providers in my State—and you will hear from Mary McKenna of Orange, Texas later this afternoon—tell me that although more than half of their clients are medicare eligible, few hospices are seeking certification because fund raising and cost shifting from private patients cannot make up the difference between the low level of medicare reimbursement and actual costs.

While some urban hospices have a large enough volume of private patients to generate revenues that subsidize the medicare beneficiary, rural hospices do not, and the discrepancy between cost and reimbursement is an insurmountable barrier to participating in this program. The result, of course, is that medicare patients are denied a service to which they are entitled.

When the hospice benefit was incorporated in the TEFRA legislation, I and other conferees assumed that reimbursement rates would be based on the latest available cost information, updated regularly. Yet the $46.25 paid today was established using highly controversial data and, to my knowledge, no plans are in progress to adjust the rates in the near future. In fact, the cost information needed to make such adjustments and to provide Congress the statutorily required report on hospice care by January of 1986 is not even being collected.

I am deeply disturbed by the failure of HHS to begin the data collection needed to comply with TEFRA, and I look forward to hearing from Dr. Davis today that corrective action will be taken immediately. Continued delay is inexcusable both because it results in a denial of service to the most vulnerable medicare beneficiaries, and because it will make impossible an objective assessment of the program when it comes up for reconsideration in 1986.

STATEMENT OF THE HONORABLE MAX BAUCUS

The new hospice benefit under Medicare is one of the few recent legislative changes that has directly benefitted our elderly citizens.

Hospice care helps the terminally ill patient who chooses to remain free from pain and in his own home as long as possible. The new benefit should provide a humane and sensible alternative for the dying patient who does not want high-tech intervention and hospital-oriented medical treatment.

Like the more traditional forms of health care, the new hospice benefit has the potential of providing many patients with health care which is less costly and more satisfactory to the patient than institution-based care.

The hospice benefit also has the potential of saving the Medicare program significant amounts of money. Costs per day for hospice patients, whether cared for at home or in hospital-based hospices, are significantly less than for the same patients as conventional hospital inpatents. By offering this hospice benefit, we are not denying any Medicare patient the best that modern hosptials can offer; but we are offering an option to terminally ill patients, to choose alternative hospice care in their final weeks if they wish.

But out of approximately 1,500 hospice programs nationwide, only about 110 have been certified to participate in Medicare. So the new benefit is being made available to only a few senior citizens. In fact, there are no Medicare certified hospices in my own state of Montana.

When the hospice benefit was enacted there was uncertainty over several aspects of the legislation. There were questions of how hospices should be organized and paid. The cost impact was also unclear. As a result, the new benefit is scheduled to sunset at the end of October 1986, and HCFA was directed to conduct a study of the new benefit and to report its findings and recommendations to the Congress before January 1, 1986.

I am concerned about the apparent lack of progress on this timetable, and I am disturbed by the low level of participation nationwide. As one who has always supported home health care, including the right to choose the hospice alternative, I believe that the hospice benefit deserves to be given every chance to succeed during its three-year period and that decisions about the future of the benefit should be based on a full and fair evaluation.

IMPLEMENTATION OF MEDICARE'S
HOSPICE BENEFIT

Background Paper

Prepared for the Use of the Members of
The Senate Committee on Finance

September 1984

IMPLEMENTATION OF MEDICARE'S HOSPICE BENEFIT

This document provides (1) background information on hospice care and a summary of current law provisions authorizing coverage for hospice care under Medicare; (2) information on the National Hospice Study; (3) information on the implementation of the hospice benefit; and (4) a discussion of hospice issues.

I. BACKGROUND

A. Description of Hospice Care

Hospice care has recently emerged as an alternative way of caring for the terminally ill. The hospice concept generally emphasizes palliative care--medical relief from pain--rather than curative care for patients for whom there is no chance of a cure.

Hospice care is designed to help terminally ill patients remain free from pain and in the home environment as long as possible. By and large, patients are considered "terminal" when the prognosis for life expectancy is 6 months or less. Typically, care is delivered to such persons by an interdisciplinary team composed of a physician, nurses, and some combination of social worker, psychiatrist, psychologist, clergy, trained volunteers, and family members. Services are provided both to terminally ill persons and their families to help in adjusting to the patient's illness and death.

Hospice care is delivered through a variety of program models including the freestanding hospice, with or without direct hospital affiliation; the hospice unit within a hospital; the hospice team within a hospital; the hospice unit in a skilled nursing facility; and the so-called "hospice without walls" providing home care exclusively, most often through home health agencies and visiting nurses associations.

The Joint Commission on Accreditation of Hospitals (JCAH) has collected information on the number, location, and characteristics of hospice programs in the country and has recently developed standards for accreditation. A JCAH survey completed in June 1984 identified an estimated 1,429 hospice programs which are either currently operational or in development. The following Table 1 indicates that most hospices are either hospital-owned, independently owned (not owned by any other institution or agency), or home health agency-owned. JCAH has also found that of the 1,429 identified hospice programs 687 are providing home care and/or inpatient care. For another 671 hospices, JCAH has not been able to determine their service status at this time. Seventy-one hospices indicated that they were in the planning stages of development. Table 2 details this data by State.

Table 1. JCAH Survey of Hospice Programs: Estimated Total Number of Hospice Programs, by Ownership and Service Status, June 1984

Hospice Program Ownership	
Hospital	543
Independent	541
Home health agency	303
Long-term Care Facility	40
Psychiatric	2
	1429
Service Status	
Providing home care and/or inpatient care	687
Unknown service status	671
In development	71

Table 2. JCAH SURVEY OF HOSPICE PROGRAMS:
ESTIMATED NUMBER OF HOSPICE PROGRAMS BY STATE, JUNE 1984

	Hospice program ownership						Service status		
	Hospital	Independent	Home health agency	Long-term care facility	Psychiatric facility	Total	Providing services (Home care and/or inpatient)	Unknown	In development
Alabama.............	10	7	14	1		32	12	13	7
Alaska..............		2				2	2		
Arizona.............	5	6	3	1		15	6	6	3
Arkansas............	2	5				7	5	1	1
California..........	59	67	34	6		166	95	68	3
Colorado............	8	15				23	17	5	1
Connecticut.........	20	11	12	1		44	11	31	2
Delaware............	2	1				3	1	1	1
Dist. of Columbia...	1	1	3	2		7	2	5	
Florida.............	9	21	6			36	17	19	
Georgia.............	13	7	2	2		24	13	8	3
Hawaii..............	3	2				5	2	3	
Idaho...............	3	1		2		6	2	4	
Illinois............	38	17	17	3		75	48	21	6
Indiana.............	9	12				21	12	9	
Iowa................	18	8	2	1		29	11	17	1
Kansas..............	2	16	5			23	8	14	1
Kentucky............	10	19	4			33	9	23	1
Louisiana...........	6	4	1			11	4	3	4
Maine...............	4	14	2	1		21	14	6	1
Maryland............	11	10	8	2		31	16	14	1
Massachusetts.......	15	27	20	2		64	37	26	1
Michigan............	16	16	12	3		47	19	28	
Minnesota...........	13	9				22	13	9	
Mississippi.........	16	1	3			20	2	18	
Missouri............	14	14	6			34	16	15	3
Montana.............	3	12				15	5	10	
Nebraska............	11	1	1	1		14	6	6	2
Nevada..............		1	1			2	1	1	
New Hampshire.......	2	12	7			21	9	12	
New Jersey..........	23	9	9	1		42	31	9	2
New Mexico..........	1	4	3			8	6	2	
New York............	32	10	10	1	1	53	20	30	3
North Carolina......	8	26	6	1	1	42	20	13	9
North Dakota........	4	1				5	1	4	
Ohio................	17	24	15	1		57	31	26	
Oklahoma............	3	4	1			8	3	4	1
Oregon..............	9	9	5			23	7	16	
Pennsylvania........	41	17	37	2		97	47	47	3
Rhode Island........	1	2	5			8	2	6	
South Carolina......	4	6				10	5	5	
South Dakota........	2	2				4	3	1	
Tennessee...........	17	7	8			32	16	14	2
Texas...............	16	13	17	1		47	15	28	4
Utah................	2	6				8	4		2
Vermont.............		6	7			13	5	8	
Virginia............	11	9	3	3		26	10	15	1
Washington..........	9	20	9	1		39	17	22	
West Virginia.......	5	10	1			16	6	10	
Wisconsin...........	15	16	4	2		37	20	15	2
Wyoming.............		1				1	1		
Total..........	543	541	303	40	2	1429	687	671	71

B. Legislative History

Hospice care has been a subject of Federal study since 1973 when the National Cancer Institute funded a project to develop a national demonstration center for home care of the terminally ill and their families. Since then, several other studies and projects have been undertaken, including a Health Care Financing Administration (HCFA) demonstration project to assess the cost-effectiveness of providing hospice care to terminally ill Medicare beneficiaries. For purposes of this two-year demonstration, HCFA waived program restrictions on payment under Medicare and Medicaid for custodial care at home, for bereavement counseling and other supportive services to the family, and for pain controlling drugs used at home. Beginning in October 1980, HCFA paid for all hospice care provided to terminally ill Medicare/Medicaid patients by 25 hospice organizations selected to participate in the two-year demonstration projects. Certain preliminary findings from these projects are discussed in the next section of this report.

Legislation to cover hospice care under Part A of Medicare until October 1, 1986 was contained in the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, P.L. 97-248. Prior to this legislation, Medicare did not recognize hospices as a separate category of provider eligible for reimbursement under the program, although some hospices were participating in the program within existing provider classifications (e.g., as a hospital, skilled nursing facility, or home health agency). As such, these organizations received reimbursement for certain hospice services they provided, which when considered singly were Medicare covered services (e.g., home health care services). Certain other hospice services, such as outpatient drugs that can be self-administered or services which might be considered custodial care, were not covered and therefore not reimbursed under Medicare even if provided by a certified provider.

Since 1982, Medicare's hospice benefit has been amended twice. In 1983, Congress passed H.R. 3677 (P.L. 98-90) to establish a new hospice care cap of $6,500 per beneficiary per year. For accounting years that end after October 1, 1984, the cap will be adjusted by changes in the medical care component of the Consumer Price Index. Prior to this amendment, the hospice cap was to be calculated in the following way: first, the Secretary was required to identify, by using Medicare program records, those individuals (or a representative sample of individuals) who die during a specified base period, for whom the primary cause of death was cancer, and who had received Medicare benefits during the six months preceding their deaths. Next, the aggregate amount of Medicare payments made for services to these individuals during the 6 months preceding their deaths was to be estimated and then divided by the total number of such dying beneficiaries. The resulting per capita amount was subsequently to be adjusted to reflect the different costs of delivering health care in different regions of the country. Finally, the regional per capita "cap amount" for purposes of hospice services was to be set at 40 percent of this regional average per capita costs, adjusted to reflect changes in the medical care component of the consumer price index. In proposed regulations published prior to the enactment of the cap amendment, HCFA estimated that the average cap amount per beneficiary for the first year of the hospice program would have been $4232.

In 1984, the Deficit Reduction Act, P.L. 98-369, included a provision to allow the Secretary to waive the nursing care "core services" requirements for hospices that are located in rural areas, that were in operation on or before January 1, 1983, and that have demonstrated a good faith effort to hire a sufficient number of nurses to provide nursing care directly. A waiver request will be granted automatically unless expressly denied by the Secretary within 60 days. In addition, the Secretary is required under this amendment to conduct a study on the necessity and appropriateness of the requirements that certain core services be furnished directly by a hospice and report findings of this study to Congress prior to January 1, 1986.

These amendments are included in the following summary of current law provisions authorizing coverage for hospice care under Medicare.

C. Summary of Medicare's Hospice Benefit

1. Eligibility and Conditions of Coverage

For the period November 1, 1983, to October 1, 1986, Medicare Part A coverage includes hospice care services provided to terminally ill Medicare beneficiaries with a life expectancy of 6 months or less. A Medicare beneficiary may elect to receive hospice care in lieu of most other Medicare benefits for up to two periods of 90 days each, plus an additional period of 30 days (totaling 210 days). During the time a hospice election is in effect, the beneficiary will be deemed to have waived entitlement to (1) hospice care provided by another hospice program (except when the hospice from which the individual elected to receive care makes arrangements with another hospice to provide services it does not offer directly); and (2) any Medicare services related to the treatment of the individual's terminal illness, or services equivalent to or duplicative of hospice care. However, the waiver does not apply to services provided by the beneficiary's attending physician if the attending physician is not employed directly by the hospice program. Further, the waiver only applies to those services provided by or under arrangements with the hospice.

After an individual makes a hospice election, he may revoke it; however, he will be deemed to have used benefits for the entire election period then in effect. Any time after revocation, he may execute a new election for a subsequent period if he is otherwise entitled to hospice benefits. In addition, once each election period, the individual may change hospice programs.

For an individual to have payments made on his behalf for hospice care during the first 90-day election period, his attending physician and the medical director (or physician member of the interdisciplinary group) of the hospice providing the care must each certify not later than 2 days after hospice care is initiated that the individual is terminally ill. The attending physician is defined as the physician, who may be employed by a hospice program, whom the beneficiary electing hospice care identifies as having the most significant role in the determination and delivery of his medical care at the time election of hospice care is made. At the beginning of subsequent periods, the medical director or physician member of the interdisciplinary term must recertify that the individual is terminally ill. A beneficiary is considered terminally ill if there is a medical prognosis that his life expectancy is 6 months or less.

In addition to these certifications, a written plan must be established for the care to be provided an individual electing hospice care. This written plan must be established before care is actually provided and must be periodically reviewed by the individual's attending physician and by the medical director and the interdisciplinary group of the hospice.

2. Benefits.

Hospice care benefits covered by Medicare include the following:

(a) Nursing care provided by or under the supervision of a registered professional nurse;

(b) Physical or occupational therapy, or speech-language pathology;

(c) Medical social services under the direction of a physician;

(d) Services of a home health aide who has successfully completed a training program approved by the Secretary, and homemaker services;

(e) Medical supplies (including drugs and biologicals) and the use of medical appliances;

(f) Physicians' services;

(g) Short-term inpatient care (including both respite care and procedures necessary for pain control and acute and chronic symptom management) in an inpatient facility meeting such conditions as the Secretary determines to be appropriate to provide hospice care; and

(h) Counseling, including dietary counseling, with respect to care of the terminally ill individual and adjustment to his death. Hospices must provide bereavement counseling, but such counseling will not be considered a reimbursable cost under the hospice benefit.

Nursing care and home health aide and homemaker services may be provided on a 24-hour continuous basis only during periods of crisis and only as necessary to maintain the terminally ill individual at home. The aggregate number of inpatient care days provided in any 12-month period to individuals electing a particular hospice program may not exceed 20 percent of the aggregate number of days of hospice coverage provided to these persons. In addition, respite care may be provided only on a intermittent, nonroutine, and occasional basis and may not be provided consecutively over longer than 5 days. (Although respite care is not defined, it is generally considered to consist of temporary, short-term relief services provided in a facility or the patient's home, so that family members or those providing primary care in the home may have a few hours or days of rest from caring for the patient.) Counseling services, including nutritional and dietary counseling, will be covered, but not be billed for as separate services.

Beneficiary copayments are required for outpatient drugs and respite care. Hospice programs are required to establish drug copayment schedules so that beneficiary charges approximate five percent of the cost of the drug to the hospice program, but in no case may they exceed $5 per prescription. For respite care, the coinsurance amount is to be equal to five percent of the estimated payments to the hospice program for respite services, but should not exceed the applicable Medicare hospital deductible during the period of hospice election (as long as the hospice election is not broken by more than 14 days). No other cost sharing charges are permitted for hospice services provided during the period of a hospice election.

3. Requirements for Hospice Programs

Hospice programs will be eligible to participate in Medicare if they are either public agencies or private organizations primarily engaged in providing the hospice services described above and if they make such services available (as needed) on a 24-hour basis, in individuals' homes, on an outpatient basis, and on a short-term inpatient basis.

The hospice must routinely provide directly substantially all of the following "core" services: nursing care, medical social services, physicians' services, and counseling services. However, the Secretary may waive the nursing care "core service" requirement for hospices that are located in rural areas, that were in operation on or before January 1, 1983, and that have demonstrated a good faith effort to hire a sufficient number of nurses to provide nursing care directly. The remaining "non-core" hospice services may be provided either directly by the hospice or under arrangements with others, in which case the hospice must maintain professional management responsibility for all such services furnished to an individual, regardless of the location or facility in which such services are furnished.

The hospice program must have an interdisciplinary group of personnel which includes at least one physician, one registered professional nurse, and one social worker employed by the hospice, plus at least one pastoral or other counselor.

Other requirements that a hospice must meet include: (1) maintenance of central clinical records on all patients; (2) agreement not to discontinue care to a patient because of the inability of the patient to pay for such care; (3) use of volunteers in the provision of services in accordance with standards set by the Secretary to ensure a continuing level of effort to use volunteers; (4) maintenance of records on the use of volunteers and the cost savings and expansion of care and services achieved through the use of volunteers; (5) licensure in accordance with any applicable State or local law; and (6) meeting other health and safety standards set by the Secretary.

The hospice must be certified to participate in Medicare in accordance with requirements pertaining to a new separate category of hospice provider. However, where any hospice provider requirements are the same as requirements already met by the provider under other agreements with the Secretary (for example, as a home health agency, skilled nursing facility, or hospital certified to participate in Medicare), then the Secretary will consider the provider to have met those hospice requirements. The Secretary must also coordinate surveys for determining provider certification so as to provide, to the extent feasible, for simultaneous surveys of an entity which seeks to be certified as a hospice program and as a provider of services for another type. Hospices certified as more than one type of provider must have separate provider agreements and must file separate cost reports accounting for services rendered and funds spent in connection with hospice care and any other services provided.

4. Payment for Hospice Care

Reimbursement to hospice providers of services will be an amount equal to the costs which are reasonable and related to the cost of providing hospice care, or which are based on such other tests of reasonableness as the Secretary may prescribe, subject to a "cap amount." This "cap amount" for a year is $6,500 per beneficiary per year adjusted for accounting years that end after October 1, 1984, by changes in the medical care expenditure category of the Consumer Price Index. The cap amount is applied on a aggregate rather than a case-by-case basis.

5. Waivers of Certain Hospice Requirements

For hospices which began operations before January 1, 1975, the Secretary shall waive until October 1, 1986, those requirements pertaining to: (1) the reimbursement "cap amount"; (2) the limitations on frequency and number of respite care days; and (3) the aggregate limit on number of inpatient care days.

6. Effective Date

Coverage for hospice benefits under Medicare is authorized for the period November 1, 1983 to Ocotber 1, 1986. However, an individual who on October 1, 1986, has a hospice election in effect is entitled to hospice benefits after that date for the remainder of the then current election period and for any subsequent consecutive election period to which the individual would have been entitled had the program not expired.

7. Studies and Reports

The Secretary is required to report to Congress prior to September 30, 1983, on the effectiveness of the demonstration projects and certain other matters. This report has not as yet been provided to the Congress. In addition, prior to January 1, 1986, the Secretary is required to report to the Congress on whether the reimbursement method and benefit structure (including copayments) for hospice care under Medicare are fair and equitable and promote the most efficient provision of care. This report must also include a discussion of the feasibility and advisability of providing for prospective reimbursement for hospice care; an evaluation of the inclusion of payment for outpatient drugs; an evaluation of the need to alter the method of reimbursement for nutritional, dietary, and bereavement counseling as hospice care; and any recommendations for legislative changes in the hospice care reimbursement or benefit structure.

The Secretary is also required to conduct a study on the necessity and appropriateness of the requirements that certain core services be furnished directly by a hospice and report findings of this study to Congress prior to January 1, 1986.

II. NATIONAL HOSPICE STUDY

In 1979, HCFA implemented a demonstration program to gather data on the costs, use, and quality of care provided by hospice organizations and to determine which care models best incorporate the hospice concept. In 1980, HCFA, in conjunction with the Robert Wood Johnson Foundation and the John A. Hartford Foundation, selected Brown University to conduct an in-depth, independent evaluation of the hospice project. The ultimate objective of this study is to assess the cost-effectiveness of providing hospice care to terminally ill Medicare beneficiaries. A final report is expected to be completed in the Fall of 1984.

In January 1984, HCFA published A Preliminary Report of the National Hospice Study. This report analyzes the first 15 months of reimbursement for Medicare patients at 25 hospices--14 hospital-based (HB) and 11 home care-based (HC) beginning in October 1980. The final report will cover 24 months of the project.

Major findings of the preliminary report include the following:

- Utilization--The average length of stay in a hospice was 62 and 72 days, respectively, for HB and HC patients. HB patients spent an average of 18.2 days in an inpatient setting compared with only 5.2 days for HC patients. About 10 percent of all hospice patients stayed more than 210 days and nearly 10 percent were discharged alive.

- Hospice Costs--The average hospice cost per HC patient was $4,758 or $66 per day. The average per HB patient was $5,890 or $95 per day, reflecting greater use of inpatient services.

- Hospice versus Conventional Care Costs--Costs for HC hospice patients are significantly less than for conventional care (CC) patients regardless of length of stay. For HB patients, however, costs were less than for conventional care patients for stays under 60 days, but more than conventional care patients for stays 60 days or longer.

- Interventions--Hospice patients in both types of hospice were significantly less likely than conventional care patients to receive some form of intensive medical intervention such as chemotherapy, surgery, radiation therapy, etc. Hospice patients were also significantly less likely to receive blood tests or X-rays. However, no statistically significant differences between hospice and nonhospice patients were observed in the probability of receiving respiratory support services such as oxygen or respiratory therapy. Social service use was more prevalent among hospice patients served in both types of hospice than among conventional care patients.

- Quality of Life--Various dimensions of patient quality of life were measured: overall quality of life, pain, satisfaction with care, and social involvement.

  --Overall quality of life was not different in the three groups as patients approached death.

  --HB hospice patients report less pain than CC patients in the last three weeks of life; the level of pain reported for HC patients was not statistically different from that of CC patients.

  --No differences were found comparing patient's reported satisfaction with care.

  --The level of involvement by friends and relatives was significantly higher among HC patients than either HB or CC patients. In addition, while all patients tended to experience high overall social quality of life as reported by patients' families, the overall social activity measures for CC patients were slightly higher than those of either hospice group.

- Volunteers--Organizations which provide hospice services exclusively, known as freestanding hospices, had nearly four times the level of volunteer service than either HB or HC groups. The level of patient care volunteer hours per patient day remained stable in all types of hospices despite universal growth in patient census.

Additional analysis of preliminary findings of the National Hospice Study (NHS) was published recently in the American Journal of Public Health, "What does Hospice Cost" by Howard Birnbaum and David Kidder (July 1984). Among other things, Birnbaum and Kidder conclude that the economies often associated with hospice persist for HC hospices, regardless of time spent in hospice, and progressively diminish and essentially disappear for longer stays in HB hospices. They add that while results such as these will be useful in predicting hospice experience under Medicare, Medicare's hospice costs in the future will probably be greater than those found in NHS:

> This is because NHS conventional care comparisons do not include noncancer patients or patients discharged alive from hospice; care for both groups was more costly than for cancer patients who died in hospice. The TEFRA Medicare program includes these patients, and they may be expected to enroll in TEFRA hospice. Another reason for expecting higher hospice costs in the future is that the TEFRA legislation imposes no obstacles to the entry of patients without primary care persons (PCP) [i.e., relatives or friends who act as informal care givers] into hospice, whereas the demonstration did so. Since NHS hospice patients who live alone cost more than those who do not, it can be inferred that hospice patients without a PCP also cost more than patients with a PCP. Costs per patient under TEFRA therefore may be higher than those experienced in the NHS if patients without a PCP enter hospice in large numbers.

III. IMPLEMENTATION OF MEDICARE'S HOSPICE BENEFIT

On August 22, 1983, the Health Care Financing Administration (HCFA), DHHS, published proposed regulations which would implement Medicare's hospice benefit. These regulations specified eligibility requirements and reimbursement standards and procedures, defined covered services, and delineated the conditions a hospice must meet to be approved for participation in the Medicare program.

On September 15, 1983, the Senate Finance Committee held a hearing on these proposed regulations. Final regulations, together with discussion of comments received on the proposed regulations, were published December 16, 1983.

Shortly after the publication of the proposed regulations in August, State survey agencies, at the request of HCFA, began sending letters about Medicare's hospice benefit to entities known to be hospices or considered to be providing hospice services. Eventually 1,554 such letters were sent by State agencies.

HCFA received 493 positive replies from entities which indicated they would be intersted in participating at that time or in the future.

As of August 3, 1984, a total of 163 surveys have been completed to determine a hospice's compliance with certification requirements specified in regulations; final decisions, however, have not been made on each of these surveys. As of August 3, 108 hospices have been certified for participation. Five hospices were determined not to meet the various conditions of participation required for certification and are not participating. Another 12 entities withdrew their initial request to participate. At this time, data are not available on the number of patients being served, their clinical status, or services provided these patients by certified hospice providers.

IV. ISSUES

Concern has been expressed about the relatively small number of hospices currently certified to provide services under Medicare's hospice benefit. As noted earlier, 108 hospices have been certified for participation. JCAH has identified an estimated 1,358 hospices which are currently operational and another 71 which are in development. Some of the major issues raised as explanations for relatively few hospices seeking Medicare certification include the following:

A. Payment Rates

The proposed and final regulations establish a prospective cost-based payment methodology for hospice care. Under this methodology, four payment categories have been established for four different levels of hospice care: routine home care; continuous home care; inpatient respite care; and general inpatient care. For each day that a Medicare beneficiary is under the care of a hospice, the hospice is reimbursed an amount applicable to the type and intensity of the services furnished to the beneficiary for that day. The actual payment rates specified in the proposed regulations for the four levels of hospice care were derived from preliminary data obtained from the Medicare hospice demonstration project. The final hospice regulations modified three of the payment rates on the basis of an analysis of additional data from the hospice demonstration project. In the final regulations, payment rates were reduced for routine home care and inpatient respite care and increased for continuous home care.

Table 3. Daily Payment Rates for Hospice Care

	Proposed Regulations	Final Regulations
1. Routine Home Care	$ 53.17	$ 46.25
2. Total Continuous Home Care	311.96	358.67
3. Inpatient Respite Care	61.65	55.33
4. General Inpatient Care	271.00	271.00

Revised calculations for the individual payment rates included in the final regulations reflect, among other things, lower utilization rates for various service components included in the rates and a longer average length of stay in the hospice demonstrations.

The lowering of the routine home care rate from $53.17 under the proposed regulations to $46.25 under the final regulations has been a special concern to many hospices. These hospices suggest that at this rate hospices will be unable and/or unwilling to provide care to Medicare beneficiaries. It is expected that most care provided by the hospices will be at the level of routine home care, and thus the payment rate for this care will be the hospice's principal source of reimbursement for services provided to Medicare beneficiaries. In response to the lowering of payment rates in the final hospice care regulations, bills have been introduced to amend the Medicare statute to specify in law the payment rates which the Secretary of DHHS must establish for hospice care. S. 2725 and H.R. 5141 would increase the routine home care and inpatient respite care rates promulgated in final regulations of December 1983 to levels initially proposed by the Secretary in regulations issued in August 1983. Another bill, H.R. 5386, would increase only the routine home care rate to the level initially proposed in the August regulations.

B. Core Services

As originally enacted, the Medicare statute required that hospices routinely provide directly substantially all of the following "core" services: nursing care, medical social services, physicians' services, and counseling services. The remaining "non-core" hospice services may be provided either directly by the hospice or under arrangements with other providers. These services include physical therapy, occupational therapy and speech-language pathology services; home health aide and homemaker services; medical supplies, including drugs and biologicals; and short-term inpatient care. For non-core services, the hospice would be required to maintain professional management responsibility for all such services furnished to the individual, regardless of the location or facility in which such services are furnished. The conference agreement on Medicare's hospice benefit (as established in TEFRA of 1982) indicates that conferees intended with the statutory requirements for core and non-core services that hospices provide a basic and coordinated range of services while giving hospices the flexibility to provide, under arrangements, for some services.

With regard to core services, implementing regulations define "directly" to require that services be provided by hospice employees. "Routinely and substantially" have been generally defined to mean that the services provided directly by the hospice should be adequate to meet the general needs of the hospice. However, a hospice could use contracted staff for core services to supplement hospice employees during periods of peak patient loads and under extraordinary circumstances.

These regulations have raised questions as to whether all core services should be provided by hospice employees and whether there should be other circumstances in which a hospice should be permitted to provide such services under arrangements with other providers. For example, at the Committee's hearing on the proposed regulations, a number of witnesses indicated that "core" service requirements for nursing care services would adversely affect rural hospice programs, especially coalition hospices which exist through cooperative arrangements among various providers of hospice services, or visiting nurses' associations which might have hospice subdivisions but which do not have sufficient nursing staff available to designate to that subdivision on a full-time basis.

The recently enacted Deficit Reduction Act, P.L. 98-369, included a provision to allow the Secretary to waive the nursing care core services requirements for hospices that are located in rural areas, that were in operation on or before January 1, 1983, and that have demonstrated a good faith effort to hire a sufficient number of nurses to provide nursing care directly. A waiver request must be granted automatically unless expressly denied by the Secretary within 60 days.

According to HCFA officials, regulations have been developed for this amendment but have not yet been published. In addition, procedures have been developed for processing waiver requests. HCFA has not yet received a request for a waiver of the nursing care core requirements, nor are a great many expected. HCFA estimates that no more than 8 of the 108 hospices currently certified for participation are rural hospices.

C. Reporting

Regulations on Medicare's hospice benefit require hospices to provide reports and keep records as the Secretary determines necessary to administer the program. Supplementary information included with the proposed regulations stated that prospective payment for hospice care will enable HCFA to design a system of reporting requirements which is less comprehensive than the requirements that are necessary to operate a retrospective cost-based system. This supplementary information also indicated that HCFA is not proposing any specific mechanism to adjust the prospective rates after reimbursement has begun. Rather, HCFA will monitor the cost and utilization experience of participating hospices through the submission of cost reports filed by selected hospices and will adjust the rates as an examination of these reports dictates. Final regulations stated that HCFA will collect cost data from all hospices because it is important to have as complete a data base as possible for updating the payment rates and for use as a basis for evaluation of the hospice benefit in general.

Certain hospices have expressed concern about the current lack of a cost reporting form for participating hospices. These hospices argue that without cost information, payment rates can not be properly adjusted to reflect the experience of participating hospices (as opposed to demonstration hospices); nor will HCFA and the Congress be able to adequately evaluate the benefit before coverage ends October 1, 1986.

According to HCFA officials, a draft cost report form was submitted to all certified hospices in early June 1984. The comment period for this draft report closed July 20 and HCFA is currently considering comments received on the draft. Six responses were received. In general, responding hospices were concerned with the quantity of data required to be reported.

HCFA expects to apply this draft cost report to freestanding hospices and to require different versions of this report to be submitted by provider-based hospices (hospital-based, skilled nursing facility-based, and home health agency-based hospices). According to HCFA officials, the draft cost report should be ready for approval in September.

Certified Hospices as of 9/7/84

ALABAMA:

Hospice of Baptist Medical Center
Montgomery, Alabama

Baptist Medical Center
Montclair Hospice
Birmingham, Alabama

ARIZONA:

Valley of the Sun Hospice
Phoenix, Arizona

St. Mary's Hospice
Tucson, Arizona

CALIFORNIA:

Hospice of Monterey Peninsula
Carmel, California

Pacifica Home Care
San Pedro, California

Hospice of San Francisco
San Francisco, California

Vesper Hospice
San Leandro, California

Hospice of Marin
San Rafael, California

Comprehensive Community Home
Daly City, California

Kaiser Foundation Hospital
Norwalk Hospice
Norwalk, California

Hospice of North County
Porway, California

Hospice of the Valley
San Jose, California

COLORADO:

Pikes Peak Hospice
Colorado Springs, Colorado

Hilltop Hospice
Grand Junction, Colorado

Hospice of Metro Denver
Denver, Colorado

Boulder County Hospice, Inc.
Boulder, Colorado

Hospice Inc. of
Weld County, Inc.
Greeley, Colorado

DELAWARE:

Delaware Hospice
Wilmington, Delaware

FLORIDA:

Hospice of Northeast Florida
Jacksonville, Florida

Methodist Hospital Hospice
Jacksonville, Florida

Hospice By The Sea, Inc.
Boca Raton, Florida

Hospice Care of Broward County
Ft. Lauderdale, Florida

Hospice, Inc. (Broward)
Lauderhill, Florida

Hospice of Gold Coast
Home Health Service
Pompano Beach, Florida

Hernando-Pasco Hospice
Hudson, Florida

Hospice of Martin
Stuart, Florida

Hospice of Central Florida
Winter Park, Florida

Hospice, Inc. (Dade)
Miami, Florida

Hospice of Hillsborough
Tampa, Florida

Hospice Care, Inc.
Pinellas Park, Florida

Hospice of Palm Beach County
West Palm Beach, Florida

GEORGIA:

Hamilton Medical Center Hospice
Dalton, Georgia

Grady Hospice
Atlanta, Georgia

Hospice Savannah, Inc.
Savannah, Georgia

American Hospice
Decatur, Georgia

Hospice of Georgia
High Shoals, Georgia

Northside Hospice
Atlanta, Georgia

Hospice of the Golden Isles
Brunswick, Georgia

Hospice Atlanta
Atlanta, Georgia

HAWAII:

St. Francis Hospital
Hospice Program
Honolulu, Hawaii 96817

IDAHO:

Hospice of the Palouse
Moscow, Idaho

Idaho Home Health and Hospice
Twin Falls, Idaho

ILLINOIS:

West Town Nursing Service
Berwyn, Illinois

Hospice of Adams County
Quincy, Illinois

St. John's Hospice
Springfield, Illinois

Belleville Hospice
Belleville, Illinois

Home Health and Hospice
of Illinois
Chicago, Illinois

IOWA:

Hospice of Central Iowa
Des Moines, Iowa

Holy Family Hospice
Estherville, Iowa

KENTUCKY:

Community Hospice of Lexington
Lexington, Kentucky

Hospice of Louisville
Louisville, Kentucky

Ashland Community Hospice
Ashland, Kentucky

MARYLAND:

Stella Maris Hospice Care
Towson, Maryland

MICHIGAN:

Good Samaritan Hospice
Battle Creek, Michigan

Michigan Home Care,
Terminal and Bereavement
Indian River, Michigan

Hospice of the Straits
Cheboygan, Michigan

St. Mary's Hospital Hospice
Saginaw, Michigan

Hospice of Southeastern Michigan
Southfield, Michigan

Michigan Home Care, Inc.
Traverse City, Michigan

Hospice of Greater Kalamazoo
Kalamazoo, Michigan

MISSISSIPPI:

North Mississippi Medical
Center Hospice
Tupelo, Mississippi

The Hospice of Home Health
Agency Multi-County, Inc.
Hattiesburg, Mississippi

MISSOURI:

Hospice of Southeast Missouri
Springfield, Missouri

Hospice of Care,
Texas County Hospital
Houston, Missouri

NEW JERSEY:

Hospice of Morris County
Morristown, New Jersey

Rahway Hospital Hospice
Rahway, New Jersey

Hospice of Burlington County
Moorestown, New Jersey

Medical Center at
Princeton Supportive Care
Program
Princeton, New Jersey

Passaic Valley Hospice
Wayne, New Jersey

Hackensack Medical Center Hospice
Hackensack, New Jersey

Muhlenburg Hospital Hospice
Plainfield, New Jersey

Overlook Hospital Hospice
Summit, New Jersey

Center for Hope
Union, New Jersey

Hospice, Inc.
Montclair, New Jersey

Karen A. Quinlan Center
Center for Hope
Newton, New Jersey

West Essex Hospice
West Caldwell, New Jersey

NEW MEXICO:

Messilla Valley Hospice, Inc.
Las Cruces, New Mexico

Hospital Home Health
Care Hospice
Albuquerque, New Mexico

Roswell Hospice
Roswell, New Mexico

NEW YORK:

Capital District Hospice
Schenectady, New York

United Hospital and Hospice
Port Chester, New York

Our Lady of Lourdes
Binghamton, New York

Hospice of Buffalo
Buffalo, New York

Metropolitan Jewish Geriatric
Nursing Home
New York, New York

NORTH DAKOTA:

Hospice of Red River Valley
Fargo, North Dakota

OHIO:

Hospice of Lake County, Inc.
Mentor, Ohio

Hospice of Miami Valley
Hamilton, Ohio

Hospice of Dayton
Dayton, Ohio

Northwest Ohio Hospice Association
Toledo, Ohio

OREGON:

Providence Medical Center Hospice
Portland, Oregon

McKenzie-Willanette Hospital Hospice
Springfield, Oregon

PENNSYLVANIA:

Wissahickon Hospice
Philadelphia, Pennsylvania

Chandler Hall Hospice
Newtown, Pennsylvania

Hospice-Albert Einstein
Medical Center
Philadelphia, Pennsylvania

Home Nursing Agency of
Blair, Huntington and Fulton Counties
Altoona, Pennsylvania

Hospice of Pennsylvania, Inc.
Scranton, Pennsylvania

Forbes Hospice
Pittsburgh, Pennsylvania

Home Hospice Agency of
St. Francis
New Castle, Pennsylvania

RHODE ISLAND:

Hospice Care of Rhode Island
East Providence, Rhode Island

SOUTH CAROLINA:

Spartanburg General Hospital Hospice
Spartanburg, South Carolina

TENNESSEE:

Hospice of Murfreesboro
Murfreesboro, Tennessee

Alive Hospice of Nashville, Inc.
Nashville, Tennessee

TEXAS:

South Texas Home Health
and Hospice Services, Inc.
Alice, Texas

Spohn Hospice
Corpus Christi, Texas

Community Hospice of St. Joseph
Ft. Worth, Texas

St. Benedict Home Health Hospice
San Antonio, Texas

Dallas Hospice Care, Inc.
Dallas, Texas

Hospice of El Paso
El Paso, Texas

VIRGINIA:

Hospice of Northern Virginia
Arlington, Virginia

WASHINGTON:

Hospice of Snohomish
Everett, Washington

Highline Community Hospital
Hospice
Seattle, Washington

Hospice of Spokane
Spokane, Washington

Hospice of Whatcom County
Bellingham, Washington

Southwest Washington Hospital's
Cancer Program/Hospice Services
Vancouver, Washington

Community Hospice
Longview, Washington

Hospice of Clark County
Vancouver, Washington

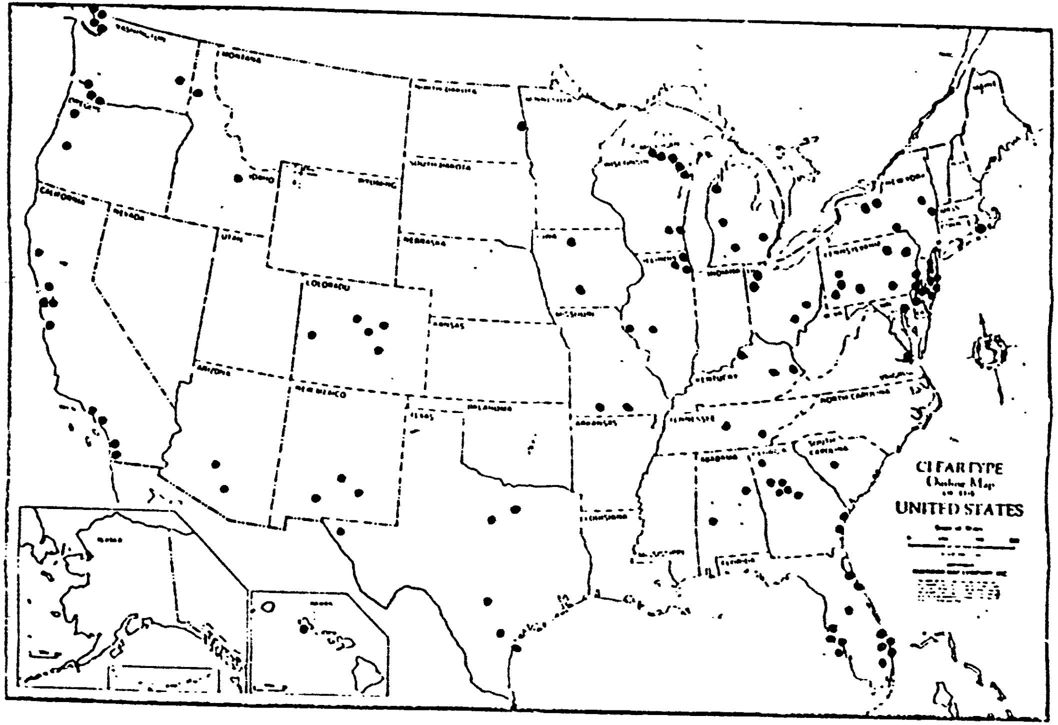
WISCONSIN:

Rogers Memorial Hospice
Oconomowoc, Wisconsin

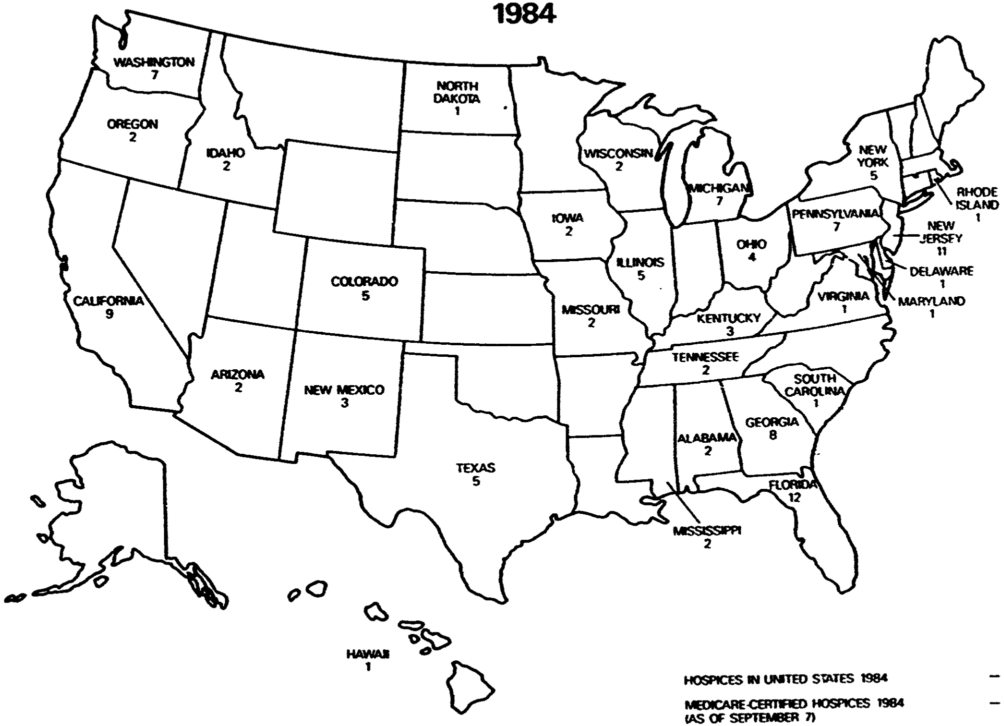
Milwaukee Hospice Home Care
Milwaukee, Wisconsin

HOSPICES CERTIFIED

AS OF 9/7/84 (119)



MEDICARE-CERTIFIED HOSPICES IN THE UNITED STATES
1984



HOSPICES IN UNITED STATES 1984	–	1,500
MEDICARE-CERTIFIED HOSPICES 1984 (AS OF SEPTEMBER 7)	–	119
STATES WITH NO MEDICARE-CERTIFIED HOSPICES	–	20

Senator DURENBERGER. The hearing will come to order. I appreciate everyone being here today, and I appreciate the willingness of the witnesses we have scheduled before us to express their concerns about one of the elements of the health care delivery system that is close to all of our hearts. More than a decade ago now, my wife spent the last 3 months of her life in a hospital. At that time, we were not aware of any alternatives to dying to an institution like a hospital. Something like 8 years, I guess, after that, Hubert Humphrey, who held this seat before I did in the U.S. Senate, was walking around the Senate gym within a month of his death saying goodbye to people.

And the point of these experiences is that only in America has the sensitivity to terminal illness come upon us in a wide variety of ways in recent years that bring us now to this hearing around a word which was not common to our vocabulary at the time, 13 years ago, when my wife died. Today's hearing will focus on hospice, which was included as a new Medicare benefit under the Tax Equity and Fiscal Responsibility Act of 1982, thanks in large part to my colleague from Pennsylvania who has joined us here today.

Hospice is an alternative for the terminally ill. It is medical and social services provided to a patient and the patient's family, which enhances the quality of life in its final stages. In terms of cost, it will be beneficial both in terms of dollars spent and in terms of the physical and emotional strain on the patient and his or her family.

As everyone here knows, this Congress has been supportive of the hospice concept, but even during our initial discussion on whether or not we should provide Medicare coverage for hospice services, there was concern that maybe we were moving too quickly; that we didn't have the experience or the data necessary to define the appropriate components of hospice care.

But we forged ahead, and I, for one, am glad we did. But now I'm hearing that after 10 months of operation, only 108 hospices in the entire country are certified for Medicare. In a recent visit to my own State of Minnesota, I was surprised to learn that at the time I was there in July, there were no Medicare certified hospices in the State. I believe there are two today.

In my discussions with hospice providers, I heard concerns about the inadequacy of the payment rate; particularly, the daily home rate; questions about the mandated core services and the lack of essential reporting requirements. This hearing will examine these points and explore how nonparticipating hospices are providing services to Medicare beneficiaries, who is paying for the service, and why they aren't participating in Medicare.

In the process of today's hearing, I think it's important to keep two things in mind. One, the newness of hospice services. And, two, the future of the Medicare Program.

First, hospice is a relatively new concept in this country. In 1978, there were only 59 operating hospice programs compared to over 1,400 accredited hospice programs today. That's only the accredited hospices. Hospice programs cover a wide range of program structure, service, delivery, design, and organizational affiliations. In my State, there are only 22 accredited hospice programs, but the National Hospice Organization reports over 40 Minnesota hospices as members.

We must closely monitor the implementation of this new benefit, and collect the information needed to make any necessary adjustments in the benefit structure. You all are aware that the hospice benefit was established for only a 3-year period. Congress will need to reevaluate the benefit in terms of cost, reimbursement methods, and benefit structure. The establishment of specific reporting requirements are of extreme importance to the success of the program.

And, second, as I indicated, we must keep in mind that the Medicare Program is undergoing some radical changes. The implementation of the new prospective payment system for inpatient hospital services is just the first step. Financial incentives are now provided to hospitals to focus on the provision of cost effective as well as quality care.

I would anticipate the expansion of the current prospective system to include other Medicare covered services, including skilled nursing facilities, home health, and hospice; one lump sum to be made to the full range of services needed for an entire spell of illness.

So it is important that the newest Medicare benefit, hospice, be structured well to facilitate the implementation of an expanded prospective payment system.

I look forward to hearing from our witnesses today. It will help us understand the barriers to hospice participation in Medicare, and I look forward to working with all of you as we explore the options for an expanded prospective payment system for Medicare services.

Mr. Chairman, do you have an opening statement? John, I guess you were here first. We will go with you.

Senator HEINZ. I would be happy to yield to our chairman.

Senator DOLE. The early bird rule.

Senator HEINZ. Well, Chairman Durenberger, first I must say I'm very pleased to be here with you and Chairman Dole to review and assess the implementation of Medicare's hospice benefit. As one of the authors of this legislation, I firmly believe that the new hospice benefit provides the terminally ill with an innovative, compassionate and cost effective alternative to acute care.

As you mentioned, Mr. Chairman, it has come to our attention that less than 10 percent of all the hospices in this country have been certified by Medicare. When we enacted the legislation back in 1982, it was estimated that the program would serve as many as 31,000 people during its first year of operation. Since the program was implemented in December 1983, a mere 1,000 Medicare beneficiaries, 1,000, not 31,000, have received the new hospice benefit. It appears that fewer eligible Medicare beneficiaries have access to hospice care than Congress intended—by far.

One of the principal concerns raised by the hospice administrators in my State of Pennsylvania, as well as other States, is reimbursements. Specifically, I have been told that the rates paid by Medicare for routine home care and inpatient care are simply too low. And while the great majority of the Nation's hospices are interested in serving Medicare beneficiaries, the fact is that they are electing to stay out of the program. They are excluding Medicare beneficiaries, in effect.

Why? Because they are afraid that they might go broke. Now I know that there has been some discussion and some disagreement about the way in which Medicare rates were calculated. Much of this debate has focused on whether or not the demonstration project, that we will hear more about today, should have been in the first place or should be used now to fix the rates.

Fortunately, the debate about the appropriateness of the data from the demonstration project need not continue much longer.

There are now over 100 Medicare-certified hospices and half of them have been operating for more than 6 months. Surely we can use the actual cost experiences of these certified hospices to evaluate the rates paid by Medicare, and not wait until 1986 to do it. If the rates turn out to be reasonable, fine. If the rates are either too low or too high, Congress will have the option of adjusting the rates well before the October 1986 sunset date.

I must say, Mr. Chairman, it appears that up until recently there has been some reluctance on the part of the administration—maybe I'm wrong—to provide Congress with the cost data that we have been seeking. It has been 2 years since the law was enacted; almost a full year since it was implemented. And I don't know why it has taken up until today for HHS to get their cost forms out and to bring this cost data in. But I'm glad that it is about to happen at last. I hope that the cost data will not be delivered to Congress a day late and a dollar short.

Last month many of us wrote to Secretary Heckler asking when this information would be available. I certainly hope that Dr. Davis will be prepared to tell the committee today when we can expect to see some cost data based on actual experience of certified hospices.

We are all here today to assure that eligible Medicare beneficiaries have access to hospice care. I look forward to working with my colleagues on the committee to further this goal

Mr. Chairman, I thank you for this hearing.

Senator DURENBERGER. Thank you very much.

Senator Dole.

Senator DOLE. Mr. Chairman, what I would like to do is put a statement in the record. I think both you and Senator Heinz have touched on the highlights. I read all the material the staff put together on my way to Kansas on Friday. Coming from Kansas I guess the thing that caught my attention was that map. There is nothing in it. [Laughter]

You noticed that too?

Dr. DAVIS. I did notice that, believe me, Mr. Chairman.

Senator DOLE. So it did peak my interest a bit. I don't normally read all that staff material, but I did read all this.

My only interest—both Senator Heinz and Senator Durenberger—all three of us, I think, have a commitment to see that this program works. And I'm not partialing out the blame, but we want to make it work. I mean if there is something we can do working with HHS or the private sector—we have got National Hospice Month. That doesn't cost anything. We passed that. And we haven't had a lot of interest in that from the industry, I must say.

It just seems to me that we have got a lot of work to do on both sides. And many of us, hopefully—we have been chided by some saying we are just opening up another Pandora's box and there is no limit on what this will cost. We believe we can demonstrate otherwise if we have a lot of cooperation. So I won't repeat what has been stated very well by my colleagues except I'm certain that you know that we are interested in this, as is the administration. And I'm going to stay as long as I can. We have a trade bill coming up at 2:30 so I may have to leave fairly soon.

Thank you very much.

Senator DURENBERGER. Thank you.

Our first witness is Dr. Carolyne Davis, Administrator of the Health Care Financing Administration. Carolyne, welcome.

Dr. DAVIS. Thank you, Mr. Chairman.

Senator DURENBERGER. Your full statement will be made part of the record.

Dr. DAVIS. Good. I would just like to highlight several of the talking points then that relate to the summary of what I did submit.

STATEMENT OF DR. CAROLYNE K. DAVIS, ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, WASHINGTON, DC

Dr. DAVIS. First of all, I would like to introduce to you Bob Streimer who is on my left. He's the Deputy Director of the Bureau of Eligibility, Reimbursement, and Coverage.

Let me just summarize by indicating that clearly there has been a dramatic growth in the hospice movement which culminated in Medicare's hospice benefit being enacted under the Tax Equity and Fiscal Responsibility Act of 1982. That particular benefit was carefully designed by Congress to include safeguards to assure that a hospice would, indeed, provide a coordinated continuum of health care services in a cost-effective manner.

I think that the hospice that was prescribed in law does not necessarily reflect the multiple types of hospice organizations that are now in existence, some of which cover all types of services, and some of which only cover certain types of services.

So we must be careful when we say that there might be somewhere between 1,200 and 1,500 hospice-type organizations. Not all of those would be expected to qualify for the benefit that was passed by Congress. Congress tried very deliberately to craft a hospice benefit which had certain selective components such as core services and the 20 percent limit on inpatient hospital and respite care; the kinds of requirements, which we think were a careful balance to encourage appropriate utilization of the benefit.

I would like to just spend a moment or two updating you on the implementation of the benefit and discussing some of the issues that may be influencing participation in the hospice program.

First of all, in terms of implementation, in September of 1983 we notified anyone that called themselves a "hospice" that we would have a new Medicare benefit. We gave them some detailed information, as much as we knew at that time, and then followed up later with further information. We began to train our surveyors to go out and to survey hospices to make certain that organizations met the conditions of participation.

By September 15, 1984, we have completed or scheduled 180 surveys. We have now certified 119 hospices that are now able to fully participate in the Medicare Program.

We have pending an additional 43, meaning that they have been scheduled for survey or have been surveyed by the State agency and are in review as part of the certification process. An additional 14 surveys are now being scheduled.

So I think we can look forward in the near future to close to 200 of the surveys being completed and certification of nearly that many.

If you look, you will find that the largest number of certified hospices, some 41, are based in home health agencies. That tends to be the largest model with an additional group of 39 hospices that are free-standing. We have about 32 hospices that are hospital-based, and then we have 7 which are skilled nursing facility-based.

And as Senator Heinz said, by September approximately 1,300 Medicare patients had chosen the hospice benefit. I will come back to that later.

Remember, we are asking our Medicare beneficiaries to make an optional selection: to move from their current benefit package by waiving current Medicare coverage to move into a hospice program. And I think that takes education; that takes time. And it may well be that that is one of the significant forces in effect here too.

The Medicare payment rates were developed with the most up-to-date data that we had available from the comprehensive assessment that was performed under the National Hospice Demonstration Program. The data we used for constructing the rates were known to you all, and we have submitted that information to you.

We also used other Medicare data sources where the demonstration data did not contain sufficient data that was consistent with the benefit structure.

Demonstration data was used to construct the home care rates, and the cost of routine skilled nursing facility services is the basis for the inpatient respite rate. Cost components were then added to what our data to reflect hospice services that needed to be included that had not been under the hospice demonstration, such as outpatient drugs, home respite care, and some additional outpatient therapy services; primarily, for radiology services. The rates also reflect the cost of the hospice interdisciplinary group. We then inflated those rates to 1984 costs. We believe that the rates were designed to pay for the care provided under the specific requirements of the hospice law which was constructed by Congress in a specific style.

To comply with the Medicare statute and regulation, we believe that there are some operational changes that perhaps need to be made by some hospices, and that may be slowing the movement toward seeking certification.

For example, a number of the hospices would have to make fundamental changes, such as hiring of personnel to provide the core services if they don't currently have the core service personnel capability. Others feel that the provision of an inpatient capacity is something that they must negotiate with a hospital. And making those arrangements and assuring that the hospice has the professional management capability for those patients, of necessity, takes some time.

There may be some hospices that might have philosophical problems also with the idea of participating as a Medicare provider, fearing that the disintegration of the voluntary aspect of the traditional volunteerism might be negated somewhat by the availability of Federal payments.

We know, too, that some hospices might be thinking of the possibility of having to judge when a patient is ready for admission in order to stay within the last 6 months of life or the hospice benefit period. There may be some hospices who yet need to deal with the learning curve in relationship to judging to when a patient does need hospice services.

It's also true that there are some hospices who may find that it's not worthwhile for them to make the changes that are necessary to provide the services under the hospice benefit label because they may be paid for many of those services now as a freestanding home health agency or other entity, such as skilled nursing facility. So that, too, may be something that they are weighing. Indeed, some of the hospices have told us that up to 85 percent of the care that they provide is now being paid for through regular Medicare coverage. And particularly since that is paid on a cost basis system and has not yet moved to a comprehensive system of prospectively set payments, hospices may simply be more secure in using that particular method.

For example, hospices that are now certified as a home health agency can continue to receive payments for the services that they are providing to Medicare patients. And patients might then receive hospice services through a home health agency, keeping in mind that there are cost limits on that, and that they have to meet the requirements for homebound and intermittent care. But I believe that many of the home health agencies might find that there isn't as much incentive to seek Medicare hospice status since so many of their services are currently covered.

What we have been trying to do is to finalize our strategy also in terms of looking forward to the evaluation component of the Medicare benefit experience, which we think is so important to provide the report to Congress by the January 1, 1986, deadline. And we did include material in our submission to you which outlines for you how we intend to meet that target. I think that is very important and we intend to meet that deadline.

Although our time will be limited to collect sufficient and accurate data, we intend to have data available at that point in time. And we will continue to work to provide even further data beyond that point.

So in conclusion, I think that the hospice benefit is on track. I believe that hospices and other health care providers, some of which may now be weighing how best they can furnish the kinds of terminal health care services considering their own personal circumstances. But if I look back over the history of any new provider coming into this program, I note that the first 6 to 9 months tend to move very slowly. And then if you look to year two—and I have done an assessment that I will submit for the record—our experience with rural health clinics, with ambulatory surgical centers and even with home health agencies show that by year two participation normally just about doubles. So I think we are on track in this particular endeavor.

Senator DURENBERGER. Thank you very much.

[The prepared written statement of Dr. Davis follows:]

STATEMENT OF
CAROLYNE K. DAVIS, PH. D.
ADMINISTRATOR
HEALTH CARE FINANCING ADMINISTRATION

I APPRECIATE THIS OPPORTUNITY TO DISCUSS WITH YOU THE IMPLEMENTATION OF THE MEDICARE HOSPICE BENEFIT AND OTHER ISSUES CONCERNING HOSPICE CARE. WITH ME IS ROBERT STREIMER, DEPUTY DIRECTOR OF THE BUREAU OF ELIGIBILITY, REIMBURSEMENT AND COVERAGE.

AS YOU KNOW, THE HOSPICE MOVEMENT IN THIS COUNTRY HAS EXPERIENCED DRAMATIC GROWTH IN RECENT YEARS. IN 1978, THE GENERAL ACCOUNTING OFFICE REPORTED THAT THERE WERE 59 OPERATIONAL HOSPICES. TODAY, RECENT DATA COLLECTED BY THE JOINT COMMISSION ON ACCREDITATION OF HOSPITALS (JCAH) INDICATES THAT ALMOST 1,500 ORGANIZATIONS DESCRIBE THEMSELVES AS HOSPICES. HOWEVER, THE JCAH POINTS OUT THAT THIS FIGURE CAN BE MISLEADING SINCE ONLY A FEW STATES HAVE LICENSURE PROGRAMS, AND ORGANIZATIONS RESPONDING TO THE JCAH SURVEY QUESTIONNAIRE CAN INDICATE THEY PROVIDE HOSPICE CARE EVEN IF THEY WOULD NOT MEET CERTAIN STANDARDS FOR PROVIDING CARE. NEVERTHELESS, THE GROWTH IN THE HOSPICE MOVEMENT SEEMS TO REFLECT THAT HOSPICE CARE, BY HELPING PATIENTS CONTINUE TO LIVE AT HOME IN MAXIMUM COMFORT WITH A MINIMUM OF DISRUPTION, IS SEEN AS A DESIRABLE ALTERNATIVE TO CARE PROVIDED IN CONVENTIONAL SETTINGS.

THE INTENSE INTEREST IN THE HOSPICE MOVEMENT CULMINATED IN THE ENACTMENT OF THE MEDICARE HOSPICE BENEFIT IN 1982 AS

PART OF THE TAX EQUITY AND FISCAL RESPONSIBILITY ACT (P.L. 97-248). THE HOSPICE BENEFIT ENACTED BY CONGRESS WAS CAREFULLY DESIGNED TO INCLUDE SAFEGUARDS TO ASSURE THAT HOSPICES WOULD BE RESPONSIBLE FOR PROVIDING A COORDINATED CONTINUUM OF HIGH QUALITY CARE IN A COST-EFFECTIVE MANNER. HOWEVER, THE HOSPICE PRESCRIBED IN LAW DOES NOT REFLECT THE WIDELY VARYING ORGANIZATIONS WHICH CURRENTLY CONSIDER THEMSELVES AS HOSPICES OR WHICH PROVIDE HOSPICE-TYPE SERVICES.

TODAY, I WOULD LIKE BRIEFLY TO BRING YOU UP-TO-DATE ON THE IMPLEMENTATION OF THE HOSPICE BENEFIT AND DISCUSS SEVERAL ISSUES THAT MAY BE INFLUENCING HOSPICES' PARTICIPATION IN MEDICARE.

IMPLEMENTATION STATUS

IN SEPTEMBER 1983, OUR REGIONAL OFFICES SENT LETTERS TO ALL THE ORGANIZATIONS WHICH HAD IDENTIFIED THEMSELVES ON THE JCAH SURVEY AS HOSPICES. THESE LETTERS INFORMED THE HOSPICES OF THE NEW MEDICARE BENEFIT AND REQUESTED THAT THEY RETURN ANY EXPRESSION OF INTEREST IN PARTICIPATING AS A MEDICARE PROVIDER. AT THE SAME TIME, WE ALSO BEGAN TRAINING STATE SURVEYORS ON HOW TO APPLY THE CRITERIA (CONDITIONS OF PARTICIPATION) THAT HOSPICES MUST MEET IN ORDER TO OBTAIN

MEDICARE PROVIDER STATUS. SUPPLEMENTARY SURVEYOR TRAINING WAS CONDUCTED FOLLOWING THE PUBLICATION OF THE FINAL REGULATIONS IN DECEMBER 1983.

BY SEPTEMBER 1984, AFTER JUST NINE MONTHS OF IMPLEMENTATION ACTIVITIES, WE HAD COMPLETED OR SCHEDULED 180 SURVEYS AND HAD CERTIFIED 119 HOSPICES FOR PARTICIPATION IN MEDICARE. CERTIFICATION IS PENDING FOR ANOTHER 43 HOSPICES. OF THE HOSPICES CERTIFIED, THE LARGEST NUMBER, 41, ARE BASED IN HOME HEALTH AGENCIES. THIRTY-NINE HOSPICES ARE FREESTANDING; 32 ARE HOSPITAL-BASED; AND 7 ARE BASED IN SKILLED NURSING FACILITIES. OUR RECORDS SHOW THAT BY THE BEGINNING OF THIS SEPTEMBER, 1,280 MEDICARE PATIENTS HAD CHOSEN THE HOSPICE BENEFIT.

HOSPICE RATES

BEFORE I DISCUSS IMPLEMENTATION ISSUES FURTHER, I WOULD LIKE TO SAY A FEW WORDS ABOUT THE HOSPICE PAYMENT RATES AND HOW THEY WERE DEVELOPED. THE ALLEGATION HAS BEEN MADE THAT THE MEDICARE PAYMENT RATES HAVE DISCOURAGED PARTICIPATION. HOWEVER, WE BELIEVE THE RATES HAVE BECOME A CONVENIENT EXCUSE RATHER THAN A TRUE DISINCENTIVE TO PARTICIPATION.

THE MEDICARE HOSPICE RATES WERE DEVELOPED WITH THE MOST UP-TO-DATE DATA AVAILABLE FROM THE MOST COMPREHENSIVE AND SYSTEMATIC ASSESSMENT YET PERFORMED ON HOSPICE CARE PROVIDED TO MEDICARE PATIENTS. THE DATA FROM THE NATIONAL HOSPICE STUDY OF THE MEDICARE HOSPICE DEMONSTRATION PROVIDED US WITH THE BASIS FOR DEVELOPING THE RATES, PARTICULARLY THE HOME CARE RATES, TO BE PAID UNDER THE MEDICARE HOSPICE BENEFIT.

HOWEVER, THE MEDICARE HOSPICE DEMONSTRATION DIFFERED IN SEVERAL WAYS FROM THE BENEFIT ENACTED BY CONGRESS. FOR EXAMPLE, MEDICARE PATIENTS IN THE DEMONSTRATION WERE NOT RESTRICTED, AS UNDER LAW, TO RECEIVING ALL THEIR CARE FROM THE HOSPICE. THEY COULD ENTER HOSPITALS, RECEIVE OUTPATIENT SERVICES AND SEEK OTHER CARE OUTSIDE OF THE HOSPICE. IN ADDITION, UNDER THE DEMONSTRATION, THERE WAS NO LIMIT ON INPATIENT CARE NOR WERE HOSPICES REQUIRED TO MAINTAIN PROFESSIONAL MANAGEMENT RESPONSIBILITY FOR ALL CARE THAT PATIENTS RECEIVED. CONSEQUENTLY, WE HAD TO CONSTRUCT THE HOSPICE RATES USING COST AND UTILIZATION DATA FROM THE NATIONAL HOSPICE STUDY, WHERE IT WAS CONSISTENT WITH THE LEGISLATED BENEFIT, SUPPLEMENTED WITH COST INFORMATION FROM OTHER MEDICARE DATA SOURCES.

IN PAYING HOSPICES UNDER THE MEDICARE PROGRAM, WE DECIDED TO USE A PROSPECTIVE SYSTEM TO AVOID THE NEGATIVE INCENTIVES INHERENT IN A COST-BASED REIMBURSEMENT SYSTEM. AS YOU KNOW, WE DEVELOPED FOUR PER DIEM RATES TO REFLECT THE VARIOUS LEVELS OF CARE PROVIDED BY HOSPICES: ROUTINE HOME CARE, CONTINUOUS HOME CARE, INPATIENT RESPITE CARE AND GENERAL INPATIENT CARE.

THE BASIS FOR THE ROUTINE HOME CARE RATE AND THE CONTINUOUS HOME CARE RATE IS THE COST AND UTILIZATION DATA FROM THE HOSPICE DEMONSTRATION. FOR ROUTINE HOME CARE, WE CALCULATED THE AVERAGE PER VISIT COST AND ADDED COST COMPONENTS FOR THE HOSPICE INTERDISCIPLINARY TEAM, DRUGS, SUPPLIES, EQUIPMENT, HOME RESPITE CARE AND HOSPITAL OUTPATIENT THERAPIES, SUCH AS PALLIATIVE RADIATION OR CHEMOTHERAPY. THE CONTINUOUS HOME CARE RATE WAS CALCULATED FROM DEMONSTRATION COST DATA ON AN HOURLY BASIS WITH COST COMPONENTS ADDED FOR THERAPY VISITS, DRUGS, SUPPLIES, EQUIPMENT AND THE HOSPICE INTERDISCIPLINARY TEAM. BOTH HOME CARE RATES WERE ADJUSTED FOR INFLATION THROUGH 1984.

BECAUSE OF LIMITED EXPERIENCE UNDER THE DEMONSTRATION, WE HAVE NO DIRECTLY COMPARABLE DATA TO CONSTRUCT AN INPATIENT RESPITE RATE. CONSEQUENTLY, THE RATE WAS CALCULATED FROM MEDICARE PROGRAM DATA ON THE COST OF ROUTINE SKILLED NURSING FACILITY SERVICES. COST COMPONENTS WERE ADDED REPRESENTING

THE DAILY COST OF SUPPLIES, DRUGS, EQUIPMENT AND THE HOSPICE INTERDISCIPLINARY GROUP. THE GENERAL INPATIENT RATE IS BASED ON DEMONSTRATION DATA ON THE INPATIENT ROUTINE AND ANCILLARY OPERATING COSTS OF HOSPITAL-BASED HOSPICES. IN CALCULATING THE RATE, AVERAGE MEDICARE HOSPITAL DATA WERE USED IN COMBINATION WITH THE ACTUAL DEMONSTRATION COSTS TO ARRIVE AT A RATE THAT WOULD BE REPRESENTATIVE OF A NATIONAL SAMPLE OF HOSPICES. BOTH INPATIENT RATES WERE INFLATED TO 1984 DOLLARS.

THE RATES, THEREFORE, ARE DESIGNED TO PAY FOR CARE PROVIDED UNDER THE SPECIFIC REQUIREMENTS OF THE LAW BY HOSPICES WHICH MEET ORGANIZATIONAL AND OPERATIONAL QUALIFICATIONS SPECIFIED UNDER THE STATUTE.

ISSUES INFLUENCING PARTICIPATION

TO COMPLY WITH THE MEDICARE STATUTE AND REGULATIONS, OPERATIONAL CHANGES MUST BE MADE BY MOST HOSPICES. FOR SOME, IT MAY MERELY BE A MATTER OF IMPROVING EXISTING ACCOUNTING SYSTEMS. HOWEVER, FOR MOST HOSPICES MORE FUNDAMENTAL CHANGES HAVE TO BE MADE SUCH AS HIRING NURSES AND OTHER STAFF TO PROVIDE CORE SERVICES, PROVIDING FOR AN INPATIENT CAPACITY, MAKING ARRANGEMENTS TO ASSURE THE HOSPICE'S RESPONSIBILITY FOR PROFESSIONAL MANAGEMENT OF ALL

PATIENT CARE AND SETTING UP ADEQUATE ADMINISTRATIVE PROCEDURES TO PROVIDE DOCUMENTED COMPLIANCE WITH MEDICARE REQUIREMENTS.

HOSPICES MAY ALSO HAVE PHILOSOPHIC PROBLEMS WITH PARTICIPATING AS A MEDICARE HOSPICE PROVIDER. HOSPICES MAY FEAR THAT THE TRADITIONAL VOLUNTEERISM THAT THEY HEAVILY RELY UPON MAY DISINTEGRATE WITH THE AVAILABILITY OF FEDERAL PAYMENT FOR CARE. OTHER HOSPICES DO NOT WANT TO BE PLACED IN THE POSITION OF POSSIBLY JUDGING WHEN POTENTIAL PATIENTS SHOULD BE ADMITTED IN ORDER TO ASSURE THAT MEDICARE PAYMENTS WILL COVER THE DURATION OF HOSPICE CARE.

MANY ORGANIZATIONS PROVIDING HOSPICE CARE MAY FIND IT NEITHER DESIRABLE NOR BENEFICIAL TO MAKE THE OPERATIONAL AND IDEOLOGICAL CHANGES NECESSARY TO PROVIDE SERVICES UNDER A BENEFIT LABEL THAT IS LIKELY TO END OR BE CHANGED IN THE NEAR FUTURE.

SOME HOSPICES HAVE TOLD US THAT UP TO 80 TO 85 PERCENT OF THE CARE THEY PROVIDE IS PAID FOR THROUGH REGULAR MEDICARE COVERAGE OR OTHER FUNDING SOURCES. FOR INSTANCE, A HOSPICE MAY BE CERTIFIED AS A HOME HEALTH AGENCY AND RECEIVE REIMBURSEMENT FOR HOME HEALTH SERVICES FURNISHED TO TERMINALLY ILL BENEFICIARIES. HOSPICES MAY NOT FIND IT WORTHWHILE TO QUALIFY AS MEDICARE HOSPICE PROVIDERS IN ORDER

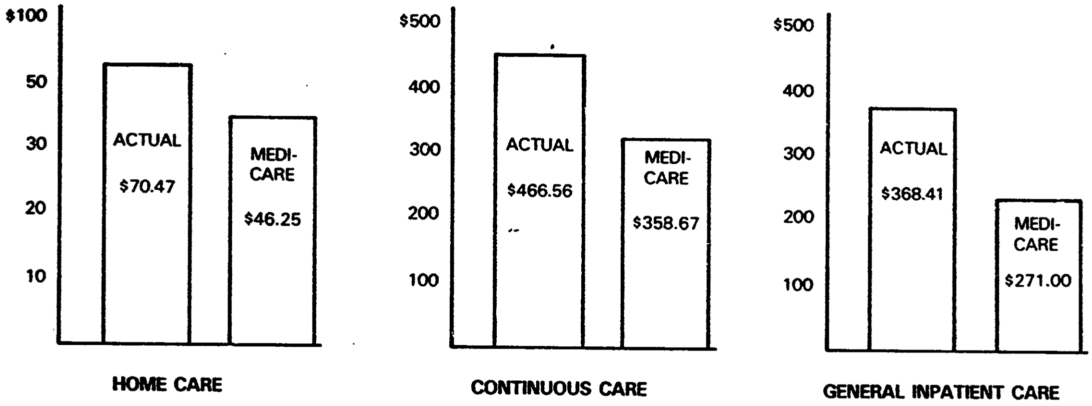
TO RECOVER THE MARGINAL COSTS NOT REIMBURSABLE UNDER THE REGULAR MEDICARE HOME HEALTH BENEFIT. IN FACT, SOME HOME HEALTH AGENCIES MAY RECEIVE MORE MEDICARE REIMBURSEMENT PROVIDING HOSPICE-TYPE SERVICES AS A HOME HEALTH AGENCY THAN PROVIDING THOSE SAME SERVICES AS A HOSPICE. HOME HEALTH AGENCIES HAVE LITTLE INCENTIVE TO BECOME HOSPICE PROVIDERS SINCE THEY ARE REIMBURSED ON A RETROACTIVE COST BASIS AND ARE NOT SUBJECT TO THE HOSPICE CAPS ON OVERALL SPENDING AND INPATIENT UTILIZATION.

WE HAVE RECENTLY MADE FINAL OUR STRATEGY FOR EVALUATING THE MEDICARE HOSPICE BENEFIT EXPERIENCE TO PROVIDE THE REQUIRED REPORT TO CONGRESS BY JANUARY 1, 1986. WE WILL EXAMINE THE BENEFIT STRUCTURE AND COSTS OF THE PROVISION OF TERMINAL CARE BY PARTICIPATING HOSPICES AND BY CONVENTIONAL MEDICARE PROVIDERS. WE WILL ALSO REVIEW THE IMPACT OF THE CORE SERVICES REQUIREMENT ON HOSPICE OPERATIONS. ALTHOUGH THE TIME IS LIMITED TO COLLECT SUFFICIENT, ACCURATE DATA, WE HOPE TO BE ABLE TO MAKE RECOMMENDATIONS THAT WILL ASSURE THAT TERMINALLY ILL MEDICARE BENEFICIARIES RECEIVE APPROPRIATE CARE FROM ALL PROVIDERS CAPABLE OF FURNISHING HIGH QUALITY SERVICES.

CONCLUSION

THE IMPLEMENTATION OF THE HOSPICE BENEFIT IS ON TRACK. ALTHOUGH I REALIZE MANY HAD ANTICIPATED MORE ORGANIZATIONS WOULD APPLY TO BECOME CERTIFIED MEDICARE HOSPICES, I BELIEVE THE EXISTING HOSPICES AND OTHER HEALTH CARE PROVIDERS ARE WISELY WEIGHING HOW THEY MAY BEST FURNISH TERMINAL HEALTH CARE, GIVEN THEIR PARTICULAR CIRCUMSTANCES. WE HOPE THAT OUR EVALUATION OF THE MEDICARE HOSPICE BENEFIT EXPERIENCE WILL PROVIDE GUIDANCE FOR FUTURE EFFORTS IN ASSURING THAT APPROPRIATE HEALTH CARE SERVICES, INCLUDING THOSE UNIQUE TYPES OF SERVICES TRADITIONALLY PROVIDED BY HOSPICES, ARE WIDELY AVAILABLE TO ALL MEDICARE PATIENTS WHO REQUIRE THEM. WE STILL NEED TO DETERMINE HOW HOSPICES AND OTHER PROVIDERS CAN BEST PROVIDE TERMINAL CARE TO MEDICARE PATIENTS IN A MANNER WHICH WILL NOT NEGATIVELY IMPACT ON THE FINANCIAL STABILITY OF THE MEDICARE TRUST FUND.

ACTUAL COSTS OF PROVIDING HOSPICE CARE
VS.
MEDICARE PAYMENT RATES
SEPTEMBER 1984*



*RESPITE CARE RATE – INSUFFICIENT DATA AVAILABLE DUE TO LACK OF UTILIZATION

SOURCE: NATIONAL HOSPICE ORGANIZATION SURVEY OF MEDICARE-CERTIFIED HOSPICES, SEPTEMBER 1984

Senator DURENBERGER. John, do you want to start with your questions? I'm afraid if I get going, I might bog down and take up some of your time.

Senator HEINZ. I have one or two, Mr. Chairman. Thank you.

Dr. Davis, can you explain why HCFA has been so slow in implementing the cost collection process?

Dr. DAVIS. Yes. Let me just summarize briefly some of our activities as it relates to the development of the cost report form. First, as you know, when we published the NPRM, we did not anticipate at that point in time that we would do a total cost collection effort. We anticipated at that point that we would be doing a survey to collect the data. Based upon input from people who wrote in—which I would add does indicate that we do take seriously comments that are sent to us on an NPRM—we concluded that in the final regulations we should establish a cost report and collect the data from all of our hospices.

Having made that decision, we published that regulation in December. I think it was mid-December. And by mid-March of this year, we had our first attempt at a cost report form. Following our usual format, we submit that for critique by others. In this particular case, Congress had asked GAO to, in effect, oversee some of our activities in relationship to the collection of hospice data, and the GAO commented on the form. Their comments resulted in our developing an even more extensive cost report form. Then we next submitted that second version to the provider community. They reacted with great distress that it was so detailed. And as a result of their input, we then scaled it back. It has taken us a number of months to go through those iterations and we have only recently concluded our discussions in relationship to those forms. And the first of those forms have now just been sent to the OMB for their approval. So we expect that we will expedite our activities from here on in.

Senator HEINZ. Will it take long to get OMB approval on those forms?

Dr. DAVIS. I don't anticipate that it should take that long now.

Senator HEINZ. So how long would it take before the Department gets into the field to intermediaries and hospice providers and starts collecting cost information?

Mr. STREIMER. I think if all goes well and we get a prompt approval of the forms and get them distributed, we hope certainly by the end of the year the forms and the instructions will—

Senator HEINZ. The fiscal year or calendar year?

Mr. STREIMER. I would say by the end of the calendar year those forms would all be distributed to the hospice providers.

Senator HEINZ. If it takes you that long to get all that paperwork together, I hate to think how long it will take you to process it.

When could we expect meaningful information coming back?

Dr. DAVIS. I think that the most meaningful information coming back will probably take at least a year or two to collect and to bring in. We will ask the hospices to come on line in relationship to their fiscal reporting year, although clearly we will ask for information to be filled out on supplemental forms so we can capture some of their past data. I expect that we will have some of that data in-house so that we will have a decent aggregate of data for the January 1986 report. But I doubt that we are going to have a great deal in terms of interim data much before then.

Senator HEINZ. I'm advised that the National Hospice Organization is going to propose some suggested reimbursement rates, to the committee and to you today. Could you report back to the Congress with an evaluation of those rates? And if so, how soon? When?

Dr. DAVIS. Since I haven't seen the data that they are about to submit, I can't take a very firm stand as to whether it is adequate or not, and, therefore, how long it would take us to do an assessment of them and how long it would take us, then, to get back.

Senator HEINZ. What's the outer limit on something like that? Three months? Four months?

Dr. DAVIS. I would think it would be all of that, if not longer. Four months would assume that all the data are in and that we all agree on it and there are no questions to really hinder our moving ahead. If you recall, we are about to come forward with our final report on our hospice demonstration and that moves us from the data on 4,000 hospice patients to approximately 7,000. That report was just finished and reached us last week on Wednesday, I believe. We are now looking at the report and we will want to move that forward.

I think that we would certainly feel comfortable getting the data that we have there to you in the very near future. And I would think that might be very useful, Senator.

Senator HEINZ. In your testimony you note that there are some 1,500 organizations that describe themselves as hospices, and then on page 3 you go on to detail that you completed or scheduled 180 surveys, certified 119 hospices. To what extent is it due to the inadequacy of HHS resources in surveying and certifying that only a relatively modest number of hospices have been certified and to what extent is it due to other factors? Is there a waiting list of any kind for surveys beyond the numbers listed here?

Dr. DAVIS. The numbers that are listed there, I believe, include 14 that are now scheduled and have not yet been surveyed. But I don't think that's a long waiting list. In general, that's a fairly rapid turnover. I believe that we do have sufficient surveyors. As you know, we contracted with the States to perform those services.

Senator HEINZ. So you think you are relatively current?

Dr. DAVIS. I believe we are. I get a weekly report on what is going on. Excuse me, it's now——

Senator HEINZ. And it's your belief that there are factors other than Medicare payment rates that have discouraged participation here.

Dr. DAVIS. I think it's several other factors, Senator Heinz. I believe that it's not the rates as much as it is the whole idea of fitting within the intent of the legislation. Namely, the fact that core services be provided directly. Second, the fact that those core services—excuse me, that in addition to core services that there should be services established for inpatient care. A number of hospices that are not related to a hospital need, of necessity, to have time to work out arrangements with a hospital to provide inpatient services. And because of the philosophy of hospice, the law indicated very clearly that the professional management of the hospice patient ought to be done by the hospice staff. That, again, takes some agreements in working out the professional management responsibilities in a contract with the hospitals. So I think those are the kinds of issues. And you have the issue that the hospice itself needs to focus on related to the 80-20 cap: the idea that there should be no more than 20 percent of the total patient-days that should accrue to inpatient care as opposed to home care. So I think it's a number of those requirements.

Senator HEINZ. I imagine that we will hear a good deal more about that from the various hospice organizations that will be testifying. But I have a letter here dated September 12 from the South Hills Family Hospice located in Pittsburgh, PA, which says in part, and I quote:

> A financial study prepared for South Hills Family Hospice regarding feasibility of entering the Medicare system has confirmed the inadequacy of Medicare reimbursement. The fear of going into debt is strong. Not as much for the daily rate, although that is a consideration, but more for the crisis situation which could develop from an extended or complicated hospitalization.

Now that sounds to me like they are saying they don't have much confidence in the reimbursement system. Is that what it says to you?

Dr. DAVIS. No, sir. What it would say to me is that they may have a fear of going past the cap. That sounds more like, you know, if there is an unusual extenuating circumstance that would expend dollars beyond the cap. But, frankly, the history of what we can look at from our demonstration indicates that the cap was set fairly at $6,500, and I wouldn't think that there would be that fear. Although, clearly, I think that there are people around the country who feel some degree of nervousness about the cap.

Senator HEINZ. Many of these organizations are fairly small.

Dr. DAVIS. Yes.

Senator HEINZ. They may have a daily census of 10 or fewer patients. If by circumstance one should get a clustering of very severe cases—say three or four or five all at once—this would not be statistically unlikely—a larger operation would be able to remain in business long enough to ride out that statistical oddity. But smaller hospices may not have the staying power to survive that kind of statistical aberration. Do you suppose that's a problem here?

Dr. DAVIS. Well, I suppose that in any one small organization that could be. But, again, I would think that if you look at the data that we have had from our demonstrations, it does not appear that anyone has had a problem with the cap.

Senator HEINZ. Maybe that's self-selection, Dr. Davis. Let me quote a second part of this letter, which says, "More than one-half of the Pennsylvania hospices are small, this 19 having a daily census of 10 or fewer patients, and 22 having a daily census of between 11 and 20 patients." This is not megabusiness. These are small operations.

I must say I don't find your response terribly convincing of the fact that no one is having problems here. It means that the ones that might have problems have somehow avoided them in the program.

Let me ask you this: What is the average patient census of the 119 hospices now participating?

Dr. DAVIS. We would have to submit that for the record.

Senator HEINZ. That would be an interesting statistic and it would shed some light on your experience to date. You may, as I say, have a kind of a self-selective sample of some kind here.

[The information from Dr. Davis follows:]

AVERAGE DAILY PATIENT CENSUS IN MEDICARE CERTIFIED HOSPICES

119 Hospices Self Reported*

Average Daily Census (all patients)

	Less than 10	10-20	20-30	30-40	more than 40
Providers	53	28	19	6	13

Average daily Census (Medicare only)

	Less than 5	5-10	10-15	15-20	more than 20
Providers	69	25	12	2	11

*Per telephone calls by regional offices to individual hospices.
ALL DATA ESTIMATED

Certified Hospices as of 09/14/84 (119)

Average daily census (all patients/Medicare patients) appears following each hospice category designation.*

Region I

Rhode Island

1. Hospice Care of Rhode Island
   1240 Pawtucket Avenue
   East Providence, Rhode Island 02916
   (HHA-Based) 22/5

Region II

New Jersey

1. Hospice of Morris County
   282 W. Hanover Avenue
   Morristown, New Jersey 07960
   (Freestanding) 10/1

2. Muhlenburg Hospital Hospice
   Park Avenue and Randolph Road
   Plainfield, New Jersey 07061
   (HHA-Based) 35/1

3. Rahway Hospital Hospice
   865 Stone Street
   Rahway, New Jersey 07065
   (Hospital-Based) 16/8

4. Overlook Hospital Hospice
   193 Morris Avenue
   Summit, New Jersey 07901
   (HHA-Based) 30/24

5. Hospice of Burlington County
   214 W. Second Street
   Moorestown, New Jersey 08057
   (Freestanding) 20/12

6. Center for Hope
   1379 Morris Avenue
   Union, New Jersey 07083
   (Freestanding) 23/12

7. Medical Center at Princeton Supportive Care Program
   253 Witherspoon Street
   Princeton, New Jersey 08540
   (HHA-Based) 13/3

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*Self reported by individual hospices - all data estimated.

8. Hospice, Inc.
331 Claremont Avenue
Montclair, New Jersey 07042
(Freestanding) 21/5

9. Passaic Valley Hospice
50 Galesi Drive
Wayne, New Jersey 07470
(HHA-Based) 50/33

10. Karen A. Quinlan Center for Hope
175 High Street
Newton, New Jersey 07860
(Freestanding) 7/4

11. Hackensack Medical Center Hospice
385 Prospect Avenue
Hackensack, New. Jersey 07601
(HHA-Based) 58/36

12. West Essex Hospice
3 Fairfield Avenue
West Caldwell, New Jersey 07006
(HHA-Based) 5/3

<u>New York</u>

1. Capital District Hospice
514 McClellan Street
Schenectady, New York 12304
(Freestanding) 20/14

2. Hospice of Buffalo
2929 Main Street
Buffalo, New York 14214
(HHA-Based) 23/9

3. United Hospital and Hospice
406 Boston Post Road
Port Chester, New York 10573
(Hospital-Based) 8/1

4. Metropolitan Jewish Geriatric Nursing Home
4915 10th Avenue
Brooklyn, New York 11219
(SNF-Based) 20/10

5. Our Lady of Lourdes
165 Riverside Drive
Binghamton, New York 13905
(Hospital-Based) 60/45

Region III

Delaware

1. Delaware Hospice
3509 Silver Side Road
Wilmington, Delaware 19810
(Freestanding) 21/10

Maryland

1. Stella Maris Hospice Care
2300 Dulaney Valley Road
Towson, Maryland 21204
(SNF-Based) 25/11

Pennsylvania

1. Wissahickon Hospice
8831 Jermantown Avenue
Philadelphia, Pennsylvania 19118
(HHA-Based) 17/1

2. Hospice of Pennsylvania Inc.
916 Wyoming Avenue
Scranton, Pennsylvania 18503
(HHA-Based) 115/40M

3. Chandler Hall Hospice
1502 Buck Road and Barclay Street
Newtown, Pennsylvania 18940
(SNF-Based) 30/25

4. Forbes Hospice
6655 Frankstown Avenue
Pittsburgh, Pennsylvania 15206
(SNF-Based) 40/6

5. Hospice - Albert Einstein Medical Center
York and Tabor Roads
Philadelphia, Pennsylvania 19141
(Hospital-Based) 8/6

6. Home Hospice Agency of St. Francis
South Mercer at Phillips Street
New Castle, Pennsylvania 16101
(Hospital-Based) 13/9

7. Home Nursing Agency of Blair, Huntington
and Fulton Counties
201 Chestnut Avenue
Altoona, Pennsylvania 16603
(HHA-Based) 2/2

Virginia

1. Hospice of Northern Virginia
4712 N. 15th Street
Arlington, Virginia 22205
(Hospital-Based) 72/36

Region IV

Alabama

1. Hospice of Baptist Medical Center
2105 East South Blvd
Montgomery, Alabama 36198
(Hospital-Based) 3/0

2. Baptist Medical Center Montclair Hospice
800 Montclair Road
Birmingham, Alabama 35213
(Hospital-Based) 20/4

Florida

1. Hospice of Northeast Florida
3599 University Blvd. South
Suite 3
Jacksonville, Florida 32216
(Freestanding) 5/1

2. Methodist Hospital Hospice
580 West 8th Street
Jacksonville, Florida 32209
(Hospital-Based) 12/2

3. Hospice By The Sea, Inc.
1580 N.W. 2nd Avenue
Suite 6
Boca Raton, Florida 33432
(Freestanding) 9/1

4. Hospice of Central Florida
500 North Knowles Avenue
Winter Park, Florida 32789
(Freestanding) 12/1

5. Hospice Care of Broward County
3625 North Andrews Avenue
Ft. Lauderdale, Florida 33309
(Freestanding) 4/0

6. Hospice, Inc. (Dade)
111 Northwest 10th Avenue
Miami, Florida 33128
(Freestanding) 8/2

7. Hospice, Inc. (Broward)
2331 North State Road
Lauderhill, Florida 33313
(Freestanding) 6/1

8. Hospice of Hillsborough
6400 North 15th Street
Tampa, Florida 33610
(Freestanding) 8/2

9. Hospice of Gold Coast Home Health Service
4699 N. Federal Highway
Pompano Beach, Florida 33064
(Freestanding) 9/2

10. Hospice Care, Inc.
3400 - 70th Avenue, North
Pinellas Park, Florida 33565
(Freestanding) 4/2

11. Hernando-Pasco Hospice
13825 U.S. Highway #19
Suite 401
Hudson, Florida 33567
(Freestanding) 3/2

12. Hospice of Palm Beach County
444 Bunker Road
West Palm Beach, Florida 33405
(Freestanding) 8/2

13. Hospice of Martin
925 Lincoln Avenue
Stuart, Florida 33494
(Freestanding) 3/2

Georgia

1. Hamilton Medical Center Hospice
P.O. Box 1168
Dalton, Georgia 30720
(Hospital-Based) 5/0

2. Hospice of Georgia
P.O. Box 37A
High Shoals, Georgia 30645
(SNF-Based) 5/1

3. Grady Hospice
80 Butler Street S.E.
Atlanta, Georgia 30303
(Hospital-Based) 3/2

4. Northside Hospice
1000 Johnson Ferry Road
Atlanta, Georgia 30042
(Hospital-Based) 3/0

5. Hospice Savannah, Inc.
P.O. Box 23015
3025 Bull Street
Savannah, Georgia 31403
(Freestanding)7/1

6. Hospice of the Golden Isles
1326 Union Street
Brunswick, Georgia 315210
(Freestanding) 12/5

7. American Hospice
1322 Columbia Drive
Decatur, Georgia 30032
(HHA-Based) 1/0

8. Hospice Atlanta
100 Edgewood Avenue N.E.
Suite 1500
Atlanta, Georgia 30303
(HHA-Based) 5/0

Kentucky

1. Community Hospice of Lexington
1105 Nicholasville Road
Lexington, Kentucky 40503
(Freestanding) 5/0

2. Ashland Community Hospice
2201 Lexington Avenue
Ashland, Kentucky 41011
(Freestanding) 4/1

3. Hospice of Louisville
101 West Chestnut Street
Louisville, Kentucky 40202
(Freestanding) 10/5

Mississippi

1. North Mississippi Medical Center Hospice
1030 South Madison
Tupelo, Mississippi 38801
(Hospital-Based) 5/1

2. The Hospice of Home Health Agency Multi-County, Inc.
P.O. Box 3409
Hattiesburg, Mississippi 39403-3409
(HHA-Based) 1/0

South Carolina

1. Spartanburg General Hospital Hospice
101 East Wood Street
Spartanburg, South Carolina 29303
(Hospital-Based) 8/1

Tennessee

1. Hospice of Murfreesboro
602 East Bell
Murfreesboro, Tennessee 37130
(HHA-Based) 2/0

2. Alive Hospice of Nashville, Inc.
P.O. 120033
1908 21st Avenue South
Nashville, Tennessee 37212
(Freestanding) 7/0

Region V

Illinois

1. West Town Nursing Service
2140 South Wesley
Berwyn, Illinois 60402
(HHA-Based) 15/11

2. Hospice of Adams County
1005 Broadway
Quincy, Illinois 62301
(Hospital-Based) 14.1/6

3. St. John's Hospice
   801 East Carpenter
   Springfield, Illinois 62702
   (Hospital-Based) 22.25/1

4. Home Health and Hospice of Illinois
   Masonic Medical Center
   836 West Wellington
   Chicago, Illinois 60657
   (Hospital-Based) 13/0

5. Belleville Hospice
   315 N. Church
   Belleville, Illinois 62221
   (Hospital-Based) 16/8

Michigan

1. Good Samaritan Hospice
   450 North Avenue
   Battle Creek, Michigan 49017
   (HHA-Based) 16/9

2. Hospice of Southeastern Michigan
   22401 Foster Winter Drive
   Southfield, Michigan 48075
   (SNF-Based) 47/28

3. Michigan Home Care, Terminal and Bereavement
   6861 Wilson Road
   Indian River, Michigan 49749
   (HHA-Based) 5/1

4. Michigan Home Care, Inc.
   955 East-Commerce Drive
   Traverse City, Michigan 49684
   (HHA-Based) 4/2

5. Hospice of the Straits
   P.O. Box 419
   748 South Main Street
   Cheboygan, Michigan 49721
   (Hospital-Based) 3/2

6. Hospice of Greater Kalamazoo
   247 West Lovell Street
   Kalamazoo, Michigan 49007
   (HHA-Based) 2/2

7. St. Mary's Hospital Hospice
830 South Jefferson
Saginaw, Michigan 48601
(Hospital-Based) 6/4

Ohio

1. Hospice of Lake County, Inc.
5976 Heisley Road
Mentor, Ohio 44060
(HHA-Based) 25/5

2. Hospice of Dayton
2181 Embury Park Road
Dayton, Ohio 45414
(HHA-Based) 99/59

3. Hospice of Miami Valley
24 North "E" Street
Hamilton, Ohio 45013
(HHA-Based) 10/5

4. Northwest Ohio Hospice Association
3350 Callinwood Blvd.
Toledo, Ohio 43610
(Freestanding) 15/8

Wisconsin

1. Rogers Memorial Hospice
34810 Pabst Road
Oconomowoc, Wisconsin 53066
(Hospital-Based) 19/15

2. Milwaukee Hospice Home Care
1022 N. 9th Street
Milwaukee, Wisconsin 53233
(Freestanding) 26/13

Region VI

New Mexico

1. Mesilla Valley Hospice, Inc.
2906 Hillrise
Las Cruus, New Mexico 88001
(HHA-Based) 10/4

2. Roswell Hospice
1302 North Kentucky
Roswell, New Mexico 88201
(Freestanding) 12/5

3. Hospital Home Health Care Hospice
500 Walter N.E.
Suite 316
Albuquerque, New Mexico 87102
(HHA-Based) 5/0

Texas

1. South Texas Home Health and Hospice Services, Inc.
County Road 242
Route 3, Box 21
Alice, Texas 78332
(HHA-Based) 8/8

2. Community Hospice of St. Joseph
1401 South Main Street
Ft. Worth, Texas 76104
(Hospital-Based) 13.5/9.2

3. Spohn Hospice
600 Elizabeth Street
Corpus Christi, Texas 78404
(Hospital-Based) 5/0

4. St. Benedict Home Health Hospice
323 East Johnson
San Antonio, Texas 78204
(HHA-Based) 16/2

5. Dallas Hospice Care, Inc.
5722 Oram Street
Dallas, Texas 75206
(Freestanding) 23/13.1

6. Hospice of El Paso
1900 N. Oregon
El Paso, Texas 79902
(Freestanding) 18/2

Region VII

Iowa

1. Hospice of Central Iowa
2116 Grand Avenue
Des Moines, Iowa 50312
(HHA-Based) 33/16

2. Holy Family Hospice
826 N. 8th Street
Estherville, Iowa 51334
(Hospital-Based) 3/2

Missouri

1. Hospice of Southeast Missouri
2550 D S. Campbell
Springfield, Missouri 68507
(Freestanding) 6/4

2. Hospice of Care Texas County Hospital
1333 South Highway 63
Houston, Missouri 65483
(Hospital-Based) 3/3

Region VIII

Colorado

1. Pikes Peak Hospice
601 N. Tejon
Colorado Springs, Colorado 80903
(HHA-Based) 21/2

2. Boulder County Hospice, Inc.
2825 Marine
Boulder, Colorado 80303
(HHA-Based) 25/11

3. Hilltop Hospice
1100 Patterson Road
Grand Junction, Colorado 81501
(HHA-Based) 6/0

4. Hospice Inc. of Weld County, Inc.
18011-16th Street
Greeley, Colorado 80631
(HHA-Based) 12/1

5. Hospice of Metro Denver
1719 East 19th Avenue
Denver, Colorado 80218
(HHA-Based) 85/3

North Dakota

1. Hospice of Red River Valley
P.O. Box 389
1325 South 11th Street
Fargo, North Dakota 58107
(Freestanding) 13/9

Region IX

Arizona

1. Valley of the Sun Hospice
214 E. Willetta Street
Phoenix, Arizona 85004
(HHA-Based) 38/0

2. St. Mary's Hospice
1601 W. St. Mary's Road
Tucson, Arizona 85745
(Hospital-Based) 85/0

California

1. Hospice of Monterey Peninsula
8900 Carmel Valley Road
Carmel, California 93923
(SNF-Based) 35/7

2. Comprehensive Community Home Health Agency and Hospice
P.O. Box 682
Daly City, California 94017
(HHA-Based) 11/11

3. Pacifica Home Care
1386 B-West 7th Street
San Pedro, California 90732
(HHA-Based) 11/1

4. Kaiser Foundation Hospital, Norwalk Hospice
12500 S. Hoxie Avenue
Norwalk, California 90650
(Hospital-Based) 53/28

5. Hospice of San Francisco
2225 30th Street
San Francisco, California 94131
(HHA-Based) 28/12

6. Hospice of North County
12709 Porway Road
Suite E-2
Porway, California 92004
(Freestanding) 9/9

7. Vesper Hospice
311 MacArthur Blvd.
San Leandro, California 94577
(Freestanding) 30/2

8. Hospice of the Valley
1150 S. Bascon Avenue
#7A
San Jose, California 95128
(Freestanding) 9/6

9. Hospice of Marin
77 Mark Drive
#17
San Rafael, California 94903
(HHA-Based) 33/22

Hawaii

1. St. Francis Hospital Hospice Program
2230 Liliha Street
Honolulu, Hawaii 96817
(Hospital-Based) 20/0

Region X

Idaho

1. Hospice of the Palouse
P.O. Box 9461
Moscow, Idaho 83843
(Freestanding) 1.75/1.71

2. Idaho Home Health and Hospice
200 2nd Avenue North
Twin Falls, Idaho 83301
(HHA-Based) 3.7/3.7

Oregon

1. Providence Medical Center Hospice
4805 North East Glisan
Portland, Oregon 97213
(Hospital-Based) 12-14/5.8

2. McKenzie - Willanette Hospital Hospice
1460 "G" Street
Springfield, Oregon 97477
(Hospital-Based) 3/2

Washington

1. Hospice of Snohomish
1010 Southeast Everett Mall Way
Everett, Washington 98206
(Freestanding) 0

2. Southwest Washington Hospital's Cancer Program/Hospice Services
600 Northeast 92nd
Vancouver, Washington 98668
(Hospital-Based) 6/4

3. Highline Community Hospital Hospice
16200 8th Southwest
Seattle, Washington 98166
(Hospital-Based) 5/1

4. Community Hospice
1035 - 11th Avenue
Longview, Washington 98632
(Freestanding) 11.3/6

5. Hospice of Spokane
North 1620 Monroe
Spokane, Washington 99210
(Freestanding) 20/6

6. Hospice of Clark County
316 East 4th Plain Blvd.
Suite B
Vancouver, Washington 98663
(HHA-Based) 3/1

7. Hospice of Whatcom County
1111 Cornwall
Bellingham, Washington 98225
(HHA-Based) 0/0

Senator **Heinz**. What was the average daily census in the demonstration?

Mr. **Streimer**. It varied quite a bit all over the place. There were some very small and there were some very large ones. We could submit a schedule for you with the precise number of patients per demonstration site.

[The information from Mr. Streimer follows:]

Hospice Demonstration Sites

	Average daily census all patients
Genesee	28
Connecticut	90
Overlook	60
Medical College of Virginia	12
Hospice Care Inc	90
Providence	12
Bethesda Lutheran	19
Community Home Health Care	60
Cabreni	56
San Diego	125
Northern Virginia	72
Santa Barbara	25
University of Massachusetts (Demonstration only, no longer a hospice)	30
Torrance	120
Pacifica	24
Hospice, Inc.:	
Dade	60
Broward (2 sites)	25
Good Sheperd	24
Marin	28
Lutheran	15
Vermont (5 sites):	
—Burlington	10
Franklin	3
Lamoille	2
Orleans, North Essex	8
Caledonia	4
Albuquerque	47
Rogers	19
Bellin (No longer a hospice did not seek certification)	11
Dalles	185
St. Benedict	10
Boulder	17

Note: Approximately 75 to 80 percent Medicare.

Senator **Heinz**. There is no average?

Mr. **Streimer**. I do not have an average on the sheet I was just handed.

Senator **Heinz**. In this day of computers, it is not an insurmountable difficulty.

Mr. **Streimer**. No, no.

Dr. **Davis**. It's a range.

Mr. **Streimer**. There certainly is a range to them.

Senator **Heinz**. Well, could I see that at your convenience?

Mr. **Streimer**. Surely.

I did want to mention, though, that in developing the payment rates from the hospice demonstration data, it was necessary to assume certain average characteristics in developing the payment rates. Individual hospices may want to look to some——

Senator HEINZ. Hold it, hold it. Don't go any further. I can save you a lot of time.

Mr. Chairman, the smallest number of patients on here is 65.

Mr. STREIMER. That's for a year.

Senator HEINZ. Is that at any one time?

Mr. STREIMER. No; that's for a year, Senator.

Senator HEINZ. That's for a year. Do we know what the average length of stay is?

Mr. STREIMER. The average length of stay for all the demonstrations was approximately 70 days.

Senator HEINZ. So you could have 700—we need a computer. [Laughter.]

You are right. They vary all over the lot. Is it correct that all the number of patients are based on a year, a full year's operating experience?

Mr. STREIMER. We believe that the numbers on that sheet—we will have to have our experts look at that. But we think those are 2-year cumulative patient counts for each of the hospices.

Senator HEINZ. I think we could use a little further analysis.

I thank the Chair.

Senator DURENBERGER. Thank you very much.

Senator Dole.

Senator DOLE. Thank you, Mr. Chairman. They want to pass the trade bill right away. I don't think it will happen in the next hour, but maybe the next couple of hours.

I may need to submit some of these questions in writing. I did ask in January of this year—in fact, your office was kind enough to provide me answers to a number of questions. And at that time you projected that 300 to 400 of the approximately 1,500 organizations would participate in the first year of the program. And I think you may have addressed the rather slow response in some of your comments, but I may want to resubmit those questions and see if there is any reason that we can focus on.

I want to follow up just briefly on what Senator Heinz was pursuing. I do understand that the average length of stay was about 70 days, but there would also be indications from other witnesses that their average lengths of stay are substantially shorter. And I am just wondering if they are shorter, would shorter length of stay warrant a higher per diem for home care?

Dr. DAVIS. Senator Dole, one of the things that I would have to know is over what period of time their average length of stay had been calculated. You recall that when we initially calculated our rates in the NPRM, we did it on the basis of 900, a sample of 900 patients. And by the time that we got to a sample of 4,000, we found that the length of stay had lengthened so that instead of the shorter length of stay that we had been working with before, which I think was more in the average of 40 or 50 days, it had lengthened to 70 days because we were dealing with a larger base of patients over a longer period of time. And, therefore, we were capturing those that had stayed in the system longer.

I would have to know from whence their data base came. And the caution I would say is that it could be a skewed base—if you just take a snapshot over a short period—and that's the problem we had when we first started with ours. So one needs to be cautious of that.

Senator DOLE. Well, I know somebody will have available the testimony. Maybe we can make that determination.

I just have one more question. I will submit some in writing.

You did indicate in January that the average cost per patient for hospice care was about $4,750 for the home health agency-based units, and $5,890 for hospital-based units. Has there been any further information that might lead you to change these estimates?

Dr. DAVIS. No; I don't believe there has been, Senator. I think that was based upon our interim report data. We have only this last Wednesday received the final report from Brown University and we will be taking a look at that. We don't expect to see any changes. If we do, we will certainly let you know.

Senator DOLE. Right. And I assume when the final report is available, we will have a chance to review that.

Dr. DAVIS. Absolutely.

Senator DOLE. It will be made available to us?

Dr. DAVIS. Yes.

Senator DOLE. Well, thank you very much. And thank you, Mr. Chairman. I have three or four other questions that I think might be helpful for the record.

Senator DURENBERGER. Thank you very much.

[The questions from Senator Dole follow:]

United States Senate
COMMITTEE ON FINANCE
WASHINGTON, D.C. 20510

September 21, 1984

BERC: ACTION
CC: DAVIS, SCOTT, WYLIE
AAP,AAEA,AAO,AAMSS
SPIEGEL, WHITE, BUTO,OLP
ADMIN. SIG. DUE 10/18

Carolyne K. Davis, Ph.D., R.N.
Administrator
Health Care Financing Administration
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Dr. Davis:

Thank you for the time you spent at the Subcommittee's hearing on September 17, 1984. In following up on that hearing, I would ask that the following questions be answered for the record.

1. What is your current estimate of the savings or costs of medicare's hospice benefit? What is the basis of your estimate? How many hospices do you now believe will participate in the program?

In response to a question that I posed to you last January, you indicated that a large majority of hospices could meet the $6,500.00 cap. The hospices with us at the September 17, 1984, hearing complained that this may not be realistic given the difference in requirements.

2. What is your response to their concerns given the data you currently have on payments to the participating hospices?

Thank you again for your testimony.

Sincerely yours,

BOB DOLE
Chairman

BD/sbj

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

The Administrator
Washington, D.C. 20201

DEC 18 1984

The Honorable Robert Dole
Chairman
Committee on Finance
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

You raised several questions in connection with my appearance at the Subcommittee hearing on the hospice benefit.

Your first request was for a current estimate of the savings or cost of Medicare's hospice benefit. Data accumulated for the recently enacted hospice benefit have been limited, and the most comprehensive and voluminous hospice data still remain those data which were compiled in the hospice demonstrations. Since the enactment of the hospice benefit, some data have been received and, in addition, a significant change (the enactment of prospective payment for hospitals) has occurred which could impact significantly the hospital savings component of the hospice cost estimate. Thus, it may be appropriate at this time to revise the hospice cost estimates to reflect the following conditions:

1. The original study the Health Care Financing Administration did to estimate the cost impact of the hospice benefit included an estimate of the savings which would probably result from decreases in hospital usage. This estimate was based on the cost-reimbursement system which was in effect for hospitals at the time the hospice benefit was enacted. Subsequent enactment of prospective payment for hospitals has virtually eliminated the powerful financial incentive for the continued hospitalization of terminally ill patients for the purpose of maintaining a high occupancy rate and maximizing Medicare reimbursement, and so the original hospital savings estimate is no longer valid.

2. Preliminary data for the new hospice benefit suggest that the average length of stay in a hospice at this time is considerably shorter than the average length of stay assumed in deriving the original hospital savings and therefore the time which might otherwise have been spent in a hospital is proportionally shorter.

   Based on the impact of implementation of prospective payment and the decrease in hospice length of stay, our current estimate of hospital savings resulting from the hospice benefit is one-third the saving derived in the original cost estimate.

3. Preliminary data for the hospice benefit suggest that the average payment per admission is between $1,500 and $2,000. Therefore, it is assumed that the average hospice payment per admission is $1,750. It must be remembered that this estimate is based on very early data and will probably change as more data are received.

4. The number of hospice admissions in fiscal year 1984 was about 2,100. This is a fraction of the 31,000 hospice admissions assumed in the original hospice estimates. Based on continued growth in the number of certified hospices of about 10 per month, it is assumed that there will be 15,000 hospice admissions in fiscal year 1985, and 25,000 in fiscal year 1986.

To arrive at our revised cost estimates, the number of admissions was multiplied by the average payment per admission and the revised hospital savings estimate was subtracted from this total. Based on the assumptions described above, the net cost of the hospice program would be as follows:

Fiscal Year	Cost (millions)
1984	$ 2
1985	15
1986	30

Your second question concerned our estimate of the number of hospices which will participate in Medicare. As indicated above, we are assuming a continued growth in the number of participating hospices of about 10 per month. We now have 132 participating hospices and we estimate that we will have about 250 participating by this time next year and about 370 by October 1986.

You also asked for our response to the concerns of hospices about meeting the $6,500 cap. The final data from the demonstration project showed that less than one-third of the sites exceeded an aggregate average of $6,500 and, as you know, these sites were reimbursed on the basis of cost and they were not subject to the inpatient limits or the cap provision in the Tax Equity and Fiscal Responsibility Act. Therefore, with an average hospice cost per patient of $1,750, we believe the cap is sufficient to cover the aggregate costs of almost all hospices.

Thank you for your continuing interest in the hospice benefit.

Sincerely yours,

CAROLYNE K. DAVIS

Carolyne K. Davis, Ph.D.

Senator DURENBERGER. Senator Baucus.

Senator BAUCUS. Mr. Chairman, thank you.

Dr. Davis, I'm a strong supporter of home health care and hospice care. I think there is a lot of potential to help bring down health care costs and not sacrifice quality care.

If you will look at the map over there, you will see no red dots in Montana.

Dr. DAVIS. I noticed that too, sir.

Senator BAUCUS. And I understand from Montana hospice centers that basically they just don't want to go through the hassle of applying. I'm not quite certain precisely what that means. I can guess. And I just want to encourage you very strongly to do what you can to get this program on line, and cut out a lot of this red tape so we can at least give the program a chance to work.

There are 15 hospice centers in Montana. None have applied. I'm not saying we should have 15 red dots up there, but I think there should be at least more than none. And so I encourage you to move in that direction. I will be coming back to talk to you about this as months go by.

One question I do have though is this: How long do you think it will be before the payment rates that are now in effect can either be invalidated or corrected?

Dr. DAVIS. Well, I believe we can review the rates as soon as we have studied the final report, the demonstration report.

Senator BAUCUS. How long will that take?

Dr. DAVIS. I expect we should have that up to Congress in December. As I said, we got it last Wednesday and it will take us a little bit of time to read it and have all of our people double check it and then cross walk from that data base into——

Senator BAUCUS. Any way you can speed that up a little bit?

Dr. DAVIS. We will be working as fast as we can to do that, sir. There are a lot of people that need to get involved in looking at it. You are talking about 6 weeks from when we get it to doing that.

Senator BAUCUS. I would like to reinforce my view that I think hospice care can have a very major role in bringing down health care costs. I held five or six hearings on medical and health care costs in Montana over the summer. And I can tell you that at every hearing—there were two very interesting phenomena. The general one is that I found doctors, hospital administrators, nursing home administrators, senior citizens, nurses, various people in the provider field and beneficiaries all agreed that the common problem is rising health care costs generally. And nobody pointed a finger of blame at the other guy without pointing the finger of blame at himself too. It's very interesting that at every hearing that came out. And these hearings were very, very widely attended. In fact, I was surprised how much interest there really was in it.

But No. 2, at every hearing, administrators, senior citizens, representatives and others also very strongly came out in favor of home health care and hospice care as a way to help bring down health care costs. So I want to encourage you to move even more expeditiously and aggressively to make this program work. There is no strong and critical data that is going to work, but I'm just telling you what the gut feeling is of a lot of people who are very closely associated with it.

Dr. DAVIS. I appreciate that. I think I too feel a warm empathy with the hospice movement. As you know, I came out of the nursing field, and nursing is clearly the key role in the development of the hospice as well as the home health program. So despite some people's assumption otherwise, I feel a strong kinship to those programs and believe that we must carefully target our resources.

The danger, of course, is that if one doesn't carefully target the resources, one will end up finding an additive resource instead of being used in lieu of another. I think those are the things that we are learning now as we move through this.

Senator BAUCUS. The next time we talk, we will find some red in Montana on that map.

Dr. DAVIS. I would certainly hope to see at least one there too, sir.

Senator BAUCUS. Thank you.

Senator DURENBERGER. I guess as they move east, people become more hostile because there is nobody in Minnesota blaming themselves for our problems. [Laughter]

Senator BAUCUS. You ought to come to the wide open spaces.

Senator DURENBERGER. I have been there. Very nice folks.

We got 119 certified, 43 hospices pending certification. Is that a function of the number of applications or a function of the availability of staff and resources?

Dr. DAVIS. Well, once the initial survey is done by the State, it then must come through several check points. It comes into the regional office, and then from the regional office it moves into the central office. And we must check with the Office of Civil Rights to make certain that there is no violation of civil rights activities. That is a component part of our overall certification process.

So we have 43 in one phase or another. Some of them are in the mail from one check point to another. But they move through, I think, fairly quickly on that. In addition we have another 14 hospices which are just in the process of being scheduled now.

Senator DURENBERGER. So the real world is that out of the 1,400 or whatever it is that are out there, at this stage there is a very small number that have even started into the process.

Dr. DAVIS. Yes. We never had anticipated, I think, during this first year that we would have a large number. I think initially we had said we probably would have something like, oh, 300 maybe. And at the ninth month, I don't think this is bad at all.

If you will look—and I will submit for the record—at the record of how we have progressed in the past as we bring on a new provider—strictly a brand new one like, say, the rural health clinics or the ambulatory surgical centers or comprehensive outpatient rehab facilities—we tend to see a very slow start, and then a doubling effect after that.

[The information from Dr. Davis follows:]

CERTIFICATION OF VARIOUS PROVIDERS BY TYPE

Home Health Agencies

1966 - 1,848
1967 - 1,849
1968 - 2,093
1969 - 2,209
1970 - 2,350
1971 - 2,284
1974 - 2,248
1975 - 2,242

1976 - 2,361
1977 - 2,385
1978 - 2,723
1979 - 2,762
1980 - 2,923
1981 - 3,241
1982 - 3,671
1983 - 4,047

Rural Health Clinics

Final regulations published 2/78
effective 3/1/78 for Medicare

3/78 - 14
7/78 - 147
1/79 - 272
6/79 - 329
12/79 - 359
12/81 - 409
9/82 - 420
9/83 - 419

Ambulatory Surgical Centers

Final regulations published 8/82

effective 9/7/82

NOTE: did not start certifying until 1/1/83

2/83 - 10

4/83 - 28

7/83 - 75

12/83 - 150

3/84 - 179

6/84 - 215

8/84 - 236

Comprehensive Outpatient Rehabilitation Facilities

Final regulations published 12/82

effective upon publication.

2/83 - 1

6/83 - 11

12/83 - 30

3/84 - 42

6/84 - 47

8/84 - 49

*NOTE: A lawsuit was brought against the Department for delaying publication of regulations. The Department lost the suit and facilities were allowed retroactive certification to July of 1981.

Senator DURENBERGER. I guess the whole purpose of this hearing is to try to find out whether or not the process is being slowed down by cost reporting forms, apprehension about reimbursement, or by the inability of a large number of the 1,400 institutional providers to be able to respond to the Medicare certification requirements.

Dr. DAVIS. I have been so concerned, Senator, that I have from the beginning of the initiation of this program asked for weekly reports from my staff. So there is nobody in HCFA that does not know and is not fully aware of our interest is moving the certification process along. And I believe we have an adequate number who are working on this particular program.

Senator DURENBERGER. My impression is from your reply that you didn't expect very many to try to get into the pipeline in the first year anyway. And that must have been on the basis of what you knew about existing hospices in America and so forth. Is that correct?

Mr. STREIMER. I think that's correct. Let me mention one statistic to you from the JCAH's survey, of which there were 1,429 organizations that called themselves "hospices." Only 687 of those reported providing services themselves. The statute, as it is set up, requires not only that they provide services but actually prescribes which services they must provide. So I think there is a wide diversity of organizations that call themselves "hospices" which do not match very cleanly with what the statute describes as a hospice organization for participation purposes.

Senator DURENBERGER. But if this benefit is as good as we all believe it is, those numbers in total should expand considerably, should they not? I mean 1,400 ought to get closer to the 600 and something accredited, and we ought to be looking at 2,800 and then 5,600. No reason why we couldn't have large numbers of hospices all over the country, is there?

I mean is your impression that we are encouraging or discouraging the growth of the hospice movement right now? It's a general question.

Dr. DAVIS. Well, my impression is that we are trying to encourage the growth of a certain type of a hospice. In other words, as Congress developed the legislation, it very clearly said hospices should have core services. Congress wanted to make sure that hospices provide quality of care. And, therefore, we have moved in to protect the ability to carry out the hospice's philosophical concept by having mandated professional management responsibilities even if the patient is moved into an inpatient hospital setting vis-a-vis their own setting.

So I think there were some of those kinds of requirements that we construe for the type of hospice which could become a Medicare provider, but is somewhat different than perhaps some of those who offer hospice-type services. They may not offer all services. They may only offer selected components. And I think our belief is that a core of services are needed to provide for the whole spirit and philosophy of a hospice. So that when you say, can we expect to see *x* number of participating hospices, I think we will see them grow.

If you look at the history of the movement in terms of home health agencies, they have almost doubled over time. If you look at the development of ambulatory surgical centers, they have more than doubled in just a few years. You do tend to find that others move in to emulate a new direction, once it is created, over a period of time.

Senator DURENBERGER. All I'm trying to get at with the question—I'm not doing it very well—is that there is a version of hospice that we've encapsulated in the law. It seems to me—and I deliberately started this statement out by reference to my personal situation—that it really wouldn't make a heck of a lot of difference whether we had two psychiatrists or one and whether we had full-time nurses or whatever. In retrospect, it would have been awful nice to have a more dignified, less expensive way to die, to boil it down to the vernacular. And are we starting into this process here of constructing a benefit with certain preconceived notions that there ought to be only one way to do hospice in this country in order to qualify for Medicare benefit, or that there might be a number of ways?

Dr. DAVIS. No. I think we recognize that there are a number of ways. But I believe what we have said—and we are doing it because the Congress very clearly believed that there should be certain core services—is that you ought not call yourself a full spectrum hospice unless you could offer those services in the home and provide a continuity of care into the hospital setting; unless you could offer as part of your whole hospice nursing service care, physician care, social services. So I think there were certain activities that we——

Senator DURENBERGER. Then what is the function of the election? Now it strikes me, again, that the election process is a family process.

Dr. DAVIS. Yes; it is. It should be.

Senator DURENBERGER. That's right. And that in the election process somehow or another—I hate to use the word "marketing," but there's an information process, there is an exchange of information that perhaps the doctor facilitates or some other person that you rely very heavily on for professional advice, facilitates at that particular point in time. I think your statement says there are only 1,280 Medicare patients that have chosen the benefit as of now so maybe we don't know much of how the election process is working, but there are a lot of red dots on that map.

On what basis is the election being made today of hospice benefits? Can you give me an example or two or maybe I should ask some of the folks when they get up here later.

Dr. DAVIS. Well, I suspect the individuals who are probably best equipped to answer that are the people who are running the hospices. But having visited one or two, I will tell you anecdotally what I have seen.

I think very clearly we have asked that the physician should interact with the patient and the family; should let them know about the benefits; and should make an assessment that that individual does have or is within the parameters of the last 6 months of life. That is a judgment factor that the physicians must make, obviously, in referring the patient into the facility.

And, second, the family and the patient must then make a determination to, in effect, waive their right for normal Medicare coverage and move into the hospice benefit. Now to what degree that puts a constraint on the family and they are hesitant to do that, I don't believe we have got data that would relate to that.

Mr. STREIMER. No.

Dr. DAVIS. No. We will be trying over the next couple of years to get some data that is relevant to that factor. But at this moment in time, I don't have any data at all.

Senator DURENBERGER. Maybe some of the other witnesses can respond to that one.

Let me take you to Montana and Kansas then where you have no dots. And let me refer you to the IGR or the inspector general's report summary of findings in which the inspector general says that by the end of fiscal year 1985, which is better than year from now,

> 23 percent or less of the Medicare patients receiving hospice services will have their care paid for under the new benefit. This represents less than 5 percent of all Medicare cancer deaths. The remaining 77 percent will have the eligible hospice care services they receive reimbursed under the conventional Medicare benefit.

Now that obviously leads me to ask you about DRG's. And I know you can either pick Montana or Kansas or some other State that has red and blue dots in it and tell me what is going on out there now that the prospective payment system is in effect. There are caps on reimbursement in some of these areas, and certain Medicare certified alternative hospice care are not available. What's happening?

Dr. DAVIS. I think you would find that many of the individuals can get a large number of those services from, say, a freestanding home health agency. Many of the hospice benefits model very closely to what a home health agency would give in terms of nursing care, therapy, and other services. So I think, as has been indicated, and even in my remarks, that home health agencies estimate about 85 percent of their benefit services could be covered under regular Medicare. So I suspect you will find that same pattern is true for other providers as long as we have the rest of the system under a cost-based system. It still is attractive for them to use that method rather than become a hospice.

Senator DURENBERGER. Then what is the value of Medicare certification? Does it mean that the first guy in town that gets a Medicare certification gets all the business? Is that one of the reasons people ought to seek Medicare certification as just a marketing tool? If you are in a competitive hospice environment or you are competing with other providers of hospice care, that the quicker that you get that certification, the more business you are going to get in your hospice?

Dr. DAVIS. Well, that clearly could be one thing, but I think there are other things. Indeed, because the hospice benefit covers some services that are not provided for in the general home health benefit. For example, under the hospice benefit we would pay for a patient's drug therapy and respite care services. If the family needed a break, they could place their family member in a respite service provided under the hospice benefit. So I think there are some advantages to participating, too.

Senator DURENBERGER. A couple of other specific questions. Somebody is going to testify today that their hospice was certified in April but it wasn't until June that they got the claim forms and were instructed on how to submit admissions, and they have yet to receive any payment under the hospice benefit. Is that typical?

Dr. DAVIS. We went out and asked our—as you know, we decided that we should pay by freestanding operations through only two fiscal intermediaries. But we also felt that we should allow a hospice that was not a freestanding provider, if they provided other Medicare services, to continue to use the same intermediary as they do for their regular business rather than to have to create two separate costing systems. So we have worked with more than just our two intermediaries to provide training. Those intermediaries have gone back out and have visited with all their known hospices to try to show them how to fill out the reports; to give them training sessions in other words. I can't answer as to why payment has not been made in the case you cite. I would be happy to submit that for the record. But one of the things that we have found is that many of these individual hospices are coming onboard, and they themselves are slow in submitting their claims. And we certainly can't pay them until they have submitted them and we have reviewed them. So I think you have to look at the whole spectrum. If you can provide me with the name of the hospice, I would be happy to go back and submit for the record the rationale.

Senator DURENBERGER. I think others are complaining about late payments—60 to 100 days.

Dr. DAVIS. Well, in one case that I know that was part of the testimony today, we have looked and the average length of time for payments under Prudential has been running about 30 days. That was even when they were processing them manually. They have now moved to processing them automatically so they can do a daily processing now as opposed to holding them and batching them for a week. That should improve processing time even more.

I believe the allegation really dealt with one specific case that took approximately 100 days. And it was roughly about, I think, $2,500. And there was some differences of opinion about that. Some of the claims do have to go through medical review which can be part of the process.

Senator DURENBERGER. Do you have the ability to monitor the extent to which certified hospices turn down hospice patients because the anticipated cost will exceed Medicare's payment?

Dr. DAVIS. Well, we have talked about trying to do that. And as you know, under our conditions of participation, hospices do have to report on how they acquire their patients. If they do have certain requirements for entry into their hospice, such as a patient care helper, so long as they apply that equally across all patients, then it's acceptable. That's no different than it would have been in our hospice demonstration. But they can't take special steps to require certain things for just our Medicare beneficiaries. And that is the part that is checked when hospices apply for certification. We can monitor it through that process.

Senator DURENBERGER. One last question, and then I guess we will have to submit the rest of them for the record. But do you anticipate or would it be your recommendation that we eventually move to a fully prospective capitated rate for hospices and that eventually that rate be included in the DRG payment made to hospitals?

Dr. DAVIS. It's too soon for us to make a final recommendation, but we clearly are working to develop the DRG methodology. We will need a couple of years of data in order to do such a thing. And then as we bring in the data and see how they relate to diagnosis—we know that roughly 95 percent or so of the diagnoses tend to be cancer, that's pretty clear—we can develop relevant DRG's that are relevant. They become the other group. We have to track which ones they are and do some more relevant data. But we clearly will be modeling and working toward whether or not we should do that. In other words, we are working on the feasibility and advisability of developing hospice DRG's. I can't say at this point until we have done the feasibility part.

Senator DURENBERGER. Clearly, then, we have at least a small problem here. I take it that the data that you will need will come out of this new form that you colloquied with Senator Heinz about.

Dr. DAVIS. That's right.

Senator DURENBERGER. And that will be out by the first of the year or something like that. You say it will take a couple of years of data. We have a problem that the current demonstration authorization expires October 1 of 1986. We would sure like to do something at the latest as of 1986 so that everybody who cares about this knows where their future is.

Dr. DAVIS. I agree, sir.

Senator DURENBERGER. How do you expect all of this to come together? Should we have one of these hearings every 6 months?

Dr. DAVIS. No.

Senator DURENBERGER. We can talk about this, that, and the other thing.

Dr. DAVIS. I hope you realize that we are on track as we go through on this. We have two types of studies that we are doing. We will have data for the January 1986 target deadline. That's very clear. We are working now to get that data in, and we will be looking at the whole issue of reimbursement methods and the benefit structures.

In addition to that, we will have a longer range report the following year. And in January of 1987 be prepared to look even further at a whole spectrum of issues that relate not just to our own cost data that we have from our own sample of the hospices that are Medicare qualified, but we will also be going out to get data from hospices that are not Medicare qualified. So we will have a larger data sample.

Senator DURENBERGER. Have you yet awarded the study that is supposed to be delivered——

Dr. DAVIS. We awarded the first part of the longer range evalation study. And we will continue to make awards. The study is based on about four or five evaluation contracts. And we will probably do the final RFP awards, I would say, in December or January. It is some of that data that we will be using to look at the construction of the DRG type material. And we need to look at other issues relating to volunteer compliance and some of those kinds of issues that we won't get out of a cost report.

Senator **Durenberger**. This is not a question but a statement. What is bothering me is that all of this is going to happen—you know, this very intense analysis of what is really going on, in 1985. Most of the people in this room don't even know what it is you want to go on in 1985 or they aren't real clear on what it is we are looking for in this area, as will be abundantly clear, I think, when we get into some of this testimony. And I guess I am just apprehensive.

Dr. **Davis**. I can understand that, sir. I would like to suggest that perhaps our staffs can sit down and we can sketch out for you what the two-part evaluation is composed of so that you can clearly see that we are on track, and should be meeting those deadlines.

Senator **Durenberger**. All right. Very good. Thank you very much for your testimony. We appreciate it. Mr. Streimer, yours too.

Our next witness is Caroline Martin, senior vice president of the Riverside Hospital, Newport News, VA on behalf of the American Hospital Association.

Welcome. Your full statement on behalf of the American Hospital Association will be made part of the record. You may summarize it or read it, as you see fit, in the shortest period of time as possible.

Thank you for being here.

Ms. **Martin**. Thank you.

STATEMENT OF M. CAROLINE MARTIN, SENIOR VICE PRESIDENT OF THE RIVERSIDE HOSPITAL, NEWPORT NEWS, VA ON BEHALF OF THE AMERICAN HOSPITAL ASSOCIATION, WASHINGTON, DC

Ms. **Martin**. Good afternoon.

Last year in hearings before this subcommittee, the American Hospital Association commended Congress for enacting the hospice benefits in response to the pressing needs of terminally ill beneficiaries. At the same time, we expressed reservations about the Medicare hospice benefit because methods to deliver care consistent with the hospice concept were still evolving, and could be jeopardized by a rigid, overly restrictive approach to implementation of a hospice benefit.

We particularly urged the subcommittee to reconsider the core services requirements, the 80–20 rule limiting inpatient utilization, the inflexible payment structure, and the rigid professional management responsibility requirement.

In the year since that hearing and particularly in the 9 months since HCFA issued final regulations, existing hospice programs have had to face the difficult decision of whether to seek certification, balancing their concern for the continued viability and integrity of their programs against the desire to provide access to the richer hospice benefit package for their medicare patients. Unfortunately, the vast majority of hospices have found that the barriers to certification are insurmountable. Consequently, the hospice benefit is either unavailable to Medicare beneficiaries in many communities or is available only through a limited number of programs that may be poorly integrated with other providers. Despite increasing limitations on Medicare utilization, however, these uncertified programs are committed to the continued provision of hospice services to their Medicare patients under traditional Medicare benefits.

We are pleased that the subcommittee has closely monitored the hospice benefit's implementation in reexamining whether the benefit meets the needs of the terminally ill Medicare beneficiaries and the hospice providers who care for many of them. We do not believe that it does. Furthermore, we believed that the past year's experience demonstrates that the problems are not limited to payment level. Basic public policy and ethical issues must be addressed if the availability of hospice care is to be promoted.

Resolving these issues will require careful study and a reopening of the legislative debate. The experience of all providers of hospice care during the remaining 2 years of the trial period can contribute substantially to this debate.

Included in our full statement are several specific recommendations addressing key problems that remain. We believe the elimination of barriers to hospice certification will require action both by Congress and HCFA. We urge you to reaffirm at the outset that the hospice benefit is one option in the range of Medicare benefits and to take whatever steps are necessary to ensure that hospice programs certified under other Medicare categories can continue to provide their services to beneficiaries and to ensure their lack of Medicare hospice certification is not viewed as a judgment on the quality of care they provide or the legitimacy of their claims to be a hospice.

Above all, we urge that Congress take a deliberate yet flexible approach in modifying Medicare coverage for hospice services. Hospice is not a different type of care. It is a philosophy of care that coordinates and augments the traditional elements of health care services. Existing health care providers, hospitals not the least, should be encouraged to offer hospice care. Hospice staff are not a type of staff. They are health care professionals, such as doctors, nurses, and social workers who have been trained in and have embraced the hospice philosophy of care. Unnecessary barriers should be removed so that hospice care can become an integral part of the American health care system.

Thank you for giving me the opportunity to appear before you. I will be happy to answer any questions you may have and to share with you our experience at Riverside Hospital as we developed our hospice program and considered seeking Medicare hospice recertification.

[The prepared written statement of Ms. Martin follows:]

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STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION TO THE SENATE FINANCE COMMITTEE'S SUBCOMMITTEE ON HEALTH ON COVERAGE OF HOSPICE CARE UNDER MEDICARE

September 17, 1984

Presented by M. Caroline Martin
Senior Vice President
Riverside Hospital
Newport News, Virginia

SUMMARY

Last year in hearings before this Subcommittee, the American Hospital Association commended Congress for enacting a hospice benefit in response to the pressing needs of terminally ill beneficiaries. At the same time, we expressed reservations about the Medicare hospice benefit because methods to deliver care consistent with the hospice concept were still evolving and could be jeopardized by a rigid, overly restrictive approach to implementation of a hospice benefit. We particularly urged the Subcommittee to reconsider: the core services requirement; the 80/20 rule limiting inpatient utilization; the inflexible payment structure; and the rigid professional management responsibility requirement.

In the year since that hearing, and particularly in the nine months since HCFA issued final regulations, existing hospice programs have had to face the difficult decision of whether to seek certification, balancing their concern for the continued viability and integrity of their programs against the desire to provide access to the richer hospice benefit package for their Medicare patients. Unfortunately, the vast majority of hospices have found that the barriers to certification are insurmountable. Consequently, the hospice benefit is either unavailable to Medicare beneficiaries in many communities or is available only through a limited number of programs that may be poorly integrated with other providers. Despite increasing limitations on Medicare utilization, however, these uncertified programs are committed to the continued provision of hospice services to their Medicare patients under traditional Medicare benefits.

We are pleased that the Subcommittee has closely monitored the hospice benefit's implementation and is reexamining whether the benefit meets the needs of terminally ill Medicare beneficiaries and the hospice providers who care for many of them. We do not believe that it does. Furthermore, we believe that the past year's experience demonstrates that the problems are not limited to payment levels. Basic public policy and ethical issues must be addressed if the availability of hospice care is to be promoted. Resolving these issues will require careful study and a reopening of the legislative debate. The experience of all providers of hospice care during the remaining two years of the trial period can contribute substantially to this debate.

We urge Congress to reaffirm in the interim that the hospice benefit is one option in the range of Medicare benefits, and that it take whatever steps are necessary to ensure that hospice programs certified under other Medicare categories can continue to provide services to beneficiaries and that lack of Medicare hospice certification is viewed neither as a judgment on the quality of care they provide nor the legitimacy of their claims to be a hospice.

Above all, we urge Congress to take a deliberate yet flexible approach in modifying Medicare coverage for hospice services. Hospice is not a different type of care; it is a philosophy of care that coordinates and augments the traditional elements of health care services. Existing health care providers, hospitals not the least, should be encouraged to offer hospice care. Hospice staff are not a type of staff; they are health care professionals, such as doctors, nurses, and social workers, who have been trained in and have embraced the hospice philosophy of care. Unnecessary barriers should be removed so that hospice care can become an integral part of the American health care system.

INTRODUCTION

Mr. Chairman, I am M. Caroline Martin, Senior Vice President of Riverside Hospital in Newport News, Virginia, a 641-bed hospital that has offered hospice care to its terminally ill patients since 1979. I am here to present the views of the American Hospital Association, which represents most of the nation's hospitals, of whom more than 500 sponsor their own hospice programs, while many others support and work with community-based hospices. AHA has long been committed to increasing the scope of cost-effective, community-based health services and programs for the elderly and the terminally ill.

Terminal illness is a major issue for the Medicare program, in that the majority of persons who die each year in the United States are age 65 or older and are Medicare beneficiaries. Moreover, terminal illness presents significant expenditure issues. Although annually about 5 percent of Medicare beneficiaries die, HCFA reports that during the last year of their lives they account for more than 25 percent of total Medicare expenditures.

Last year in hearings before this Subcommittee, the AHA commended Congress for enacting a hospice benefit in response to the pressing needs of both beneficiaries and the Medicare program. Still, we expressed reservations about the Medicare hospice benefit because methods to deliver care consistent with the hospice concept were, and still are, evolving, and could be jeopardized by a rigid, over-restrictive approach to implementation of a hospice benefit. Major studies were underway, including one by the Joint Commission on

Accreditation of Hospitals (JCAH) and a demonstration project funded by HHS. These studies continue to provide insights into the variations in hospice program design that can ensure high quality care while remaining responsive to community and patient characteristics. The new JCAH voluntary hospice accreditation program, which began surveying hospices in January 1984, is demonstrating that quality of care can be addressed rigorously without dictating a universal approach to the organization of hospice programs.

Unfortunately, HCFA has not yet released either the final report of the National Hospice Study or its assessment of the federal demonstration project. However, preliminary results from these studies indicated in 1983 that the viability of many hospice programs would be jeopardized by participation as Medicare certified hospices under current legislation and regulations. Now, one year later, HCFA's regulations have been finalized. Several of the regulatory amendments recommended in 1983 by AHA were adopted by HCFA in the final regulations; others were not. On the legislative side, Congress enacted, as part of the Deficit Reduction Act of 1984 (P.L.98-369), a limited exception to the core nursing requirement for rural hospices and required that the Secretary of Health and Human Services conduct a study and report to Congress on the necessity and appropriateness of the core services requirement.

Since HCFA's final regulations were issued in December 1983, only 108 hospices of the estimated 1,300 programs nationwide have been certified to provide the special hospice benefit. Of that number, 27 are hospital based, 45 are home health agency based, 32 are independent, and 4 are skilled nursing facility based. About an equal number of programs are in the process of becoming certified. Clearly, this meager level of participation in the program signals that major problems still exist. The last nine months have proved difficult for most hospices in deciding whether to seek Medicare certification. They have agonized over their decisions, balancing their concern for the continued viability and integrity of their programs against their desire to give their patients access to the more comprehensive Medicare hospice benefits package. A report issued last week by HHS' Office of Inspector General (IG) echoes AHA's experience in working with hospice programs during these last nine months:

- The vast majority of hospices will not seek certification under the program as it is currently structured. In IG's words: "On the whole, those hospices which are not applying for certification felt better about their decision to stay out of the program than the applicants did about applying for certification."

- The barriers to certification and the disincentives to participation are insurmountable for most programs and related to a variety of issues, not just the prospective pricing rates set by HCFA. Although the inadequacy of the rates, particularly that for routine home care, is a real problem, there are other equally, if not more, significant structural problems and financial risks that derive from the statute.

- Those programs that have decided against seeking certification are determined to continue providing hospice care to their communities and to Medicare beneficiaries under the traditional benefits package. These programs worry that their lack of hospice certification will be misconstrued by their communities as an indication of substandard care. They also are concerned that if they continue to provide identifiable hospice services under their hospital, skilled nursing facility, and/or home health agency certifications, their claims filed under traditional Medicare benefits will be rejected.

We are pleased that the Subcommittee is holding hearings once again to reassess implementation of the hospice program. As part of your considerations, we recommend that you examine:

- The extent to which the Medicare hospice benefit is pushing hospice care in the direction of a separate delivery system. Such a separation would severely compromise the cost effectiveness of hospice care, create additional stress and discontinuity of care for Medicare beneficiaries, prematurely eliminate alternative hospice program models, and limit the positive effects that involvement in hospice can have on the delivery of care to all patients, including the entire population of terminally ill Medicare beneficiaries.

- The appropriate use of data from the HCFA demonstration hospices and from those hospices that participate in the program during the three-year trial benefit period. HCFA should release to the public both the long overdue report of the National Hospice Study and its evaluation of the demonstration projects. The data that should be contained in the report are critically needed to increase our understanding of hospice programs as well as to shed additional light on how hospice payment levels were developed. Given the substantially different conditions under which demonstration hospices provided services, as compared to the requirements of the Medicare benefit, HCFA should report in detail on its effort to take those differences into account. Furthermore, as long as so few hospices participate in the program, Congress should exercise caution in using data collected during this three-year trial period from participating hospices only.

- The equity of making the hospice benefit available only to those Medicare beneficiaries whose illness admits of an accurate six-month prognosis and who have supportive home environments. This issue presents some of the most difficult aspects in fashioning a hospice benefit. Is a Medicare beneficiary dying from chronic obstructive pulmonary disease or a degenerative neurological disorder any less in need of hospice care than a cancer patient, just because his or her time of death is less precisely predictable than for many forms of cancer? Is the over-75 beneficiary who lives alone -- the fastest growing segment of the Medicare population -- any less in need of hospice support than the younger beneficiary who has a spouse or children who are available around the clock to act as care givers? We think not.

In the following pages we describe the specific problems we believe still exist with the design of the hospice benefit. We ask you to debate these issues in detail, but we urge that you reaffirm at once that the hospice benefit is only one option in the range of Medicare benefits, and to take whatever steps are necessary to ensure that hospice programs certified under other Medicare categories can continue to provide their services to beneficiaries and to prevent the lack of Medicare hospice certification from being misconstrued as a negative judgment on the quality of care they provide or on the legitimacy of their claims to traditional Medicare benefits.

Two major categories of issues are raised by the Medicare hospice legislation and regulations: (1) barriers to Medicare certification; and (2) payment for hospice care. Of the issues presented to this Subcommittee and to HCFA in 1983, the final rules published by HCFA in December 1983 included revisions that responded, at least in part, to the AHA's recommendations on:

- Redefining "hospice physician services" to allow non-employed attending physicians to provide the majority of day-to-day hands-on medical care required by hospice patients.

- Removing the requirement that employees of a parent provider work substantially full-time for the hospice program in order to be defined as hospice employees for the purpose of meeting the core services requirement.

- Clarifying that the inpatient care requirement for a "decor which is homelike in design and function" would be applied flexibly in order to avoid requiring expensive renovations and approvals of capital expenditures.

- Collecting cost and utilization data from all participating hospices, not just a sample, in order to increase the data available at the end of the three-year trial period.

- Modifying the home care rates to (1) reflect respite care delivered in the home, rather than in an inpatient, setting; (2) adjust for inflation between 1981 and 1984; and (3) reflect the cost of special outpatient procedures.

However, many significant problems remain as a result of provisions in both the statute and the final regulations. Our revised recommendations for legislative and regulatory amendments follow the discussion of each issue below. It should be noted that regulatory recommendations were developed within our understanding of the constraints of the current hospice law.

BARRIERS TO MEDICARE CERTIFICATION

The Medicare legislation limits hospice certification to programs that can meet three critical requirements: the 80/20 limit on inpatient care, the core services requirement, and the professional management responsibility requirement. Taken together, these requirements are preventing the majority of existing hospice programs from seeking certification as Medicare hospice providers, thereby limiting beneficiary access to the hospice benefit.

The 80/20 Utilization Rule

The legislation requires that the aggregate number of inpatient days (general and respite) not exceed 20 percent of the total number of Medicare days of care provided by the hospice. Preliminary data from the National Hospice Study suggest that variations in inpatient utilization between inpatient-based and home care-based hospice programs are related to differences in their patient populations regarding the availability of extensive home support, level of disability, degree of illness, and the amount of time prior to death when patients select hospice care. Hospices that serve higher proportions of patients who have less home support and are more ill can usually delay inpatient admission through use of broader home care services if patients are referred to them more than a few days before death. We support the emphasis of home care under hospice programs. However, we are concerned that the 20 percent inpatient utilization limit would impose inequitable and restrictive hospice admission criteria related to the availability of caregiving support in the home.

Consequently, AHA recommends the following amendments:

Legislative: Eliminate the 20 percent limit on inpatient utilization in order to remove unjustified and inequitable access barriers for Medicare beneficiaries who do not have adequate home support or who are too ill to be cared for at home. Alternatively, modify the statute to clearly establish the 20 percent limit as a goal for certification only and require that the Secretary take into account any higher levels of inpatient care required by the hospice's case mix and the availability of home support.

Regulatory: Modify the rigid application of the 20 percent limit on inpatient care as a certification requirement by allowing hospices to work toward that goal and by not imposing financial penalties on those hospices that exceed the limit due to their mix of patients.

The Core Services Requirement

The statute requires that "substantially all" physician, nursing, social work, and counseling services be "routinely" provided by employees of the hospice program, either directly by or under the supervision of the hospice interdisciplinary team. The team must include at least one professional registered nurse, one physician, one social worker, and one counselor, all of whom must be employees of or volunteers in the hospice program. This "core services" requirement presents several distinct problems.

- Impact on Cooperative Arrangements. Of the 513 hospital-based hospices, only about 40 percent directly provide home health care as well as inpatient care. The remaining hospices would be ineligible for certification unless they dissolve or substantially reduce cooperative arrangements with community-based home health care and visiting nurse associations. Substantial efforts were made to achieve coordinated delivery of home health care and to develop specialized hospice home care services in these communities. Also, urban hospices that extend their services to surrounding rural communities may be forced to reduce their service areas if the geographic area is too large to be served by a centralized staff and the number of hospice patients in a rural community are too few to support out-based home care staff.

In the first eight months of its hospice accreditation program, the JCAH has found no relationship between the quality or continuity of care and whether or not home care is provided directly, under subcontract, or under a coalition arrangement with other community providers. With respect to hospices that serve rural areas, we do not believe that the exception amendment included in the Deficit Reduction Act of 1984 will provide any significant relief. Many of the hospices serving rural areas are based in urban areas and, hence, are ineligible for the exception. Furthermore, for many hospices, the problem is not that registered nurses are unavailable for hire; it is that their programs are too small to support the hiring of additional RNs to ensure that employed RNs are available to provide continuous home nursing care needed for infrequent and unpredictable crisis periods.

- Impact on Role of Attending Physicians. Although designed to ensure continuity of care, the core services requirement restricts one of the most important methods for achieving continuity -- the continued active involvement of the patient's own attending physician. Although the statute explicitly preserves coverage for non-employee attending physicians, it still bars them from being official physician members of interdisciplinary teams. The core services requirement, in effect, promotes the use of two different physicians -- attending and hospice -- with the non-employed attending physician in the unofficial or inferior position on the interdisciplinary team. By imposing this second class status on attending physicians, the core services requirement is inconsistent with the statute's own definition of attending physician; that is, the physician identified by the patient as having the most significant role in determining and delivering medical care. The only way to avoid this problem is to establish an employment relationship which presents severe financial disincentives for both the attending physicians and the hospice program. Only payments to employed physicians are subject to the hospice cap; payments to non-employed attending physicians are made under standard Part B rules and are not counted toward or affected by the hospice cap on total payment. We believe promoting active involvement of the attending physician in the delivery of both traditional curative care and hospice care would best suit both patient and Medicare program objectives.

- Effect on Volunteer Medical Directors. The interplay between the core services requirement and the treatment of physician payments under the hospice cap has created a similar problem for volunteer medical directors. A substantial number of hospices have benefited in the past from the willingness of physicians to volunteer their services as hospice medical directors. In order to support hospice voluntarism without conflicting with the core services requirement, the final regulations include volunteers within the definition of employees. However, once defined as an employee for any function, an individual is defined by regulations as an employee for all purposes. Consequently, volunteer medical directors are subjected to the same financial disincentive described above. Because for most hospices the physicians who serve as volunteer medical directors are the most active and committed attending physicians with the most private patients served by the program, their continued service as volunteer medical directors carries a heavy price.

To resolve all of these problems, the AHA recommends the following amendments:

Legislative:	Remove the core services requirement and require instead that the hospice directly provide counseling services, coordination and care planning across all settings, and at least one level of care (home care or inpatient care).

- Provide a positive incentive, or at least remove the current disincentives, for attending physicians to continue providing day-to-day medical care to their patients, to participate as hospice team physicians in care planning activities, and to serve as volunteer hospice medical directors.

Regulatory:

- Remove the financial disincentive for attending physicians who also serve as volunteer hospice medical directors.

Professional Management Responsibility

The "professional management responsibility" requirement applies to non-core services provided under arrangements with the hospice and, as elaborated by HCFA, subjects hospices and contracting providers (primarily hospitals) to a variety of untenable legal problems.

For hospices without their own inpatient beds, the Medicare requirements dictate that current referral arrangements -- carrying little or no legal or financial liability for the hospice -- be converted to formal contracts that create a shared liability for medical decision-making between the hospice and contracting facility. This may present an insurmountable obstacle for many hospices. For the acute care facilities that would provide inpatient care to these hospices, HCFA's regulations could require contractual commitments at odds with their other legal responsibilities. Requirements for contracts must preserve the ability of each party to negotiate provisions that enable it to meet all its obligations.

The purpose of the "professional management responsibility" requirement is to ensure that the hospice fulfills its case management and continuity of care responsibilities. We believe these responsibilities can more appropriately be met the following modifications are made:

Legislative:	Remove the professional management responsibility requirement and require instead that a hospice providing care under arrangements with other providers establish mechanisms that allow the hospice to meet its coordination/care planning responsibilities and to resolve any differences of opinion on the care to be provided to individual patients.
Regulatory:	Require mutually agreed-upon procedures between the hospice and the contract provider that address coordination, care planning, and resolution of conflicting opinions, rather than mandating contractor compliance with hospice orders without regard to other legal obligations.

MEDICARE PAYMENT FOR HOSPICE CARE

The major issues regarding Medicare payment for hospice care fall into three areas: (1) the appropriateness of a prospective pricing system for hospice care at this time; (2) the method used to set the "cap" on total hospice revenues; and (3) the prospective rate structure adopted in the final regulations.

Appropriateness of a Prospective Pricing System for Hospice Care

HCFA has adopted a prospective pricing system rather than the reasonable cost reimbursement mechanism envisioned by Congress. As the Subcommittee knows, AHA supports prospective pricing mechanisms under Medicare. A prospective price-setting mechanism is likely to provide more predictable expenditures for the Medicare program, more predictable payment levels for hospice programs, and stronger incentives for efficient operation. However, a prospective pricing system is feasible only when a solid base of knowledge concerning patient characteristics, costs, and utilization has been established. At this time, the base of information on hospice care is inadequate. The limited data available are drawn primarily from the 26 HCFA demonstration hospices which operated under substantially different conditions. Once a firm knowledge-base has been developed, a prospective pricing system for hospice services would be appropriate. Consequently, AHA recommends the following modifications:

Legislative: Require cost-based payment until the knowledge-base needed to design a workable prospective pricing system has been established. If experimentation with prospective pricing for hospice services is viewed as desirable at this time, each hospice should be allowed to choose either cost-based reimbursement or prospective pricing. In addition, any experimentation with prospective pricing methods should explicitly address capitation methods of payment for hospice care.

"Cap" on Total Payment

The payment method established by the hospice statute included a "cap" on total Medicare payments. The cap amount originally was expressed in terms of a formula intended to represent the relationship between average hospice costs and average Medicare expenditures for cancer patients. Having discovered technical problems with the formula, Congress has set the cap at $6,500 in the first year. Increasing the cap to $6,500 reduces the degree of financial risk, but does not address other issues regarding the validity of the cap.

The cap is an attempt to superimpose elements of a capitation payment method on a cost-based payment method in order to guard against increased expenditures, rather than to create desired incentives. A capitation payment system must include actuarial adjustments to reflect the age, disability status, geographic location, etc., of the enrolled population because all these factors will affect utilization and costs. The use of capitation in other parts of the Medicare program (e.g., HMO participation) recognizes the need for these adjustments. Even for those elements of Medicare that do not use capitation, payment rates or cost limits are adjusted to reflect prevailing wage levels in different geographic areas. Although the hospice per diem rates are adjusted for area wage levels, the cap itself is not adjusted. Consequently, hospices in higher wage areas are substantially more at risk of being penalized by the cap. Because the hospice per capita limit is not adjusted for any other actuarial factors, the hospice also is at risk for all variations in utilization related to the need for care. Added to these problems is the statutory requirement that hospices continue to provide care to beneficiaries who exhaust the 210-day hospice benefit regardless of their ability to pay for continued services. Because the time limit on the benefit is applied on an individual basis, there is no opportunity for balancing short-stay patients against long-stay patients. Consequently, the hospice bears all the risk for any beneficiary who lives beyond the 210-day limit into the days--uncovered--that are likely to be the most resource intensive (the days immediately preceding death). These risks are inordinate given recent study findings regarding significant variations in patient populations, the duration of hospice care, and expenditures for different types of cancer.

HCFA has itself stated that a pure capitation method was not -- and cannot be -- adopted due to the significant lack of knowledge concerning the critical relationships among costs, utilization, and patient characteristics (both medical and social). However, the inability to adjust for these factors makes the cap equally invalid as a payment limit until it can be adjusted appropriately.

Consequently, AHA recommends the following modifications:

Legislative: Eliminate the cap amount, because its use is inappropriate unless modified into a true capitation payment with positive incentives for cost containment, not just negative sanctions. If Congress decides that it must retain the aggregate cap limit, the cap provision should be amended to:

- Provide an adjustment for regional variations in prevailing wage levels.

- Provide an exceptions adjustment process to review payment to hospices that experience significant utilization or patient mix variations.

- Require that within 12 months the HHS Secretary establish a method to adjust automatically the cap amount to account for patient utilization and service mix variations that are due to disability status, duration of care, and diagnosis.

The Prospective Rate Structure

The final regulations published by HCFA retained the proposed prospective pricing structure based on four levels of care: routine home care, continuous home care, inpatient respite care, and general inpatient care. As indicated above, several revisions in the rates responded positively to issues raised by AHA and others during the public comment period.

However, several additional revisions were made that substantially reduced the routine home care rate -- from $53.17 per day to $46.25 per day. Based on the limited information available, the AHA believes that the routine home care rate may not support an adequate quantity of home care visits to meet the needs of hospice patients. Given the severe restrictions on inpatient care and the reported difficulty in obtaining payment at continuous home care rates, the utilization component of the routine home care per diem will substantially affect the quantity of care provided to hospice patients. The routine home care rate is a per diem rate based on average per visit costs and average use of home care visits per day (computed by spreading average total visits across the average length of stay).

Our concerns relate to the basis for the average per day utilization component. HCFA's final rule stated that all utilization occurring after the first 210 days of admission to demonstration hospices was disregarded in order to reflect the Medicare benefit's 210-day coverage limit. Given the fact that demonstration patients were not subject to a 210-day limit, HCFA's method of trimming utilization may have inappropriately limited or eliminated the care provided on resource intensive days prior to death. Alternatively, HCFA could have counted 210 days backward from the point of death, but that method of trimming might also have inappropriately eliminated the initial home care visits that generally occur immediately after admission in order to stabilize patients in the home environment. We do not believe it is safe to assume that participating hospices will not be more cautious in timing the admission of Medicare beneficiaries who are not clearly within six months of death. The utilization component needs to reflect the more intense use of services that occurs immediately after admission and immediately prior to death. Trimming utilization from either end of the longer stay demonstration patients highlights the extent to which the demonstration data provide an inadequate data base for setting prospective prices for hospice care.

Furthermore, HCFA has not indicated whether the average home care utilization component represents the level of home care required by the 80/20 rule. The demonstration hospices did not operate under a special limit on inpatient care; inpatient care was subject to standard medical necessity reviews performed by Medicare's medical review agents. Preliminary demonstration data indicate that those hospice models that would have met the 80/20 rule provided significantly higher levels of home care than did those demonstration hospices that would not have met the 80/20 rule. HCFA's computation description does not indicate whether the utilization component is based on the experience of all demonstration hospices or only on the experience of those that would have met the 80/20 requirement. If the utilization was not based on the limited group of hospices, it does not reflect the quantity of home care needed to achieve the level of home care substitution required by the 80/20 rule.

So that these and other critical questions can be answered, we urge that the Subcommittee use its influence to obtain and make publicly available HCFA's final report on the demonstration project and require that the report provide in adequate detail the demonstration data and adjustment methods used by HCFA to compute the prospective rates.

CONCLUSION

Hospice care provides one alternative way to address the problem of terminal illness for both the Medicare program and for terminally ill Medicare beneficiaries. Even though it represents only potential -- not guaranteed -- savings in total Medicare expenditures, hospice care definitely responds to the care needs of a segment of the terminally ill Medicare population.

Additionally, some benefit design aspects of hospice care may be effectively offered to terminally ill beneficiaries who are not ready to consider the hospice option.

Above all, we urge that Congress take a deliberate, yet flexible, approach in modifying Medicare coverage for hospice services. Hospice is not a different type of care, it is a philosophy of care that coordinates and augments the traditional elements of health care services. Existing health care providers, hospitals not the least, should be encouraged to offer hospice care. Moreover, hospice staff are not a type of staff, they are health care professionals, such as doctors, nurses, and social workers, who have been trained in and have embraced the hospice philosophy of care. Unnecessary barriers to their participation in hospice programs should be removed. The hospice concept has much to contribute to the delivery of all health services; accordingly, hospice care should be made an integral part of the American health care system.

Senator DURENBERGER. I wonder if you would respond for us to the question I asked Carolyne Davis relative to what is going on out there with the DRG's in place in the absence of the substantial number of certified hospices. To what extent do you believe that noncertified settings are meeting the need where they are present for hospice care, and to what degree might they be limited in what patient care they can provide, if they are not certified?

Ms. MARTIN. As you know, many of the hospital-based hospice programs have decided not to seek certification. We are one of those hospitals who at the moment has decided not to. We are being reimbursed currently under the DRG payment system for our inpatient care, and Riverside Hospital does have a licensed home health agency as well. That's the manner in which we are delivering our hospice services.

I can tell you in those 5 years since we have been operating a hospice that through that program we are much better meeting the needs of our terminally ill patients. I think if we could make those changes that we have recommended in our full testimony, that we would better be able to receive payment for those services under a hospice benefit. However, we are currently receiving them under the DRG method.

Senator DURENBERGER. Did you make some reference in your statement about conflicts between a hospital's contractual commitment to a hospice and its legal responsibilities or something like that?

Ms. MARTIN. Yes, sir. We did make reference to that. We do have concerns regarding the core service requirement, although I must hasten to say that we certainly believe the interdisciplinary team is essential to the whole hospice movement. The way that the regulations construe the core services makes it very difficult, and in fact in our setting, impossible to meet those requirements. We have particular difficulty in our situation with the volunteer medical director. And I personally believe that the private physician can be part of that core team, and more appropriately so if we are truly interested in the coordination and continuity of service.

Senator DURENBERGER. On the subject of the 6-month prognosis of death and how that limits the number of patients that might be served, in your experience with your own hospice over the last 5 years, what is your experience? How long has your longest living patient been provided care? And what has been your average length of hospice treatment? How many people live beyond 210 days? Can you respond to that?

Ms. MARTIN. We have very close percentages, to the 95 percent of our patient load that are cancer patients. For those patients, we find the length of stay much less than 6 months. I think a lot of that has to do with the whole educational process and what hospice still means to a lot of care givers as well as patients, and their reluctance to enter that program until later on in their terminal disease.

We do, however, have some patients that are noncancer patients, some of whom have been in our program for 3 years. That is a very small number. And the intensity of the services that the hospice provides to them has certainly varied tremendously over that period of time.

But we are concerned about patients who have a terminal illness other than the diagnosis of cancer.

Senator DURENBERGER. Last question. What would be the effect of raising the 20 percent cap on inpatient days or just eliminating the cap entirely? Do you think hospital-based hospices would still be able to hold costs to below the $6,500?

Ms. MARTIN. I would be reluctant to answer that for the whole industry. I think the 20–80 rule—in our own situation, we couldn't meet that at this time. We are about 30–70 at this time. And I think that's for a number of reasons. Early on in development of our hospice program, we elected to take patients into the program who didn't have a care giver in the home, which means that we do take patients that don't have that personal support system. As a matter of fact, our hospice becomes their family. So that is one reason.

Another reason I think that hospital-based hospices are going to have a higher intensity mix, and a higher intensity illness level in their programs as well. I do think it's a laudable goal, however. I do believe that hospice care should be home care centered and focused. And I think we all have a lot of learning to get to that point. However, it's unfortunate to exclude or put such barriers to hospital-based programs in my opinion because I think all communities ought to have the benefit of quality hospice programs and to provide those kinds of disincentives, I think, is inappropriate. And what is particularly bothersome to me is that it is a barrier to making hospice part of the mainstream health care delivery.

Senator **Durenberger**. All right. Thank you very much for your testimony. I appreciate it a lot.

Our next witnesses will be a panel of three, consisting of: Jay Mahoney, executive director of the Boulder County Hospice, Boulder, CO; Mary McKenna, administrator of Southeast Texas Hospice, Orange, TX; Ms. Carolyn Fitzpatrick, president of the National Hospice Organization, Washington, DC.

Welcome, all three of you. And your testimony will be made a part of the record in full. You may proceed to summarize that testimony, beginning with Mr. Mahoney.

Ms. **Fitzpatrick**. Senator, I'm going to start first. Senator Durenberger. You can start anywhere you want. Make Mr. Mahoney last. [Laughter.]

Ms. **Fitzpatrick**. Second. How about second?

Senator **Durenberger**. Second? Oh, all right. So I take it Ms. Fitzpatrick is going first.

Ms. **Fitzpatrick**. Yes.

STATEMENT OF CAROLYN FITZPATRICK, PRESIDENT OF THE NATIONAL HOSPICE ORGANIZATION, WASHINGTON, DC AND DIRECTOR OF GOOD SAMARITAN HOSPICE CARE, BATTLE CREEK, MI, ON BEHALF OF THE NATIONAL HOSPICE ORGANIZATION, WASHINGTON, DC

Ms. **Fitzpatrick**. Mr. Chairman, I'm Carolyn Fitzpatrick, president of the National Hospice Organization, representing more than 2,000 organizations and individuals who provide health services to terminally ill patients and their families. Back home I operate a small but comprehensive inpatient and home care hospice where we make extensive use of volunteers as well as paid staff.

Good Samaritan Hospice Care is in Battle Creek, MI, and is typical of the mainstream of hospice care in America.

Mr. Chairman, I would like to make a few very brief, but important, point this afternoon. The National Hospice Organization wanted this legislation. We wanted very much to make this work. We still want this legislation, and we still want very much to make it work. But it is not working. It is not working because many hospice programs are not participating. And if hospices do not become Medicare certified to provide this benefit, then terminally ill cancer patients will not be served and the benefit and the cost savings that we all thought would occur for the Medicare system will simply not take place.

That we have low participation is an indisputable fact. We have our own chart here. As you can see, that of the Nation's 1,500 hospices, there are only 119 certified programs. Out of the Nation's 268,000 terminally ill Medicare recipients this year, only 1,200 have elected to receive care under this benefit as of August 1984. That means that 99 percent of Medicare eligible terminally ill patients have no access to this benefit. In 20 of the states, like yours and Senator Dole's, Senator Baucus', there are no Medicare certified hospice programs.

The effect of this low participation is tragic, and ironic.

Senator DURENBERGER. Tell me why because what the other witnesses said is, well, most of them are being taken care of through home health reimbursement under Medicare in a hospice-like setting.

Ms. FITZPATRICK. Hospice programs thought that they had finally been offered a system to properly care for their patients. And they are finding that they simply cannot participate and continue to survive financially.

NHO has actively encouraged hospices to explore certification, but programs are fearful and they are very hesitant because of the actual cost of providing the care. Patients who thought that the Congress had extended this compassionate and meaningful alternative have found that they do not have access to this benefit. The Congress promised that this hospice benefit would be available regardless of where you lived in the United States.

This administration, who believes so strongly in cost cutting, is scuttling the one health care benefit that can save the system money. This administration that is so widely heralding as a first term accomplishment the addition of a hospice benefit is not faithfully executing the hospice reimbursement law that was enacted by this Congress 2 years ago.

Hospices, Senator, as you know, are not big. They are not expensive programs. They are not fat or rich health care providers. No other health care provider offers more to patients and families at less cost. Hospices already receive tremendous community and philanthropic support. They utilize volunteers extensively and they cut costs wherever possible. But American hospices cannot be asked to double their philanthropic and community giving simply to subsidize the Medicare benefit.

In a survey that the National Hospice Organization conducted just 1 week ago, the—conducted this of the current Medicare certified hospice programs in the United States, 119 of them. We asked them what their experience had been in providing this benefit. And this is what they told us. All of those hospices who are participating report costs that are exceeding the rates that Medicare is paying us. With few exceptions, certified hospice programs are experiencing extreme financial difficulty and many say that they are threatened with closure of voluntary decertification.

Mr. Chairman, hospices only want one thing and that is for this benefit to be given the chance to work. The Medicare hospice benefit that you so carefully constructed must be universally available to patients, who are, as you know, the most frightened and most vulnerable patients in the health care system. We simply want our Medicare payments to reflect our actual Medicare costs.

The NHO urges Congress to pass without delay legislation which will assure that payment rates reflect the cost associated with the provision of this care. We respectfully submit that the Congress should mandate that the rates be adjusted accordingly and that it be done immediately in order that we might fulfill the promise that this benefit holds out for terminally ill patients and their family.

The National Hospice Program Organization does not believe that the intent of the hospice law is being fulfilled. The Nation's hospices are still prepared to carry out the policy that Secretary Heckler committed this administration to practicing. That all terminally ill Medicare patients and their loved ones will be given the opportunity of choosing hospice care.

Thank you for your time and your caring concern for terminally ill patients.

Senator DURENBERGER. Thank you.

[The prepared written statement of Ms. Fitzpatrick follows:]

TESTIMONY OF THE NATIONAL HOSPICE ORGANIZATION

Before the Health Subcommittee of the Finance Committee
of the United States Senate

September 17, 1984

Mr. Chairman:

I am Carolyn J. Fitzpatrick, President of the National Hospice Organization, representing more than two thousand organizations and individuals who provide health services to the terminally ill and their families in all fifty states. In my capacity as NHO President, I serve as an unpaid volunteer.

Back home, I operate a comprehensive inpatient and home care hospice which makes extensive use of volunteers as well as paid staff. The hospice I direct is a small, independent charitable organization serving a semi-metropolitan, semi-rural community. Good Samaritan Hospice Care in Battle Creek, Michigan, is typical of the mainstream of the hospice movement in our country.

Those of us who <u>serve</u> America's hospices -- as volunteers and as professionals -- and those who <u>are served</u> -- our patients and their families -- are deeply grateful to you, Mr. Chairman, to each Member of this Subcommittee and full Committee, and, indeed, to your outstanding Professional Staff for developing and enacting in 1982 what one of the nation's leading newspapers editorially described as " . . . the most promising improvement in health law passed in this decade, with equal potential for improvement in care and cost."

The Medicare Hospice Benefit is replete with potential and with promise.

- The potential and the promise of compassion - legislation inspired and crafted out of compassion for those in need of care instead of the convenience of those billing for the care.
- The potential and the promise of common sense - policy devised and designed to diminish the ironic financial incentives that keep dying patients in institutions, where they don't want to be - common sense that recognized the need to provide an intensive enough array of covered services to allow families to care for their loved ones outside of hospitals, primarily at home, where they want to be.
- The potential and the promise of cost savings - not the addition of another service, but the substitution of a comprehensive system of inpatient and home care hospice services instead of the system of hospitalization and home health agency services which consumes, for patients in the last six months of life, a fourth of the entire Medicare budget to care for a tenth of Medicare beneficiaries.

Hospice is not a partisan issue. Bob Dole introduced the Medicare hospice bill in the Senate and Geraldine Ferraro co-sponsored its House companion. Tip O'Neill pushed it, and Ronald Reagan signed it. The 1984 Republican platform takes credit for "secur[ing] for the hospice movement an important role in federal health programs" and promises to "do more to enable persons to remain within the unbroken family circle."

In promulgating the rules and the rates that she promised would result in access to this benefit, Secretary Margaret Heckler (a co-sponsor of the legislation as a Member of the House of Representatives) said, "For the first time, all terminally ill Medicare patients and their loved ones will be given the opportunity of choosing hospice care if they believe it is right for them."

Such was the potential and the promise of the Medicare Hospice Benefit.

No one wishes more than I, and those for whom I speak, that the essence of our testimony today could be a litany of the successful practice of the potential of this benefit and the faithful performance of its promise.

Today, we are at high noon between the dawning and the sunset of the Medicare Hospice Benefit -- two years since its passage into law and two years until its potential passage into history. This is a good time to compare where we are with where we expected to be in the implementation of the hospice benefit.

No one expected <u>all</u> of the 268,000 Medicare-eligibles presenting with the physiological need for hospice in 1984 to make Medicare Hospice elections in 1984.

No one expected all of the 1,500 entities who use the term "hospice" to describe some or all of what they do to be able to qualify or to want to qualify as a Medicare-certified hospice.

Not all physicians will refer all terminally ill patients to hospices, nor should they.

Not all terminally ill patients and their families will choose hospice care, nor should they.

Not all hospices will admit into care every potential patient/family, nor should they.

Moreover, there are features of the Medicare Hospice Benefit, itself, which limit utilization by patients and limit certification by providers. Many of those limits are conscious policy decisions adopted by the Congress and accepted by the hospice movement, with the understanding that they be reviewed in 1986:

- the requirement for a six-month prognosis or less validated by two physicians
- the 210-day lifetime benefit limit and the $6,500 aggregate payment cap
- the design of the benefit not as an "add-on" but as an alternative, thus requiring beneficiaries to elect hospice in lieu of and not as a topping for other Medicare-covered services for the terminal condition
- the requirement that a hospice must have, at least, its own minimum core team of volunteers and employees, including a doctor and a nurse

- the 20-percent limit on inpatient days for a hospice in a reporting year
- the financial risks explicit for the provider in requiring services that aren't reimbursed and the prohibition against dumping patients who outlive their benefits

Then there are a dozen or two other philosophical, geographical, political, or localized issues. Finally, there is the graduality of utilization and participation inherent in implementing anything new.

That's why data from the National Cancer Institute, the Administration on Aging, and many other sources led the Congressional Budget Office to project that comprehensive hospices meeting the requirements of the National Hospice Reimbursement Act would care for 41,000 Medicare - eligibles in 1984 increasing to 59,000 in 1985, 76,000 in 1986, and 96,000 in 1987. CBO estimated that utilization of the Medicare Hospice Benefit would not be less than 15 percent and not more than 35 percent of those patients who qualified for it.

Those estimates were made with the assumption that the Administration would pay hospices based on what it costs to provide the covered services.

The Administration's own projection estimated the following utilization by beneficiaries:

1984 . . . . 31,000 patients

1985 . . . . 40,000 patients

1986 . . . . 49,000 patients

Apparently some officials within the Administration believed these numbers to be too conservative. The Office of Management and Budget suggested a sort of hospice lottery where thirty-one thousand Medicare patients would be allowed in and the thirty-one thousand and first dying person would be turned away and assumedly told to come back next year. OMB also suggested a kind of hospice auction where hospices would bid against each other for a limited amount of Medicare provider numbers.

Republican and Democratic Members of Congress refused to consider the legislative changes suggested by OMB.

In a move which has proven to have been just as damaging, however, the Department -- in violation of an understanding with Members of Congress and the National Hospice Organization and under intense pressure from the Office of Management and Budget -- slashed the hospice home care payment rates which had been published in the August 22, 1983, Notice of Proposed Rule Making.

The $53.17 per day home care rate, as published in the NPRM was, itself, too low. It had been based on three-year-old inapplicable demonstration experience, unadjusted for inflation, and did not sufficiently account for extremely significant gaps in HCFA's own data base and calculations.

Even accepting the flawed assumptions that HCFA demonstration data could be applicable to rate setting for this prescribed Medicare Benefit, the demonstration data base relied upon by the Administration in August, 1983, demonstrated not a $53.17 per day home care cost, but a $72.16 per day home care cost. NHO so testified before this Subcommittee on September 15, 1983.

Yet, OMB forced a further reduction of reimbursement levels even below $53.17 down to $46.25 for the most utilized hospice care level, routine home care, which is required by law to constitute the vast majority of days of care.

The Department did not lower the standards for providing hospice care or diminish the mix or intensity of the covered services required to be delivered within the rates. The final rule issued in December, 1983, increased the costs of being a hospice while significantly lowering hospice home care payments.

What effect did those rate cuts have on the potential and promise of the Medicare Hospice Benefit?

After the rate cuts were made, HCFA Administrator Carolyne Davis wrote to this Subcommittee: "We estimate that only 300-400 of the approximately 1,500 organizations that identify themselves as hospices will apply for Medicare certification during the first year."

But, in reality, as of September 7, 1984, HCFA reports that only 119 hospices are certified. Only 57 have submitted bills to Medicare.

After the home care rate was cut to $46.25, Dr. Davis wrote this Subcommittee: "We estimate that approximately 31,000 beneficiaries will elect the Medicare Hospice Benefit in FY 84."

But, in reality, as of mid-August, HCFA reports that 1,280 beneficiaries have elected the Medicare Hospice Benefit thus far in FY 84.

In her testimony before this Subcommittee a year ago, Dr. Davis responded to Senator Dole: "Our (cost) estimates were published in the NPRM. They have not changed since then. We estimate that it will be a net cost in 1984 of $80 million; and in 1985, $110 million; and then in 1986, $160 million."

But, in reality, as of mid-August, HCFA reports that the gross total payments made to all hospices for all beneficiaries for all services in FY 84 has been $2,374,223.61. That's not net cost; that's gross expenditures without accounting for one dime of substitution in lieu of expensive forms of care.

There's been a wide gap between potential and practice and between promise and performance. There's been a wide gap between the numerical projections and actuarial calculations of HCFA and the real world of hospice care in America. And, Mr. Chairman, here we are on the first anniversary of the last time we told you so.

LOW RATES BASED ON INAPPLICABLE DATA UNDERMINE PARTICIPATION AND UTILIZATION

There are two reasons why the Hospice Benefit is not available to most terminally ill Medicare beneficiaries:

1. Hospices cannot and will not provide comprehensive services to terminally ill patients and their families in return for payments substantially lower than the cost of rendering those services.

2. In ascertaining costs and in setting rates, the Administration continues to excuse itself based on a HCFA Demonstration Project that is inapplicable, inaccurate, inconsistent, and inconsequential.

Why does the National Hospice Organization say that the Administration's payment rates are substantially less than it really costs to render the covered services?

To understand that question, Mr. Chairman, you must put yourself in the place of those who serve as volunteers on the Boards of Directors of the nation's hospices. These voluntary boards must look at financial realities because they carry legal and fiduciary responsibilities.

At least four out of five hospices have average daily censuses of twenty or fewer patient/families.

When the Administration's reduced payment rates are applied to the budget realities of operating a hospice, here is what you find:

- Even by paying many hospice caregivers less than they could make working for other providers, and
- Even by making extensive use of volunteers to fill not only traditional voluntary roles but to act as key members of the hospice team, and
- Even by getting most accounting and legal fees donated (and that's the hardest hypothesis to fulfill), and
- Even by begging discounts and borrowing equipment from other organizations, and
- Even by assuming that hospice inpatient care can nearly always be provided for the $271 inpatient rate, and
- Even by convincing retail druggists to sell prescriptions at Medicaid prices, and
- Even by getting the hospice offices donated rent-free.

Nonetheless, it costs $670,000 to operate a typical comprehensive hospice, serving twenty patient/families per day, for a year.

And, Mr. Chairman, on the revenue side, here is what you find:

- Even if 70 percent of your patients (the national average) are Medicare-eligibles, and
- Even if the remainder of your patients who aren't indigent are covered by sufficient private insurance, and
- Even if you are eligible to receive other Medicare payments for your patients who do not elect the hospice benefit, and

- Even if your hospice raises at least as much philanthropic income from donations as it takes to cover the costs of indigent care,

Nonetheless, your hospice will end the year with a $106,518 loss attributable to the difference between the expenses of providing the covered services, on the one hand, and the revenues generated at the levels of the current Medicare rates, on the other.

Appended to my testimony and requested to be included as a part of the Record is an expense and revenue statement and annual operating budget of such a typical American hospice. It's the set of realities that face the Boards of Directors of hundreds of American hospices -- hospices who look at those realities and decided not to seek Medicare certification.

In polling our membership, we have consistently heard two incontestable refrains:

1. A huge percentage of those hospices not participating in the Medicare Hospice Benefit name the low routine home care rate as the principal reason for not participating.

2. All of those hospices who are participating report costs exceeding rates. With few exceptions, the certified hospices are experiencing extreme financial difficulties and many say they are threatened with closure or voluntary decertification.

The National Association for Home Care has complained vigorously that the core services requirement in this legislation prevented providers from participating. However, in surveying some 2,800 health care providers, including what they claim as "all the hospice programs in the nation," the core services requirement was ranked eighth out of eight potential reasons for non-certification, mentioned by fewer than 22 percent of respondents. Four out of the top five reasons cited for not pursuing certification related to inadequate reimbursement. The most important reason, listed by 54 percent of all respondents to NAHC's survey, is that the rates are too low.

The Inspector General of the Department of Health and Human Services, in a draft of his report on the Medicare Hospice Benefit, lists inadequate reimbursement as the leading reason for non-participation among hospices, with the home care rate being most often singled out as the most problematic disincentive.

America's hospices will find the volunteers to supplement and even substitute for paid staff. America's hospices will find the free office space and the donated equipment and the vendor discounts. America's hospices will find the memorials and donations and grants from private sources to fund indigent care for many and bereavement care for all. But, Mr. Chairman, the typical American hospice will not and should not be required to nearly triple its philanthropic income in order to subsidize the Medicare Hospice Benefit. Few Americans can be persuaded to consider the Office of Management and Budget their charity of choice.

DEMONSTRATION DATA FLAWED AS BASIS FOR HOSPICE RATES

The Administration's rationale for reducing hospice payments -- even before the Medicare Hospice Benefit was implemented -- was that new data had become available from HCFA's Hospice Demonstration Project. This new data suddenly became available just after OMB's previously described schemes had been discredited, but not in time for this Subcommittee's use at its hearing on September 15, 1983, and just at the time when Congress was recessing for the year-end holidays. Perhaps the timing was coincidental.

In any case, HCFA wrote to principal sponsors of the Medicare Hospice Benefit, stating:

> "Cost and utilization data from the National Hospice Study provided the cornerstone for the two home care rates established for the Medicare hospice benefit and also components of the inpatient rates."

The HCFA Hospice Demonstration Project has a history which renders it a shaky cornerstone on which to build public policy.

In 1982, when the Congress was considering the hospice legislation, widely varying testimony was presented concerning this demonstration project and the extent to which its design or results would implicate the Medicare Hospice Benefit.

Here is what the Health Care Financing Administration testified:

> "Frankly there are many questions about hospice that cannot be satisfactorily answered at this time. A good example that comes to mind is the definition of hospice itself. . . .
>
> ". . . we must clearly define what we would pay for and to whom, in order to meet our responsibilities to patients, providers and the taxpayers.
>
> "Other questions that must be answered concern:
>
> "The scope and extent of hospice services. -- How much utilization will be stimulated by the expansion of medicare services and should limits be placed on certain services? Should a broad range of supportive services be covered and if not, which ones will contribute the most toward care of the terminally ill? How comprehensive should services be and should a minimal set of services be required? What is the appropriate mix of medical and social services for the medicare population?
>
> "The delivery system for hospice services. -- What is the relationship between inpatient hospital and inpatient hospice care? Is it best to emphasize home-centered care? To what extent should hospices be integrated with other segments of the health care community? Has any delivery setting shown itself to be more effective than others? Are certain staffing patterns more effective and efficient in providing care to the terminally ill? Are hospices a better way to care for terminally ill medicare patients than currently provided in traditional health care settings?

"<u>The quality of hospices services</u> -- Will the emphasis on palliative and supportive services in hospice dilute the quality of medical care available? Should hospices be required to meet certain standards of care and if so, which ones are the critical factors in assuring quality? Are there controls that can protect against misutilization or excessive utilization of hospice services? And finally,

"<u>The cost of hospice services</u>. -- What will be the impact on the medicare trust funds? Considering all the variables in the concerns I have just mentioned, can a hospice benefit be designed that is of comparable or less cost than the existing system and that would provide health care of at least the same quality, in addition to other social and emotional support services?

"<u>While we do not have these answers to these questions now, we have taken steps to assure that we will have them soon</u> [emphasis added]. The Health Care Financing Administration recognized that the hospice movement was rapidly gaining momentum and decided to examine it as a potential benefit for medicare beneficiaries. A two-year demonstration program was initiated in September 1980 to gather information on hospice care including the quality of services provided, and costs and benefits compared to the more traditional modes of health care currently available to medicare patients. . . .

"In conjunction with the demonstration, a national evaluation of hospice care is being conducted by Brown University. . . . Brown is studying the demonstration in terms of cost, and the use and quality of care provided to hospice patients and their families. . . . A preliminary report on the hospice evaluation is scheduled to be submitted in September 1982, with the final report due the following September."

A far different appraisal of the HCFA Demonstration was given by NHO founder Dennis Rezendes, the principal individual from the hospice movement involved in the design and development of the demonstration project:

> " . . . .
>
> "After substantial preliminary negotiation in 1976 with Congressional personnel and within the Department the decision was made, informed by the strong views of staff of the Senate Finance Committee, to seek a demonstration of hospice care reimbursement alternatives through HCFA under the authority given HCFA in Section 402 of the 1967 Social Security Amendments.
>
> "The goal was to provide basic cost data, definitions, and alternative methodologies that would serve to inform a national reimbursement policy.
>
> "In 1977, commitments were made within the Department to proceed to design such a demonstration effort. We were assured by responsible persons in high authority in the Department that a project could be underway 'in a matter of a few months.'
>
> "However, a year and ten months went by, consumed by continuous work with HEW and the beginning of what would be a record of delays, missed deadlines, and befuddled schedules plaguing this project.
>
> "Finally, on October 4, 1978, the Secretary of HEW, Joseph Califano, announced the Hospice Demonstration Project publically before the National Hospice Organization convention. The commitment was made to proceed. Scheduling promises were made that led the hospice movement to conclude that 'in a matter of a few months' the project would be underway.

"Yet, contrary to assurances, it was a full twelve months more before the Department finally announced that there would be 26 demonstration sites. By then, October 1979, had arrived.

"Then, what was to have been a 90-day start-up phase turned into yet another year of deliberations, waiting, false starts, and missed deadlines.

"It was not until October 1980, that the Demonstration actually, finally got underway.

"The choice of an independent evaluator, a lynch pin in the meaningfulness of the entire effort, was not finalized, either, until October 1980, well after promised deadlines.

"The unfortunate fact is that, leaving aside the two years of design time from 1976-1978, a further two years of delays were consumed after the Secretary, himself, publically announced the start of the project before the project actually began. And, on the date of beginning, October 1, 1980, no definite evaluation plan or model had been developed or agreed upon to monitor or evaluate the sites.

"Associated with these major delays were repeatedly-missed, month-to-month deadlines and postponements from March 1980 (a 'final' start-up date solemnly promised by HCFA) until October 1980, the actual date of start-up.

"Frankly, it was in large part through congressional pressure and the serious personal concern of Members of Congress that the project was finally underway in late 1980. Members of Congress who had been persuaded by HCFA assurances and who had then passed those assurances on to constituents suffered embarrassment.

"So much unnecessary cost and so many unexplained delays were incurred that HCFA and it [sic] independent evaluator ultimately decided, in 1981, to simply discount and ignore the first half and perhaps the first full year of cost data as being unusable for the demonstration's goals.

"The impact of this admission is that only the last one-half of the demonstration project period can be looked at for any reliable data, at all, particularly insofar as cost is concerned. The likelihood is that only the third quarter 6-month period (months 13-18) will be considered in an effort to have data sooner than called for in the timetable of the project.

"In any case the fact is that HCFA will not have audited cost figures on the first year ending September 30, 1981, until July of 1982, and that final audited cost figures on the second twelve-month period ending September 30, 1982, will not even be generated by the sites, themselves and then authenticated for even audit accuracy purposes before July, 1983.

"In connection with the decisions to discount much of the first half of the demonstration cost data, it is interesting to note than [sic] on-site evaluation staff were not even in place until July, 1981 (the project was nearly half over by them [sic]), and did not begin to actually evaluate the programs before August, 1981.

"The first eleven months of the HCFA Hospice Demonstration Project passed with no on-site evaluation taking place.

"In fact, beginning in 1977 the HCFA Hospice Demonstration Project has been victimized by a series of missed deadlines and re-designs that continued well into late 1981. In fact, the evaluation by the independent evaluator is not targeted to even be given to HCFA until the end of 1983.

"How far into 1984 will it be before HCFA gets around to analyzing the evaluation and begins to formulate internal policy options and internal recommendations? How much more time will then elapse as the Department, itself, having discovered the extent to which the data needs to be discounted, focuses on a position? How much more time will it take for the Administration, even given a generally supportive attitude toward hospice, to make legislative proposals to the Congress?

"Given the record, I cannot give the Congress much reason to take comfort in HCFA's assurances on this matter.

". . . there are other serious questions about the value of the data as it relates to a national reimbursement policy. . . .

"One of the primary reasons why Congressional direction led to a HCFA hospice study was to test hospice vis-a-vis reimbursement methodologies. Yet, it must be noted for the Record that the study is not testing or studying reimbursement techniques whatsoever.

"The first of many sacrifices to the integrity of the evaluation process was the decision by HCFA to not study reimbursement alternatives, despite the original study design and announcement.

" . . . .

"When this demonstration is over, the Administration and the Congress will know no more than they know today about the effect of varying approaches to reimbursement on the delivery and costs of hospice care.

"Furthermore, no effort is being made to study or evaluate the substitution effect of hospices as an alternative in any scientifically useful way.

" . . . .

> ". . . a major flaw in the HCFA Demonstration is its lack of any testing of a consistent, standard definition of hospice care. . . ."
>
> "This means that the major cost data of the demonstration will be to documentation of the negative effect of the current jumble of reimbursement systems and policies on a hospice program of care [sic]. The demonstration project will document the problem but not implicate the proposed solution. . . ."
>
> "Although utilization levels within a hospice for types of service are being looked at in the demonstration, no scientifically meaningful research is being conducted to help define the market for hospice care in America. Questions the Administration has about induced utilization won't be answered and aren't even being asked by the demonstration project.
>
> "The HCFA demonstration will shed no further light on what is already known about who will choose the hospice alternative.
>
> "The market-limiting factor of mandated substitution in H. R. 5180 will not be addressed by HCFA's data or data-gathering approaches.
>
> " . . . .
>
> "Rather than hiding behind the social scientists' understandable need to 'complete one more study' before making a decision which will be uninformed and too late to be effective, HCFA should . . . put itself in the position of managing the emergence of hospice instead of having to catch up with hospice later.
>
> " . . . ."

Experience proves which testimony was most based in reality. Rezendes was realistic and prophetic.

As to the matter of timeliness, the House Ways and Means Committee pressed HCFA. Here was the answer HCFA gave:

> "Four years from the first gleam in the researcher's eye to the final data being available."

When would that be?

> "A preliminary report on the hospice evaluation is scheduled to be submitted in September, 1982."

What could go wrong?

> "We have every intention, assuming no acts of God intervene, to see the study on time. . . ."

That testimony was given in March, 1982, before the House Ways and Means Committee.

The law passed in August, 1982, required the following with regard to HCFA's Demonstration Study:

> "Prior to September 30, 1983, the Secretary shall submit to Congress a report on the effectiveness of demonstration projects referred to in paragraph (1), including an evaluation of the cost-effectiveness of hospice care, the reasonableness of the 40 percent cap amount for hospice care as provided in section 1814(i) of the Social Security Act (as added by this section), proposed methodology for determining such cap amount, proposed standards for requiring and measuring the maintenance of effort for utilizing volunteers as required under section 1861(dd) of such Act, an evaluation of physician reimbursement for services furnished as a part of hospice care but which are not reimbursed as a part of the hospice care, and any proposed legislative changes in the hospice care provisions of title XVIII of such Act."

A year later, on September 15, 1983, two weeks before the final deadline set by law, Dr. Davis appeared before this Subcommittee and testified:

> "Brown (University) will be using this (demonstration) data to prepare the report which we are scheduled to receive later this month.
>
> "The report will discuss in detail the spectrum of cost and quality-of-life issues for both hospices and conventional care patients.
>
> "We, of course, are expected to do a careful analysis of the report for any implications to the current hospice benefit and any possibility of necessary changes that should be considered in the future.
>
> "I might point out that these findings from this report will be the basis for the Secretary's report to Congress on the hospice demonstration, as mandated by the TEFRA."

Yet, as had every other deadline involving this Demonstration Project, September 30, 1983, was a day like any other day. Promises but no performance.

Now it's September, 1984, and here we are again. The Congress, the Health Care Financing Administration, and the hospice movement having our annual fall reunion to wonder about the HCFA Hospice Demonstration Project. Only it seems that, after six years, we'll have to find something new to bring us together next fall. The yellow brick road of demonstration and evaluation has come to an end at last. Oz is in sight and the Wizard is belching forth.

HCFA DEMO RESULTS DON'T IMPLICATE RATE-SETTING FOR HOSPICE BENEFIT

Please understand, Mr. Chairman, our need to sneak behind the smoke machine and peek behind the curtain.

While it may take another six months or a year to fully evaluate the evaluators, two salient realities are already obvious:

1. Claims by the Administration that the Demonstration data justifies low hospice payment rates are based on an artificially long length of stay experienced in the Demonstration Project. This long length of stay, over 70 days, resulted in HCFA actuaries spreading the end-loaded costs of terminal illness over about twice as many days as are really being experienced, on the average, by patients utilizing the Medicare Hospice Benefit.

   HCFA says it only costs $46.25 a day to provide comprehensive hospice care at home because HCFA took the total home care costs experienced by the Demonstration and divided those costs by 70+ days.

   In reality, the hospices participating in the Medicare Hospice Benefit are not experiencing a 70-day length of stay over which to spread their end-loaded costs. They are experiencing a length of stay that is less than 30 days.

   If one were to use HCFA's own demonstration data and work backward 32 days from the date of death of demonstration patients, and then do an "apples and apples" cost comparison, the result would likely support not a lowering but a raising of the hospice home care rate.

Why are Medicare-certified hospices experiencing a shorter length of stay than hospices in the demonstration?

Mr. Rezendes predicted the answer in 1982 and we testified in the same vein in 1983 before both House and Senate Committees: patients in the Demonstration Project were able to obtain hospice services as an "add on" without "giving up" their simultaneous access to other services related to the management of their terminal illness. Patients electing the Medicare Hospice Benefit, on the other hand, must consciously choose hospice care in lieu of curative therapies. Such mandated substitution is likely to limit length of stay.

2. The principal author of HCFA's National Hospice Study has already confirmed, for reasons he knows best, the inapplicability of the data base to setting rates under the Medicare Hospice Benefit.

Here is the disclaimer in his own words. Dr. David Greer, M.D., Dean of School of Medicine, Brown University:

". . . the NHS cost data is based on our observed length of stay distribution and many factors could affect it in the future. An increase in the number of patients dying from diseases other than cancer, the inclusion of patients without principal care persons, and the requirement that patients waive their other Medicare benefits under TEFRA are a few examples of the factors which might affect length of stay in either direction.

" . . . .

"We made no attempt to separate out those programs in the demonstration whose service mix approximates the

> requirements of the statutory Medicare benefit.
>
> " . . . .
>
> "We have been providing federal officials with an almost continuous stream of data. . . .
>
> "Throughout the process, we have been quite candid concerning the applicability of this data to the conditions of the Study exclusively and have made no claims that it would accurately reflect hospice experience under the different conditions established by TEFRA."

Whatever else we will learn by studying this report, at least now know for certain that the Demonstration Project and the Benefit are very different in design and the hospices participating in the Demonstration did not provide the same services in the same way for the same costs over the same length of time as hospices certified for the Medicare Hospice Benefit. That's why the principal investigator of HCFA's own study discounts its use in rate-setting.

The National Hospice Study also addresses itself to various clinical and qualitative issues regarding hospice care. The National Hospice Organization is distressed, but not surprised, that the clinical analysis in this study is subject to many of the same vagaries as the cost analysis.

While we will undoubtedly have more to say on the subject in the future, I have appended to my testimony and request inclusion in the Record our "Initial Review and

Evaluation of The National Hospice Study and the UCLA Veterans Administration Study." This evaluation of the evaluators was authored by Dr. Barrie R. Cassileth, Chairperson of NHO's Research and Evaluation Committee, with collaboration from the members of her Committee and Advisory Panel.

DATA COLLECTION FOR 1986 IS ALREADY OFF SCHEDULE AND OFF COURSE

The report at last emerging from the Administration is not the only hospice study Congress has mandated that HCFA undertake. So, perhaps, we will have occasion to be together again next year to discuss more missed deadlines and lost initiatives.

TEFRA also includes the following requirement:

> "The Secretary of Health and Human Services shall conduct a study and, prior to January 1, 1986, report to the Congress on whether or not the reimbursement method and benefit structure (including copayments) for hospice care under title XVIII of the Social Security Act are fair and equitable and promote the most efficient provision of hospice care. Such report shall include the feasibility and advisability of providing for prospective reimbursement for hospice care, an evaluation of the inclusion of payment for outpatient drugs, an evaluation of the need to alter the method of reimbursement for nutritional, dietary, and bereavement counseling as hospice care, and any recommendations for legislative changes in the hospice care reimbursement or benefit structure."

At the very least, responding to that statutory mandate requires some system of cost reporting and data gathering. One year ago, in the hearing record of this Subcommittee, the following colloquy ensued between Senator Dole and Dr. Davis:

Senator Dole:

> "You indicate in the regulations that you are not proposing a specific mechanism to adjust the prospective hospice rates after reimbursement has begun. Instead, you will monitor the cost and utilization experience of selected hospices and adjust the rates as an examination of selected cost reports dictates. How will you assure that these selected hospice cost reports are representative of all participating hospices? Will these cost reports be as detailed as those required for other Medicare providers?"

Dr. Davis:

> "As we have noted, HCFA prefers to retain the flexibility to respond to the impact of the prospective rates as the need dictates. We had said that we would examine a sample of hospice cost reports and had anticipated that this would be a scientifically valid sample which, by definition, would be representative of this hospice population. However, we received so many comments on the proposed regulation which suggest that the sample should, during the initial stages of the program, be a complete one that the final regulations provide for cost reporting data from all hospices. The cost reports for hospices will be designed with the objective of avoiding unnecessary detail while recognizing the need to capture the full costs of hospice operations."

However, one year later, I must report to you that not only is there not cost reporting from <u>all</u> hospices, as promised by Dr. Davis, there is cost reporting from <u>no</u> hospices at all.

The first piece of cost data has yet to be collected. The first cost report has yet to be requested.

In fact, despite the continuing requests of the National Hospice Organization for some collaborative effort with HCFA to assist in meeting the statutory mandate, HCFA cannot even decide upon or finalize a cost reporting form or methodology.

Mr. Chairman, it's as if we were back in 1980 and looking down the same yellow brick road. But, now we know that beyond the smoke machine there's a curtain and behind the curtain, there's only a voice.

Mr. Rezendes predicted to the Congress in 1982 with respect to the paucity of reliable data that would be available in 1984, so I must predict today that on January 1, 1986, the Congress will not have reliable cost or qualitative data on the Medicare Hospice Benefit.

A year has already gone by and nothing has happened. If HCFA distributes a cost reporting methodology tomorrow morning, the first quarterly cost report probably would not be audited for accuracy until 1986.

There is a lesson in all this for those who are tempted to wait for HCFA to develop, generate, and report reliable data about hospice. HCFA's spokesperson expressed it in Congressional testimony opposing hospice reimbursement in 1982:

> "I think, as George Santayana first indicated, he who forgets his history is doomed to repeat it. We have a number of examples in the Medicare program."

I trust that the irony of HCFA's historical analogies is not lost in this Committee's review of HCFA's historical analysis.

CONCLUSION AND RECOMMENDATION: CONGRESS MUST ACT TO FORCE PERFORMANCE

Clearly, Mr. Chairman, real costs must be ascertained and realistic rates must be set. We must look somewhere other than the HCFA Hospice Demonstration Project for that reality. Respectfully, sir, we must also look somewhere other than the protestations of good faith and the promises of HCFA for performance.

The National Hospice Organization urges the Congress to pass without delay legislation which will mandate the collection of real costs associated with the provision of the covered services of the Medicare Hospice Benefit. We respectfully submit that, unless the mandating of such cost reporting does not include "teeth" to help motivate HCFA, we will be back here again next year for another of our annual reunions.

It comes down to a question of what we're trying to accomplish. If the Congress believes that it's good to discourage terminally ill patients from obtaining hospice care, then the current course is the right one. If the Congress believes that it fulfills the intent of the law to have gone through this entire legislative and regulatory exercise so that 54 hospices can bill for 1,280 patients and receive $2,300,000, then we ought to congratulate the Administration. If we have come all this way all these years and still, 99.52 percent of the Medicare-eligible terminally ill have no access to Medicare-covered hospices services, then all is well.

But that isn't what this law is all about. That isn't what hospice is all about. America's hospices are still ready to deliver compassion and common sense and cost savings. The needs of the dying and their families still compel us. The potential and the promise you enacted into law still inspire us.

It is already high noon between dawn and sunset for the Medicare Hospice Benefit.

> "All terminally ill Medicare patients and their loved ones will be given the opportunity of choosing hospice care."

That's the policy Secretary Heckler committed this Administration to practicing.

We now wait upon the Administration. When does the performance begin?

APPENDIX
TO NHO TESTIMONY

SAMPLE ANNUAL BUDGET

FOR A HOSPICE WITH AN AVERAGE DAILY CENSUS OF 20 PATIENTS/FAMILIES OPERATING AT CURRENT MEDICARE RATES

EXPENSES

Full-time Equivalents (FTEs)	Staff Salaries	
1.0	Administrator	$ 25,000
1.0	RN Coordinator	22,000
1.0	Volunteer Coordinator	18,000
.5	Bereavement Coordinator	9,000
.5	Chaplain	---
.25	Physician	15,000
1.0	Secretary	14,000
1.0	Bookkeeper	14,000
2.0	Registered Nurse	39,000
3.0	Home Health Aide	30,000
1.0	Homemaker	9,000
1.0	Social Worker	18,000
	Subtotal	$213,000
	Fringe Benefits @ 20%	42,600
	Subtotal Salaries and Fringes	$255,600

ASSUMPTIONS

- Hospice professional staff will work for hospice program at no higher and often lower salaries than paid by other providers
- A considerable amount of office work is performed by volunteers
- Chaplain will volunteer services
- One nurse can serve 10 patient/families
- Bookkeeper, with part-time help and some donated outside accounting
- Professional management of inpatient care can be handled by the described staff

--more--

OVERHEAD EXPENSES

Office Space	$ -0-
Utilities	4,000
Telephone	3,000
Legal fees	1,000
Accounting/Audit	2,500
Office Equipment	8,000
Office Supplies	5,000
Travel	12,000
Insurance	15,000
Printing, Publicity, and Public Education	5,000
Miscellaneous	10,000
Subtotal Overhead	$65,000

ASSUMPTIONS

- Office space donated
- Nearly all legal fees donated
- Accounting and audit fees partially donated
- Some equipment donated
- Some supplies donated
- Professional patient care staff paid $.21 per mile; all home care patients live within 30 miles of office; volunteers donate all travel and auto expenses
- Nearly all public education donated
- Intermediaries pay within 30 days, thus the hospice incurs no interest expense for Medicare receivables

HOME CARE ANCILLARIES

Drugs and Biologicals (6,570 days X $5)	$32,850
Medical Supplies/Oxygen (6,570 days X $4)	26,280
Durable Medical Equipment (6,570 days X $3)	19,710
Therapies (Radiation, Chemotherapy, PT, ST, OT, and all others) (6,570 days X $2)	13,140
Subtotal Home Care Ancillaries	$91,980

ASSUMPTIONS

- Drugs can be obtained at Medicaid prices from retail pharmacies
- Reduced rates for supplies can be obtained from suppliers
- Some hospice patients can use crank, not electric hospital beds; hospice will maintain some donated equipment; Americ Cancer Society will place free equipment in homes of some indigent patients
- Hospice nurses, aides, and volunteers will directly perfo most basic therapies; very limited use of outside service

--more--

PATIENT CARE CONTRACTS

Inpatient general (686 days X $271)	$185,906
Inpatient "outliers" (22 days X $450/day)	9,900
Inpatient respite (22 days X $60/day)	1,320
On call ($2/hour; $15/visit)	15,000
Continuous care (2,364 RN hours X $12/hour)	28,368
(2,364 home health aide hours X $7/hour)	16,548
Subtotal Patient Care Contracts	$257,042

ASSUMPTIONS

- Inpatient care can be provided at $271 per day (including ancillaries)
- "Outliers" (abnormally difficult or costly cases) can be addressed for $450 per day and that these cases will be limited to 3% of all inpatient days
- Respite care can be purchased for $60 per day
- That in a hospice with 20 patients/families on a given day, 2 will be in hospice inpatient care (respite, general, or "outlier")

2 patients/families X 365 days/year = 730 days

Respite: 3% of 730 = 22 days
Outlier: 3% of 730 = 22 days
General: 94% of 730 = 686 days

EXPENSES SUMMARY

Subtotal Salaries and Fringes	$255,600
Subtotal Overhead	65,500
Subtotal Home Care Ancillaries	91,980
Subtotal Patient Care Contracts	257,042
TOTAL EXPENSES	$670,122

--more--

REVENUES		ASSUMPTIONS

NOTE: Revenue assumptions based on national, unadjusted daily rates.

REVENUES	
Routine Home Care (6,373 days X 85% X $46.25/day)	$250,539
Continuous Home Care (197 days X 85% X $357.67/day)	60,059
Inpatient General Care (708 days X 90% X $271/day)	172,681
Inpatient Respite Care (22 days X 85% X $55.33)	1,035
Physicians' Services* (104 visits X $50/visit)	5,200
Total Revenues	$489,514
Net Annual Income (Loss)	$(180,608)

ASSUMPTIONS

- That in a hospice with 20 patients/families on a given day, 18 will be in home care and 2 will be in inpatient care
- 70% of all patient days will be covered by Medicare
- 15% of patient days at home will be a combination of free care and bad debt
- 10% of inpatient days will be a combination of free care and bad debt
- That of all home care, 97% is routine; 3% is continuous. That of inpatient care, 94% is general; 3% is respite; and 3% is "outlier."

*Outside daily rates but included under the cap on total payments

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INITIAL REVIEW AND EVALUATION
of
THE NATIONAL HOSPICE STUDY
conducted in conjunction with the HCFA Hospice Demonstration
and the
UCLA VETERANS ADMINISTRATION STUDY

September, 1984

BARRIE R. CASSILETH, Ph. D.
Chairperson
Committee on Research and Evaluation of
the National Hospice Organization

1984

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Two major research projects, one conducted by Brown University and the other by investigators at the University of California at Los Angeles (UCLA) failed to find differences in the quality of life of hospice versus non-hospice patients. This monograph summarizes those studies and discusses issues raised by their results. It is an effort to help us understand and explain to others how and why these important studies generated their unexpected conclusions. Hospice boards, legislators, and others may question the value of hospice or the need to continue hospice programs on the basis of reports summarizing these studies. This monograph is designed specifically to assist hospice program directors and staff to respond effectively in such situations.

Readers interested in detailed professional reviews and reports should pursue the many journal articles published on subjects related to hospice research. Some of these articles are listed at the end of this monograph under "References."

The Brown University Study

In 1979, the Health Care Financing Administration (HCFA) selected 26 "demonstration" hospices from 233 applicants to participate in an evaluative study of hospice costs and quality of life. Demonstration hospices received Medicare reimbursement not then available to other programs, consisting of reimbursement for actual hospice costs. Brown University competed for and was awarded a grant to conduct the study. In addition to the 26 demonstration hospices selected by HCFA, Brown University added 14 similar non-demonstration hospices and 14 conventional care settings to the study in order to obtain "control" or comparison data.

The final report of the Brown University study has not yet been published, although cost data from the study were published recently (1). This summary is based on a preliminary report produced by Brown University in November, 1983 (2). Preliminary analyses conducted by Brown University researchers were based on 7,954 patients in home-care hospices (defined as hospices lacking inpatient facilities); 5,420 patients in hospital-based hospices (defined as affiliated with or licensed as hospitals); and 493 patients receiving conventional care. Data on patients' pain, overall quality of life, and social involvement were obtained from patients' primary caregivers during approximately bi-weekly interviews. Information on patient satisfaction was obtained from patients at the same time. Major study results concerning quality of life are listed below.

1. Home-care hospice patients spent less time as inpatients (average 5 days) than did hospital-based hospice patients (average 18 days).

2. Hospice versus non-hospice patients were significantly less likely to receive intensive treatment and diagnostic tests, but the use of oxygen or respiratory therapy in the last weeks of life was not significantly different for hospice versus non-hospice patients.

3. Use of social services was more prevalent for hospice as opposed to conventional care patients. However, the Brown University report indicates that this difference existed prior to admission to hospice, and was due to the process of applying for hospice care rather than to increased services after admission to a hospice program.

4. Better pain control was achieved in hospital-based (i.e., inpatient) hospices than in home-based hospices or in conventional hospital settings.

5. Spitzer's Quality of Life Index, which primary caregivers used to assess patients' "perceived health," activities of daily living, outlook, and family support, showed no differences between hospice and non-hospice patients.

6. Patients' functional performance, or capacity to function, was measured by observers using the Karnofsky Index. No differences between hospice and non-hospice patients were found.

7. Caregiver assessment, using the Emotional Quality of Life Index also taken from Spitzer, revealed no differences between hospice and non-hospice patients in levels of depression, loneliness, and emotional comfort.

8. No differences in patient alertness among hospice versus non-hospice patients were detected in the last five weeks of life.

9. Caregiver assessment of overall social quality of life, involving quality of family support and relations, was uniformly high but slightly better with conventional care.

10. Patients' satisfaction with care did not differ by hospice versus non-hospice care.

What Do the "Quality of Life" Results Mean?

A methodologic problem with the Brown University study was its manner of assessing patients' quality of life. It would have been difficult, as the Brown report noted, for some terminally-ill patients to complete questionnaires. Most quality of life questionnaires available at the time of their study were indeed physically and mentally taxing. Brown University used the next best device then available: caregiver assessment with a questionnaire based on Spitzer's Quality of Life Index.

The difficulty with caregiver assessment is twofold. First, quality of life is extremely subjective and personal. No one but the individual can truly assess the quality of his own life. If there were such a thing as "objective" quality of life, we would not have suicides among young, healthy, attractive people, nor would there be so few suicides among seriously disabled or fatally-ill patients, whose "objective" quality of life is extremely poor. Therefore, assessment of one person's quality of life by another produces indirect information and questionable results.

The second difficulty with caregiver assessment is that caregivers may sense the patient's quality of life to be a reflection of the effectiveness of their own caregiving. Caring families could not emotionally sustain the idea that their efforts were ineffective, resulting in poor quality of life for the patient. Positive caregiver assessment reflects the caregiver's own experience, which is very important as such. Here, it is tantamount to saying: "I have done my best; we have found the best place and the best care for our loved one."

Some of these points pertain as well to the issue of patient satisfaction. Hospice and non-hospice patients in the Brown University study were found to be equally satisfied with their care. Patients in any setting tend to express satisfaction with care that they selected and on which they are dependent during a critical and vulnerable time in their lives. Expressing dissatisfaction with care would be equivalent to feeling that one made a bad choice and is incapable of altering the situation, a position of emotional discomfort that patients, and the rest of us, tend to avoid. A fundamental psychological phenomenon or facet of human nature is our tendency to feel very positive about major decisions once we have made them.

Finally, quality of life probably is closely related to disease or clinical status. We do not know from the Brown University Study whether patients in home-based hospice programs were similar in terms of disease status to patients in hospital-based hospice programs. It is possible that a process of self-selection occured here, with sicker patients going to hospital-based hospice programs than to home-based programs.

An additional problem is one that is intrinsic to many studies of human beings. When a person or a program knows that it is part of a study, that very knowledge can alter its behavior or quality. We do not know the extent to which programs of the same type were similar to one another, nor do we know whether different types of programs grew to become similar to one another as a function of being studied.

We must view the quality of life results with caution, understanding that not patients, but others assessed patients' quality of life, that "satisfaction" with care is difficult to measure meaningfully, and that these issues generally are faught with numerous influencing variables and therefore extremely difficult to assess.

The UCLA Study

This second study of hospice costs and quality of life was published in The Lancet (3). Terminally ill cancer patients at the UCLA Veterans Administration hospital were randomly assigned to hospice or conventional care. Both types of care were delivered in the same VA hospital. Hospice patients awaiting admission to the hospice inpatient unit were cared for elsewhere in the hospital by conventional physicians, with help and advice from hospice staff.

Several measures were applied to assess outcome variables. Pain scores were based on Melzak's work; the symptom scale employed was adapted from the California Pain Assessment profile; and well-validated tests of depression, anxiety, satisfaction with environment, and involvement with care were used. Although the authors do not indicate whether patients themselves completed these scales, most of these measures were designed to be self-report. Functional status was assessed by the Katz Activities of Daily Living scale. Patients in this study were men who typically had held blue collar jobs. Their mean age was 64. The UCLA study reached the following conclusions pertaining to quality of life issues:

1. There was no difference in survival time or number of inpatient days for hospice versus non-hospice patients.

2. The number of days spent in intensive care units did not differ significantly in the two groups.

3. Three percent of hospice patients died at home; 7% of non-hospice patients died at home.

4. Although the majority of both hospice and non-hospice patients received no major treatment, hospice patients received significantly more surgery and chemotherapy than did non-hospice patients.

5. There were no significant differences between hospice and non-hospice patients in the proportion of patients experiencing pain or in the amount of pain experienced.

6. Hospice patients did not differ significantly from non-hospice patients by symptoms, activities of daily living, depression, or anxiety.

7. Hospice patients expressed greater satisfaction with interpersonal care and with involvement in care.

8. Hospice as opposed to non-hospice caregivers displayed less anxiety and greater satisfaction with involvement in care.

What do these UCLA Results Imply?

Hospice patients in this study spent about as many days in the hospital (51 days) as did non-hospice patients (48 days). However, this is an example of how data can be misleading and interpreted in more than one way. The UCLA article compared the average number of inpatient days for hospice versus non-hospice patients, rather than the average proportion or percent of inpatient days, and it did not include nursing home days in the inpatient calculation. Using information given in Table II of the article, and including nursing home days as inpatient days, hospice patients spent an average of 52 days as inpatients (54% of their time), and non-hospice patients spent an average of 59 days as inpatients (61% of their time). Looking at these same figures from the "days at home" point of view, hospice patients spent 46% of their time at home, while non-hospice patients spent 39% of their time at home. This meaningful difference was not discussed in the article.

Similarly, information about major treatment procedures is reported in a way that makes it difficult to evaluate the impact of hospice. The average number of procedures per patient (less than one for each hospice as well as non-hospice patient) is reported. However, we are not told whether hospice patients received chemotherapy, radiation therapy, or surgery when they were in the hospice inpatient unit or when they were cared for elsewhere in the hospital. (Hospice patients spent an average of 29 days on the hospice unit, 13 days on general medical floors, and 8 days in "intermediate care." That is, only slightly over half of hospice patients' inpatient time was spent on the hospice unit). It is possible that palliative treatment was needed and ordered appropriately by hospice staff; it is possible alternatively that these procedures were ordered by conventional staff during patients' stays in conventional areas of the hospital. This is not discussed, nor is there mention of the fact that palliative treatment techniques may be a needed and appropriate component of hospice care.

The UCLA study found no differences in various quality of care and quality of life factors among hospice versus non-hospice patients. The article presents these findings as evidence that hospice is no better than conventional care.

There is, however, another way to look at these results. The article notes that, when hospice patients were cared for in conventional-care areas of the hospital, hospice staff worked with conventional staff in rendering care. Remember that hospice patients spent almost half of their inpatient time in conventional-care areas of the hospital.

A logical conclusion that may be drawn from these observations is that hospice caregivers were successful in educating conventional physicians and nurses to hospice principles. One may conclude legimately that a successful program of informal transfer of education from hospice to non-hospice staff occured, resulting in improved care for non-hospice patients. Also, heightened sensitivity and effort on the part of non-hospice staff may have occured simply as a result of their having participated in the study. The lack of difference in pain control, symptoms, and quality of life reflects this transfer of knowledge and technique and, as such, represents a triumph for hospice and an affirmation of the superior quality of hospice-type care for the terminally ill. The Lancet authors alluded to this in stating: "Better management of pain and symptoms is a medical skill that can be propagated by education. The hospice movement may have made its contribution by sensitizing practitioners to their inadequacies."

The article's conclusion that "Intensive hospice care did not yield the expected benefits in pain or symptom relief or in alleviation of psychological distress..." is arguable on two counts. First, the hospice patients in this study did not receive "intensive" hospice care. They received a mix of hospice and conventional care. Second, benefits in pain, symptom relief, and psychological distress occured in the best of ways: even patients under conventional care benefited from the skills that their conventional caregivers learned from hospice staff.

There is a methodologic concern with regard to quality of life results. Quality of life was measured in patients who were at different points in time vis a vis proximity to death. That is, patients who were very sick and near to death, and patients who were less sick and much further from death, were mixed together to obtain average quality of life data. This is a confounding feature that should be kept in mind when evaluating these results.

In addition, remember that the patient sample in this study was comprised of patients at a Veterans' Administration hospital. Almost all patients were male, and neither patients nor their families are representative sociodemographically of the general population. Finally, the home care component of the UCLA study is not addressed, and we do not know how this important hospice feature (or its absence) influenced study results.

What About the Cost Results?

Both the Brown University demonstration project and the UCLA study looked at the relative or comparative costs of hospice care. The Brown study found that, for both hospital-based and home-based hospice programs, short hospice stays (under two months) were significantly less costly than conventional hospital care. As noted in Science: "Overall costs for home-based patients were $4,758 compared with $5,890 for inpatient hospices. No comparable figure was supplied for conventional care where costs may average $1,000 in the final week" (4).

The UCLA study, on the other hand, did not find a difference in the costs of hospice versus non-hospice care. This may be due to the similarity in the absolute number of inpatient days for hospice and non-hospice patients combined with an apparent lack of programatic emphasis on home care; to the fact that hospice and non-hospice patients all were treated in the same hospital, often by the same physicians; to the indirect fashion of assessing costs that was applied; or to some combination of these factors.

Few published studies have focused on clinical or qualitative differences between hospice and non-hospice care. However, several important studies in addition to those conducted by Brown University and UCLA have addressed the issue of cost. For example, a 1980 study of the last two weeks of patients' lives found that the cost of hospital care was ten times as great as the cost of home care (5). Another study compared various types of care for 364 cancer patients during their last six months of life (6). The average cost per patient during this six-month period was lower for home care hospice ($1,319) and nursing home hospice ($1,866) than for municipal hospital ($8,559) or teaching hospital care ($10,341).

A major study of hospice costs was conducted by researchers at Case Western Reserve University (7). They analyzed insurance claims for 152 cancer patients served by a hospice home care program and 1397 patients who never received home care. Hospice cost savings of 43-47% were found at two, four, eight, and twelve weeks prior to death.

Nine studies of the cost of hospice care have been summarized in a review article (8). In contrast to the UCLA results but consistent with the Brown University findings, each of these studies found substantial savings for hospice care.

Although the great majority of cost studies report savings for hospice care, the extent and specifics of savings differ from study to study. These differences highlight the complexities and potential problems of cost-related research.

Cost data have to be maintained in an identical fashion for each group involved in a study. The relationship between the costs of hospice and non-hospice care depends entirely on the programs selected to represent each type. It would be easy to show that hospice care is much more costly than conventional care by comparing $600/day, acute-care hospital-based hospice care with inexpensive community hospital standard care. Alternatively, it would not be difficult to "prove" the reverse, by comparing community-based hospice programs that use little or no inpatient time with expensive, primarily inpatient, conventional care. Cost studies in the future will have to use large and representative samples of both types of care, with costs assessed in the same way, in order to produce meaningful, generalizable results.

The Challenge of Hospice Research for the Future

So far as quality of life issues are concerned, these factors should be measured by patient assessment when feasible. A simple, effective, and well-validated self-report quality of life questionnaire was published following the Brown University study (9). It is a better measurement technique, and one that terminally ill patients can complete themselves. However, important differences in quality of life as a function of type of care always will be difficult to uncover. Quality of life is an extremely abstract, highly personal, and singularly individualized matter. Assessment measures can detect differences due to clinical status. It is much more difficult to detect differences due to type of care among patients with approximately the same clinical status.

Clinical and disease status, severity of illness, the amount and quality of family support and assistance, patient self-selection of one type of care versus another, and other such factors must be assessed and taken into account. We must recognize the fact that all hospice patients are not alike, and that when we mix different patients together to obtain average scores, we may dilute or lose a very real effect. Similarly, it is important to concern ourselves with the fact that not all hospice programs, even those of the same type, are alike. Is the particular program studied representative of that type of program? If not, study results cannot be generalized or applied to other programs.

Studies of hospice care to date provide interesting information that must be interpreted with caution. We learn from the similarities as well as the differences of their findings that hospice assessment is limited by current technology and by the numerous factors that must be taken into account. Finally, as stated in a recent editorial, "the real issue should be which type of hospice provides better services for various categories of patients" (10).

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STATEMENT OF JAY MAHONEY, EXECUTIVE DIRECTOR OF THE BOULDER COUNTY HOSPICE, BOULDER, CO, ON BEHALF OF THE NATIONAL HOSPICE ORGANIZATION, WASHINGTON, DC

Senator DURENBERGER. Mr. Mahoney.

Mr. MAHONEY. Mr. Chairman, thank you for the opportunity to talk to you today. My name is Jay Mahoney, and I'm the executive director of Boulder County Hospice in Boulder, CO.

Boulder County Hospice was a participant in the hospice demonstration project, and was certified as a Medicare hospice February 6 of this year. I would like to speak with you today about one of the most significant problems facing Boulder County Hospice. That is diverting our philanthropic dollars away from indigent care, new programs, research and education, and putting them into the support of patient care that is supposed to be paid for through the Medicare hospice benefit.

Through the first 6 months of 1984, our average daily cost is $56.47 compared to our reimbursed Medicare rate of $46.19, a loss of approximately $10 for every Medicare hospice patient for every day of home care.

I submit to the committee that the problem is not one of excessive cost, but of rates that are unrealistically low. The rates, as presently structured, are based on an average length of stay of 70-plus days, as determined by using statistics developed through the hospice demonstration project. However, at Boulder County Hospice, the average length of stay is 27 days for Medicare hospice patients. Boulder Hospice is not atypical in this, as noted in the National Hospice Organization survey which shows the national average length of stay of 28 days.

I believe this gap is due to a number of reasons. Among them, under the demonstration there was no time for monetary restrictions of any significance. This resulted in patient days exceeding 210 days as being common. The demonstration project was an add-on to patient Medicare benefits. Under the new DRG system of reimbursement, hospitals are referring patients who might otherwise have died in a hospital bed.

These reasons not only decrease the average length of stay but also have the effect of providing hospice services only at the highest and most expensive point of need instead of over a period of time when the cost of services can be averaged over a period of low and high needs.

Hospices all over the country have for years raised money necessary to run their programs. We will continue to do so because there will be services to the terminally ill that will never be paid for through traditional reimbursement systems. But it is simply unfair for the Government of the United States to force hospice programs around the country to subsidize the Medicare system, which is exactly what is happening at the present time. Hospices, I guarantee you, would much rather be putting their community dollars into indigent care, education, services to terminally ill children and their families, research and bereavement. For programs like Boulder County Hospice are going to be the one to provide the services to the vast majority of those seeking hospice care through Medicare. With appropriate reimbursement, we, the Government, and the hospice programs have the opportunity to provide a most appropriate and humane way of serving the terminally ill, while at the same time saving taxpayer dollars.

Thank you.

Senator DURENBERGER. Thank you very much.

[The prepared written statement of Mr. Mahoney follows:]

Testimony of John J. Mahoney
Executive Director, Boulder County Hospice, Inc.
Boulder, Colorado

Boulder County Hospice was organized as a non-profit, tax-exempt corporation in late 1976 by an interdisciplinary group of physicians, nurses, mental health workers, clergy, social workers, administrators and highly dedicated lay people to serve the unmet needs of the terminally ill in Boulder County. In 1977, the agency began providing home nursing care and social support services, initiated a bereavement follow-up care program and established an education program committed to community education and professional training in the areas of death, grief and hospice care. In November 1983, Hospice began to offer inpatient backup services for patients needing acute inpatient hospice care. While Boulder County Hospice began providing this service as a result of new Medicare legislation the positive response to the service has been most encouraging. Since November over 50 patients have received care in the inpatient unit. (Space is leased from Boulder Community Hospital.) This service has allowed us to maintain better continuity of care, as well as allowing us better patient management resulting in shorter lengths of stay in an inpatient setting than what otherwise might be realized.

Through June 1984 Boulder County Hospice has cared for approximately 625 patients and provided supportive services to an estimated 1,700 family members. Hospice's education program has reached over 40,000 persons and has provided an intensive team training course to approximately 700 persons, both volunteers and health care professionals.

Since its early days as a pioneer in hospice care, Boulder County Hospice has become a national model of a community based hospice. It was recognized as such in 1980 with its selection as a participant in Health Care Financing Administration's

Hospice Demonstration Project. Members of the Hospice staff have given presentations and served as consultants throughout the United States and Canada and were instrumental in the formation of the Colorado Hospice Organization.

The long-range administrative objective of Boulder County Hospice has always been to increase the financial self-sufficiency of the agency. In pursuit of this objective, the agency became a Medicare-certified home health agency in 1979 and was thus entitled to third party reimbursement for the medical component of its service. In February 1984, Hospice became a Medicare-certified hospice program. As commercial insurance carriers follow this precedent by amending home health benefits to include coverage of the total range of hospice services, the expanded base of funding sources will allow further integration of hospice into the established health care reimbursement system.

Even though Hospice has been able to achieve significant success in increasing its revenues generated through fees, almost $120,000 must still be raised through the generosity of the community. As long as Boulder County Hospice maintains its commitment to providing education and bereavement services, and because of its overriding commitment to providing all necessary services regardless of ability to pay, Hospice will continue to depend on foundation and community support to meet the needs of the terminally ill in Boulder County.

Therein lies one of the most significant problems facing Boulder County Hospice, i.e. diverting our philanthropic dollars away from new programs, research, and education and putting them into the support of the services that are supposed to be paid for by the Medicare program.

In the first six (6) months of 1984, eliminating the patients served through the

Hospice Demonstration Project, and the revenues and costs associated with those patients Boulder County Hospice has an average daily cost of $56.47, compared with our Medicare routine home care rate of $46.19.

The above figure was determined using the following statistics:

Total Home Care Costs 6/30/84	$ 147,812
Volunteer Costs (65% of total volunteer costs)	10,527
Training/Orientation	12,000
Sub-Total	170,339
Less Demo	47,333
TOTAL	$ 123,006
Total Home Care Billable Days	4,129
Less Demonstration Billable Days	(1,951)
TOTAL	$ 2,178

∴ $123,006 ÷ 2178 = $56.47

The question arises, is Boulder County Hospice spending too much to provide medical care to its patients? The answer is no. The vast majority of expenses associated with hospice care are personnel costs. On an annualized basis the amount we pay our medical personnel is about $3,000 - $7,000 less than what they can earn in a hospital setting.

I submit to the Committee that the problem is not one of excessive costs, but of rates set unrealistically low.

The rates, as presently structured, are based on an average length of stay (ALOS) exceeding 70 days. This ALOS was determined using statistics developed through the Hospice Demonstration Project. However, at Boulder County Hospice the average length of stay for patients admitted under the Medicare Hospice Benefit is 27.4 days.

I believe this very large gap in the ALOS can be explained as follows:

1. Under the demonstration there were no guidelines or caps to address the questions of patients who survived their original six month prognosis. In addition the allowable costs for respite and continuous care were so generous that families were able to manage patients at home for longer periods of time. Consequently, a patient with a length of stay exceeding 210 days was common.

2. Under the demonstration project hospice services were, in effect, an add-on to a patient's existing Medicare benefit. With the waivers that must be signed under the new benefit physicians and patients are waiting longer before making referrals to hospice.

3. Under the new D.R.G. system hospitals are referring patients who might otherwise have died in a hospital bed. This not only decreases the ALOS, but also has the effect of providing hospice services only at the highest point of need instead over a period of time when the cost of services can be averaged out over low and high needs periods.

To maintain our level of service to our patients we are having to divert our philanthropic dollars. Hospices around the country are used to raising dollars in their communities. The people, foundations and corporations of Boulder have always been more than generous to us. We use their dollars to:

- Provide care for patients and families that have no money for hospice care, but who have a great need.
- To address the special needs of terminally ill children and their families. We have come to accept the inevitable death of a much older family member

or friend, but the death of a child is a loss felt so deep in a parent that it will last a lifetime.

- To research and address the needs of the terminally ill that cannot stay at home and cannot or will not go into a nursing home. Fear of death is made up of many fears - fear of pain, fear of being lonely and alone. There is much for us to learn about death, much for us to do.
- To provide Bereavement Services.

However, now we're finding that significant philanthropic dollars, estimated at over $40,000 for 1984, (including inpatient costs) are going to adhere to regulations or directly support services to Medicare benefit recipients. To paraphrase the Executive Director of our largest and most stable foundation supporter:

> We are most supportive of the hospice philosophy of care. We are convinced that it is a more humane and more economical form of care for the terminally ill. We are particularly supportive of Boulder County Hospice, but we cannot and will not continue to fund proposals that are in effect subsidizing the federal government's Medicare program.

I cannot say that what is happening in Boulder is true for every hospice program. However, Boulder County Hospice is a very typical hospice program in this country. The vast majority of programs are small, 15 - 30 patients per day; Boulder has an average of about 24 (including demonstration patients) patients per day. These are the programs that are going to provide services to the vast majority of the 250,000 plus terminally ill patients that could take advantage of hospice services. If these programs cannot find it economically feasible to participate in Medicare certification then the Medicare system loses an opportunity to save itself millions of dollars. And, thousands of terminally ill people around this country will lose a valuable service.

STATEMENT OF MARY McKENNA, ADMINISTRATOR OF SOUTHEAST TEXAS HOSPICE, ORANGE, TX, ON BEHALF OF THE NATIONAL HOSPICE ORGANIZATION, WASHINGTON, DC

Senator DURENBERGER. Ms. McKenna.

Ms. McKENNA. Good afternoon, Mr. Chairman. Thank you for the opportunity to speak to you today. My name is Mary McKenna. I am the administrator of the Southeast Texas Hospice in Orange, TX. I am also the president of the Texas Hospice Organization, and a board member of the National Hospice Organization.

The Southeast Texas Hospice was incorporated November of 1976. It was the first hospice program in the State of Texas. We serve patients and families in five counties in southeast Texas. On a given day, our census is approximately 16, and patients stay with us an average of 42 days.

By the way, Mr. Chairman, the National Hospice Organization statistics of 1,200 American hospices indicates the medium home care daily census is 15.9 so that we are a perfectly typical hospice program in America.

Mr. Chairman, my board of directors and our staff of professionals and volunteers have studied the Medicare hospice benefit. It is a good benefit. It is exactly what terminally ill patients and their families need and want. We believe that if we were Medicare-certified, we would do a far better job of keeping patients in the home free of pain during their last weeks and months. We could provide continuous care. We could provide drugs and equipment. We could continue to manage the care of our patients when our inpatient stay is absolutely necessary.

Unfortunately, however, we simply cannot afford to be Medicare certified at this time. We don't know what our costs will turn out to be, but we are guessing that we would lose roughly $8 for every Medicare patient every day. Our calculations indicate that this would mean an extra $46,000 a year to be raised in our small community. Our entire operating budget this year was only $125,000, and we are already depending on some $40,000 in donations for indigent care and the care of underinsured patients.

If we become Medicare certified, we would have to double our fundraising efforts, as well as shift costs to private paid patients. We are unsure whether we could make ends meet. And so, our board of directors is unwilling to take the risk of becoming Medicare certified.

In closing, Mr. Chairman, let me reiterate what the inadequacy of the Medicare payment rates means to terminally ill patients in southeast Texas. The 100 patients and families whom we will care for this year will receive the best care that we can provide, given the restraints which are imposed on us by the traditional medical care system. If we are able to become a Medicare certified hospice, we would be able to provide an alternative to that system, to those patients and their families. We are depending on you and the Members of this Congress to fulfill the promise which you made to those citizens 2 years ago. That the alternative of hospice care would be made available to them in their final days.

Thank you.

[The prepared written statement of Ms. McKenna follows:]

Testimony of Mary McKenna
Before the Subcommittee on Health
Senate Finance Committee
September 17, 1984

GOOD AFTERNOON Mr. Chairman. Thank you for the opportunity to speak to you today. My name is Mary McKenna. I am the administrator of the Southeast Texas Hospice in Orange, Texas. I am also privileged to serve hospices in Texas as the President of the Texas Hospice Organization and hospices across the nation as a board member of the National Hospice Organization.

The Southeast Texas Hospice was incorporated in November, 1976. It was the first hospice program in the state of Texas. Those of us who created the Southeast Texas Hospice were responding to a real need in the community for a special kind of care for terminally ill patients and their families.

Since initiating care in January, 1979, our hospice has served over 400 dying patients and their families. We are certified as a home health agency, so that Medicare reimburses us for some of our costs. On average, our community has provided over 50 percent of the operating budget of the hospice program each year through charitable contributions.

We serve patients and families in five counties in the Southeast corner of Texas. On a given day our census is approximately 16, and patients stay with us an average of 42 days.

Mr. Chairman, my board of directors and our staff of professionals and volunteers have studied the Medicare hospice benefit. It is a good benefit. It is exactly what terminally ill patients and their families need and want. We believe that if we were Medicare certified, we would do a far better job of keeping patients in the home, free of pain during their last weeks and months.

If we were Medicare certified, we could provide continuous care, so that a patient's family would not have to call the rescue squad in emergencies. If we were Medicare certified, we could provide drugs and equipment, so that pain could be better managed. If we were Medicare certified, we could continue to manage the care of our patients when an inpatient stay is absolutely necessary.

Unfortunately, however, we simply cannot afford to be Medicare certified at this time. I am attaching and ask to be made a part of the record of this hearing, an estimate of the costs which we would incur for a routine home care day if we were Medicare certified, compared with the routine home care rate which we would receive for such care. You will see that for our hospice program, the average cost to provide the services mandated by the Medicare benefit would be $53.57. Since we would be paid only $45.21 per day, we would lose roughly $8.00 for every Medicare patient every day we care for them. Our calculations indicate that this would mean an extra $46,000 per year to be raised from our small community. We are already depending on some $40,000 in donations for indigent care and for the care of underinsured patients. If we became Medicare certified, we would have to double our fund raising efforts as well as shift costs to private-pay patients. At the moment, we are unsure whether we could make ends meet, and so our board of directors is unwilling to take the risk of becoming Medicare certified.

In closing, Mr. Chairman, let me reiterate what the inadequacy of the Medicare payment rates means to terminally ill patients in Southeast Texas. The 100 patients and families who we will care for this year will receive the best care that we can provide given the restraints which are imposed on us by the traditional medical care system. If we were able to become a Medicare certified hospice, we would be able to provide an alternative to that system to those patients and their families. We would be able to fill the gaps in which too many of our elderly dying citizens fall. Quite frankly, however, we are depending on you and the members of this Congress to fulfill the promise which you made to those citizens two years ago: That the alternative of hospice care would be made avaialble to them in their final days.

Thank you for listening to me and for caring about the people whose right to spend their last days in comfort and peace is our mission.

ATTACHMENT

<u>Southeast Texas Hospice</u>

Total Expenses	$ 124,953
Total Reimburseable Visits	1,708
Total Patient Care Days	4,556
Average Cost/day	$27.40

Additional Costs for Medicare Certification

Drugs, Equipment and Supplies/day	$ 12.00
Homemaker Service/day	2.63
Home health aide/day	2.96
Counselor/day	3.29
OT, PT, or ST /day	3.29
Outpatient Ancillaries	2.00
Average Cost/home care	53.57

Senator **Durenberger**. Let me try to, if I can, do a summary that will be inadequate because a summary is always inadequate. This will be of what I have heard so far and then I will ask you to talk to me about the reality. What I have heard from the administrator at HCFA is that they didn't anticipate a whole lot of applications for qualification for this program anyway, and they seem to be coming in at about the rate that they expected them. That there are 119 that have applied and been granted certification. That there are 43 in the pipeline, and another 14 ready to find out where the pipe is and start marching in at that end, and presumably behind that are a lot of other people.

Now when I listen to the testimony I have just heard, I can't understand why any of those 156 people or whatever the total is even bother. And that's one of the questions. I asked earlier, well, maybe it's like the Good Housekeeping seal of approval that if you are in competition, you try to make it up in volume or something like that because if you can get the Medicare certification and nobody else in your community or your region gets it, then you would just get more business in one way or another. If you turn down the people that look like they are going to stay too long, and you selectively choose who comes into your hospice, because you are going to have everybody coming there because you have the HCFA seal of approval on your program in the selection process—maybe that's how they are doing it. Then I just heard that—I mean I sort of tentatively come to that conclusion because I just heard from both Ms. Fitzpatrick and Ms. McKenna that in order to conform with these guidelines and get the reimbursement under the system you have to double the contribution in financial terms and/or that you would have to shift the cost to private paying patients. And I'm left a little uncertain about what the reality is out there because apparently—I don't even know if we are going to hear from any of the certified people.

Ms. FITZPATRICK. We are.

Senator DURENBERGER. You are all certified?

Ms. FITZPATRICK. Yes.

Senator DURENBERGER. You two tell me where you get the money to be certified.

Ms. FITZPATRICK. There are two parts to your question that I think are important for the record. The first is that Dr. Davis said that they didn't anticipate very many programs; they are sort of on track here. Not exactly. Last fall, the Secretary of Health and Human Services authorized the sending out of an information sheet to all hospices in the United States asking how many of them would be interested in a Medicare survey. That was last fall when we still believed that the payment rate was going to be somewhere around $53.17.

Senator DURENBERGER. Do you know how many replies she got?

Ms. FITZPATRICK. Almost 500 said "yes, that we would participate in the first year." So they did think that there would be a few more than 119.

Second, why did we participate? Our hospice program was certified on November 1, 1983. We were certified believing that the payment rate was $53.17. On December the 16th, the final rules came out, letting our board know that our payment was going to be $46.25. We were already in the system. We already had terminally ill patients that were being cared for. Many of us had already become a part of this system before we even realized that we were going to be losing $50,000 this year.

Senator DURENBERGER. Well, how much longer are you going to survive losing that kind of money? And when are you going to ask for decertification or can't you do that?

Ms. FITZPATRICK. Well, I hope we are not going to have to. I hope that we are successful in pleading our case. All we would like to have the payment rate based on the cost, the real cost of providing our care.

Senator DURENBERGER. I know that's what you would like. But you are a live example of someone who unless you disprove what I have said has been existing since December of last year on the current payment rate. Yes, you would like to get more money, but if I can keep you in the program, and keep the folks lined up at the pipeline, why should I raise my rates?

This may be unfair and maybe you want to answer that question in writing because I am deeply concerned at what the reality may be and I'm putting you on the spot here. But you are losing money and that you are doing some cost shifting, and that you are making it up in some way. And maybe the fairer way to respond to that question would be to give both of you some time or maybe some practical experiences.

I mean when you throw doubling at me, I come right back to you and say, hey, wait a minute, that doesn't sound quite right. And that's why I asked you this kind of question.

Ms. FITZPATRICK. We do do cost shifting.

Senator DURENBERGER. There is a problem. I would like to get the dimension of it, though.

Ms. FITZPATRICK. You mentioned one of the things that we do and that is cost shifting to private industry. We shift the cost of what it actually costs us because private industry will pay what our costs actually are. So, in effect, not only are our philanthropic dollars supporting the Medicare system, but so is the private industry.

Senator DURENBERGER. Do you want to put any dimension to that?

Mr. MAHONEY. Well, Senator, in our program we were in the similar situation to Carolyn. We had already started the process by the time that we knew what the final rates were going to be. And my board decided that we had already started the process, that we had been a demonstration project, and we would continue on serving in that manner.

At the present time, the reason that we stay as a certified hospice program is basically because, number one, it is a good program. It is a good program for those people receiving care. It is not a good program for the provider. We stay because it's a good program for the person receiving our care.

The second thing is that we have philanthropic dollars that we are diverting into this program. Our largest and most stable foundation source has said that they would support us in that manner this year simply because they felt that there was a good chance that we would have an opportunity to come back to the Congress and do something about the rates. They have made it very clear that they will not continue that support. And without that kind of support, then I don't know what we will do. We will probably end up decertifying at some point.

You are right. We can't lose money year in and year out like that.

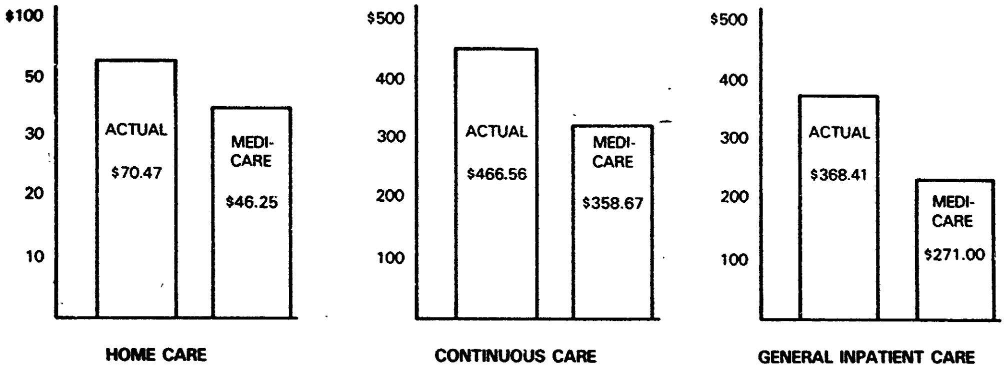
Senator DURENBERGER. Senator Heinz said, when he was asking questions, that you were going to have some new rate proposal to present to that. Is that incorporated in your written statements?

Ms. FITZPATRICK. We have, which I will submit for the record, the actual cost of providing care as of last week. And those are the rates that we would submit for the record, which are our costs. These are developed along the same cost reporting system that the Health Care Financing Administration—you heard about this morning. They are developing that cost report. It has taken them a year and a half now to do that. We put something together at the National Hospice Organization and had our Medicare certified hospice programs fill it out last week. And they helped us determine what the actual cost was.

[The information from Ms. Fitzpatrick follows:]

FITZPATRICK TESTIMONY

ACTUAL COSTS OF PROVIDING HOSPICE CARE VS. MEDICARE PAYMENT RATES SEPTEMBER 1984*

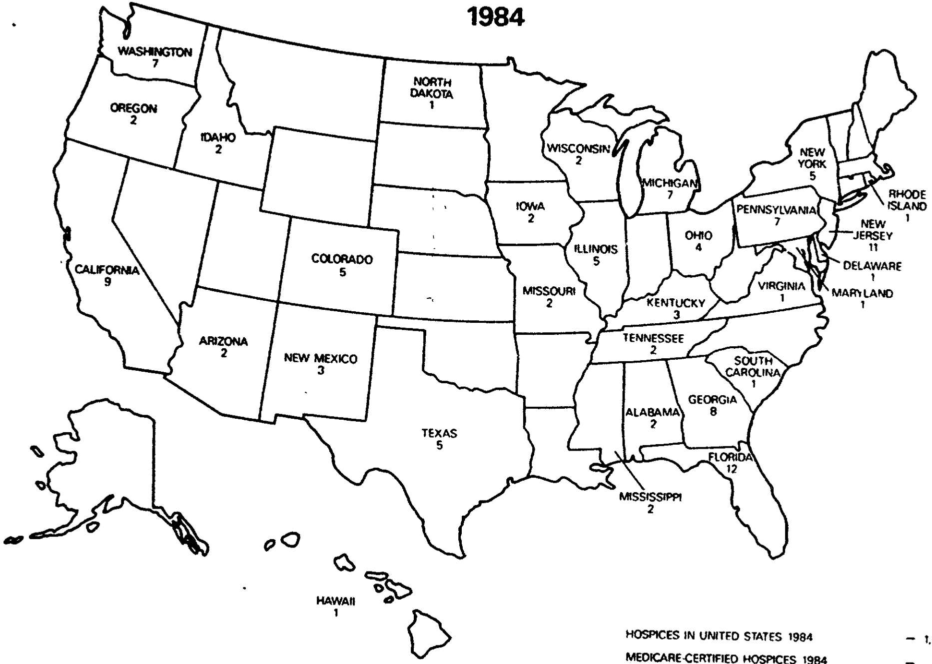


*RESPITE CARE RATE – INSUFFICIENT DATA AVAILABLE DUE TO LACK OF UTILIZATION

SOURCE: NATIONAL HOSPICE ORGANIZATION SURVEY OF MEDICARE-CERTIFIED HOSPICES, SEPTEMBER 1984

FITZPATRICK [illegible]

MEDICARE-CERTIFIED HOSPICES IN THE UNITED STATES 1984



HOSPICES IN UNITED STATES 1984	— 1,500
MEDICARE-CERTIFIED HOSPICES 1984 (AS OF SEPTEMBER 7)	— 119
STATES WITH NO MEDICARE CERTIFIED HOSPICES	— 20

NHO
National Hospice Organization

9/5/84

COST SURVEY
MEDICARE CERTIFIED HOSPICE PROVIDERS

Name of Provider ______________________________

City, State ______________________________

Date Certified ______________________________

Time Period Covered by this Report ____________________

Costs Per Patient Day from Worksheet A[1]

Routine Home Care	$__________
Continuous Home Care	$________ per day $__________ per hour
General Inpatient Care	$__________
Respite Inpatient Care	$__________

What did you include as Inpatient Costs?

. the actual cost of services provided	__________
. usual and customary charges	__________
. discounted charges to you	__________

Number of Medicare Hospice Patients Served to Date	__________
Average Length of Stay of Medicare Hospice Patients to Date	__________

1/ If no objection, please return Worksheet A to us with this form.

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9/5/84

Guidelines for Cost Analysis (Exhibit A)

A. Direct Cost (col. 1) - The direct cost for each distinctive service (i.e., home nursing services, medical social services, counseling, etc.) should be captured. For purposes of this analysis, routine and continuous home care costs are commingled and will be segregated later.

The direct cost of bereavement services and billable physician services should be identified but not included in subsequent calculations in determining Medicare costs.

Costs incurred with a related organization should reflect the actual costs for the services provided (not the amount charged by the related party). If services from an unrelated organization are received at a discount (such as inpatient hospitalization at the Medicare reimbursement rates), then it is suggested that such costs be grossed up to the usual and customary charge (or cost, if known) of the contracting organization to reflect true costs rather than a deflated cost.

B. Indirect Cost (col. 2) - The indirect cost of providing patient care services should be identified and allocated on a reasonable basis. Those familiar with the "stepdown" method should use it to allocate the indirect cost of the general service cost centers. Exhibit B with its guidelines provides a means to allocate such costs if assistance is necessary.

C. Total Cost (col. 3) - The sum of direct and indirect cost (col. 1 + 2).

D. Units of Service (cols. 4 and 5) - This data represents the statistical units for each distinctly identified service applicable to all patients. Recommended units are suggested similar to those used by the Medicare program.

E. Unit Cost (col. 6) - Total cost divided by units of service (col. 3 ÷ 4).

F. Medicare Hospice Units of Service - Data comparable to item D above but only as it relates to units applicable to Medicare hospice patients electing the new Medicare benefit.

G. Medicare Hospice Cost - Unit cost multiplied by Medicare units of service (col. 6 x 7).

H. Distribution of Medicare Cost - A method is necessary to distribute the Medicare cost which is applicable to the four units of care for which reimbursement is given (i.e., routine care, continuous care, general inpatient, and inpatient respite). At this point in time, it may be difficult to identify home care routine cost versus home care continuous cost. Therefore, it is suggested that home care nursing costs be distributed to routine and continuous care levels based upon the number of nursing hours of care rendered. All other home care costs can be distributed based upon the proportion of routine and continuous care days to total days by those levels of care, unless a more discreet cost finding methodology is available.

I. The final step is to accumulate the Medicare costs attributable to each care level and to divide this cost by the number of Medicare days for each of these care levels. For continuous care, also compute the cost on an hourly basis using the actual number of continuous care hours provided. It is important to note that the units by care level should cover the same time period as costs, even though the services may not have been billed to the Medicare intermediary. The result will thus be the actual cost per day for each of the four reimbursement categories.

9/4/84

MEDICARE COST ANALYSIS BY LEVEL OF CARE
Exhibit A

Cost Center	1 Direct Cost	2 Indirect Cost	3 (1+2) Total Cost	4 Units of Service: # for All Patients	5 Units of Service: Recommended Unit	6 Cost/Unit (3÷4)	7 Medicare Hospice Units	8 Medicare Hospice Cost	9 Distribution of Medicare Cost: Home Care: Routine	10 Distribution of Medicare Cost: Home Care: Continuous	11 Distribution of Medicare Cost: Inpatient: General	12 Distribution of Medicare Cost: Inpatient: Respite
Home Care												
Nursing - Intermittent					Hours							
Nursing - Shift					Hours							
Home Health Aide					Hours							
Physical Therapy					Visits							
Occupational Therapy					Visits							
Speech Pathology					Visits							
Homemaker Services					Hours							
Social Services					Visits							
Nutritionist Services					Visits							
Counseling					Visits							
Drugs/Biologicals					Charges							
Medical Appliances					Charges							
Supplies					Charges							
Other Ancillary					Charges							
Inpatient Care - General												
Routine					Days							
Drugs/Biologicals					Charges							
Supplies					Charges							
Other Ancillary					Charges							
Inpatient Care - Respite												
Routine					Days							
Drugs/Biologicals					Charges							
Supplies					Charges							
Other Ancillary					Charges							
Non-Inclusive												
Bereavement					N/A							
Physician fees												

TOTAL COST
DAYS (Home and Continuous)
COST/DAY (days)

DAYS | # HRS
Cost/DAY | Cost/Hour

9/5/84

Guidelines for Cost Allocation (Exhibit B)

Introduction

As a supplement to the cost analysis, Exhibit B allows for the allocation of what is considered to be the 5 typical general service cost centers. The purpose of this allocation is to distribute the indirect cost (i.e., not directly identifiable to a specific type of patient care treatment) to the patient care modalities which derive a benefit from the incurrence of the general service cost.

Cost Allocation

A. Direct Cost (col. 1) - The direct cost for each general service cost center and distinct patient service. This is a repeat of column 1 on Exhibit A.

B. Depreciation - Building (cols. 2 and 3) - The worksheet is structured to reflect the statistics for the allocation of building depreciation expense and the actual allocation of this cost in adjacent columns. Column 2 should reflect the square footage of all areas occupying space. The total square footage is then divided into the total cost to be allocated and the resulting unit cost multiplier (ucm) is applied to the various individual cost centers' statistic. This will yield that particular cost center's share of building depreciation expense.

C. Depreciation-MME - Similar methodology as above.

D. Operation of Plant - Similar to above except that costs to be allocated should include both direct operation of plant expenses and any indirect expenses allocated to it. The ucm is then computed and the "full" cost of this general service cost center is allocated. As a reminder, once a general service cost center is stepped-down, it is considered closed and no further indirect cost is allocated to it.

E. Admin. and General - Similar to above. The statistic normally used to allocate A and G is accumulated cost. Accumulated cost would be the sum of direct cost for all cost centers plus any allocated indirect cost.

F. Dietary - Similar to D above.

G. Once all general service costs have been distributed, the total indirect costs can be compiled by patient care service (col. 13). As a check, the sum of indirect costs tallied in column 13 should equal the sum of the direct cost for the 5 general service cost centers. The indirect cost thus derived can be forwarded to column 2 of Exhibit A.

1/-/84

GENERAL SERVICE COST ALLOCATION

Exhibit E

	1	2	3	4	5	6	7	8	9	10	11	12	13
		Depreciation Bldg.		Depreciation - MME		Operation of Plant		A + G		Dietary			
COST CENTER	Direct Costs	Stat Basis (Sq. Footage)	Cost Allocation	Stat. (Sq Ft or $ Value)	Cost Allocation	Stat. (Sq FT)	Cost Allocation	Stat (Accum Cost)	Cost Allo	Stat (# Meals)	Cost Allo.		TOTAL INDIRECT COSTS
GENERAL			ucm		ucm		ucm		ucm		ucm		(col. 3+5+7+9)
Depreciation - Building													
Depreciation MME													
Operation of Plant													
Admin. & General													
Dietary													
HOME CARE													
Nursing: intermittent													
Nursing: shift													
Home Health Aide													
Physical Therapy													
Occupational Therapy													
Speech Pathology													
Homemaker Services													
Social Services													
Nutritionist Services													
Counseling													
Drugs & Biologicals													
Medical Appliances													
Supplies													
Other													
INPATIENT CARE - GENERAL													
Routine													
Drugs & Biologicals													
Supplies													
Other													
INPATIENT CARE - RESPITE													
Routine													
Drugs & Biologicals													
Supplies													
Other													
NON-INCLUSIVE													
Bereavement													
Physician													

TOTAL

Senator DURENBERGER. But what I see up there are totals. I take it that in your actual recommendation that you are going to lay on the record today that you will deal with some of the problems of service limitations and those caps that we have built into the program.

Ms. FITZPATRICK. Senator, those things are not as much a problem, I believe, as the administration would like us to believe. Those of us who are providing the care every day to terminally ill patients and families do not find the cap, for instance, to be a detriment in any way. The cap is an aggregate cap. And our hospice program has not come within $3,000 of that cap since November of last year. The cap is really not an issue.

Senator DURENBERGER. And your problem—and I didn't state this well—is like the per diem. Jay, you indicated in your testimony, it just isn't 70 days. It's the average of 28 in your case. It's 27 or something like that for someone else. That means that the per capita costs for a shorter stay average are going to be higher than the per capita cost for——

Mr. MAHONEY. Exactly, Senator. And I think that there are reasons for that too. The demonstration project and the Medicare benefit are two different things. And they are not comparable across the board the way we have been doing. I think very clearly the idea of a waiver and the idea of physician certification has done a lot to influence the people and the time the people get into the Medicare hospice benefits. Those are things we didn't have under the demonstration projects. I think we had much longer lengths of stay in the demonstration project.

Ms. FITZPATRICK. You asked Dr. Davis about the average length of stay of the Medicare certified hospice programs. That's one of the questions we asked last week on our survey. The average length of stay for Medicare certified hospice patients is 29 days.

Senator DURENBERGER. The American Psychological Association will testify that psychological services may be precluded from some hospice programs. What are your thoughts on this matter, and does the NHO support the inclusion of such services? How important are they?

Ms. FITZPATRICK. I'm not certain that I understand how or why psychological services are excluded. Our hospice program utilizes psychological counseling both in bereavement care and prior to the death of the patient; whenever it is indicated. There is no restriction that I know of, that I'm aware of. The National Hospice Organization is very supportive of the utilization of all kinds of services that will benefit the terminally ill patients.

Senator DURENBERGER. Can any of you describe for us the difficulty with meeting some of the core service requirements?

Ms. FITZPATRICK. We did not have a difficulty meeting the core service requirements. We initially contracted with a nursing agency prior to becoming Medicare certified, and it was not a problem. Nurses want to work for hospice programs.

Senator DURENBERGER. I asked the previous witness about the 20-percent limit on inpatient days. Has that been a problem?

Mr. MAHONEY. We have our own inpatient unit, and we run right—right now we are running at around 90-10 for the 80-20 question. It is now a problem for us. And we haven't had any difficulty establishing contractual relationships with hospitals. They have been very cooperative with us.

Senator **DURENBERGER**. What has your experience been with the cost sharing requirements? Anybody have adverse experiences with cost sharing requirements?

Ms. **FITZPATRICK**. We have had since November a contractual arrangement. We do not have our own inpatient unit. We contract for services. It's an unusual arrangement, to be sure, for the hospital, especially in the beginning when they were developing the arrangement. But it has worked out very, very positively for both the hospital staff and the hospice staff in our case. And there are 119 other programs who have managed to create this sort of arrangement. The best thing about it is it's good for the patients because the patient has the continuity of care that everybody really wants.

Senator **DURENBERGER**. What about relating to the election or revocation of hospice benefits? The final regulations permit the family to make the election where the beneficiary is unable, if that is permitted by State law. Are you aware of any difficulties with that provision in the regulation?

Mr. **MAHONEY**. In Boulder County we haven't had any difficulty. I would be hard pressed to say all hospice programs have had the same experience, but we haven't had any problem in Boulder.

Senator **DURENBERGER**. Can one of you briefly tell me something I probably should know the answer to and that is why did we get a 70-day average length of stay out of the demonstration when the reality is 29? There is probably a very obvious answer that I have missed somehow or another.

Mr. **MAHONEY**. Well, again, Boulder County Hospice was a demonstration project. And I think there are two reasons why we had a 70-day length of stay. And our average length of stay was a little under that. But I think there are two reasons for it. No. 1, people are having to sign a waiver now. They are having to waive their other Medicare benefits. Under the demonstration project, they did not have to waive any other Medicare benefits. So the people are thinking twice about that. That concerns them. It's a system that they are used to. And when someone comes in and says, "We are going to give you these benefits," and although these are better benefits perhaps, they have a certain sense of, well, I know what my other stuff is and so there is a little bit of reluctance to sign away those other Medicare benefits.

I think the other thing is that the physician certification of a terminal illness with a prognosis of 6 months—that's another thing that we did not have under the demonstration project. I think that there is a certain reluctance on the part of physicians to sign that right now. They are being a little bit more cautious than what it was before. They didn't have to sign it so there was no reason to sign it. Now they have to sign something. And I think that is reducing—they are putting the people into the hospices a little later because they want to make absolutely sure.

Senator **DURENBERGER**. So if we found a way to solve the election problem, and the physician prognosis problem, are you saying, then, that we would get back to approximately a 70-day average, and you would be satisfied with the $46, or whatever it is?

Mr. **Mahoney**. I'm saying that those are the reasons that I have identified.

Senator **Durenberger**. This is your personal experience?

Mr. **Mahoney**. It's my personal. Looking at the differences between the demonstration project and the——

Senator **Durenberger**. Well, this is a pretty important question. And maybe the organization can give a little effort in trying to come up with some of the answers because, in effect, if we have changed the nature of hospice with the election possibly, with some of these other things, and—I wonder if that was appropriate.

Ms. **Fitzpatrick**. Senator, it took the demonstration projects 2 to 3 years to have average lengths of stay of 70 days. If in 2 to 3 years we find that hospice programs have average lengths of stay or Medicare certified programs of 70 days, then the $46 may well be the appropriate dollar amount.

Senator **Durenberger**. Once we go up, we never go down.

Ms. **Fitzpatrick**. We are willing to go with real costs and with actual data.

Ms. **McKenna**. Having never been a demonstration project, but having been a hospice for 5 years, our average length of stay has never been higher than 45 days in the 5 years that we have served hospice patients. So I found that number to be a bit out of the range of what our hospice has experienced.

Senator **Durenberger**. That's interesting.

All right. I thank you all very much for your testimony. I appreciate it a great deal. And I guess I have raised a couple of questions that we might need a little help in answering as we go on.

Ms. **Fitzpatrick**. We will be glad to provide you with some additional data.

Senator **Durenberger**. Thank you very much.

The final panel consists of three witnesses: Hugh Westbrook, President of Hospice Care, Inc., of Miami, FL, on behalf of Hospice Care of Delaware, Inc.; Dr. William Liss-Levinson, director of the Brooklyn Hospice, New York, on behalf of the American Psychological Association; and Anne Katterhagen, executive director of the Hospice of Tacoma, Tacoma, WA, on behalf of the National Association for Home Care, Washington, DC.

I thank all three of you for your patience and your willingness to be here. And we will include your printed statements in full in the record. And you may proceed to summarize it.

If you are willing to go in the order you were introduced, go ahead. Mr. Westbrook.

STATEMENT OF REV. HUGH WESTBROOK, PRESIDENT OF HOSPICE CARE, INC., MIAMI, FL, ON BEHALF OF HOSPICE CARE OF DELAWARE, INC.

Reverend **Westbrook**. Thank you, Senator. I did submit an additional written piece of testimony this morning that I would ask be included in the testimony which I am giving.

Senator **Durenberger**. It will be made part of the record. Thank you.

[The additional information from Reverend Westbrook follows:]

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"SAVING THE MEDICARE HOSPICE BENEFIT FROM CERTAIN FAILURE"

Testimony and Recommendations to the Health Subcommittee of
The U. S. Senate Finance Committee

September 17, 1984

Hugh A. Westbrook, President of Hospice Care, Inc.

I am Hugh Westbrook, President and Chief Executive Officer of Hospice Care, Incorporated, a privately owned proprietary organization founded for the purpose of establishing and operating hospice programs of care of the highest quality in communities with significant unmet need for hospice services.

We currently operate three comprehensive home care and inpatient hospices - two of which we manage for nonprofit community organizations, in Miami, Florida, and Fort Lauderdale, Florida, and one which we both own and operate in Dallas, Texas. All three of the hospices we operate are certified for participation in the Medicare program under the terms of the National Hospice Reimbursement Act.

I have devoted myself to the development and delivery of hospice care since 1977, when I joined with concerned nurses, clergy, physicians, and others to found Hospice of Miami. We worked as volunteers for at least the first year. People gave up paying jobs to work for no pay to care for dying patients and their families. We operated out of a local church.

Eight years later, the first volunteer we ever recruited is still with us volunteering his time. The first professional caregiver we hired is still with us. The family of the first patient we cared for back in 1977 now helps us take care of other families in 1984. We didn't charge that family anything for the care we provided. They should have charged us because they taught us so much.

*. . . a family of caring
caring for families all over . . .*

There's never been a time since 1977 when there haven't been two or three times as many unpaid volunteers working in our organization as paid staff. That's the case today, as well, in Miami, Fort Lauderdale, and Dallas. There's never been a time since 1977 when we have turned away anyone because they couldn't pay. That's the case today, as well, in the three hospices we operate. I know something about struggling, volunteer-intensive hospices with high ideals and hard cases. I know something about the grass roots of the hospice movement. I am a hospice grass root.

Members of Congress know and their staffs know that I was among those who insisted that the Medicare Hospice Benefit reflect high ideals and require of hospices high performance, including, for instance, three requirements not asked of home health agencies, hospitals, and nursing homes:

(1) That to be a Medicare-certified hospice, one must sustain volunteer involvement in all aspects of the hospice program and not diminish volunteer intensity with the availability of Medicare payments;

(2) That to be a Medicare-certified hospice, one must not dump patients whose ability to pay has run out;

(3) That to be a Medicare-certified hospice, one must provide bereavement care and counseling to hospice families after the patient has died even though the Congress decided not to reimburse for bereavement care.

In some cases, I don't think the Congress or the Administration went far enough in assuring the integrity of the hospice concept in structuring the conditions of participation and the requirements for Medicare certification.

However, the Administration took another course. Instead of focusing on preventing "bad" providers, the Administration's reimbursement policy and rates have had the effect of preventing many of the best hospices in America from participating in this benefit.

<u>The Medicare Hospice Benefit is failing to fulfill the intent of Congress or the needs of the hospice movement</u>:

(1) <u>Only 119 of the nation's 1,500 hospices are certified to provide the Medicare Hospice Benefit</u>. This level of participation is less than half of the lowest, most conservative estimate ever given by the Administration - even after the Administration's most recent round of rate cuts. Even OMB Director David Stockman was willing to "let in" more than 119 hospices.

(2) Only 1,280 terminally ill Medicare beneficiaries have accessed the Medicare Hospice Benefit from its inception through mid-August. This level of utilization fulfills less than one-half of one percent of the hospice need among Medicare-eligibles in 1984. Current utilization, even annualized, is approximately 95 percent lower than the lowest, most conservative estimates ever given by the Administration - even after the Administration reduced the home care rate to $46.25. Even OMB Director David Stockman was willing to "let in" 31,000 hospice patients the first year.

(3) Data collected by the federal government, itself, as well as by home health trade groups and hospice organizations universally indicates that the low routine home care rate is the single most troublesome disincentive to participation by hospices and, hence, utilization by patients.

(4) The application of significant economies of scale, efficient operational management, and adequate private capitalization of "start-up" or "expansion" costs cannot bridge the gap between the costs of providing hospice care under Medicare and the daily rates of reimbursement paid by Medicare for those hospices with an average daily census of 70 or fewer patients. Given the self-limiting factors otherwise built into the Medicare Hospice Benefit, there will be no more than 100 Medicare-certified hospices in the United States who can be financially viable under the existing daily rates.

(5) If the routine home care rate is not increased (together with the application of managerial efficiency and the continuance of at least the current level of private support for hospice care), the few Medicare-certified hospices that survive will, more and more, have the following attributes:

- mostly suburban, where a significant "able to pay," non-Medicare patient population can be found and "cost-shifted" upon;

- mostly based in hospitals or very large home health agencies, where double and triple Medicare certification will allow the shifting of patients back and forth and the controlled management of the timing of hospice admissions in order to maximize reimbursement (or located under circumstances where the hospice, itself, can be triply certified as a hospice, a hospital, a home health agency, and perhaps quadruply certified, also, as an SFN);

- *nearly all located in more-affluent-than-average communities*, where larger-than-average philanthropic revenues can be generated on a continuing basis;

- *increasingly subject to conscious or unconscious "screening out" of Medicare patients with complex physical and emotional needs* requiring an intensity of service affordable at the Medicare home care rates. (Ironically, it is the care of such complex patients by hospices upon which the substitution/cost savings justification of the Medicare Hospice Benefit is based. It is predictable that the "screening out" of complex patients as candidates for hospice home care will be accompanied by more aggressive demands for a liberalization of the 80/20 home care/inpatient ratio on the part of hospitals, thus further eroding the substitution/cost savings potential of hospice.)

- *likely to be features or sub-functions of chain operations or venture schemes*, such as Hospital Home Care of California or hospice-specific companies such as our own;

- *nearly exclusively in the nation's largest metropolitan areas*, where there is a large enough pool of potential hospice users to make a 70-patient average daily census a comparatively easy and rapidly obtained objective.

While the Congress may have no objection to the operation of hospices such as those aforedescribed, *it is, to us, an unintended and alarming public policy which seems to find nothing wrong with discriminating against hospices which have the following attributes*:

- *serving a higher-than-average proportion of the old and the poor*, including the "under-insured" patient such as the dying child;

- *located in the inner cities or the rural areas*, both of which have proportionately fewer "able to pay" non-Medicare, employer-employee paid private insurance patients upon which to "cost-shift;"

- *accepting patients irrespective of inability to pay*;

- *accepting patients requiring high-intensity services* and then providing those services in the home instead of relying heavily upon institutionalization of "hard cases;"

- seeing substitution for hospital care as part of their mission;

- are either small, community-based organizations existing only as hospices or are subunits of other small providers;

- existing under circumstances or in localities (such as Florida) where regulations protective to other providers result in HCFA denying hospices certification as home health agencies and hospitals, thus denying them more than one reimbursement vehicle;

- using virtually all revenues from all sources in order to provide care and having neither the inclination nor fiscal ability to divert patient care funds to finance Medicare receivables resulting from slow Medicare Hospice Intermediary payment performance;

- operating in communities or under conditions which are highly unlikely to generate an average daily hospice census of 70 or more. (Alone, this financial break-even point means that the Medicare Hospice Benefit can never be available in more than three-fourths of the nation's towns and cities and never in a fourth of the nation's fifty states.)

The fact that a provider with the first set of attributes can be viable and that a provider with the second set of attributes cannot be viable under the current rate structure does not comport with the motivations of those who drafted and gained passage of this Benefit nor the intentions of those in the Congress who worked and voted for this Benefit.

(6) HCFA has so convincingly demonstrated its inadequacies in planning for, implementing, and evaluating this Benefit that a reasonable person would be forced to conclude that HCFA, by itself, is either unable to unwilling to save the Medicare Hospice Benefit from the certain failure toward which it is heading pell-mell.

- The mysterious "new" data which HCFA used to justify slashing the routine home care rate turned out to be an artificially long (70 days-plus) length of stay in a Demonstration Project which induced artificially long stays because patients were not required to substitute hospice for traditional care, but were permitted to add it as a "topping."

- The real world of the Medicare Hospice Benefit indicates, as we told HCFA it would, a length of stay less than half of that experienced in the Demonstration Project. The real world of the Medicare Hospice Benefit shows, as HCFA denied it would, a significant gap between the costs of care and the payments for care due to the combination of length of stay and intensity of care.

  Did HCFA know that the Demonstration Project was inapplicable and apply it anyway - or did HCFA not know and apply it anyway?

- The closely held but fervently advocated budget calculations HCFA used to justify its testimony to press, public, and Congress that hospice would cost instead of save money turned out to be a scare story to hold down rates. One year ago this week, Dr. Carolyne Davis told this Subcommittee that the Medicare Hospice Benefit would cost the federal government $80 million in 1984 - that's not payments to hospices, that's net cost after accounting for all substitutions and cost-savings effects.

  The real world of the Medicare Hospice Benefit indicates, in stark contrast to HCFA's budget estimates, total payments to hospices, as of 45 days from the end of the fiscal year, of less than $2,500,000.

  If all of the payments made to hospices represented 100 percent cost add-ons, if all of the patients who have made Medicare Hospice Elections would have simply vanished from sight and not otherwise accounted for one single day in the hospital or one single visit by a home health agency, HCFA still turns out to be 3,000 percent wrong in estimating the impact of this Benefit on the Medicare Trust Fund.

  In order to make the budget estimates of HCFA's actuaries actually come true in 1984, HCFA would have had to spend $53,000 on each patient making a Medicare Hospice Election. Now, we hospices have received something less than $3,000.

  Did HCFA know that their budget projections were wildly off course, but use them anyway - or did HCFA not know and use them anyway?

- The commitment made to the hospice movement and to this Subcommittee that HCFA would obtain cost data from all participating hospices, and then review the adequacy of rates, turned out to be a way to change the subject and counsel inaction and more studies when Members of Congress wanted to stop HCFA from cutting the home care rate below what even HCFA's own data showed to be the minimum costs of providing care.

  In the real world of the Medicare Hospice Benefit, not only hasn't HCFA collected cost data from all hospices, HCFA has collected cost data from no hospices. Our continuous requests for action on cost collection - or even for dialogue on a cost collection and evaluation methodology - have been met with a wall of silence fronted by a swampland of lethargy. The fact is that a cost reporting methodology hasn't even been cleared by OMB yet. The fact is that if the process finally began today, it's already too late to collect even one year's worth of data, maybe not even three-quarters of data, in time for the Congress to consider the extension of the Medicare Hospice Benefit in 1986, if that extension is to be based on the Secretary's report, mandated by law to be delivered to the Congress on January 1, 1986.

  Does HCFA know that it is leading the Congress and the hospice movement into another blind alley and doing it anyway - or do they not know what they are doing and doing it anyway?

In planning for, implementing, and evaluating the Medicare Hospice Benefit - in mis-applying the Demonstration Project data, mis-figuring the budget implications, and just plain missing the opportunity and the mandate to collect real-world costs - in its whole approach to hospice, is HCFA malevolent or is HCFA ignorant? In either case, the result will be failure in fulfilling the intent of the Congress and the needs of the hospice movement.

The Hospice Care, Inc., experience in this current situation:

We started Hospice Care, Inc., the proprietary company, for the same reason that eight years ago we worked in the church basement to start Hospice of Miami, the community charity: to assure that dying people have a choice between institutionalization, on the one hand, and being with their own families, on the other - between the expensive cycle of the hospital and the home health agency, on the one hand, and the less costly system of hospice, on the other - between generalized care, including inappropriate and unhelpful use of curative therapies which will neither lengthen life nor improve its quality, and specialized care, which focuses competently on controlling successfully the noxious symptoms that make living with a terminal illness so unendurable.

For us, the auspice of the hospice - community charity or proprietary company - is simply a way to do hospice care, the vehicle at hand with which to practically satisfy our original motivations. Hospice Care, Inc. is not a group of business people who went into hospice; it's a group of hospice people who went into business because going into business was a way to find the dollars to develop hospices in order to render care.

Unlike the home health agency, whose start-up and build-up costs can be amortized over five years and recaptured from the federal government in cost-based reimbursement, the hospice of whatever auspice must capitalize itself with private dollars from some source.

Unlike the cost-based home health agency, which can use higher levels of government reimbursement in the beginning in order to finance its development in meeting conditions of participation, the hospice must be financially viable based on its own operations from the very beginning.

We have been the route of obtaining loans from financial institutions to finance the significant front-loaded expenses required in order to be what a hospice should be and what Medicare requires it to be. But there's a limit to the ability of hospice people to collateralize loans on their personal signatures. And, due to a technicality in Medicare regulations, a Medicare provider cannot truly assign its receivables as collateral. A Medicare receivable cannot be "factored" in the fashion banks require. For a cost-based home health agency able to amortize its start-up and developmental expenses over five years and get the federal government to capitalize the business, the inability to factor Medicare receivables is less of a survival issue than for the hospice, which is paid a flat per diem irrespective of costs.

So we went to Wall Street.

Wall Street, we found, is a little different than the church basement.

But there are some similarities between Wall Street investors, private foundations, and commercial bankers. They all want their money to go to groups who have a reasonable chance of financial viability.

To that extent, when I face my stockholders, I share the same burden of viability carried by my colleagues who run hospices just like ours but under different auspices.

Mr. Chairman, we did not expect the federal government to capitalize our operations. We did not expect the federal government to pay the difference between what it cost to render care in a start-up period and the costs of rendering care at the point the hospice performed in a financially viable fashion. We found the money to accomplish those objectives by going to Wall Street.

We did expect the Health Care Financing Administration and its Fiscal Intermediaries to review our billings efficiently, pay us promptly, and reimburse us at a level that would result, at some point, in our Medicare revenues being equal to our Medicare costs. I would think that in those expectations we are joined by any hospice of whatever auspice.

However, those expectations have not been fulfilled. Therefore, the circumstances under which the operations of a Medicare-certified hospice can be financially viable are extremely and rigidly limited.

Our experience, as opposed to our expectations, has been as follows:

> The first four months of operation of Dallas Hospice Care, from April through July of 1984, show the realities faced by a new hospice in trying to reach financial viability under the existing home care rate.

In those first four months of operation as a Medicare-certified hospice, our Dallas organization cared for more than 50 patients, of which 26 were Medicare Hospice Election patients who died during the four-month period.

Of those 26 Medicare patients who died between April and July 31, all received routine hospice home care, two received hospice inpatient care, and four received hospice continuous care. None received inpatient respite care.

The average length of stay for those patients was not 60 days but 19 days. Those patients who used inpatient care utilized an average inpatient length of stay of three days. Of those patients who used continuous care, the average utilization was 38 hours which, given HCFA's methodology, converts to 2.5 days of continuous care per patient.

Put another way, the Medicare patients who had died by July 31 were cared for 97 percent with routine home care, 2 percent with continuous care, and 1 percent with inpatient care.

The total amount charged to Medicare for the care rendered to these patients was $27,769.04 for an average cost to Medicare per hospice case of $1,068.04.

Ninety percent of these patients died at home. Ten percent died in inpatient care.

However, the costs to us for providing that care exceeded, by multiples, the amount charged to Medicare. In our case, the difference was made up by private money we had obtained. The hospice without our financial resources would have probably gone out of business even with massive infusions of charitable income and massive cost-shifting to non-Medicare payment sources.

In other words, the community-based charitable organization that wanted to start a hospice to meet the needs of patients and families in a community would not be in business today if it tried to provide the mandated and covered services for the existing rates. Perhaps that is why, to our knowledge, the only new hospice which has been certified by Medicare has been Dallas Hospice Care, owned and operated by a proprietary organization.

The problems associated with converting an existing hospice, even one which had been reimbursed under HCFA's Demonstration Project, to the Medicare Benefit are dramatically exacerbated by the low payment rates for home care. As I testified, Hospice, Inc. in Miami and Hospice, Inc. in Fort Lauderdale had to turn to us for $400,000 in borrowed money. Half of the borrowing needs resulted from HCFA's contorted, confused, and lethargic payment and medical review process. Half of the borrowing needs represented the difference between the costs of providing the Medicare-covered services and the reimbursement rates. Because Hospice, Inc. in Miami is 88 percent home care and Hospice, Inc. in Fort Lauderdale is 90 percent home care, that borrowing was really necessitated by the too-low home care rate.

Of the 119 hospices certified to provide the Medicare Hospice Benefit, not one does not subsidize the cost of caring for Medicare patients by diverting other money. In our case, we have the advantage of long-term capital investment. Therefore, we are diverting money intended to be used to open additional hospices in order to support our three existing programs. But that's our problem. The real problem is that nearly all of the rest of the 119 hospices are diverting charitable contributions intended for the care of poor people, including the care of under-insured patients like dying children, to subsidize Medicare. One of the long-term effects of the low Medicare home care per diems is that hospices will be forced to cost-shift onto non-Medicare patients whose bills are being paid by America's employers and America's unions.

The result is that the Medicare Hospice Benefit is a failure for America's hospices and America's terminally ill.

The only hospices which can be viable will be chain operations or venture schemes. The only people rendering hospice care will be those who can afford to wait for four to five years for a break-even point. The only communities where Medicare-covered hospice care will be available will be those which can support extremely high average daily censuses.

Frankly, Mr. Chairman, our analysis indicates that unless the home care rate is raised, and assuming about a third of the terminally ill need and want hospice care under Medicare and assuming the census it will take to be viable, fewer than 100 communities in America will have Medicare-certified, financially viable hospices ever. None of those communities will be in rural America.

This Subcommittee, in its wisdom, recently developed and assured the enactment of a waiver provision whereby hospices in rural areas wouldn't have to comply with the core services requirement. Somebody convinced you that core services compliance was the barrier to hospice delivery in rural America. I point out respectfully that, although the waiver provision is now law, not one rural hospice has applied for a waiver. The problem in rural America is the same as in urban America when it comes to access to the Medicare Hospice Benefit. The problem is that the home care rate is so low that a hospice, supported by either charity or by private investment, can't be viable in rural America.

<u>The Congress must act now and in specific terms to save the Medicare Hospice Benefit from certain failure</u>:

(A) <u>The routine home care rate should be immediately raised</u> to the level which would allow the typical American hospice, which meets the conditions of participation, to become Medicare-certified.

A survey of those hospices who do meet the conditions and who have been certified indicates that <u>the real cost of providing the covered services is $70.47 per day</u> for routine hospice home care. The $70.47 is not a number concocted from extrapolated calculations of what might be and what could be. It is the real-world cost now being experienced by Medicare-certified hospices.

The $70.47 routine home care cost does <u>not</u> represent or include start-up costs. Of the 119 hospices certified by Medicare, all but three were started earlier than 1983. In other words, after a hospice is already operational and after a hospice has already met the conditions of participation, it costs $70.47 a day to provide routine home care.

In theory, HCFA should have been collecting these costs and, as promised to this Subcommittee one year ago by Dr. Davis, HCFA should be adjusting the rates to reflect real costs. In the real world, HCFA isn't collecting costs and HCFA won't, by itself, fix this single greatest disincentive to the workability of the Medicare Hospice Benefit.

Therefore, in the same real world in which the Congress had to act to set the aggregate cap in law at $6,500, Congress, itself, must act legislatively to set the home care rate.

(B) The per diem rate system, if it is to be retained now and after 1986, must be able to be indexed to provide comparatively more reimbursement to those hospices which are small, poor, and independent and comparatively less reimbursement to those hospices which are larger, richer, and more able to take advantage of economies of scale and affiliations among and with other providers. Let there be discrimination among hospices on the basis of their meeting the conditions of participation, not on the basis of their inability to cost-shift to the private sector or on the basis of their favorable demographic or economic location.

If not now, the Congress must mandate that in 1986 the implementation of the Benefit and the setting of rates be exorcised of this current perverse discrimination and that the vast majority of American hospices be given a level playing field. Today, only 3 percent of certified hospices have average daily censuses of 60 patients or more at home. To compete fairly and even to exist viably, the other 97 percent should receive a higher level of reimbursement.

If the Congress, itself, does not mandate that proposals for prospectively set rates include "fairness indexing," then I fear that any data the Congress ever receives from HCFA and any rate-setting HCFA ever does will be based on "high averages" that will be almost impossible for providers like me to achieve and truly impossible for the typical provider to achieve.

(C) A prospective interim payment (PIP) system should be immediately established to ease cash-flow crises caused by the confusion, misunderstanding, and slow payment performance of HCFA's chosen intermediaries. The Congress should require HCFA to demonstrate that its Hospice Intermediary system works efficiently enough to obviate the need for a PIP system instead of requiring hospices to finance Medicare receivables at high interest rates, thus diverting funds to bankers which should be used to care for dying patients.

(D) The Medicare Hospice Benefit should be extended to 1988 in order to give HCFA the time required to fulfill what I urge to be a stern congressional mandate to evaluate evaluate this Benefit and report accurately to the Congress.

If the Congress acted now to extend the Hospice Benefit by two years, then the Congress would have two years of hard cost experience and other analysis to review before deciding to establish this Benefit permanently within the Medicare program. If the Congress does not act to extend the initial sunset date, the decision about the structure and permanence of hospice within the federal health care system will have to be made based on experience which is neither representative, reliable, or reportable.

(E) The implementation of this Benefit must become a labor of love upon which the Administration and the hospice movement engage together. The cost report format which HCFA has taken a year to develop, and still doesn't have, is a vehicle which hospice providers will have to make workable in the real world. Frankly, if HCFA would let us in the room, a cost report and a reporting methodology could be designed in two days.

On the West Coast, Blue Cross of California and the HCFA regional office and hospice providers have established a three-party structure for resolving problems and agreeing upon interpretations. As a result, the turnaround time for billings is less than 30 days thus far. On the East Coast, Prudential not only doesn't seem to talk to hospice people, they don't seem to talk to HCFA, either. As a result, some billings are running 100 days or more, and payments for routine home care are being held hostage to questions about the medical necessity of inpatient care.

In each region, HCFA's regional office should convene a working, problem-solving group including intermediaries and providers. Nationally, HCFA should establish a similar working group with representation from intermediaries and certified providers - not a political discussion-and-debate society among the trade associations, but a process designed and a group chosen for technical orientation and practicality in making the Benefit work and evaluating how it works.

Sadly, HCFA, itself, should and could take all of the steps I have recommended, save only the extension of the Benefit until 1988, without the need for action by the Congress. And, if the statutory mandate for data collection and evaluation which was consciously put into the law in 1982 were being followed in 1984 by HCFA, Congress wouldn't need to act to extend the Benefit either.

But HCFA hasn't acted. HCFA won't act to save the Medicare Hospice Benefit. We know it. You know it. They know it. Perhaps what will never be known for certain is whether the cause is malevolence or ignorance.

However, if recommendations such as those we are making today are not converted to action, and that means action prompted by the Congress, then the Benefit will surely fail, at least for the vast majority of those it was intended to serve.

I am, perhaps, one of the few Americans who has read the Republican and Democratic platforms. I was delighted and encouraged when I read, in the Republican platform:

> "REPUBLICANS HAVE SECURED FOR THE HOSPICE MOVEMENT AN IMPORTANT ROLE IN FEDERAL HEALTH PROGRAMS. WE MUST DO MORE TO ENABLE PERSONS TO REMAIN WITHIN THE UNBROKEN FAMILY CIRCLE.
>
> "...WE INSIST THAT THEY BE TREATED WITH DIGNITY AND FULL MEDICAL ASSISTANCE."

A copy of the Republican platform - stapled to an increase in the home care rate, a mandate for "fairness indexing" and a PIP system, and a two-year extension of the Medicare Hospice Benefit - should be conveyed to the Health Care Financing Administration without delay.

Reverend **Westbrook**. Thank you, Senator.

I am Rev. Hugh Westbrook. I'm president and chief executive officer of Hospice Care, Inc., which is a privately owned proprietary organization that was founded for the purpose of establishing and operating hospice programs of care in communities that have significantly unmet needs for hospice care and for providing management services to existing hospices around the United States.

I have been involved, Senator, in developing hospice care in one way or another since 1977. As a volunteer, as a member of staff, as part of a community group. I have struggled to establish all volunteer, nonprofit hospice organizations, relying upon sweat equity and the investment of community commitment and support. I have been involved with hospices that have had to rely upon foundation support, to get underway and to operate. Most recently in developing and continuing my involvement in the provision of hospice care in this country to Americans who need it, I have been involved in developing a hospice company with investments from the private sector.

There are a number of things that I have covered in my written testimony that have already been addressed here today. I won't go over that again.

I was fairly calm and collected until I sat and listened to Dr. Davis reply to a number of your questions and the questions of other members of the Committee. And so I would like to come directly to several points.

Dr. Davis answered your question, saying that the benefit is encouraging the development of a certain type of hospice. I would like to respond with her that yes the Government is. With the payment rates and the mechanisms for implementation of this benefit that the administration has put forth, we are seeing the development of hospices in this country which are going to be mostly suburban, mostly based in hospitals or very large home health agencies, nearly all located in the more affluent communities from around the States. Government policy is encouraging hospices that as they mature will increasingly be subjected to having to screen the patients that they take care of; hospices that are likely to be features or subfunctions of chain operations or venture schemes, such as Hospital Home Care of California or hospice specific companies such as my own.

Nearly exclusively all of these hospices will be located in the Nation's largest metropolitan areas. I don't think there will be many more dots put on many of the States that don't already have them on the administration's map. And of those that are there, I question how many are going to be able to continue with any financial viability.

We have learned a great deal about hospice care over the years; principally, what it is about for the dying person and their family. That's part of what I have been about in my professional career for at least the last 7 or so years. I'm also a consumer of hospice care, as a member of a family that participated in it that way.

We are not business people who have gone into hospice care. We are hospice people who have learned, and have had to learn, the business and other skills necessary to be able to provide the kind of care that terminally ill people and their families need and want from hospices.

Today I sit here as part of an organization that is responsible for hospice care being delivered today to over 325 individuals and family members. The way we are able to provide hospice care, and do so successfully, under the rate structure that is in effect and the payment mechanisms that are in effect is that we are a large hospice consortium. We operate two nonprofit community organizations now under a management contract. One in Fort Lauderdale and one in Miami. We own and operate a new hospice which we have established in Dallas, TX.

The way that we can continue to provide hospice care is to build upon the skills that we have learned, and the economies of scale and the efficiences of shared services in our new company.

Not everyone is going to be able to do that. Most of the hospices in this country will not be able to do that. Most, therefore, of the Medicare beneficiaries in this country who are in need and would choose to have hospice care in this country will not have it available to them because those economies of scale and those other necessary circumstances don't exist in all communities.

I had four points that I wanted to propose by way of solution, because I don't think we need to wring hands; I don't think we need to come here anymore and have our annual fall reunion to listen to the administration make promises to hospices, make promises to dying people, and make promises to the Congress.

I would like to propose, first, that the rate for routine home care be raised. The National Hospice Organization has calculated a specific rate for you and I believe that that is part of their testimony. Just looking at the way the hospice demonstration data was calculated; recalculating that data suggests that the routine home care rates should have been set at approximately $63.68.

I would like to make it clear now that I also believe from our perspective as a hospice company that is going to survive and is going to succeed in providing hospice care, that that rate structure be related to a fairness index so that hospices that are newer and so that hospices that have shorter lengths of stay, get relatively larger amounts of reimbursement than hospices that are more mature, that have a longer length of stay, and have established themselves in a community so that they are able to effectively and efficiently offer the care that dying people need within the rate structure that the Government would set for them.

Second, I would like to propose that the Congress establish a prospective interim payment system. A PIP for Hospices. It was very interesting to listen to Dr. Davis say that Prudential is paying in less than 30 days and others are paying in whatever cycle they are paying in. I will be glad to give you a spread sheet with aged receivables from Prudential that go back to last April. And then we will talk about the rapidity with which those claims are being processed.

Third, we have heard Dr. Davis in her own words talk about the availability of data and meeting deadlines, yet again, that the Congress has established. I would like to believe that those deadline commitments would be true. I don't. I believe that instead of coming back here again 6 months from now, as you questioned whether we should, and a year from now, as I know we will, and ask the question of where the data is, where the basis is on which we can make reasonable, logical judgment and public policy—that instead, today we ought to put this to rest, and that the Congress ought to extend the sunset provision in the Hospice benefit for an additional 2 years.

Dr. Davis made a statement that she was going to have data by the end of this next calendar year in order to meet the deadline imposed. She then went on to say, though, that there wouldn't be much of that data. And I think we really ought to want to question the quality of what is going to be there in any case.

This benefit was structured by hospice care givers, by people who were recipients of hospice care, and by Members of the Congress and their staffs who sat down and collaborated with one another to structure and develop good, sound public policy. That door was soon closed by the administration.

The fourth element of the proposal I would like to make is that, believing that the intermediaries and that the people at HCFA are professionally committed to good public policy in the area of health, that they and hospice providers be invited to sit down in working groups directly with one another to resolve some of the immediate daily problems associated with the implementation of the benefit.

I have a fifth point, if you will, that Dr. Davis brought up for me today. She said that one of the barriers in the development of the availability of the hospice benefit is that beneficiaries out there perhaps haven't learned about it yet. One of the things that we asked HCFA to do in the beginning was to inform and educate beneficiaries about the availability now of the hospice benefit. This they have refused to do in any meaningful fashion. They developed and printed a brochure which is available in your local Social Security office. If the dying person will take the bus and go downtown and walk in and take it off the rack then they can have that brochure. I suggest to Dr. Davis today that they at least mail out that brochure to all of the Medicare beneficiaries in any of the cities, towns, or States where there is today, a Medicare certified hospice, and at least do that to promote the utilization of the hospice benefit.

Thank you, Senator.

Senator DURENBERGER. Thank you very much for that testimony.

[The prepared written statement of Reverend Westbrook follows:]

TESTIMONY OF HUGH WESTBROOK

President, Hospice Care, Inc.

September 17, 1984

BEFORE THE SUBCOMMITTEE ON HEALTH OF THE FINANCE COMMITTEE
OF THE UNITED STATES SENATE

Mr. Chairman:

I am Hugh Westbrook, President and Chief Executive Office of Hospice Care, Incorporated, a privately-owned proprietary organization founded for the purpose of establishing and operating hospice programs of care of the highest quality in communities with significant unmet need for hospice services.

Our company commenced operations in January, 1984. We currently operate three comprehensive home care and inpatient hospices -- two of which we manage for non-profit community organizations, in Miami, Florida and Fort Lauderdale, Florida, and one which we both own and operate in Dallas, Texas. All three of the hospices we operate are certified for participation in the Medicare program under the terms of the National Hospice Reimbursement Act.

I have devoted myself to the development and delivery of hospice care since 1977, when I joined with concerned nurses, clergy, physicians, and others to found Hospice of Miami. We worked as volunteers for at least the first year. People gave up paying jobs to work for no pay to care for dying patients and their families. We operated out of a local church.

Eight years later, the first volunteer we ever recruited is still with us volunteering his time. The first professional caregiver we hired is still with us. The family of the first patient we cared for back in 1977 now helps us take care of other families in 1984. We didn't charge that family anything for the care we provided. They should have charged us because they taught us so much.

There's never been a time since 1977 when there haven't been two or three times as many unpaid volunteers working in our organization as paid staff. That's the case today, as well, in Miami, Fort Lauderdale, and Dallas. There's never been a time since 1977 when we have turned away anyone or curtailed services to anyone because they couldn't pay. That's the case today, as well, in the three hospices we operate.
I know something about struggling, volunteer-intensive hospices with high ideals and hard cases. I know something about the grassroots of the hospice movement. I am a hospice grass root.

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Members of Congress know and their staffs know that I was among those who insisted that the Medicare Hospice Benefit reflect high ideals and require of hospices high performance, including, for instance, three requirements not asked of home health agencies, hospitals, and nursing homes:

(1) That to be a Medicare-certified hospice, one must sustain volunteer involvement in all aspects of the hospice program and not diminish volunteer intensity with the availability of Medicare payments;

(2) That to be a Medicare-certified hospice, one must not dump patients whose ability to pay has run out;

(3) That to be a Medicare-certified hospice, one must provide bereavement care and counseling to hospice families after the patient has died even though the Congress decided not to reimburse for bereavement care.

In some cases, I don't think the Congress or the Administration went far enough in assuring the integrity of the hospice concept in structuring the conditions of participation and the requirements for Medicare certification.

However, the Administration took another course. Instead of focusing on preventing "bad" providers, the Administration's reimbursement policy and rates have had the effect of preventing many of the best hospices in America from participating in this benefit.

We started Hospice Care, Inc., the proprietary company, for the same reason that eight years ago we worked in the church basement to start Hospice of Miami, the community charity: to assure that dying people have a choice between institutionalization, on the one hand, and being with their own families, on the other -- between the expensive cycle of the hospital and the home health agency, on the one hand, and the less costly system of hospice, on the other -- between generalized care, including inappropriate and unhelpful use of curative therapies which will neither lengthen life nor improve its quality, and specialized care, which focuses competently on controlling successfully the noxious symptoms that making living with a terminal illness so unendurable.

For us, the auspice of the hospice -- community charity or proprietary company -- is simply a way to do hospice care, the vehicle at hand with which to practically satisfy our original motivations. Hospice

Care, Inc. is not a group of business people who went into hospice; it's a group of hospice people who went into business because going into business was a way to find the dollars to develop hospices in order to render care.

Unlike the home health agency, whose start-up and build-up costs can be amortized over five years and recaptured from the federal government in cost-based reimbursement, the hospice of whatever auspice must capitalize itself with private dollars from some source.

Unlike the cost-based home health agency, which can use higher levels of government reimbursement in the beginning in order to finance its development in meeting conditions of participation, the hospice must be financially viable based on its own operations from the very beginning.

We have been the route of obtaining start-up grants from major private foundations in order to help capitalize a hospice, but those days are ending, not because of the passage of the Medicare Hospice Benefit but because private foundations interested in hospice have changed their focus from start-up grants to more general, more national support.

We have been the route of obtaining loans from financial institutions to finance the significant front-loaded expenses required in order to be what a hospice should be and what Medicare requires it to be. But there's a limit to the ability of hospice people to collateralize loans on their personal signatures. And, due to a technicality in Medicare regulations, a Medicare provider cannot truly assign its receivables as collateral. A Medicare receivable cannot be "factored" in the fashion banks require. For a cost-based home health agency able to amortize its start-up and developmental expenses over five years and get the federal government to capitalize the business, the inability to factor Medicare receivables is less of a survival issue than for the hospice, which is paid a flat per diem irrespective of costs.

So we went to Wall Street.

Wall Street, we found, is a little different than the church basement.

But there are some similarities between Wall Street investors, private foundations, and commercial bankers. They all want their money to go to groups who have a reasonable chance of financial viability.

To that extent, when I face my stockholders, I share the same burden of viability carried by my colleagues who run hospices just like ours but under different auspices.

We convinced a group of investors to capitalize our company based on certain assumptions of financial viability:

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(1) The porportion of the reimbursement dollar devoted to indirect costs, as opposed to direct patient care, could be minimized by

   (a) spreading those indirect costs over an atypically large patient population, and

   (b) centralizing financial and administrative management, minimizing on-site overhead, and sharing support services among several hospices operated in common.

In other words, the economies of scale and the efficiencies of shared services.

(2) Dual certification and "under arrangements" agreements would result in an ability to obtain payment for services rendered to non-Medicare patients or patients not making the Medicare Hospice Election.

(3) A pre-set, four-level per diem payment system would be simpler and easier to administer from Medicare and simpler and easier to operate from the hospice, itself, compared to a cost-based, multi-tiered, unit of service reimbursement system such as is applied to home health agencies and, incidentally, such as was applied to the 26 demonstration sites in HCFA's Hospice Demonstration Project.

In other words, we relied upon the Administration's commitment to an efficient payment system based on a simple payment methodology.

We believed the Administration when they said hospices in the Medicare program don't need a Prospective Interim Payment (PIP) system, such as was used in the HCFA Demonstration Project, because under the prospectively-set per diem system, billings can be processed in an improved and simplified fashion as compared to the Demos.

We believed the Fiscal Intermediaries chosen by HCFA and supervised by HCFA would perform as promised and pay in a timely fashion. Hence, we wouldn't need to factor in a major ongoing receivables financing cost.

We believed Dr. Davis when she testified before this Subcommittee a year ago about the decision-making freedom for the interdisciplinary team regarding what services to use under what conditions -- a flexibility which was styled as one of the primary selling points to the hospice movement for prospectively-set per diems.

We believed, therefore, that we would not have to hire expensive medical review professionals to argue daily with medical review panels at the intermediary level about whether pain-killing drugs should be injected instead of given orally in order to justify a level of care change from home care to inpatient care.

We believed the Administration when hospices were promised a hospice-specific and comparatively simple medical review process. Hence, we assumed, in ascertaining the viability of hospice, that our lawyers would not have to be continually engaged as bill collectors.

And, our assumptions of the financial viability of operating a hospice, even given the foregoing assumptions, included:

(4) Adequate enough reimbursement from Medicare to pay the costs of providing the mandated covered services to Medicare patients, who nationally constitute some 70 to 75 percent of those needing and wanting hospice care.

Mr. Chairman, we did not expect the federal government to capitalize our operations. We did not expect the federal government to pay the difference between what it cost to render care in a start-up period and the costs of rendering care at the point the hospice performed in a financially viable fashion. We found the money to accomplish those objectives by going to Wall Street.

We did expect the Health Care Financing Administration and its Fiscal Intermediaries to review our billings efficiently, pay us promptly, and reimburse us at a level that would result, at some point, in our Medicare revenues being equal to our Medicare costs. I would think that in those expectations we are joined by any hospice of whatever auspice.

However, those expectations have not been fulfilled. Therefore, the circumstances under which the operations of a Medicare-certified hospice can be financially viable are extremely and rigidly limited.

Our experience, as opposed to our expectations, has been as follows:

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- HCFA has turned the opportunity to demonstrate the value and workability of a comprehensive benefit into a snarl of administrative and regulatory confusion:

  1. Our proprietary company has had to lend to the two non-profit hospices we manage nearly $400,000 to finance its Medicare receivables.

  2. Promised turn-around time for payments from the FI for free-standing hospices in the Eastern U.S. (Prudential) has not been fulfilled. Prudential promised a 10-day turnaround. In reality, we have had to wait 100 days for some payments and more than 60 days for vastly most payments.

  3. The cash flow problem has resulted from not only lethargy at the FI level but from an imposed, complicated, medical review process that bears no resemblence to the expectations of the hospice movement.

     Mr. Chairman, we had to hire lawyers and consultants to fly to Millville, New Jersey, to argue with the Prudential FI's medical review panel about why all hospice inpatients shouldn't be subjected to intervenously fed medications as a condition for payment. Part of what makes hospice hospice, clinically, is our expertise with the titration of pain medications taken by less expensive, less discomforting, less-invasive means. If pain can be controlled through oral medications, it is much more likely that the patient can go home.

     Mr. Chairman, we had to fly lawyers and experts to Millville, New Jersey, to explain to Prudential's medical reviewers why it is sometimes better and more clinically appropriate and more cost-effective to provide inpatient care that costs Medicare $271 a day instead of continuous care which costs $80 a day more. Prudential has been holding up payments for inpatient care because they thought we should use continous care first, even though it costs Medicare more, and use inpatient care as a last resort, even though it costs Medicare less.

> Mr. Chairman, we had to fly lawyers and experts to Millville, New Jersey, to explain to Prudential's medical reviewers why, in order for a hospice physician, to certify that someone has six months or less to live, a physical examination of the patient has to be performed. HCFA's intermediary wasn't sure about that and therefore held up payments.

Remember, Mr. Chairman, the pre-set per diems and the four levels of care were sold to the hospice movement by HCFA as being a comparative advantage, operationally, over the bad old cost-based system used in the HCFA Demonstration Project.

Hospice, Inc. in Miami and Fort Lauderdale was a HCFA Demo site. During three years and eight months of operation within the Demonstration Project, Hospice, Inc. submitted 30,327 bills to Medicare for Medicare patients. There were no denials of any claims for any reason.

The Administration is losing the opportunity to build a case for the concept of coordinated, comprehensive care -- a voucher system, even -- by making us all pine away for the system which was supposed to be discredited.

o <u>HCFA's hospice payment rates are inadequate to support the care rendered to Medicare hospice patients:</u>

The decision of the Administration to reduce hospice home care rates from $53.17 per day to $46.25 per day means that financial viability is not possible for a Medicare-certified hospice until and unless that hospice has an average daily census of over 70 patients who live, on the average, 60 days after admission to the hospice.

(Assuming the Hearing Record will be kept open for a few days for supplemental submissions, I ask the Chairman to permit me to share with the Committee the financial detail which illustrates that conclusion.)

The first four months of operation of Dallas Hospice Care, from April through July of 1984, shows the realities faced by a new hospice in trying to reach financial viability under the existing home care rate.

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In those first four months of operation as a Medicare-certified hospice, our Dallas organization cared for more than 50 patients, of which 26 were Medicare Hospice Election patients who died during the four-month period.

Of those 26 Medicare patients who died between April and July 31, all received routine hospice home care, two received hospice inpatient care, and four received hospice continuous care. None received inpatient respite care.

The average length of stay for those patients was not 60 days but 19 days. Those patients who used inpatient care utilized an average inpatient length of stay of three days. Of those patients who used continous care, the average utilization was 38 hours which, given HCFA's methodology, converts to 2.5 days of continuous care per patient.

Put another way, the Medicare patients who had died by July 31 were cared for 97 percent with routine home care, 2 percent with continous care, and 1 percent with inpatient care.

The total amount charged to Medicare for the care rendered to these patients was $27,769.04 for an average cost to Medicare per hospice case of $1,068.04.

Ninety percent of these patients died at home. Ten percent died in inpatient care.

However, the costs to us for providing that care exceeded, by multiples, the amount charged to Medicare. In our case, the difference was made up by private money we had obtained. The hospice without our financial resources would have probably gone out of business even with massive infusions of charitable income and massive cost-shifting to non-Medicare payment sources.

In other words, the community-based charitable organization that wanted to <u>start</u> a hospice to meet the needs of patients and families in a community would not be in business today if it tried to provide the mandated and covered services for the existing rates. Perhaps that is why, to our knowledge, the only <u>new</u> hospice which has been certified by Medicare has been Dallas Hospice Care, owned and operated by a proprietary organization.

The problems associated with converting an existing hospice, even one which had been reimbursed under HCFA's Demonstration Project, to the Medicare Benefit are dramatically exacerbated by the low payment rates for home care. As I testified, Hospice, Inc. in Miami and Hospice, Inc. in Fort Lauderdale had to turn to us for $400,000 in borrowed money. Half of the borrowing needs resulted from HCFA's contorted, confused, and lethargic payment and medical review process. Half of the borrowing needs represented the difference between the costs of providing the Medicare-covered services and the reimbursement rates. Because Hospice, Inc. in Miami is 88 percent home care and Hospice, Inc. in Fort Lauderdale is 90 percent home care that borrowing was really necessitated by the too-low home care rate.

Of the 119 hospices certified to provide the Medicare Hospice Benefit, not one does not subsidize the cost of caring for Medicare patients by diverting other money. In our case, we have the advantage of long-term capital investment. Therefore, we are diverting money intended to be used to open additional hospices in order to support our three existing programs. But that's our problem. The real problem is that nearly all of the rest of the 119 hospices are diverting charitable contributions intended for the care of poor people, including the care of under-insured patients like dying children, to subsidize Medicare. One of the long-term effects of the low Medicare home care per diems is that hospices will be forced to cost-shift onto non-Medicare patients whose bills are being paid by America's employers and America's unions.

The result of all of that will be that few hospices will care for Medicare patients and those that do will not find Medicare payments sufficient to cover costs; hence, we will begin to see a phenomenon of certified hospices not submitting bills to Medicare, but turning away Medicare patients, or gaming the Medicare system by double and triple certification, or cost-shifting to the private payors, or denying care to the poor because there's no money left after making up the Medicare difference ---- or all of the above.

The result is that the Medicare Hospice Benefit is a failure for America's hospices and America's terminally ill.

The only hospices which can be viable will be chain operations or venture schemes. The only people rendering hospice care will be those who can afford to wait for four to five years for a breakeven point. The only communities where Medicare-covered hospice care will be available will be those which can support extremely high average daily censuses.

Frankly, Mr. Chairman, our analysis indicates that unless the home care rate is raised, and assuming about a third of the terminally ill need and want hospice care under Medicare and assuming the census it will take to be viable, fewer than 100 communities in America will have Medicare-certified, financially viable hospices ever. None of those communities will be in rural America.

This Subcommittee, in its wisdom, recently developed and assured the enactment of a waiver provision whereby hospices in rural areas wouldn't have to comply with the core services requirement. Somebody convinced you that core services compliance was the barrier to hospice delivery in rural America. I point out respectfully that, although the waiver provision is now law, not one rural hospice has applied for a waiver. The problem in rural America is the same as in urban America when it comes to access to the Medicare Hospice Benefit. The problem is that the home care rate is so low that a hospice, supported by either charity or by private investment, can't be viable in rural America.

The answer is obvious. Raise the home care rate. Raise the home care rate by enough so that the typical American hospice has some chance of survival as a Medicare provider.

Frankly, even if one could trust HCFA to do a study and do it on time to answer the questions about rate adequacy, we don't need another study. Available evidence collected by hospices, themselves, aptly demonstrates that the rate should be set approximately $20 higher than it is today, at $66 or thereabouts, to allow a volunteer-intensive, highly-efficient hospice, with supplemental income from charitable or private sources, to operate viably.

The question may arise: "Why not wait until HCFA has collected some actual cost data from the Medicare Hospice Benefit and then set the rate?"

The answer is that HCFA has never met a hospice deadline since the word hospice was spoken within the Department. The answer is that HCFA hasn't collected one bit of data on the Medicare Hospice Benefit with respect to real costs. All HCFA knows it what it has paid, not what the costs are in the real world.

Mr. Chairman, the fact is that HCFA doesn't even have a hospice cost report distributed yet and probably doesn't have one invented yet.

But even if they did have a cost reporting methodology in place, and even if the cost reports went out to the hospice providers this afternoon, the following would ensue:

> In order to capture even six months (two quarters) of data from October 1, 1984, through March 31, 1985:
>
> -- The provider, by law, has 90 days to submit a final cost report at the end of the reporting period, in this case, a six-month period. That means the cost report wouldn't even be submitted to the Intermediary until July 1, 1985.
>
> -- Usually, the Intermediary takes 60 to 90 days to review a provider cost report. Let's assume they do it in 45 days. Now it's August 15, 1985.
>
> -- Now the FI begins the period of adjusting the cost report with the provider and settling differences. Let's assume that adjustments are minimal and appeals are virtually non-existent and that this process only consumes 30 days. Now, it's mid-September.

-- The adjusted cost report is now subject to audit. Let's assume all auditing and the final audit report consume only 45 days. Now it's November 1.

On November 1, 1985, the first audited cost data on the Medicare hospice benefit will be in the hands of the Health Care Financing Administration. It will be only six months worth of data.

On January 1, 1986, the Secretary must submit a report to the Congress on the Medicare Hospice Benefit. Very optimistically, that would be the first time HCFA cost data would see the light of day. It is not comforting to note that the Secretary's report to Congress on the HCFA Demonstration Project, due in 1983, is already one year late.

Mr. Chairman, if Congress wants the Medicare Hospice Benefit to be available to more than a small, small handful of big hospices and if the Congress wants the Medicare Hospice Benefit to help more than one or two thousand people in the whole nation, annually, then the Congress must act to force the Administration to equitably and fairly administer this benefit.

The Congress must act either to set the home care rate or to force the Administration to set the home care rate, just as it took the Congress to act to set the overall hospice cap at $6,500 after the Administration calculated it down to $4,200.

The Congress must realize that HCFA will not have even six months of cost data, let alone one year, by the time the extension of the Medicare Hospice Benefit comes before the Congress in late 1985 and early 1986.

Therefore, the Congress should act now, in acknowledging the realities of HCFA's past and current record, to extend the Medicare Hospice Benefit by at least one or two more years. Then, and maybe then, will HCFA have real experience, meaningful experience to report to Congress.

Mr. Chairman, I am one of those few Americans who has read the platforms of the major political parties. I was delighted to find that the Republican platform discusses hospice. The Republican platform states:

> "Republicans have secured for the hospice movement an important role in federal health programs. We must do more to enable persons to remain within the unbroken family circle...we insist that they be treated with dignity and full medical assistance."

Mr. Chairman, I respectfully submit that you should send a copy of the Republican platform to the Health Care Financing Administration stapled to a Congressional mandate to raise the home care rate and extend the hospice benefit.

Thank you.

STATEMENT OF DR. WILLIAM LISS-LEVINSON, DIRECTOR OF THE BROOKLYN HOSPICE, NEW YORK, ON BEHALF OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator **Durenberger**. Dr. Liss-Levinson.

Dr. **Liss-Levinson**. Thank you, Mr. Chairman. I am William Liss-Levinson, director of the Brooklyn Hospice, at Metropolitan Jewish Geriatric Center in Brooklyn, NY.

As a psychologist who administers a Medicare certified hospice program, I appear before you today representing the 72,000 members of the American Psychological Association, and the Association for the Advancement of Psychology.

In addition to the written testimony, I would also like to submit for the records several articles that have appeared in the November 1982 issue of the American Psychologist regarding the topic of hospice care.

Senator **Durenberger**. All right. We will make those a part of the file.

[The information from Dr. Liss-Levinson follows:]

Reality Perspectives for Psychological Services in a Hospice Program

WILLIAM S. LISS-LEVINSON *Metropolitan Jewish Geriatric Center*
Brooklyn, New York

ABSTRACT: *As one of a rare breed—a psychologist administering a hospice program—the author shares some of his concerns regarding the provision of psychological services in the hospice setting. Six major areas of importance to psychologists working with the terminally ill and bereaved are discussed. For each of these topics, the author analyzes some of the ways in which we have veered from a more reality-oriented perspective in pursuing an ideal of alleviating the emotional suffering terminally ill persons and their families may encounter.*

The first American hospice, The Connecticut Hospice, Inc., began providing its home care services to the terminally ill in 1974. According to the Joint Committee on Accreditation of Hospitals (1981), less than a decade later there are more than 440 known operational hospice programs with, at the very least, an additional 360 programs being planned. Even in communities where there are no formal hospice programs, the impact of this philosophy of caring in existing health care institutions is apparent. Palliative care teams, supportive care teams, pain management committees, bereavement teams, and so forth all reflect the ways in which the diverse needs of the terminally ill are being addressed. Perhaps the most significant indicator of the coming of age of the hospice concept in America is the recent passage of federal legislation to include hospice care services under existing Medicare benefits, signifying that hospices have successfully made the transition from a passing fad to a recognized health care service.

There does, however, appear to be a definite lack of involvement of psychologists in the hospice setting. Granted, psychologists have been prominent in the field of thanatology, as evidenced by their writings in this area (e.g., Davidson, 1978; Feifel, 1959, 1977; Garfield, 1978; Kastenbaum & Aisenberg, 1972; Schneidman, 1976; Weisman, 1972). However, psychologists are generally not employed by hospice programs with the same frequency as other health and human service professionals. For example, Buckingham and Lupu (1982, p. 458) found that only 21% of hospices surveyed employed psychologists, whereas 33% employed volunteer directors, 46% employed chaplains, 58% employed physicians, 75% employed social workers, and 93% employed nurses. In a study conducted by JCAH (1981), it was found that "The composition of the interdisciplinary team reflects the involvement of physicians, R.N.'s, M.S.W.'s, volunteers and clergy" (p. 2). Other professionals that might be called in when deemed necessary were physical and occupational therapists, art therapists, pharmacologists (p. 4). Where are the psychologists?

The reader can therefore imagine my elation at the prospect of writing an article for the *American Psychologist* on the subject of hospices. Here would be a golden opportunity to wax poetic on the need for and the role of psychologists in the hospice setting. Besides the more obvious direct clinical contact with terminally ill persons and their families, there are other areas of vital import in which psychologists could make their marks, among them: staff and volunteer training, supervision, and support; professional and lay education; consultation; and research and evaluation. Armed with my mission to proselytize, with the call of "psychologists—get ye to a hospice," I set out to write an article on the virtues of hospice work.

What I have discovered in the process (weeks and mounds of crumpled paper later) is that in reviewing my own professional experience as both a clinician and administrator over the past five years, there is a need for a different article to be written. Psychologists will gradually find their way to hospice programs. The real question that concerns me is what they will do when they become an integral part of the hospice team. More specif-

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ically, my intensive, albeit brief, experience over these years has led me to conclude that there is a need for a more realistic perspective regarding the provision of psychological services to those persons confronting a terminal illness. So casting aside the opportunity to demonstrate my less than dazzling clinical and theoretical knowledge, I offer my hard-earned perspectives on some key aspects of the realities of hospice and psychological support services for the terminally ill.

Terminal Terminology

The language we choose in labeling people and their problems serves many purposes. On the most simplistic level, it allows us to have a name for such an individual. It does, however, also serve as a means to classify an entire group by certain characteristics they may or may not have in common. Take the term *terminal*. *Webster's New Collegiate Dictionary* defines it as "occurring at or contributing to the end of life." This definition really focuses on the physiological process of dying. What we in the hospice and thanatology worlds have done is to create a new class of people—"the terminally ill." In effect we master our greatest fear of death—the fear of the unknown—by creating this group that we now can describe at length—their reactions, feelings, and psychological processes. But what have we really accomplished? Well-intentioned health care professionals armed with 6 credits of Death and Dying I and II, talk about "stages of dying," "stages of grief," "unresolved grief," and so forth. People are described by what stage they are in or should be in, by what processes they're assumed to be experiencing. In the course of all this it becomes very easy to overlook the individual behind the terminal illness. They bring to their illness and impending death, first and foremost, who they were prior to all this. Edwin Schneidman, noted for his various works in the area of death and suicide (e.g., Schneidman, 1976), in public lectures has often used the phrase "oncology recapitulates ontogeny." Simply stated, how we face a terminal illness and death is a reflection of how we have faced our life in general. To fully understand the person facing what is clearly the most stressful event of his or her life, we must know who this person was before the onset of this physiological process. Then we can put into a proper perspective all our theories of psychological processes and reactions, and perhaps lend some meaning to our label "terminally ill."

Romanticizing Death

As a society, we tend to do one of two things when faced with frightening and painful realities. We either mask them in a cloak of mystery (and thus distance ourselves from the issues) or we totally immerse ourselves in the issue (thereby romanticizing and symbolically mastering them). Death, although always a part of our lives, was seen for many years as a taboo subject. Now we have swung the pendulum the other way. Death is being discussed in every magazine and publication, on every television and radio show. This in and of itself is not dangerous. The ways in which the topic is presented, however, reflect a romanticization that far exceeds reality. I think I will scream if I see one more butterfly symbolizing death as a transition, ultimately characterized by the soaring skyward of this fragile insect. Death is not by its very nature beautiful or dignified. Granted that some people are able to transcend what is often, at the very least, a dehumanizing physiological process and retain their basic human spirit. Yes, many people can be helped to die at home or in a homelike environment surrounded by those they love. Few, however, if they had a choice, would seek out this "growth" experience for its own sake. If one of the goals of professionals in this field is to educate others about the realities of death and dying, then we had better start with ourselves.

Romanticizing death can backfire on us and on our patients/families when their experience of death does not live up to the Hollywood-like images we create or reinforce. Dying individuals and members of their families may feel about to fall apart at the seams. This is further complicated by the staff's being "all-wonderful" and seemingly able to cope with the stresses of this work.

On yet another level, we must also be wary of attempts to see ourselves in an overly romanticized way. Working with the terminally ill individual and his or her family is a difficult task, one that not every psychologist may feel personally able to assume. But work with the retarded, severely disturbed, or alcoholic individual is also difficult. The "difficulty" is, however, different. We may feel strongly about helping people who are dying; it may even be an expression of our moral or religious perspectives. We are not, however, angels of mercy. Angels (according to the latest survey reports) do not draw paychecks, pay taxes, or have personal interests above and beyond their work. Angels also report to an administrator/clinical director who can solve their fiscal problems far more readily than occurs here on earth. Finally, whoever heard of an angel experiencing burnout? If we allow ourselves these delusions of grandeur, we will exert a tremendous amount of self-pressure to live up to these standards, a feat impossible by definition.

Sex Role Socialization

If we follow Schneidman's previously cited notion of "oncology recapitulates ontogeny," then it is obvious that we must approach the provision of psychological services to the terminally ill individual from a sex role socialization perspective. Liss-Levinson (in press-a, in press-b) has discussed this issue both as it relates to males confronting cancer and to people experiencing acute grief. It is clearly unnecessary in this journal to review the traditional sex role stereotypes for males and females in America. My clinical experience has led me to believe that an understanding of societal sex-role-related messages about coping with a terminal illness and death, and the degree to which an individual subscribes to these roles, may be the most critical clinical information we need to know to help the terminally ill psychologically. If we apply this two-fold knowledge, we will have a much better sense of just how well an individual or family member is coping with this impending death. Our therapeutic goal, therefore, must be to help the individual to respond in a way which he or she feels most comfortable with and desires. It may be lovely to want a male to cry and share his feelings. If he, however, has not been reared to do this, does not value transcending this sex role socialization, and does not have a support system to support transcending this role (even if he wanted to), we had better lower our sights to help this male cope with the ensuing events as *he* feels a male should.

Whose Agenda Is It Anyway? Defining and Prioritizing Goals

The hospice philosophy of caring has always included a very active role for the "patient" and his or her family in determining the plan of care. Central to this point is the notion of giving the person as much control over his or her life as is possible. So equipped with this notion, we present ourselves and our programs to people and say, "Choose what is necessary and meaningful to you." This approach may be fine for the fairly well educated, articulate, and assertive individual, but many people are confused by this posture. First, they may not have encountered this philosophy ever before in the (generally) paternalistic, traditional health care system. Second, they are somewhat suspicious of this offer to help people in whatever way they see fit. Although we often listen to what people say they want and need, we do not, in reality, always implement a plan of care strictly according to their answers. We have a significant investment in the value of our professional training and expertise, coupled with a desire to have our services perceived as both necessary and desirable. Furthermore, we all seem to have covert agendas as to what issues are "important" for the terminally ill to explore, and these may not coincide with what the individual and/or family are presenting to us.

When these goal conflicts arise, we often shift into what I term the "vacuum cleaner salesperson approach" (i.e., we try to keep a foot in the door even when we have been asked to leave). I vividly remember one incident which occurred five years ago. I was asked by a physician to see one of his patients in the hospital. After two or three visits it dawned on me that this man had no desire to talk with me. I suggested that I could stop by his room every couple of days to say hello, and if he felt like talking about his illness we could. His reply, "If that's what you need to do, it's all right with me," made it clear that I (the vacuum cleaner salesperson) still was not getting the message that my help was not desired.

Even when we can accept patient- or family-defined goals, there still remains the issue of prioritizing these goals. As will be discussed at length below, we as psychologists, and perhaps the whole thanatology field, are guilty of overkill in our focus on psychosocial needs at the expense of other more concrete needs. We do this for two reasons. First, we are attempting to compensate for years of professional avoidance of these issues. Second, we prioritize patient/family goals according to what is most exciting to us. Dealing with "meaty" psychodynamic issues like denial, cathexis, anticipatory grief, and so forth clearly takes priority over getting a housing or energy subsidy, except that people with denial can live until they die—it is a bit harder if they do not have heat or a place in which to live until they die. Truly prioritizing goals involves giving up control *or* being able to recognize when our own priorities are getting in the way of helping the person to meet his or her needs.

Talking Does Not Put Food on the Table

Our jobs would be relatively easy if all people facing a terminal illness (be they the patient or the family) had no other problems in their lives. Alas, the experience of our hospice program and that of others across the country is quite to the contrary. Often people are also confronted with huge hospital and physician bills. Most of us tend to find out what our health care insurance covers all too late, when we are confronted with a health crisis. Negotiating the labyrinth-like mazes of the world of health care reimbursement frequently results in clinically induced neurosis even in the best of us. Ideally, no one should become terminally ill or die unless they have a highly skilled social worker in their family or at their beck and call. Since this is generally not the case, we must put our psychological expertise and services in perspective. The individual or family who states that all they really want is assistance with finances or getting on Medicaid may or may not be exhibiting resistance or denial. The only way we can even attempt to ascertain this is if we first help them to resolve these concrete service needs (directly or through referral). We must remember that for the average individual, helping him or her to understand the anxiety they are experiencing as a result of financial mayhem is really very unimportant. Solving their financial woes is really what they want, and quite frankly, it is what they need most. We tend as psychologists to think that all people have a keen interest in the understanding of themselves and the psychological process (we are sure) they (must) experience. This actually reflects the white, upper-middle-class values that permeate much of this field. We also project our needs to "psychotherapize" the dying process onto our clients in order to validate our training and profession. After all, we do have a need to be needed, and no matter how secure we are it can be devastating to hear (as I have on many an occasion), after lengthy discussion of all the psychosocial support and counseling I can offer, "So tell me, but what are you going to *do* for me?" We need to be prepared to face that question honestly as well as to have some good answers to it.

Grief and Bereavement: Some Caveats

Because of the basic philosophy of the patient and family as the unit of care and because of the recognition of the emotional and physical impact of a death of a loved one on the surviving family members, hospices are involved in the provision of bereavement follow-up services. Generally, the commitment to the family for this support extends for up to one year following the death. The nature of the services may vary from periodic phone calls to volunteer home visits to more intensive individual, family, or group counseling. Usually there is a great intensity of involvement during the days immediately following the death (with assistance with funeral arrangements and participation in wakes, funerals, and other mourning rituals not uncommon). Furthermore, most hospice programs attempt to assess the family's strengths and bereavement needs prior to the patient's death. Precisely because of the importance given to bereavement, there is a need to plan the psychological support services within the context of certain caveats.

Liss-Levinson (in press-b) refers to the notion of mourning, particularly during the acute grief period, as a "luxury." The intense introspection and egocentrism that mourning and grieving demands of an individual is a greater indulgence than we normally allow ourselves. To give expression to the numbness and pain that may be felt during this period, with the concomitant inability to participate in many normal activities, is no easy task. As an example, many bereaved family members will return to work within a few days of a funeral. There are sometimes economic concerns at stake, but many people will state that they "just can't take it"; they need to get back to work to "get their minds off" the loss of their loved one. In effect what they are indicating is that the experience of mourning, the role of being a mourner, is too difficult to endure. Witness the Americanization of the traditional Jewish period of intense mourning of seven days following the burial of an immediate family member. Many people only sit *shiva*—the Hebrew term, which literally means seven—for three days. Many of the traditional prohibitions for the Jewish mourner (e.g., regarding bathing, shaving, and other matters related to focus on one's physical appearance) are seen as antiquated. In fact, adherence to these rituals means coming to grips with a mandated style of (perceived) "negative" self-indulgence that many find abhorrent.

Another important area of concern, referred to in the preceding section on terminal terminology, are the ways in which we expect our bereaved people to grieve. I am astonished at the extent to which colleagues will talk about the problems that will "certainly" arise as a result of "unresolved" grief. We seem to be quite certain that people need to "resolve" their grief within a critical time if they are to live fulfilled lives, develop relationships, and so forth. Whatever did the world do *before* we came along? Resolution of stressful events in one's life, conceptually, is a rather luxurious task. For many people we serve, *surviving* life's stressful events is a more realistic and viable goal.

What all this means on a very pragmatic level is that we must know *who* we are "helping" *before* we attempt to help them to experience their grief for their own purported present and future mental health.

Concluding Thoughts

The professional and personal challenges that psychologists can confront in working in a hospice setting with terminally ill persons and their family members are exciting and stimulating. As in any relatively new area, we tend initially to generate many theories to help us master these challenges. Those of us who have been involved in this work for some time now need to sit back and think about what we are doing, why we are doing what we are doing, and most importantly, what we have learned. I hope that I have begun the process of accomplishing this task. In sharing my perceptions of reality I have learned some things that I am taking back to my own work.

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A Federal Role in Hospice Care?

JENNINGS RANDOLPH *U.S. Senate*

In October of 1981, my staff scheduled an appointment for me to meet with Josefina Magno, executive director of the National Hospice Organization. Dr. Magno wanted to discuss the hospice care movement in the United States and to seek my assistance in introducing a Senate resolution requesting the President to proclaim the week of November 7 through 14, 1982, as "National Hospice Week." The hospice care concept was not unknown to me at that time, but I had not really taken the time to consider the concept in its most fundamental and humane terms and in my capacity as a lawmaker.

I have served on the Committee on Labor and Human Resources for nearly 25 years. That service has included jurisdiction over public health programs—particularly the National Institutes of Health—and authorizing research and treatment programs for diseases affecting the heart, lung, kidneys, bones, blood, and many other diseases. All of these are painful and, for all too many, deadly.

In my personal life, I had just experienced several years of the devastating effects of the terminal illness of my beloved wife, Mary. Her death had occurred just a few months before Dr. Magno visited my office to discuss home care for the terminally ill. My wife, after the usual and numerous efforts to prolong her life through chemotherapy and surgical procedures had been rendered ineffective, decided that she no longer wanted additional heroic, middle-of-the-night trips to the hospital where extraordinary efforts were made to merely sustain what had become a painful existence for her. She was, I believe, at a stage where she had accepted the fact of her dying, and except for the bouts of physical pain, she was tranquil and serene, prayerful and peaceful. Mary came home to die.

Jennings Randolph

Just as my wife wanted and needed to be at home among familiar surroundings and with family and friends, today many others who have a terminal disease are making that same decision. But when patient and family decide to go home, it is necessary for them, as it was for me, to find suitable home-care professionals to care for the patient. It was imperative to find such assistance in my case because of my many absences from home to discharge my time-consuming duties as a United States Senator. Finding and keeping that kind of home-based professional care is not easy to do.

The home care that I was able to obtain was not the dedicated multidisciplinary team of professionals known as hospice care providers. I cannot

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Editor's note. Senator Jennings Randolph (D-West Virginia) started his political career in the House of Representatives and moved to his Senate seat in 1958. Since that time he has served continuously on the Labor and Human Resources Committee, and as chair of the Environment and Public Works Committee. He has also been a continuous member of the Veterans Affairs Committee. For many years he was chair of the Subcommittee on the Handicapped.

Senator Randolph recently introduced the Senate Joint Resolution proclaiming National Hospice Week in November of this year, and he is a cosponsor of both S. 1958, a proposal to enable Medicare recipients to use hospice services, and S. 2013, a proposal to authorize the use of heroin for the treatment of intractable pain.

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tell you that I was comfortable with or always able to totally rely on the professionals I was able to employ. It was most difficult to find individuals who were willing to provide round-the-clock care for a terminally ill patient. As a result, there were gaps in the quality of care provided—gaps that at times frustrated, enraged, and frightened me. For example, the night nurse might cancel at the last minute, pleading illness or perfectly plausible personal problems that had to be resolved immediately. Such a situation would leave us, however, without immediate access to a last-minute replacement, throwing our sense of order—both mine and Mary's—into chaos. I will not belabor the issue here, except to note that it was unfair, that it was frustrating in the extreme, and that it caused me great anguish and despair. But more importantly, it placed the patient at great risk, and it took away her fragile, hard-won sense of well-being.

Since then, of course, I have come to rationalize the situation that we were faced with—a situation that we had to cope with at all costs. I have come to realize that those home health care professionals, who acted and reacted to their jobs and responsibility for their patient in what appeared to be a cold and unfeeling manner, very probably did not do so because they felt no compassion or because they were uncaring. They were simply, and regrettably, untrained in the unique care required by the terminally ill, and they were unprepared by their professional training to address and cope with their own stress—stress born from the intimate, daily contact with people who are dying.

Health professionals today—doctors, nurses, psychologists, and others trained in the healing arts—are not specifically or specially trained to a great extent (if at all) in dealing with the management of the extreme pain suffered by their patients who are terminally ill. In addition to handling physical pain, professionals ought to be trained, but are not, in dealing with that patient's emotional, spiritual, and intellectual pain inherent in their knowledge that death is near.

When care is provided to the terminally ill, whether in a hospital or another setting, caretakers from the medical profession (and often family and friends) who help care for them lose sight of the fact that the terminally ill are people. These terminally ill patients have lived lives, given birth, raised families, contributed to society, painted pictures, entertained others, and so on.

When they are suddenly immobilized, in pain, given massive doses of drugs that keep them from being lucid and aware of their surroundings, removed from the familiarity of their homes and families to hospitals and nursing homes, they lose their sense of personhood unless someone helps them retain it. They are from all walks of life. They may have lost their physical ability to be creative or be in full charge of their own affairs. They may have a sense that there are loose ends that need to be tied up and be unable to articulate it. But they are still people.

Health professionals today are often in a situation where they are not just treating a disease, they are treating a terminal disease. Their patients are not going to get well. It is not a matter of administering a medicine that will cure or performing surgery that will eliminate the problem. It is not a matter of providing physical or occupational therapy and getting folks back on their feet, ready to be returned to jobs and a productive, fulfilling life.

In all the disciplines of the healing arts, not nearly enough training is directed toward the care of the terminally ill, where the whole person must be cared for and about.

That is why it is so important to know and to stress that the hospice care concept can, and does already, make a difference in treating the terminally ill. It can evolve into a nationwide support system if we can get government, as well as people, involved.

Hospice care is not just a philosophy, and a hospice is not just a place where people go to die. Hospice care, wherever it is provided and however it is defined, is people caring for and about people. It is a concept that, when carried out, focuses on individuals rather than on disease. Hospice means trained, multidisciplinary teams of doctors, nurses, pharmacists, psychologists, clergy, and lay volunteers from the community who are committed to helping the terminally ill and their families to accept the fact of death without fear, with dignity, and free from pain. Hospice care is where trained individuals, medical professionals as well as lay volunteers, have the time (and take the time) to provide loving care in a positive environment that enfolds both patient and family members.

Death is a sword with a double edge; it strikes fear into the hearts and minds of both patient and family. Hospice care providers can turn that fearful state of mind and body into a physical, emotional, spiritual, and intellectual support system that so throbs with the business of living that death is made to wait in the anteroom until it is called.

In our society, and not so long ago either, it was the rare family that would dream of taking their patient home to die. Patients normally remained at home until it was clear that they were dying, at which time they were sped immediately to a hospital specifically for that purpose. Psychologically, this process relieved guilt by implying that the family had done its best and that it was now up to the hospital and its personnel to either prolong life or give it up. A family that failed to follow this routine was considered neglectful, and supposedly it reflected their uncaring attitude toward the loved one. That is why hospice care is not merely a philosophy. Today more and more patients and their families are electing to die at home.

The hospice care concept begins when the patients themselves are encouraged to give families and doctors the cue that they have had enough: of chemotherapy that makes them even sicker, of medical procedures that cause them even more pain, of tests that are mostly experimental in nature and not really expected to help. Hospice care can begin when the medical specialists in charge know that further effort is useless and say so. Hospice care can be given when hope cannot because none is possible.

How can we convince parents, husbands, wives, and children that they should take their patient home, that they can cope with the care required for the terminally ill? How can we assure them they can cope with a patient's pain when they are not sure they can cope with their own—the grief and loss over the impending separation from a loved one?

We can tell them that there is a support system called hospice care, and if there is none in their community, we can challenge them to establish one. We can show them that they themselves can be trained to provide the loving care for a dying family member or neighbor, and we can put them in touch with someone to call on if they become frantic, anxious, or panicky because of unexpected behavioral symptoms or if patient suffering unfamiliar to them occurs.

Certainly we must challenge more and more families to take their patients home. But first we must challenge the communities across the country to create a hospice care support system that families can rely on. A hospice care support system must provide counseling and visiting health professionals, including physicians, to help them confront their own fears, to gather their courage, and to enable them to provide a pain-free, fear-free environment of comfort, tranquility, dignity, and self-fulfillment for the family member who has come home to die.

Elizabeth Kübler-Ross (1978), a pioneer in hospice care, has noted the benefits of allowing a person to die at home, with family and friends around, and a support system of hospice care professionals trained to help both patient and family during and after the death. She further remarks that if we can educate the general public that such a system requires very little time on our part and enlist them as facilitators and the catalysts for such a positive, constructive choice, then hospice care in this country will become the rule rather than the exception.

In the United States, the first hospice to provide the total patient home-care program necessary (when cure, active treatment, and prolongation of life are no longer the goal) was established in Connecticut. Since that opening, nearly 800 community centers involving volunteer and multidisciplinary teams have been established to provide hospice care in homes and other settings. Few states do not have such a facility, at least in the planning stages. My home state of West Virginia has 10 such units, strategically located so that they form a statewide network, but more are needed, and some are already being planned. We need many more hospice care units to serve a national population of more than 230 million.

The Reverend Michael Stolpman, director of the Wisconsin hospice, said, "The two promises we make to our patients are: one, we will keep them free from pain; two, they will not die alone" (Kübler-Ross, 1978, p. 139). If we become a nation committed to hospice care, those two promises alone would be considered a miracle for humankind.

No one should have to spend their final days, their final energies, their last financial resources, and all their hopes on the prolongation of a painful existence. Under hospice care, they would have dignity instead of dehumanizing machines. They would have trained staff who could take the time to care individually for and about them instead of overworked, overstressed hospital personnel who have neither the time nor the training to cope with terminally ill patients.

At present, the funding that supports hospice care comes from private donations, foundations, and local fund-raising efforts by community members. There are no regularly appropriated funds, at least at the federal level, that can generally be applied to hospice care.

As a nation, we spend more money on books to teach children and adults to cope with or confront death and dying after the fact than we do on making it possible for people to live out their final days in a pain-free environment surrounded by family and at peace with themselves. We spend more money on psychotherapy for surviving family members to help them recover from the stress and illness associated with grief than we spend on lessening the grief and associated guilt beforehand by teaching them to cope and to accept the fact of death. We spend millions of dollars a year on the costs associated with long-term care of terminally ill patients in hospitals, nursing homes, or other settings. These costs usually exceed the amount a family can pay or that private health insurers can pay.

This is not to say that we do not appreciate, are not grateful for, the care that is given to people in hospitals and nursing homes. Those facilities and the personnel who staff them, trained in the healing arts, provide a service that is expected and often demanded of them, although they may know that the patients cannot afford it and that society cannot afford it. They provide this kind of care to terminally ill patients in spite of the fact that if asked, they might urge patients who have been diagnosed as terminally ill to decline further treatment or life-support systems and urge them to seek alternate care.

It is time for this country to make an effort to achieve several goals. It is time for us to allow the use of restricted drugs, such as heroin, in managing and controlling the pain of terminal illness. It is time for the federal and state governments to allow persons eligible for Medicare to transfer that coverage from hospital to hospice if they so choose. It is time to begin a meaningful debate concerning an appropriate federal role regarding the growing need and demand for hospice care and pain control for the terminally ill. Such debate should be made an integral part of any future dialogue or decision making on the part of Congress as it continues to devise a means of controlling the health care costs that are growing rampant in this country.

There is a bill pending, S. 2013 (which I cosponsor), before the Senate Labor and Human Resources Committee to make the use of heroin legal in the treatment of intractable pain, under strictly controlled conditions. I have urged the chairperson to schedule hearings on S. 2013 at the earliest practicable date. I have cosponsored another bill, S. 1958 (which is pending before the Senate Finance Committee), to enable Medicare-eligible individuals who are diagnosed as terminally ill, with six months or less to live, to transfer Medicare payments from a hospital to a hospice if they choose.

As an interim measure, an amendment added to the Senate-passed Tax Equity and Fiscal Responsibility Act on July 22, 1982 provides for improved benefits for Medicare beneficiaries who elect to use their benefits to pay for hospice care during a terminal illness to assure, if nothing else, that pain management is available to them. This amendment, with 68 Senate members supporting it, was adopted because it was based on S. 1958 (which has more than 50 cosponsors); it differed in several respects but basically only in keeping costs in an acceptable range and to deter abuse of the Medicare program. I am pleased at this response to the hospice care concept on the part of the Senate.

These legislative initiatives represent no more than a modest, and certainly cautious, approach by the federal government to the hospice movement in the United States. They are a beginning, and we should make every effort to keep the momentum going, in the name of humanity.

I began this article by describing how I became involved in the hospice care movement. I spoke of Josefina Magno's visit to my office and her request that I sponsor a Senate resolution asking the President to proclaim the week of November 7 through 14, 1982, as "National Hospice Week."

On March 18, 1982, I introduced such a resolution (S. J. Res. 170) with 29 cosponsors. It passed the Senate on April 1, 1982, and was sent to the House of Representatives. It passed the House without amendment on May 12, and the President signed it into law on May 24—all in about two months' time.

S. J. Res. 170 makes no money available to fund expanded hospice care services in the United States, but it does express the sense of the Senate, the House of Representatives, and the President that it is possible and desirable for people who are nearing the end of life to have appropriate, competent, and compassionate care. S. J. Res. 170 commends and encourages those providers of hospice care—physicians, nurses, pharmacists, psychologists, social workers, physical and occupational therapists, clergy and lay volunteers—for caring about humankind. Resolution 170 does not guarantee anything, but it does recognize that hospice care has not yet had the national recognition necessary to create general public awareness that an alternate care system for the terminally ill is possible. During National Hospice Week we hope to educate the general public that these patients and their families need not suffer unnecessary physical, emotional, and spiritual pain attendant on terminal illnesses of all kinds. We hope to reach millions of people to let them know that hospice care is a realistic alternative to suffering, and that it is possible to live until you die in relative peace and comfort, in the joy of having your family and friends nearby, and with your personal integrity and individuality intact.

We hope to achieve a public education goal during that special week through appropriate forums, programs, and activities especially designed so that the hospice care movement can be seen as a realistic and humane response to the needs of our people. I believe that National Hospice Week could result in a national mandate to the federal government to take on a more active role in expanding the hospice care concept so that it is accessible to more and more people on a nationwide basis.

One out of every four persons now living in the United States—nearly 58 million—is expected to be diagnosed in his or her lifetime as having cancer. In 1982 alone, the National Cancer Institute projects that 832,000 persons in the United States will be diagnosed as having cancer and that 430,000 will die because of cancer. We ought not to wait much longer to at least give them hope by giving them a choice—an opportunity to choose hospice care as an alternative to a hospital or nursing home in their final days on earth.

The American public ought not to wait. We have the most modern, advanced medical technologies available. We should demand that those of our fellow men and women who will have cancer and other fatal diseases in the coming years will be able to obtain relief from intractable pain. Neither they nor we should die in agony because our own medical profession is barred from using appropriate drugs for pain management, drugs that are within our reach.

If the National Hospice Week observance does nothing else, surely it will make people aware that, through their individual efforts, hospice care can become a reality in our lifetime. Surely it will make them aware that they have a responsibility to make certain that their elected representatives at home and in Washington support these goals.

National Hospice Week will find many of us still praying for a miracle drug or procedure that will care for our terminally ill, and that is as it should be. But it will find many more of us, I hope, who are no longer willing to wait for the miracle while sitting helplessly by the bedside of a loved one not even daring to expect sufficient pain medication to ease the transition from this life to the next one. I believe in miracles. But while we keep our hopes high and our faith intact, let us begin to help ourselves and one another by changing the things we can by acting on a national scale to provide the legal instruments necessary to promote hospice care.

Let us make Reverend Michael Stolpman's promise to one another. First, "We will keep you free from pain," and second, "We promise that you will not die alone."

Nearly all of us have been touched by an experience of death or other tragedy in our own families and those of our friends and neighbors. Most of us have learned from these experiences and have been caused to take a look at our own values and to reevaluate the direction in which we are going with our lives. We have become aware of how fragile our existence is, and we have used our confrontation with death and suffering to better prepare ourselves so that if death arrives quickly and unexpectedly, we are ready to meet it. Such experiences have also helped many of us to prepare ourselves in case death announces itself in the form of a long-term, fatal illness.

But all of us will be better able to confront and accept the fact of our own dying or the death of loved ones if we know that we helped to create a mechanism, a system called hospice care, whereby we can live until we die. If we can prepare ourselves and our fellow humans to die well, then it can be said of us that we have truly lived.

REFERENCE

Kübler-Ross, E. *To live until we say good-bye.* Englewood Cliffs, N J: Prentice-Hall, 1978.

Dr. LISS-LEVINSON. Our program was designated in September of 1979 as the New York State hospice demonstration program. We have provided hospice care services in the past despite the complete absence of third party reimbursement. Thus, we welcomed the passage of TEFRA and actively sought certification as a Medicare hospice provider.

We were surveyed in October of 1983 based on draft Medicare regulations since the final Medicare regulations were not published until December 16, 1983, 3½ months after the legislation's required deadline. The reimbursement rates we anticipated at the time of our survey were significantly higher than those that appeared in the version of the final regulations.

Our experience with various bureaucratic delays, coupled with HCFA and the States' inability to clarify the meaning, intent, and limitations of but one provision of the regulations resulted in our formal certification being effective April 1984, 5 months after the survey process. And this appears not to be atypical.

Since certification, our experience has only further confirmed that the Medicare hospice benefit, as other providers have already mentioned, is really a blessing for the Medicare recipient. I think it's a competely different story, though, for our sponsoring institution, and our program in particular. These months have been fraught with great difficulty as we attempt to clarify various patient care and fiscal concerns. In dealing with both HCFA and our fiscal intermediary, I have generally encountered well intentioned persons who have only a minimal grasp of the hospice concept, the benefit and its regulations. Questions which often have immediate patient, programmatic, and fiscal implications, which require immediate answers, are rarely answered with due speed. Instead, we will receive an answer such as "thank you, you are helping us all to learn about this benefit, which is so new to all of us." We did not receive any information from either the Department of Health and Human Services or our fiscal intermediary about submitting admission and claim forms until the end of June 1984. We met with our fiscal intermediary in mid-August of this year at our own request.

To date, as you have already cited, our admission notices have yet to be processed. And, therefore, actual claims dating back to April cannot be submitted. The result is that we have yet to receive any reimbursement under this benefit, and that totals to the amount of nearly $82,000 in claims.

I might add that Dr. Davis suggested perhaps that hospices had been slow in submitting their claims. I'm afraid that the claim forms that have already been prepared are yellowing on my desk right now in anticipation of our fiscal intermediary notifying me that I can submit them.

A critical question regarding the professional and fiscal responsibility for a patient who may live beyond the three election benefit periods was just last week met with, "The central office is working on it." It is nearly 1 year after the November 1, 1983, implementation date and we need answers. And, finally, we have yet to receive any information or guidelines, draft or otherwise, regarding cost reporting forms and requirements.

Concerns have been raised regarding the requirement of the core services. I would just simply say that our experiences overall have been quite positive in complying with this. I am not totally convinced, though, that the experience of traditional home care agencies in using contractual nursing arrangements has resulted in any lower quality of care. And as an example, the core services requirement serves to preclude the creative utilization of what is commonly called fee for service nurses. Now these nurses, who would be directly employed by the hospice program, would not meet the Federal, definitions of an "employee." The experience of many home care programs such as our own nationally renowned long term home health care program indicates that this is both a quality alternative as well as cost effective to the utilization of fulltime personnel. A more liberal interpretation of the core services condition and allowances for Federal waivers of this requirement when professional resources are limited within a community, might be indicated.

Just to add my own thoughts regarding the issue of the inadequacy of the reimbursement, even in New York City where the wage index factor of 1.3675 increases the base rate of $46.25 a day to $57.87 per routine home care a day, our fiscal projections would indicate a loss of approximately $16 per patient per routine home care a day.

We also find that the continuous care level of reimbursement rules are functionally impractical and fiscally inadequate. By requiring that the care services provided during a brief period of prices, 8 hours or more, consists predominantly of nursing care, it fails to recognize what we see as the common realities of terminal care, which is that many times when there is a crisis, the increased need is for increased home health aide service houses. That is, services which do not require the particular skills of the licensed, practical/vocational nurse or a registered nurse. In those situations, we will be forced to bill at the routine home care rate and be losing money. And just as a brief example, I would anticipate if we did have a patient who required 24 hour continuous care over a 3-day period, we would probably lose $100 per patient per day over those 3 days.

I would like to indicate that our institution entered into this certification process with a strong commitment and a fiscal commitment to the hospice concept. It would seem to me, however, that cost effectiveness is not demonstrated through inadequate reimbursement.

Regarding psychologists—and I know you raised some questions to the previous panel—our implication is not that psychologists are by definition precluded. They certainly can be a part of the interdisciplinary team. However, it seems to me that the express mention of psychological services or psychologists would help to insure that they are not precluded. Our concern emanates from this: If the reimbursement is inadequate to cover even those minimally required services and staff costs, then special philanthropic dollars will be needed to merely survive as a basic hospice program. Thus, what we would probably expect is that most hospice programs will not even consider using psychologists in such vital capacities as members of the interdisciplinary care team, much less as consultants for more emotionally disturbed patients and families, leaders of inservice training groups, and facilitates the staff support, and stress reduction groups all for bereavement counseling.

Senator DURENBERGER. I didn't hear the end of that statement.

Dr. LISS-LEVINSON. What I would just simply say to you—and I know the issue has been raised—about the perception that, in fact, there is little interest in the health care community, as evidenced by the few programs certified in the hospice Medicare benefit, and also the assumption is then made that there is little consumer interest in this benefit, both of these seem to be untrue. I would say that the initially delayed and still impeded implementation of this benefit, coupled with the inaccuracy of the reimbursement, are the two main reasons for this.

And I would urge that this committee take steps to see that the benefit is implemented on a full, speedy, and unencumbered process. And also that we take a serious look at increasing the routine home care and continuous home care levels.

Thank you very much.

Senator DURENBERGER. Thank you very much.

[The prepared written statement of Dr. Liss-Levinson follows:]

TESTIMONY OF

William S. Liss-Levinson, Ph.D.

Director of The Brooklyn Hospice

at Metropolitan Jewish Geriatric Center

Brooklyn, New York

Members of the Committee, I am William S. Liss-Levinson, Ph.D., Director of The Brooklyn Hospice at Metropolitan Jewish Geriatric Center, Brooklyn, New York. As a Psychologist who administers a Medicare-certified Hospice program, I appear before you today representing the 72,000 members of the American Psychological Association and the Association for the Advancement of Psychology. I welcome the opportunity to tell you some of my concerns regarding the Medicare Hospice benefit. I will focus on four aspects of the benefit: problems in its implementation; concerns regarding the delivery of "core services;" inadequate reimbursement levels for routine home care and continuous care; and the overall impact of these problems on the involvement of psychologists in Hospice programs.

In addition, with your permission, I would like to submit for the record several articles that appeared in the November, 1982 American Psychologist on the subject of Hospice care.

The Brooklyn Hospice was designated in September 1979 as a New York State Hospice Demonstration Program. Operational since the Spring of 1980, we have provided Hospice care services over the past four years despite the complete absence of third-party reimbursement. Thus, we welcomed the passage of TEFRA and actively sought certification as a Medicare Hospice provider. We were surveyed in October 1983 by the New York State Department of Health's Bureau of HMO and Home Health Services, based on draft Medicare regulations. As you know, the final Medicare regulations were not published until December 16, 1983, three and one-half months after the legislation's required deadline. It should also be noted that the reimbursement rates we anticipated at the time of our survey were significantly higher than those that appeared in the final version of the regulations.

Our experience with various bureaucratic delays, often coupled with an inability to clarify the meaning, intent and limitations of certain provisions of the regulations, resulted in our formal certification being effective in April, 1984, five months after our survey. This appears not to be atypical for the certification process. In fact, two other New York State Hospice Demonstration Programs in New York City that were surveyed a few weeks prior to us in October of 1983 have yet to receive their certification. It is significant that on November 1, 1983, when the legislation was to have been fully implemented, with reimbursement flowing to those certified programs, only one Hospice program in the entire United States had been certified.

Since certification, our experience has only further confirmed that the Medicare Hospice benefit could be a truly wonderful blessing for the Medicare recipient, but is not. For our program and sponsoring institution, however, these months have been fraught with great difficulty as we attempt to clarify various patient care and fiscal concerns. In dealing with both the Health Care Financing Administration (Regional and Central offices) and our fiscal intermediary (Blue Cross/Blue Shield of Greater New York), I have generallyencountered well-intentioned persons who have only a minimal grasp of the Hospice concept, or of the benefit and its regulations. Questions which often have immediate patient, programmatic, and fiscal implications - and thus truly requiring immediate answers - are rarely answered with due speed. Instead, we receive an answer such as: "thank you, you're helping us all to learn about this benefit, which is so new to all of us." We did not receive any information from either the Department of Health and Human Services or our fiscal intermediary about submitting admission and claim forms until the end of June 1984. To date, our Admission notices have yet to be processed; therefore, actual claims dating back to April cannot even be submitted. The result is that we have yet to receive any reimbursement dollars under this benefit. Just last week, a critical question regarding our professional and fiscal responsibility for a patient who may live beyond the three election benefit periods was met with "The Central office is working on it." It is nearly one year after the November 1, 1983 implementation date for this legislation, and we need answers. Finally, we have yet to receive any information or guidelines, draft or otherwise, regarding cost-reporting forms and requirements. Even one less cynical than I might question the Department's and HCFA's desire to implement this legislation fully given their track record to date.

Concerns have been expressed regarding the regulations specifying that the Hospice must provide certain "core services" directly through its employees. We have, of course, complied with this, as compared to our pre-Medicare practice of contracting for nursing services, and our experience has been positive. We encounter no conflicts over issues such as control of, and responsibility for, the patient, and communication between our nursing staff and our nursing supervisors is excellent. However, I do not believe that the practice of traditional home health care programs to use contractual nursing arrangements resulted in any lower quality of care. Our Hospice program's pre-Medicare problems in the area of contractual arrangements clearly emanated from our inability to receive third-party reimbursement. Thus, the certified home health agency we dealt with (which was directly reimbursed and thus had a legal responsibility as the primary caregiver) felt the need to exercise control over patient care and decisions. It is very clear, however, from our continuing and current practice of contracting for home health aide services, for example, that we can provide a high quality of care to the Hospice patient through contractual services.

The "core services" requirement also serves to preclude some creative utilization of "fee-for-service" nurses. These nurses, while directly employed by the Hospice, would not meet the Federal definitions of an "employee." The experience of many home care programs, including Metropolitan Jewish Geriatric Center's own nationally acclaimed Long Term Home Health Care Program, has been that this approach is both a high quality and cost-effective alternative to engaging full-time personnel. A more liberal interpretation of the "core services" condition of participation, and allowances for federal waivers of this requirement when professional resources are limited within a community, might well be indicated.

Regarding reimbursement, the current routine home care rate of $46.25 per day is clearly insufficient. Even in New York City where the Wage Index Factor of 1.3657 increases that base rate to $57.87 per day, our early fiscal projections indicate a loss of approximately 14 dollars per patient per day. This estimate is based solely on our operating expenses of staff salaries and services provided under contractual agreements (for example, drugs, equipment and supplies). We, as is true for many institutionally-based programs, have heretofore not had our institution's administrative and overhead costs broken out and charged to our accounts. Preliminary estimates by our Finance Department indicate that this would yield an additional dollar and a half to two dollars in cost per patient per day. Thus we can realistically expect to be losing perhaps $16 per patient per routine home care day at the current rate. In essence, we support the comments and recommendations of the National Hospice Organization in this regard.

We find the continuous care level reimbursement rules to be functionally impractical and fiscally inadequate. By requiring that the care services provided during a brief period of crisis -- eight hours or more, consist predominantly of nursing care, the regulation fails to recognize the common realities of terminal care. Most people we have encountered, when needing increased care for a period of crisis - even up to 24-hour care - do not require that this be provided by either a Registered Nurse or a Licensed Practical/Vocational Nurse. Rather, increasing the hours of home health aides, coupled with more frequent nursing visits, is the usual and sufficient pattern. ["More frequent" here refers to perhaps as much as daily RN visits.] However, we currently find ourselves in the predicament of generally increasing home health aide hours for a brief period of crisis, but only being able to bill at the routine home care rate. Furthermore, in the rare instances where in fact a patient's needs would meet the continuous care level, we will receive $18.70 per hour (adjusted for New York City) while providing LPN services at a cost of $18 per hour, or RN services at a cost of $21 per hour -- and both these rates exclude our other service costs!

I would just note, in closing my comments on the topic of reimbursement, that Metropolitan Jewish Geriatric Center entered into this Medicare certification process with its own strong and proven fiscal commitment to the Hospice program. We welcomed the challenges of a prospective reimbursement system and other legislative and regulatory features that were designed to ensure Hospice's cost-effectiveness. It would seem, however, that cost-effectiveness is not truly demonstrated if achieved through inadequate reimbursement.

The implications of all the above problems for the involvement of psychologists in Hospice programs are perhaps subtle, but they are significant. Psychologists are not technically precluded from being members of the interdisciplinary team, where they might share their expertise in the psychosocial support of the patient and family. We would suggest the express mention of psychological services or psychologists in the statute to assure that they are <u>not</u> precluded. It is clear to me that if the reimbursement is inadequate to cover even those minimally required services and staff costs, then precious philanthropic dollars will be needed to merely survive as a "basic" Hospice program. The lack of mention of psychologists in the statute and the fiscal constraints suggests that most Hospice programs will not even consider using psychologists in such vital capacities as: members of the interdisciplinary care team; consultants for more emotionally disturbed patients and families; leaders of in-service training; facilitators for staff support and stress reduction groups; and bereavement therapists.

The emotional burdens of death and dying are not limited to patients in Hospice programs and their families. The staff have very clear needs for psychological insight and emotional support as well. Care of the dying is much more than a medical issue; in fact, physicians are quite limited in their role in dealing with it. The human issue of death, pain, and loss must be addressed by the Hospice staff, and this places the patient, the family, and the Hospice staff under incredible pressure. These are areas where psychologists can be invaluable -- and it concerns me greatly that their services may be lost due to inadequate understanding and inadequate reimbursement.

In ending my testimony, I would share with you my fear regarding the four areas I've outlined. Officials in a number of New York State Department of Health agencies have told me of a growing perception in Federal circles that there is, in fact, little interest in providing Hospice care services, as measured by the few Hospice programs that have been Medicare certified to date. They further point to the rather small number of Hospice Medicare claims received as an indication that there is little consumer interest in receiving Hospice services. Neither of these perceptions is true. HHS and HCFA's initially delayed, and still impeded implementation of this benefit, coupled with the inadequacy of the reimbursement rates, have been the major factors that have resulted in low utilization. I would urge this Committee to take the necessary steps to guarantee that both the Department of Health and Human Services and the Health Care Financing Administration proceed with the full, speedy and unencumbered implementation of this legislation. Furthermore, I would urge that the reimbursement rates for both routine home care and continuous care be re-evaluated with an eye to more reasonable and appropriate levels of reimbursement.

This legislation "sunsets" on September 30, 1986. It would be most unfortunate if we fail to create the necessary regulatory and fiscal environments to truly and fully assess the impact of this historic benefit on the quality of living and of dying in this country.

Thank you.

STATEMENT OF ANNE KATTERHAGEN, EXECUTIVE DIRECTOR OF THE HOSPICE OF TACOMA, TACOMA, WA, ON BEHALF OF THE NATIONAL ASSOCIATION FOR HOME CARE, WASHINGTON, DC

Senator DURENBERGER. Ms. Katterhagen.

Ms. KATTERHAGEN. Mr. Chairman, my name is Anne Katterhagen. I am the founder and executive director of Hospice of Tacoma in Tacoma, WA, the other Washington.

I have been involved in hospice care since 1975, and I am here to testify on behalf of both my own hospice and the National Association for Home Care, currently known as NAHC, for whom I serve as the hospice section representative to the board of directors.

NAHC is the Nation's largest professional organization representing the interests of over 2,000 home health agencies, hospices, and homemaker home health aid programs.

According to the results of a recent comprehensive national study conducted by NAHC, the Nation's hospice movement is boycotting the Medicare Hospice Program. The principal reason why existing and potential hospice providers are not seeking Medicare certification is financial. Hospices feel that reimbursement has been set at unrealistically low levels and the onerous redtape and other requirements combine to make participation in the program singularly uninviting.

The study shows that 78.5 percent of the home care agencies in the Nation currently provide hospice services and plan to continue to do so. An amazing 85 percent of the entities have not applied for Medicare certification. In other words, only 15 percent of the responding sample have applied to Medicare and only an additional 4 percent plan to apply in the future.

This means that 81 percent of the existing hospice programs in the Nation offering palliative and supportive services to the dying are boycotting the Medicare Program.

Asked to give their reasons for turning their back on Medicare, respondents almost uniformly pointed to inadequate reimbursement coupled with excessive redtape. In fact, four out of the top five reasons cited for sidestepping the Medicare Program related to inadequate financing.

The most important reason ranked first by 54 percent of the respondents was that the rates are too low. Second, 47 percent of providers mentioned their concern that the overall cap on reimbursement was too low. Almost an identical number said redtape, especially the professional management responsibility requirement; is too onerous. The fourth ranked reason for the boycott cited by 25 percent of those who responded was application of the requirement that 80 percent of hospice care must be provided at home, with a limit of 20 percent for care provided in an inpatient setting. The application of this cap as a retrospective adjustment on reimbursement seems to offend hospices.

I would like to offer this particular survey for the record also.

Senator DURENBERGER. It will be made part of the record.

[The survey from Ms. Katterhagen follows:]

1984 NAHC

MEDICARE HOSPICE BENEFITS

PARTICIPATION SURVEY

HOSPICE SURVEY RESULTS

INTRODUCTION

At its March 25, 1984 meeting, NAHC'S National Legislative Advisory Committee requested that NAHC conduct a survey of hospice and home care programs nationwide to assess how they were responding to the availability of Medicare hospice certification. This certification became effective November 1, 1983 and expires September 30, 1986, pursuant to Section 122 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA).

In May 1984 NAHC sent a one page survey to 2,784 home health agencies and hospices. A total of 678 (or 24 percent) completed usable surveys as of August 15, 1984. The first question on the survey asked whether the agency provides hospice services. The survey results which follow are presented in three groupings: (1) overall results irrespective of whether the agency provides hospice services; (2) results from agencies which said they provide hospice services; and (3) results from agencies which said they did not provide hospice services.

On a statistical basis, the 678 respondent sample size gives valid and reliable results at the 99 percent confidence level with an expected error rate of plus/minus 2 percent.

A. OVERALL RESULTS

A total of 678 agencies responded (24 percent of all those surveyed). The number responding to each question varied and is indicated in the results below.

1. Do you provide Hospice Services?

   - 78.5 percent (532) said they were providing hospice services.
   - 21.5 percent (146) said they were not providing hospice services.

2. Have you applied for Medicare certification?

   - 85 percent (577) said they had not applied.
   - 15 percent (101) said they had applied.

3. If you applied for Medicare certification, what's the status of your application?

   The responses to this question are based on a total of 101 respondents who said they had applied for Medicare certification.

Application Status	Number	Percent of Total (Total=101)
Approved	56	56
Disapproved	3	4
Pending	39	36
No Response	3	4

4. If you applied for Medicare certification and were approved, how long did the approval process take?

   The responses to this question are based on a total of 56 respondents whose applications had been approved.

Length of Time	Number	Percent of Total (Total=56)
Less than 1 month	2	2
1 - 3 months	21	38
3 - 6 months	21	38
6 - 9 months	11	20
More than 9 months	1	2

5. If you did not apply, give all the reasons you did not apply for Medicare certification.

Respondents were asked to list all the reasons they did not apply. Therefore, the number responding to each reason is listed below as a percent of the total of 577 respondents who indicated they had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=577)
1. Rates too low	312	54
2. Professional management responsibility requirement too onerous	268	47
3. Inability to subcontract for nursing services	110	19
4. Overall cap too low	273	47
5. 80/20 requirement	146	25
6. Inability to develop in-patient services contract	127	22
7. Failure to reimburse for bereavement services	137	24

6. Give the two primary reasons for not applying for Medicare certification?

Again, the percent figure is based on a percentage of the total of 577 respondents who indicated they had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=577)
1. Rates too low	288	50
2. Professional Management Responsibility Requirement too onerous	141	24
3. Inability to subcontract for nursing services	61	11
4. Overall cap too low	150	26
5. 80/20 requirement	46	8
6. Inability to develop in-patient services contract	37	6
7. Failure to reimburse for bereavement services	12	2

7. Do you intend to apply for Medicare certification?

These figures are based on the total of 577 respondents who had not applied for Medicare certification.

Intend to Apply	Number	Percent of Total (Total=577)
Yes	108	19
No	336	58
Undecided	133	23

8. When do you intend to apply for Medicare certification?

These figures are based on the total of 108 respondents who said they intend to apply.

Date	Number	Percent of Total (Total=108)
July 1984	9	8
August 1984	7	6
September 1984	14	13
Undecided	71	66
No response	7	7

B. AGENCIES PROVIDING HOSPICE SERVICES

The results in this section are based on the responses of the 532 respondents (78.5 percent of 678 total) who said they were providing hospice services.

1. When did you serve your first patient?

Date		Number	Percent of Total
Pre-1980		155	29
1980		100	19
1981		94	18
1982		90	17
1983		57	11
First Quarter	(14)		
Second Quarter	(14)		
Third Quarter	(7)		
Fourth Quarter	(22)		
1984		24	4
First Quarter	(7)		
Second Quarter	(12)		
Third Quarter	(4)		
Fourth Quarter	(1)		
No response		12	2

2. What type of hospice program do you have?

Type	Number	Percent of Total
Community-Based (All Volunteer)	62	12
Community-Based (Combination Volunteer & Professional)	8	2
Home Health Agency-Based	263	49
Nursing Home-Based	10	2
Hospital-Based	121	22
Coalition Agency	68	13

3. Have you applied for Medicare hospice certification?

19 percent (100) of the 532 agencies providing hospice services said they had applied for hospice certification. 81 percent (432) of the agencies said they had not applied.

4. What is the status of your Medicare application?

Application Status	Number	Percent of Total (Total=100)
Approved	55	55
Disapproved	3	3
Pending	39	39
No response	3	3

5. How long did the approval process take?

Length of Time	Number	Percent of Total (Total=55)
Less than 1 month	2	3
1 - 3 months	20	36
3 - 6 months	21	38
6 - 9 months	11	20
More than 9 months	1	3

6. If you did not apply, give all the reasons you did not apply for Medicare certification.

Respondents were asked to list all the reasons they did not apply. Therefore, the number responding to each reason is listed below as a percent of the total of 432 respondents who indicated they provide hospice services, but had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=432)
1. Rates too low	262	61
2. Professional Management Responsibility Requirement too onerous	225	52
3. Inability to subcontract for nursing services	96	22
4. Overall cap too low	229	53
5. 80/20 requirement	127	29
6. Inability to develop in-patient services contract	107	25
7. Failure to reimburse for bereavement services	113	26

NEEDS ASSESSMENT SURVEY RESULTS

INTRODUCTION

In May 1984 NAHC sent its second annual needs assessment survey to 1,674 member agencies in order to assess member education and training needs. The results will be used to help NAHC plan its 1985 workshops, annual meeting program and other educational and training activities. As of August 15, 1984, 339 agencies responded representing a 20 percent sample. This sample is statistically valid at the 99 percent confidence level with an error tolerance rate of plus/minus two percent.

The results are presented in four sections: (1) agency profile, (2) seminars and conferences, (3) newsletters and journals, (3) manuals and books, and (4) audio-visual materials. For purposes of comparison, the 1983 results were published in the November 1983 issue of *Caring* magazine (pages 14-15).

A. AGENCY PROFILE

1. In what year did your agency serve its first patient?

Year	Number	Percent of Total (Total=339)
Pre-1900	7	2%
1901-1930	53	16%
1931-1950	18	5%
1951-1966	40	12%
1967-1970	18	5%
1971-1980	114	34%
After 1980	89	26%

2. How many full-time clinical staff do you have, what percent are experienced, and what percent are new to your agency?

a. Numbers of Clinical Staff

Numerical Ranges of Full-Time Clinical Staff	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10	156	46%
11-30	112	33%
31-50	26	8%
51-75	18	5%
76-100	11	3%
101-150	10	3%
151-200	1	0.4%
201-300	2	0.6%
301-500	2	0.6%
501-1,000	1	0.4%
Over 1,000	0	0%

b. Experience of Clinical Staff

Ranges of Percent Experienced	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	22	7%
11-20%	4	1%
21-40%	7	2%
41-60%	40	12%
61-80%	66	19%
81-100%	200	59%

c. Clinical Staff New to Agency

Ranges of Percent New to Agency	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	175	52%
11-20%	58	17%
21-40%	61	18%
41-60%	29	8%
61-80%	3	1%
81-100%	13	4%

3. How many full-time administrative staff do you have, what percent are experienced and what percent are new to your agency?

a. Numbers of Administrative Staff

Numerical Ranges of Full-Time Administrative Staff	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10	278	82%
11-30	41	12%
31-50	12	4%
51-75	4	1%
76-100	1	.25%
101-150	1	.25%
151-200	2	.5%
201-300	0	
301-500	0	
501-1,000	0	
Over 1,000	0	

b. Experience of Administrative Staff

Ranges of Percent Experienced	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	16	4.5%
11-20%	1	.5%
21-40%	5	1%
41-60%	30	9%
61-80%	43	13%
81-100%	244	72%

c. Administrative Staff New to Agency

Ranges of Percent New to Agency	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	221	65%
11-20%	28	8%
21-40%	44	13%
41-60%	29	8%
61-80%	4	2%
81-100%	13	4%

4. How many volunteers do you have, what percent are experienced, and what percent are new to your agency?

a. Number of Volunteers

Numerical Ranges of Volunteers	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10	241	71%
11-30	40	12%
31-50	26	8%
51-100	14	4%
Over 100	10	3%
No answer	8	2%

b. Experience of Volunteers

Ranges of Percent Experienced	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	43	13%
11-20%	1	.3%
21-40%	6	1.7%
41-60%	26	7.5%
61-80%	40	12%
81-100%	197	58%
No answer	26	7.5%

c. Volunteers New to Agency

Ranges of Percent New to Agency	Number of Agencies In Each Range	Percent of Total (Total=339)
0-10%	262	77%
11-20%	12	4%
21-40%	15	4%
41-60%	12	4%
61-80%	6	1%
81-100%	23	7%
No answer	9	3%

5. For which staff is education and training most needed? Each response to a category of staff is a percent of the 339 responding agencies.

Staff Category	Number of Agencies	Percent of Total
Clinical	190	56%
Administrative	145	43%
Volunteers	67	20%
Other	64	19%

6. Does your agency have a formal education and training program?

Have Program	Number	Percent of Total (Total=339)
Yes	173	51%
No	125	37%
No answer	41	12%

7. Do your clinical staff have any mandated continuing educational needs which are difficult to fulfill?

Difficult to Fulfill	Number	Percent of Total (Total=339)
Yes	54	16%
No	278	82%
No answer	7	2%

8. If there are mandated continuing education (CE) needs which are difficult to fulfill, please list them. Each is listed as a percent of the 54 respondents who said there were such needs.

CE Need	Number	Percent of Total
Therapy Services	28	52%
High Tech Services	30	56%
Physical Assessments	15	28%
Case Management	8	15%

B. SEMINARS AND CONFERENCES

1. How available are seminars and conferences to your agency?

Availability	Number	Percent of Total (Total=339)
Readily Available	140	41%
Available, but not Homecare Focus	119	35%
Not Available	80	24%

2. Name one conference or seminar you attended. The seminars/conferences listed most frequently are listed below. There were a variety of other private or publicly-sponsored conferences/seminars listed as well. Each response category is represented as a percent of the 339 respondents.

Conference/Seminar	Number	Percent of Total
NAHC 1983 Annual Meeting	157	46%
NAHC 1983 Legislative Conference	35	10%
NAHC Regional Workshops	15	4%
NAHC Hospice Workshops	25	7%
State Association-sponsored Workshops	44	13%

3. How many conferences or seminars have you attended in the last 6 months?

Number Attended	Number	Percent of Total (Total=339)
0-2	165	49%
3-5	146	43%
More than 5	28	8%

4. How relevant to the homecare field were these conferences or seminars?

Relevance	Number	Percent of Total (Total=339)
Very	237	70%
Somewhat	93	27%
Not at all	9	3%

7. Give the two primary reasons for not applying for Medicare certification?

Again, the percent figure is based on a percentage of the total of 432 respondents who indicated they provide hospice services, but had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=432)
1. Rates too low	258	59
2. Professional Management Responsibility Requirement too onerous	111	26
3. Inability to subcontract for nursing services	55	13
4. Overall cap too low	119	28
5. 80/20 requirement	42	10
6. Inability to develop in-patient services contract	34	8
7. Failure to reimburse for bereavement services	8	2

8. Do you intend to apply for Medicare certification?

These figures are based on the total of 432 respondents who provide services, but had not applied for Medicare certification.

Intend to Apply	Number	Percent of Total (Total=432)
Yes	91	21
No	277	64
Undecided	64	15

9. When do you intend to apply for Medicare certification?

These figures are based on the total of 91 respondents who said they intend to apply.

Date	Number	Percent of Total (Total=91)
July 1984	8	10
August 1984	6	6
September 1984	11	12
Undecided	60	66
No response	6	6

C. AGENCIES NOT PROVIDING HOSPICE SERVICE

The results in this section are based on the response of the 146 respondents (21.5 percent of 678 total) who said they were not providing hospice services.

1. Have you applied for medicare hospice certification?

   Only .6 percent (one agency) of 146 applied for medicare certification, they were approved, and the approval process took 1-3 months.

2. If you have not applied, give all the reasons you did not apply for Medicare certification.

   Respondents were asked to list all the reasons they did not apply. Therefore, the number responding to each reason is listed below as a percent of the total of 145 respondents who indicated they do not provide hospice services, and had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=145)
1. Rates too low	50	34
2. Profesional management responsibility requirement too onerous	43	30
3. Inability to subcontract for nursing services	14	9
4. Overall Cap too low	47	32
5. 80/20 requirement	19	13
6. Inability to develop in-patient services contract	14	9
7. Failure to reimburse for bereavement services	24	17

3. Give the two primary reasons for not applying for Medicare certification.

   Again, the percent figure is based on a percentage of the total of 145 respondents who indicated they do not provide hospice and had not applied for Medicare certification.

Reason	Number	Percent of Total (Total=145)
1. Rates too low	30	21
2. Professional Management Responsibility Requirement too onerous	30	21
3. Inability to subcontract for nursing services	6	4
4. Overall cap too low	31	21
5. 80/20 requirement	4	3
6. Inability to develop inpatient services contract	3	2
7. Failure to reimburse for bereavement services	4	3

4. Do you intend to apply for Medicare certification?

These figures are based on the total of 145 respondents who do not provide hospice services and had not applied for Medicare certification.

Intend to Apply	Number	Percent of Total (Total=145)
Yes	17	12
No	59	41
Undecided	69	47

5. When do you intend to apply for Medicare certification?

These figures are based on the total of 17 respondents who said they intend to apply.

Date	Number	Percent of Total (Total=171)
July 1984	1	5
August 1984	1	5
September 1984	3	18
Undecided	12	72

Ms. KATTERHAGEN. What this means is that the American hospice movement ironically will continue as it developed in America as a grassroots movement supported by volunteers and philanthropy. It also means that thousands of Medicare patients eligible by law for hospice benefits are likely to go without such services. This study also found that among the 100 providers who had sought Medicare certification, 56 percent had been approved and 39 percent were pending and the remainder had been denied. This study also gave some insight into hospice sponsorship as of 1984, August. Forty-nine percent of those providing hospice and related services were home health agencies. Hospital based programs ranked second with 22 percent of the total. Community-based, free standing hospices accounted for 14 percent. And coalition models built upon community cooperation and subcontracting accounted for 13 percent. Nursing home based hospices accounted for 2 percent.

We feel that corrective action is needed now. If Congress does not act quickly to amend the hospice law and raise the rates, many legitimate providers will not participate in the Medicare hospice benefit, and thousands of legitimately needy terminally ill persons will not be served.

We do not believe this was your intent in creating the Medicare hospice benefits. Forty percent of those who applied were certified within 3 months. Fully 78 percent who applied were certified in 6 months or less.

We also pointed out that since the routine home care rate was so unrealistically low it might encourage some providers to give more than 8 hours of home care in order to qualify for the higher continuous home care rate. The irony is that while HHS lowered the original proposed routine home care daily rate—from $53.17 to $46.25—thay actually raised the continuous home care daily rate from $311.96 to $358.97.

Let me point out the absurdity of this rate system. If you render routine home care you receive a daily rate of $46.25 which comes out to $5.78 an hour—$46.25 divided by 8 hours. If you give continuous home care you receive a daily rate of $358.97 which comes to $14.94 an hour—$358.97 divided by 24 hours. I ask you—Does this make sense?

We feel that Medicare has broken a promise to the elderly of this Nation. They were led to believe by the Government press releases that they would receive essential home care services in their hour of critical need. Now we are in the position of telling them it just isn't so. This is neither right nor fair. We must do all that we can to make sure that Medicare delivers what it has promised. In enacting legislation which would raise the current rates, more quality hospices would be able to serve the Nation's terminally ill. We ask your help in doing this.

This concludes my statement. I will happy to answer additional questions.

Senator DURENBERGER. Thank you.

[The prepared written statement of Ms. Katterhagen follows:]

TESTIMONY OF ANNE KATTERHAGEN

EXECUTIVE DIRECTOR - HOSPICE OF TACOMA

TACOMA, WASHINGTON

Mr. Chairman and Members of the Committee:

My name is Anne Katterhagen. I am the Executive Director of the Hospice of Tacoma in Tacoma, Washington and have been involved in hospice care since 1975. I am here to testify on behalf of both my own hospice and the National Association for Home Care (NAHC), for whom I serve as Hospice Section Representative to the Board of Directors. NAHC is the nation's largest professional organization representing the interests of over 2,000 home health agencies, hospices and homemaker/home health aide organizations.

We would like to commend you for holding these hearings. We believe there are severe problems in both the hospice law as enacted by Congress and in the regulations promulgated by the Department of Health and Human Services (HHS). Since NAHC represents over half of the hospices in the United States, we are asking your help, as we did earlier this year, to remedy what we believe are serious problems.

According to the results of a recent comprehensive national study conducted by NAHC, the nation's hospice movement is boycotting the Medicare program. The principal reason why existing and potential hospice providers are not seeking Medicare certification is financial. Hospices feel that reimbursement has been set at unrealistically low levels and the onerous red tape and other requirements combine to make participation in the program "singularly uninviting."

The study was sent in May 1984 to 2,784 home health agencies (HHAs) and hospices to determine the level of participation by HHAs and hospices in the Medicare hospice program and the reasons for non-participation. Approximately 25 percent of those surveyed returned usable responses by August 15, 1984, resulting in a sample giving statistically valid and reliable results at the 99 percent confidence level with an expected error rate of plus/minus 2 percent. With your permission, Mr. Chairman, I would like to submit this study for the record.

The study shows that 78.5 percent of the home care agencies in the nation currently provide hospice services and plan to continue doing so. An amazing 85 percent of the entities have not applied for Medicare certification. In other words, only 15 percent of the responding sample have applied to Medicare and only an additional 4 percent plan to apply. This means that 81 percent of the existing hospice programs in the nation offering palliative and supportive services to the dying are boycotting the Medicare program.

Asked to give their reasons for turning their back on Medicare, respondents almost uniformly pointed to inadequate reimbursement coupled with excessive "red tape." In fact, four out of the top five reasons cited for sidestepping the Medicare program related to inadequate financing.

The most important reason (ranked first by 54 percent of the respondents) was that rates are too low. Second, 47 percent of providers mentioned their concern that the overall cap on reimbursement was too low. Almost an identical number said red tape (i.e., the professional management responsibility requirement) is too onerous. The fourth ranked reason for the boycott (cited by 25 percent of those who responded) was application of the requirement that 80 percent of hospice care must be provided at home with a limit of 20 percent for care provided in an inpatient hospital setting. The application of this cap as a retrospective adjustment on reimbursement seems to offend hospices.

The fifth ranked reason (mentioned by 24 percent of respondent) was the Medicare requirement that hospices must provide bereavement services but without reimbursement from Medicare. Ranked next was the inability of hospices to arrange inpatient service contracts. This was cited by 22 percent of the respondents. This was followed by the inability to subcontract for nursing care which Medicare requires must be provided by the hospice directly as a "core service."

Surprisingly, the nation's hospices did not mention the requirement in the law and regulations which requires the hospice to continue to provide care for patients after Medicare entitlement has been exhausted. Similarly, no one seemed deterred by the possibility of lawsuits or requirements with respect to supervision and medical direction. Nor did many providers mention their fear that Congress would not extend the hospice benefit when it expires in September 1986.

What this means is that the American hospice movement ironically will continue as it has developed in America as a grass roots movement supported by volunteers and philanthropy. It also means that thousands of Medicare patients eligibile by law for hospice benefits are likely to go without such services.

The study also found that among the 100 providers who had sought Medicare certification, 56 percent had been approved, 39 percent were pending and the remainder had been denied. 40 percent of those who applied were certified within 3 months and fully 78 percent who applied were certified in six months or less.

The study also give some insight as to hospice sponsorship as of August 1984. 49 percent of those providing hospice and related services were home health agencies. Hospital-based programs ranked second with 22 percent of the total; community-based freestanding hospices accounted for 14 percent; coalition models built upon community cooperation and subcontracting accounted for 13 percent; and nursing home-based hospices accounted for 2 percent.

A recent report by the HHS Inspector General's office concurs with the NAHC finding that low participation in the Medicare hospice program is correlated with the low hospice rates. The IG report, however, recommends that no changes be made in the hospice law until 1986.

We feel that corrective action is needed now. If Congress does not act quickly to amend the hospice law to raise the hospice rates, many legitimate providers will not participate in the Medicare hospice benefit and thousands of legitimately needy terminally ill persons will not be served. We do not believe his was your intent in creating the Medicare hospice benefits.

Congressman Tom Vandergriff (D-TX) has introduced legislation (H.R. 5141) which would raise the hospice rates for routine home care and inpatient respite care to levels originally proposed in HHS' August 1983 Notice of Proposed Rulemaking (NPRM). Senator Dennis DeConcini (D-AZ) has introduced parallel legislation in the Senate (S. 2725). And Congressman Leon Panetta (D-CA) has introduced legislation (H.R. 5386) which would raise the routine home care rate to $53.17 — the rate in the original, proposed regulation. We strongly endorse these legislative proposals as a good first step and feel that they are critical to the continued viability of hospice in America.

Let us make it clear that even the NPRM rates may not fully solve the problem. We see them as the minimum mandatory levels to ensure a reasonable level of participation by hospice providers and reasonable access by beneficiaries. We submitted a lengthy methodological and operational critique of the rates to Congress and HCFA last year. We noted that the current $46.25 routine home care rate (which covers up to 8 hours of care a day) was not realistically related to the cost of care given the nature of skilled care to terminally ill persons and the administrative cost of compliance with the hospice law's continuity of care and "professional management responsibility" requirements. The administrative cost burden is important because the hospice benefit is based on a quasi-prospective payment system and does not reimburse administrative cost separately so the must be absorbed in the direct service cost.

We also pointed out that since the routine home care rate was so unrealistically low it might encourage some providers to give more than eight hours of home care in order to qualify for the higher continuous home care rate. The irony is that while HHS lowered the original proposed routine home care daily rate (from $53.17 to $46.25) they actually raised the continuous home care daily rate from $311.96 to $358.97.

Let me point out the absurdity of this rate system. If you render routine home care you receive a daily rate of $46.25 which comes out to $5.78 an hour ($46.25 divided by 8 hours). If you give continuous home care you receive a daily rate of $358.97 which comes to $14.94 an hour ($358.97 divided by 24 hours). I ask you -- Does this make sense?

We feel that Medicare has broken a promise to the elderly of this nation. They were led to believe by government press releases that they would receive essential home care services in their hour of critical need. Now we are in the position of telling them it isn't so. This is neither right nor fair. We must do all we can to make sure Medicare delivers what it promised. In enacting legislation which would raise the current hospice rates, more quality hospices would be able to serve our nation's terminally ill. We ask your help in doing this.

This concludes my statement. I thank you for the opportunity to share our thoughts with you today and remain available to assist in any way possible.

Senator DURENBERGER. Let me ask each of you to respond to how things are different today from what they were 2 years ago, and leave out the part about the promise because I think I agree with you on the promise that we have made. Others might disagree with that. But leave that out, and just look at it in terms of Medicare eligible people in this country. Are they worse off today than they were in 1982 because of the broken promises? Or are they same? Or are they only slightly better off? And if we had delivered on our promise, they would be even better off?

Dr. LISS-LEVINSON. If I might start. I think those who are able to receive the benefit are better off. I think we have clearly seen a demonstration that there are many States in which people cannot receive the benefit. And, certainly, I think the point that Reverend Westbrook made about the failure of the Federal Government to publicize the benefit is another added problem. I think for those people who do receive the services under the benefit, they are better off. I think there is a longer range perspective, which is that if there is continued inadequate reimbursement ultimately no one will be better off because I believe programs will have to fold under the financial pressure. So in the short range for that person who receives it, he or she is better off.

Senator DURENBERGER. I thought our promise was to access more Americans to a quality benefit principally for the terminally ill than had access to it in 1982. It was not my impression that we were taking a step backward. We just haven't moved ahead quickly enough in the step forward. And with all this talk about thousands of people that aren't getting something or other, I don't want to be left with the impression that the people are worse off today than they were in 1982, if that is not correct. But maybe it is correct.

Reverend Westbrook. I think in some respect they are worse off. There were patients being taken care of in programs that were certified as home health agencies, they were certified as hospitals, there were nursing homes, that were part of consortium groups or other kinds of community groups that were led to believe last fall that they were going to have an expanded Medicare benefit available to them. That promise was broken. Not to those hospices, but to those patients.

We talk a lot about the inconvenience to the provider. What we have discovered is what we have discovered a number of times. Two of the programs that we operate now were Medicare demonstration programs in the HCFA demonstration. When that began in 1980, we significantly expanded the services we were able to provide because more was provided, and more became available at that point to that population. That should have happened again and it did not.

And there were people who were being taken care of in hospices who believed that they were going to have drugs covered in the home care setting, that they were not going to have to relinquish their care giver and be sent off to another institution to receive part of the care they needed; instead that they were going to be part of a hospice that was comprehensive in what it could do.

So those people are not better off. And worse than that—and, you know, I tend to sometime get involved in the feelings that we have and the passion that motivates us to be involved in hospices.

We talked about the States that don't have dots in them. There are about 22,000 constituents in the States of members of this committee that don't have dots in them, who by the time the administration gets around to reporting its data next year will be dead, and won't have had the opportunity to select hospice care. They are worse off.

Senator DURENBERGER. Wait just a minute. I said earlier—I went back and used my wife as an example for a specific reason. I want you to be honest with me and tell me—I think we were worse off than they were in 1970 when she died in a hospital. Are they worse off?

Reverend WESTBROOK. I think the hospice movement itself has made tremendous strides, along with others, in health care; in educating itself and the health care system about the special needs of the terminally ill. Health care for the terminally ill person in the typical hospital today is better for the terminally ill person today than it was 10 years ago as a result of a lot that has happened over the course of years.

Senator DURENBERGER. And I agree with that 100 percent. Now that we are on that premise, I need to know how you think that HCFA is punching holes in this boat that we have got moving out there in a more specific way. And, Mr. Westbrook, I heard you say that you wanted something that I characterized as an organization maturity payment. We are sitting here looking at $46-plus per day versus $55 a day, versus $63 a day. And if I heard your testimony correctly, you said your consortium approach where you just extend your skills and your financial capabilities out over a larger number of hospice organizations maybe could live somewhere in the $46 to $55. But there are a lot of brand new organizations, the instant organizations, that couldn't. And I need to be clear because I'm not arguing the public policy involved.

I'm curious to know whether or not the entire rates for everyone, including the mature consortia, should be raised to $63 a day in order to accommodate the instants or whether or not you're saying to me, "if, Senator, your policy is to make qualified hospice care available to everyone in this country, you can't expect consortias like mine to be all over and living with $46. You have to encourage a voluntary base, an infant kind of organization in certain areas, particularly in rural areas. Areas where there will be just small numbers. And, Senator, if you want to encourage this growth and this service, you ought to be thinking about maybe the possibility of a different fee schedule for certain kinds of organizations that perhaps are necessary in an area because of its geographic location or something else. And the fact that there are 11 people a year or 22 people a year or some other number that ever would utilize those services. And instead of penalizing them by paying them only $44 or $46 a day, you ought to be paying them $63 a day because it is just going to cost more in some area."

Reverend WESTBROOK. I don't know the exact number, whether it's $44 or $66 or whatever that would be, the bottom of that rate, that is. But that's exactly what I'm talking about. I believe that we have to recognize that the hospice care that is provided out there today, the groups and the organizations that made the difference in health care over the last 10 years—the small voluntary organizations that are part of the community in which they exist. Those are the people who are not being given the opportunity to provide, if you will, expanded hospice care to the people who need it in their community.

Yes; there should be a rate structure which is not as rigid as the one that the administration has developed, that says that everyone is like the 26 demonstration hospices, that everyone has 70 days in average length of stay, that everyone had everything that was involved in that demonstration, and none of the constraints. That's not true.

Let's develop a rate structure as well as a rate base, a dollar figure. Let's develop an implementation structure and policy and procedure, if you will, that reflects those different levels of costs involved in smaller programs. But more especially in programs where there are concentrations of people who, if you will, are more ill, whose needs are different in larger numbers than they perhaps are in other parts of the country. It's not a simple matter. It is one that could be done. And it is one that I think given the good people in the hospice movement, the good people on congressional staffs, and the good people in the administration, we could come to some conclusion of it.

Senator DURENBERGER. I wonder if one of you would tell me a little bit about who else other than Medicare eligible are served by hospices and just generally how you all go about getting business for your hospice.

Dr. LISS-LEVINSON. Well, for non-Medicare patients, we are still providing services under the old New York State hospice demonstration project, the law which requires us to utilize certified home health agencies to provide nursing services, physical therapy, occupational therapy under contractual agreement. The balance of services that we would be providing directly by a hospice staff, we are receiving no reimbursement for whatsoever for the non-Medicare patient.

Ms. KATTERHAGEN. In Washington State, Senator, we have recently passed a mandatory option requirement for private insurance for both hospice and home care. That will be operationalized—is being operationalized right now.

Senator DURENBERGER. The State law requires——

Ms. KATTERHAGEN. It requires individuals or businesses offering group insurance to offer hospice or home health as a benefit. It is being offered at no additional premium by the insurance companies in the area because they, too, believe it will not be a costly benefit for them. However, until this time, we have had no private reimbursement for hospice or home health in our States. So we have provided those services through philanthropic dollars.

Reverend WESTBROOK. The addition of mandated private insurance coverage for hospice care is something that has happened in a number of States, and we are glad to see that happening. We put in an extensive amount of time, particularly since the development of the new hospice benefit, into education of physicians, of hospitals, of hospital discharge planners, DRG coordinators, if you will, and the general public to educate them about the availability of the hospice and what it is. We negotiate contracts with specific provider type organizations such as HMOs to care for the private or third party insured patients there. There are a number of insurance companies that have a specific hospice benefit. Where they don't, if there is a home care benefit or some inpatient benefit, the hospice is able to make its charges as any other health care provider would.

Senator DURENBERGER. Why would you have to mandate, why would you have to have a State mandate for a hospice or a home health benefit? You would think Blue Cross or an HMO or whoever, having provided you with the coverage for a particular kind of illness and so forth, would just automatically reimburse these alternatives.

Ms. KATTERHAGEN. You would think that in every State but Washington, sir. That's an extremely conservative State. It has a reputation for never adding benefits in an insurance program until about 5 years after the rest of the world.

Dr. LISS-LEVINSON. A number of the insurance companies, sir, have done that. And they have done it voluntarily. Traveler's and Equitable stand out in the history of that where they made their own studies. And made those additions. A number of large employee groups, insurance plans——

Senator DURENBERGER. But please explain to me why you have to put it in as a separate benefit other than to describe what will be specifically reimbursed. I suppose if you tell somebody that it is going to be *x* number of dollars a day for every day in the hospital and someone discovers that they have terminal cancer, then that person decides whether they want to stay in a hospital or they would like to go into a hospice. And it would strike me that an insurance company can just sort of change its rules if it wants to. And it says, if you want to go into a hospice, welcome to go into a hospice. Why do they have to put it in there specifically? Is it because they can't get people out of hospitals unless they do it?

Dr. LISS-LEVINSON. A number of insurance companies have added that as a voluntary benefit. Hospice care is different.

Senator DURENBERGER. Right.

Reverend WESTBROOK. It does not fit the definition that previously existed. That's why we came to the Congress. That's why we have gone to State legislatures. That's why we have gone everywhere that we have had to go to cut a place out for hospice care. Hospice isn't just a way of thought. It isn't just a philosophy. We all have become, I think, more atuned to the needs of terminally ill people.

But not all of that better care is, if you will, hospice care. It's a specific kind of care which is delivered by a specific kind of organization. And recognizing that as a specific benefit is a growing movement, and it's something that is happening.

You ask why—I guess we thought that the Government and that Medicare would voluntarily add the hospice benefit too. But we had to come to the Congress to see that it would happen that way. Every State, every judicial group has had to respond to the need out there in the community and to mandate its happening. Bureaucracies don't move very quickly by themselves.

Senator DURENBERGER. All right. Let me see if there is anything else that I'm missing.

Do any of you—maybe you have already answered this relative to Medicaid—what are all of you seeing relative to Medicaid reimbursement for hospices?

Dr. LISS-LEVINSON. Well, briefly, when we entered into the New York State hospice demonstration in 1979, it was with the clear expectation generated by the State for discreet Medicaid rates to be developed for hospices. In fact, that never materialized. The new New York State legislation specifies Medicaid reimbursement if Federal participation is present. And I would say that the position of our institution at this point is to be very cautious as to whether or not that will materialize. I think we were badly burned by our experience of 1979 of expecting Medicaid reimbursement.

The only additional optimistic note we have in the way of reimbursement is the development of a contract with the Blue Cross/Blue Shield of greater New York to service those terminally ill Blue Cross/Blue Shield subscribers.

Ms. KATTERHAGEN. In our State, according to the director of the Medicaid Program, Medicaid does not cover hospice care. However, it is covered through the current system. So we would bill for our services as a home health agency.

Senator DURENBERGER. Oh, all right. I see. That's the same answer that I got from Carolyne Davis regarding Medicare.

Ms. KATTERHAGEN. Well, I would like to point out though what I believe Dr. Davis was trying to say is they are all the same so it really doesn't make any difference where the bills come from. And what we're trying to say is it's not the same. People do not get drugs paid for in any of the benefit programs other than hospice. There are dramatic differences.

I would also like to make a statement in answer to a question you asked about is it different. I would like to point out that according to the perception of the public, they have been promised something and not gotten it. So, yes, it is different.

Senator DURENBERGER. All right. Thank you all very much. I appreciate very much your time and your concern.

The hearing will be adjourned.

[Whereupon, at 4:32 p.m., the hearing was concluded.]

[By direction of the chairman the following communications were made a part of the hearing record:]

WILLIAM V. ROTH, JR.
DELAWARE

104 HART SENATE OFFICE BUILDING
TELEPHONE: 202-224-2441

United States Senate
WASHINGTON, D.C. 20510

COMMITTEES:
GOVERNMENTAL AFFAIRS (CHAIRMAN)
FINANCE
JOINT ECONOMIC COMMITTEE
JOINT COMMITTEE ON TAXATION
SELECT COMMITTEE ON INTELLIGENCE

September 13, 1984

The Honorable Bob Dole
Chairman
Finance Committee
United States Senate
Washington, D.C. 20510

Dear Bob:

Enclosed is a letter I have received from Delaware Hospice, Inc. I would like it included in the record of the Oversight Hearing on Hospice scheduled for September 17.

Thanks for your help.

Sincerely,

William V. Roth, Jr.
U. S. Senate

Enclosure

DELAWARE HOSPICE

September 7, 1984

Senator William V. Roth, Jr.
104 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Roth:

Delaware Hospice has been providing care for termnally ill Delawareans since October of 1982. In January of this year we became a Medicare certified hospice with the hope that this benefit would assist us financially in providing hospice care to our patients and families. We knew that in order to remain operational, we needed more funding than that which was received from donations and foundation grants. The Medicare benefit has not, however, been beneficial.

The routine home care rate provided is less than what it costs us to provide care, so we are losing money every day we care for a Medicare patient. We currently have an average census of about 20 patients. Of these 20, 10 are Medicare patients, 6 are indigent with no funds available to assist with the cost of their care, and 4 are covered by insurance campanies such as Blue Cross/Blue Shield or Connecticut General which provide hospice benefits. It costs us $77.00 per day, 365 days per year, to provide routine home care for each of our patients. We are reimbursed by Medicare at the rate of $49.09/day and by Blue Cross/Blue Shield and Connecticut General at the rate of $90.00/day. The following table reflects our daily costs/reimbursement data:

Average # Patients	Cost/day	Reimbursement
10 Medicare	$770.00	$491.00
5 Insurance	385.00	450.00
5 Indigent	385.00	-0-
Total	$1540.00	$941.00

Currently we are reimbursed for 61% of our routine home care costs and are taking a 26% loss on Medicare patients. Because of these losses and their effect on us financially, we are seriously considering withdrawal from the Medicare benefit program.

The rate set for routine home care by the Department of Health and Human Services was based on data gathered from the 276 hospices in the demonstration project. Many of those hospices would not qualify for Medicare certification under the current regulations; they were not required to provide all of the services that are currently required by Medicare. For this reason, their costs were less and do not adquately reflect the current cost of providing hospice services.

As the data from our 8 month involvement with Medicare reimbursement reflects, the actual cost of providing hospice services differs significantly from the costs in the demonstration project.

Delaware Hospice is expanding its services from a New Castle County based program to a state-wide organization with divisions in all three counties. In October of this year, we will be providing hospice care for persons in all areas of the state. With the current low reimbursement rates, we are not planning to obtain an extension of our Medicare provider number to include the two new divisions. And as previously stated, we may withdraw from the Medicare benefit entirely.

The interest of our Senators and Congressmen in hospice care and their provision of the original hospice benefit is commendable, but hospice providers cannot remain economically viable with the low reimbursement rates offered. Delaware Hospice would be able to continue to provide hospice care to Medicare patients if the reimbursement rate would at least cover our routine home care costs. I urge you to please support the bills that would raise the level of hospice reimbursement rates so that we can continue to participate in the Medicare Hospice program (H.R. 5386, H.R. 5141, S. 2725).

Thank you for your interest in hospice. If I can be of any assistance to you or if you would like more information, please do not hesitiate to contact me.

Sincerely,

Kathy Herzog

Kathryn Herzog
Acting Executive Director

KH/nmh

STATEMENT
OF THE
AMERICAN FEDERATION OF HOME HEALTH AGENCIES
PRESENTED BY
MARY FAY VERVILLE

Mr. Chairman, my name is Mary Fay Verville. I am Director of the Hospice of Gold Coast and the Gold Coast Home Health Services of Pompano Beach, Florida. My agency is the oldest non-profit home health agency in Florida. We have provided hospice care under an interdisciplinary approach for the last eight years. I am presenting testimony today on behalf of the American Federation of Home Health Agencies, a national association representing the concerns of home health agencies and the patients they represent throughout the country. I serve as Chairperson of AFHHA's Hospice Committee.

Rather than discuss all of the problems that have arisen under the Medicare hospice program and contributed to the low rate of participation, I will limit my remarks to several topics in particular.

We have serious concerns about the hospice election process. The overwhelming majority of terminally ill Medicare patients do not participate in the hospice program. The participation rate is less than one percent. One of the prime reasons, we believe, is the election procedure. Signing a form containing an acknowledgment of terminal illness and probable death within six months may represent an abandonment of hope for a fully conscious and functioning patient. Some patients or their family members may view it as signing and sealing a death sentence. Place yourself in their position and you can understand the difficulty if not impossibility of such an acknowledgment. Equally difficult is the extraordinary complexity of the hospice election agreement, which is utterly confusing to most terminally ill patients and their families. Even hospice providers are confused. We are performing a cruel disservice to Medicare patients and their families sitting them down at a vulnerable time to explain the intricacies of what they gain, what they lose, what the hospice can offer, what the hospital can provide if they have to be admitted, how to sign on, how many times they can sign on, how to sign off, and so on and on. Many of the patients to whom these complicated details are being explained do not even understand their present benefits under Social Security and Medicare. With their sketchy knowledge and limited awareness, it is no wonder that they prefer to stay with the benefits they already have.

Inpatient agreements with hospitals also continue to present a serious barrier to expansion of the hospice program. It is difficult to convince hospitals to agree to accept patients under a hospice provider agreement when they might otherwise admit them under DRGs and receive a higher level of compensation. During the hospice demonstration projects, continuous home care was not included. Now, with continuous care factored in, and with the ability of hospices to provide pain management through provision of highly skilled care, circumstances leading to hospitalization are more limited. Hospices can provide services such as IV pain management, and suctioning of the patient's airways. Many such procedures were performed on an inpatient basis during the demonstrations. But we will see hospitalization under the Medicare hospice program reserved for more complicated procedures, such as placement of tracheotomy and gastro tubes, or Hickman catheters. The daily rate for general hospital care under the hospice benefit—approximately $270.00—was figured considering the less expensive and less complicated treatment now usually provided in the home. The inpatient rate does not accurately reflect the cost of the more complicated surgical procedures for which hospice patients are now being hospitalized. It does not even come close to covering the cost, let alone the charge. AFHHA therefore urges that the hospice general inpatient care be dropped and that inpatient hospital care be provided under DRGs.

We further urge that HCFA implement a simple up-front review procedure to facilitate the provision of an appropriate level of hospice services. The UB-82 form which hospices use for billing purposes includes a form which is sent to the fiscal intermediary upon admission of a patient. Within a matter of days, the intermediary sends the form back to the hospice with an indication of the patient's eligibility for Medicare. We urge that the UB-82 form include an attachment to be sent by the hospice whenever the attending and hospice physicians determine that a patient requires continuous home care rather than routine home care. On the form, the hospice would indicate the patient's condition and specify a plan of treatment. The fiscal intermediary would then be required to return the form within a specified period of time, either confirming or denying provision of continuous home care as ordered by the physicians.

The hospice would of course have to justify all continuous home care services with documentation at billing time, and would have to discontinue continuous care if the patient's condition no longer warranted such an intense level of care.

We believe such a review and notification process is crucial to the smooth operation of the Medicare hospice program and is in the best interest of all parties concerned. If continuous home care is not warranted, in the estimation of the fiscal intermediary, the hospice can reduce services to another level of care. However a hospice which provides continuous home care over a long period of time, only to be informed much later that the intermediary will not reimburse at that level, will suffer a serious financial blow. Such losses for Medicare hospices are not covered under waiver of liability.

Denials based on determination of an inappropriate level of care can cause a loss of up to $10,000 a month for a single patient. Small hospices, many of which are operating on the margin, cannot withstand blows of this sort. Even one or two denials on this scale can bankrupt a hospice with an unfortunate impact on other patients and the community as a whole. If such a scenario develops, it would be especially tragic because it is so preventable.

It is clearly the will of the public and the intent of Congress that the hospice program work. We believe that adoption of the changes we have urged will help enable hospices to perform the services they were established to provide, without fear of serious preventable financial disruption.

Thank you for this opportunity to present our testimony.

H

HORIZON HOSPICE INC.
2800 N. Sheridan Road, Chicago, Illinois 60657 (312) 871-3658

September 28, 1984

Mr. Roderick DeArment, Chief Counsel
Senate Finance Committee
S.D. - 219 Dirksen Senate Office
Washington, D.C. 20510

Dear Mr. DeArment:

The purpose of my letter is to add testimony to Senator David Durenberger's hearing on the status of the Hospice Medicare Benefit.

Most of what I wish to add has been comprehensively covered in a report on the subject prepared by the Department of Health and Human Services (HHS). I hope you have already seen it, but if not, I am enclosing a copy for the record. In my opion, HHS has done a remarkable job of collecting representative views from hospice providers across the country.

This legislation, in its present form is not useful. I would note particularly the inability for all programs to contract for care services and the $6,500.00 cap accompanied by a "no dump" provision.

Sadly, the many hospice people who have been expressing these views for the past two years have been largely unheeded. Perhaps this is because the National Hospice Organization (NHO), which purports to have 2,000 provider and individual members, is seen as our national voice. Surely the Senators are aware that NHO leaders, who worked so diligently for this bill's passage, have now formed a national for-profit hospice corporation which may eventually be one of the few hospices large enough to make federal reimbursement legislation profitable. It is useful to note that only approximately 250 NHO members cast votes at the 1983 Annual meeting.

National hospice politics may not be of interest to the Committee, but I include it to persuade you to give heavy consideration to the HHS document because I believe it best represents the national hospice voice in this matter.

Sincerely yours,

Sally Owen-Still

Sally Owen-Still, M.A.
Executive Director
First Vice President
Illinois State Hospice Organization

SOS:zs
encl.

A Program Inspection

on

Hospice Care

Department of Health and Human Services
Richard P. Kusserow
Inspector General

September 10, 1984

Program Inspections are short-term studies of HHS programs and services conducted at the local service delivery level. They are not designed to be compliance reviews, audits, program monitoring activities, or traditional program evaluations. Rather, a program inspection consists of gathering current qualitative and quantitative information from open-ended discussions with clients and service providers. The information gathered is intended as a way for senior-level HHS personnel to obtain the views of the people most directly affected by HHS programs. Program Inspection results are meant to be used internally by Department managers as an additional source of information which, when combined with others, provides a more complete picture of program operations.

Program Inspection prepared by:

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Region IX

Summary of Findings

- There are approximately 1070 organizations in the United States that are now (or will be in the next year) providing hospice services of some type. We predict that by April 1985, about 210 (20%) of these organizations will be certified under the new Medicare hospice benefit. Independent and home health agency based hospices are most likely to seek certification. Hospital based hospices and coalition models are least likely to seek certification.

- There were few differences in attitude about the advantages and disadvantages of seeking certification between those hospices which intend to seek certification and those which do not. On the whole, those hospices which are not applying for certification felt better about their decision to stay out of the program than the applicants did about applying for certification. The primary disincentives to certification mentioned by hospices relate to:

  - Cost and Reimbursement Factors The $6500 cap was the most frequently stated reason for avoiding Medicare certification followed by concerns regarding the reimbursement rates which were generally perceived as too low. (There has not yet been sufficient reimbursement experience with the hospice benefit to objectively determine whether the rates are adequate for the benefits provided.) The core services requirement was particularly problematic for hospital and coalition models.

  - Moral and Philosophical Issues Many hospices fear that certification would force them into making decisions which could result in conflict between the patient's interest and the organization's economic survival. They are troubled about the potential necessity for closer screening of patients admitted under the benefit, manipulating time of admission to minimize losses and setting stricter standards for the availability of a primary care giver in the home.

  - Issues Relating to the Practice of Medicine Some hospices see the mandated role of the Medical Director as potentially threatening the long-standing relationship which exists between the attending physician and the patient. Responsibility for the formal management of inpatient care has caused difficulties for some hospices in negotiating contracts with hospitals.

- By the end of FY '85, it is predicted that 23% or less of the Medicare patients receiving hospice services will have their care paid for under the new benefit. (This represents less than 5% of all Medicare cancer deaths.) It is predicted that the remaining 77% will have the eligible hospice care services they receive reimbursed under the conventional Medicare benefit.

- At the projected rate of participation, pay out under the new benefit during the first two fiscal years will be less than previously anticipated; less than $22 million in FY '84 and $104 million in FY '85. It is unclear whether the new Medicare hospice benefit will result in a net savings or loss to the Medicare trust funds.

Table of Contents

Program Inspection on Hospice Care

I. Introduction

At the request of the Inspector General, a national program inspection on the implementation of the new Medicare hospice benefit was conducted by the Office of Program Inspections, Region V, Chicago. During March, 1984, site visits were conducted in 17 states, where in-depth discussions were held with representatives of 77 hospices and with persons affiliated with 49 other organizations including home health agencies, hospital associations, HCFA, and appropriate interest groups. In addition, telephone discussions were held with 167 hospices and other interested parties in 43 states who were randomly selected from a list of 1461 persons and organizations which had been sent information by HCFA regarding the new Medicare hospice benefit.

The purpose of these discussions was to:

- Develop an early estimate of the number, types and anticipated case loads of hospices that would seek to become certified and participate as providers under the new Medicare hospice benefit.
- Obtain information about how hospices perceive the advantages and disadvantages of participation under the new Medicare benefit and where they see the hospice movement going.
- Explore some of the implications for cost and access which may arise in relation to hospice care during the first year of benefit implementation.
- Consider topics related to quality, abuse and fraud under the new benefit which may be of particular interest to HCFA and to the Inspector General.

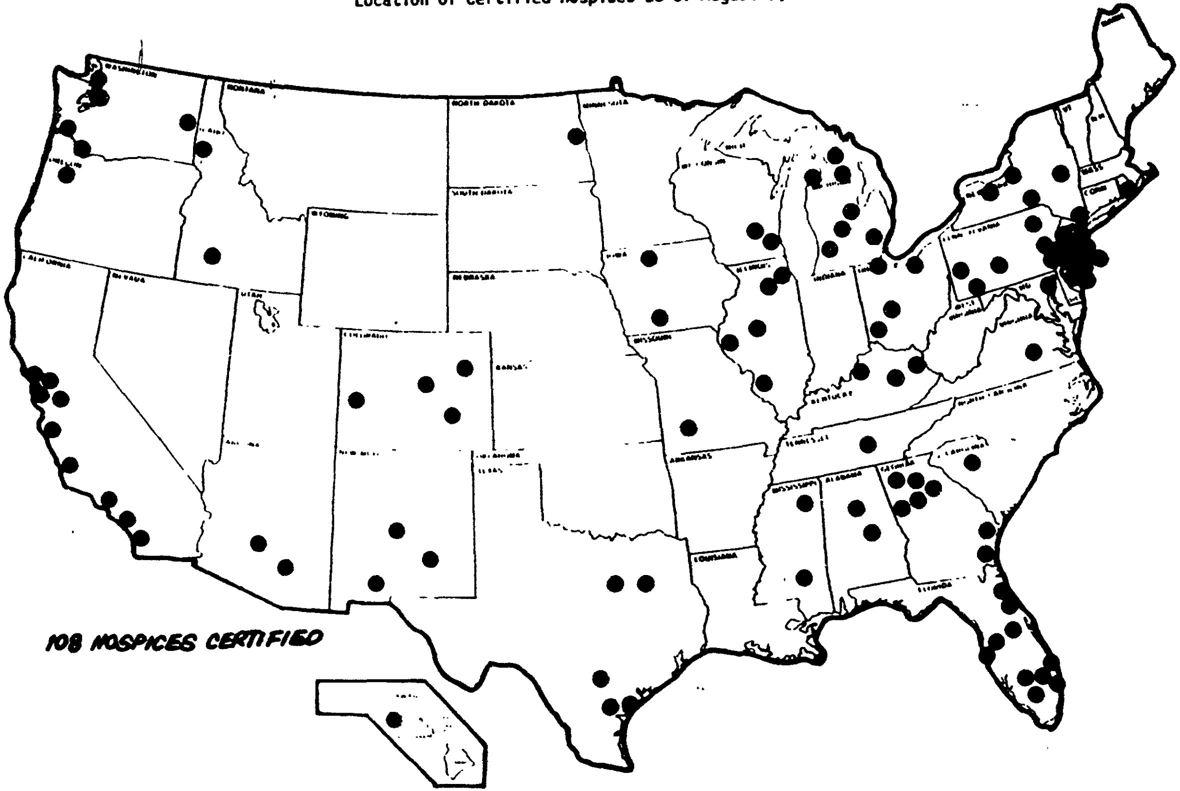
II. Overview

Section 122 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) authorized coverage of hospice care for Medicare beneficiaries for the period November 1, 1983 through September 30, 1986. Final regulations governing conditions of participation and rates of payment for hospice providers were issued on December 16, 1983. As of August 3, 1984, 493 hospices had requested clarifying information about participation in the new Medicare program, 163 had been surveyed by State Agencies and 108 were certified. (See Figure 1 for location of certified hospices.)

Hospices provide palliative care to terminally ill patients and their families in situations where active treatment of a patient's disease or condition is no longer desired. The aim of hospice care is to assist patients and families dealing with the last stages of illness in an atmosphere of dignity, care and warmth. Stress is placed on home care and pain control. Under the new benefit, services include in-home nursing and home health aide visits; physical and occupational therapy; dietary

Figure 1

Location of Certified Hospices as of August 3, 1984



108 HOSPICES CERTIFIED

and bereavement counseling; short term inpatient and respite care to stabilize pain and symptom management or to provide families with temporary relief; durable medical equipment and drugs. Traditionally, hospices have made heavy use of volunteers and there has been strong involvement of clergy in the programs.

Under the new Medicare benefit, patients may elect to receive hospice care for two 90 day periods and one 30 day period. During that time, the patient waives receipt of all other Medicare services available under Parts A and B (except for services from an attending physician and care not associated with the terminal illness), but may cancel the hospice election at any time. The patient makes no payment for covered hospice services except for a nominal copayment for outpatient drugs and respite care.

Hospices that participate in the program as certified providers are responsible for providing the complete array of covered services to the patients they accept into their programs. Hospices are reimbursed for the services they provide on a prospective basis and receive (subject to some adjustments) $46.25 for each routine home care day, up to $358.67 for each continuous home care day, $55.33 for inpatient respite care and $271.00 for general inpatient care. There is a 20 percent limitation on the number of inpatient days of care a hospice may provide and a cap of $6500 per patient times the aggregate number of patients a hospice serves in a year. If a patient continues to need services after the hospice benefit periods are exhausted, the hospice must continue providing care unless the patient no longer wants hospice services.

Prior to adoption of this new hospice benefit, Medicare patients who received eligible hospice services (hospitalization, physician services, home health services, durable medical equipment, etc.) had their care reimbursed under conventional Medicare coverage. Hospice care that was not eligible for Medicare reimbursement was paid for out of contributions to the hospice organization and some fees for service. Patients of hospices that do not seek certification under the new benefit will continue to have their eligible care paid for under the conventional Medicare Parts A and B, fees for service and voluntary contributions.

III. Number and Types of Hospices Seeking Certification

There are about 1070 organizations in the United States which are now or in the next year will be providing hospice services. These groups have a somewhat common philosophy of what hospice care entails, but there is no common organizational model for how this care is to be provided. Groups vary widely regarding which services they themselves provide to their patients and which are provided by other organizations. Included among the providers of hospice services are: large and medium sized free standing organizations (Independents) which usually deliver a comprehensive set of hospice services; hospital and home health based programs which may emphasize one aspect of care and arrange for others to provide the rest; and a large number of coalition models which often depend heavily on volunteers and directly provide few medical care services. A few skilled nursing facilities also have hospice programs. Programs also vary in the extent to which they emphasize the medical or social support aspects of hospice care.

In our telephone survey, hospice care providers indicated that over the next 12 months:

- 20% plan to apply for certification.
- 18% are undecided.
- 62% plan not to apply for certification.

If 25% of the undecided seek certification, and 80% of all which seek are certified, there would be:

- <u>210 certified hospices by April 1985</u>.

Interest in seeking certification varies considerably by type of organization. The respondents in the telephone sample can be broken down as follows:

- Coalition hospices: Less than 3% plan to seek certification, 15% are undecided and 82% will not.
- Hospital based hospices: 15% plan to seek certification, 25% are undecided and 60% will not.
- Home health agency based hospices: 41% plan to seek certification, 14% are undecided, and 45% will not.
- Independent hospices: 50% plan to seek certification, and 50% are undecided or will not.

In the 12 months prior to March 1984, about 58,800 persons, aged 65 and over, received some type of hospice care. During the next year, the number of patients 65 and over that receive hospice services in both certified and noncertified settings is anticipated to increase 18% to about 69,420. The Medicare patients served last year are distributed as follows:

- Hospices planning to seek certification served 28% of the hospice patients aged 65 and over (16,464 patients).

- Hospices which plan not to seek certification served 50% (29,400 patients).
- Hospices which are undecided served 22% (12,936 patients).

IV. Incentives and Disincentives for Certification

We found few differences in attitude between those who were planning to certify and those who were not. Almost all respondents cited a few incentives and many more disincentives with particular circumstances leading some providers to seek certification despite their misgivings or fears. On the whole, those hospices not applying for certification felt better about their decision to stay out of the program than the applicants did about applying for certification.

A. Incentives

The greatest advantage of the new benefit is that it will enable hospices to offer a wider range of reimbursable services to their patients. This incentive is most obvious and clear cut for those hospices (primarily independent or coalition models) which were not licensed as home health agencies, hospitals or SNFs, and therefore were unable to bill Medicare directly in the past. In addition, providers who previously billed under Medicare Home Health (or contracted for home health services) now will also be able to be reimbursed for 1) drugs and durable medical equipment, 2) respite care, 3) continuous home care in times of crisis, 4) visits for patients who are not "homebound," and 5) routine (non-skilled) home care.

As many respondents pointed out, however, most hospices were able to call upon volunteers and to marshal enough community support to provide at least some of these services even before the new Medicare benefit, so the additional billing categories alone did not supply enough incentive to push them into the "plan to seek certification" category. For this reason, most of those who applied identified some particular circumstance or idiosyncracy as the catalyst. For example:

- Demonstration hospices may lose a substantial part of their Medicare funding unless they are certified.
- Many hospices see certification as a "stamp of approval," so are getting certified largely to show that they can do it.
- In some states, existing or proposed hospice licensure laws closely resemble the Medicare model, so hospices are saying they will have to conform eventually anyway.

- In some regions, the home health market has become very competitive, so hospices are seeking certification in an effort to keep their market share. As one respondent put it, "If I don't certify, someone else will".

- Several hospital administrators, feeling the squeeze of DRGs, are saying they no longer can afford to operate hospice programs at a loss, so these programs must find a new funding source in order to survive.

- A few hospitals see new home health and hospice programs as a way to serve patients whose DRG payment has run out or as a means of filling surplus beds which result from shortened length of stay.

- Some independent hospices, and in particular one new for-profit corporation, are seeking certification because they are in fundamental agreement with the regulations and benefits.

may also have an unusually large patient population

- Some providers are seeking certification for defensive reasons, in the belief that HCFA plans to "tighten up" on home health reimbursement, particularly for non-certified hospices.

B. Disincentives

Almost all respondents, including those planning to seek certification, identified major disincentives in the current regulations. While the emphasis varied by type of hospice, most identified three problems: risks and problems with the reimbursement scheme, moral and philosophical issues, and other issues relating to the practice of medicine.

1) Cost and reimbursement factors

The respondents indicated that the legislation requires an intricate set of reimbursement rules and boundaries and at the same time prescribes an organizational structure which, in some cases, would add appreciably to administrative overhead and program costs. Taken together, these factors create substantial financial uncertainty. Some parts of this cost and reimbursement package were particularly troublesome:

- Reimbursement rates At this time there has not been sufficient reimbursement experience to know what effect the rates will have on those hospices who do get certified. However, in terms of considering certification, only a few providers felt that they could break even under the new benefit although the directors of one proprietary organization expected to eventually make a profit after four or more years. Most respondents expected they would lose money under the reimbursement rate structure authorized in the final regulations and feared they would have to subsidize both start up and ongoing operational costs from donations, memorials or cross subsidization from other revenue producing services.

The routine home care rate was the most common target of criticism. As one respondent noted, current best practice in quality hospice care requires a considerable amount of medication and technology just to keep the patient comfortable. Most respondents also took exception to the respite care rate. The continuous care rate was generally perceived as adequate, though some respondents, particularly in rural areas experiencing a shortage of RNs, indicated they would be willing to bill at a much lower rate if they could use home health aides under the supervision of an RN. Assessments of the inpatient rate varied considerably, with the greatest amount of criticism coming from home health agencies in cities with high hospital costs.

- $6500 cap The $6500 cap was the most frequently stated reason for avoiding Medicare certification. This issue seemed particularly problematic for smaller programs. Respondents pointed out that it was inaccurate to call this a six-month benefit because billings for a patient would reach the cap in 4½ months, even at the routine home care rate. Most important, the presence of the cap presented a formidable financial risk: What if one patient required prolonged, expensive care or a costly inpatient stay? Even though the cap is applied to the aggregate number of patients served, a bill of $30,000 with reimbursement of $6500 could easily bankrupt a smaller program.

- 20/80 requirement Most respondents did not believe the 20% limitation on inpatient days would present a problem. Because inpatient ratios tend to be higher in hospital-based programs, using a 20/80 ratio as both a reimbursement condition and a condition of participation may keep some hospital-based programs from seeking certification. Even for hospices with low inpatient rates, the 20/80 requirement adds one more hurdle and uncertainty to what many already perceive as a precarious and risky venture.

- Required core services For those who do not currently provide these services directly (primarily hospitals and coalition models) the core services requirement, plus new record-keeping and reporting obligations, may add appreciably to administrative overhead and operating costs. Some organizations expressed concern about the potential disruption of working relationships between hospitals and home health agencies which have functioned well for a number of years. The reorganization necessary to meet the core service requirements would result in some service redundancy and could increase the costs of serving all clients, even though Medicare would only be reimbursing for some of them. For example, one respondent noted that gearing up for certification raised their annual budget from $60,000 to $120,000. (The Deficit Reduction Act of 1984, passed after the field work for this Inspection was completed, allows certain rural hospices increased flexibility and may in part have eased some of the concerns of this sub-group of respondents.)

- <u>Uncertainty</u> A less important but still significant disincentive is the uncertainty surrounding the new benefit. What if a hospice gears up for the new benefit and doubles the administrative overhead and the benefit is taken away in 1986? How will HCFA and the Fiscal Intermediaries interpret the regulations? For example, will a bone cancer patient's broken hip be considered "related" to the terminal illness and therefore the financial responsibility of the hospice? Will states have the personnel and expertise to do timely and adequate surveys of hospices that apply for certification?

2) <u>Moral and Philosophical Issues</u>

Although almost all respondents were concerned about cost and reimbursement factors, some were more troubled by several moral and philosophical dilemmas they saw as emerging from these financial imperatives. While these concerns took many forms, they all were variations on a statement made by one non-certifying home health agency: "In order to take our staff and create a certified hospice, we would have to force them to act against their philosophy". For example:

- Many hospices don't want to feel forced to screen out "unprofitable" patients and thereby deny some people access to their services. "We've always had to worry about money, but it never spilled over into who you admit or making up reasons why you are really denying admissions."

- Some hospices are also uncomfortable about having the reimbursement scheme dictate <u>when</u> a patient will be admitted into the program. The optimal <u>time</u> from the hospice's financial perspective would be two to three months before death, but many providers feel very strongly that a two month length of stay "isn't hospice" because there is not enough time to do adequate counseling with the patient and the family.

- Once patients are admitted, hospices find it awkward to be in a position where a patient's longevity could hurt them. "We don't want to be penalized for an act of God." "How are you going to tell people 'you have six months to live and if you live longer I'm in deep trouble?'"

- The interests of the patient and the hospice may no longer coincide: some hospices are uncomfortable about moving from a patient advocate function to the role of rationing or rejecting services desired by the patient.

3) Issues relating to the practice of medicine

Closely tied to the moral and philosophical issues are several concerns related to the practice of medicine.

- Many hospices were confused or uncertain about the rules regarding the allowed billing practices of the Medical Director under the new benefit. A physician serving as Medical Director is considered to be an employee of the hospice and is not allowed to bill Part B for services provided to individual patients as an "attending physician". The hospice may bill Part A for these services but they are counted against the $6500 cap. In smaller communities where there are only a few recognized oncologists, this situation may restrict either the hospices' ability to attract the most qualified Medical Director or the availability of services to some patients. The hospice may be faced with two unattractive options: use the recognized oncologist, develop a payment system to compensate him for these lost revenues and absorb the risk under the cap, or use a less qualified person as Medical Director and save the oncologist for the attending physician role.

- The Medical Director's role in determining and implementing the plan of care may threaten the long-standing relationship between the attending physician and the patient, and between the hospice and attending physician. Under the new benefit there may be a perception that suddenly there is a physician standing in the middle deciding on the plan of care and telling the patient and attending physician what services may or may not be provided.

- Some hospices have been unable to negotiate an inpatient contract because hospitals are reluctant to give up "professional management responsibility" while they retain legal liability for the care of their patients,

- Although some providers found the patient's informed consent requirement entirely appropriate, others took exception, pointing out that patients have "levels of acceptance" and go "in and out of denial". According to these providers, insisting on a signed consent form at the beginning of the election period was premature since the very point of hospice is to help patients come to terms with their death.

- Others objected to the waiver requirement, stating that it was very difficult for a family to comprehend precisely what rights were being waived.

- Finally, some providers objected to the fact that bereavement counseling is required but not reimbursed under the regulations. This exclusion, they felt, supports a "medical model" in which the individual rather than the family is considered the unit of care.

V. Impact on the Hospice Movement

A. National Impact

The hospice movement currently is at a vulnerable point in its organizational history. It has experienced rapid growth in the past decade, going from only one program in 1974 to over a thousand in 1984. Moreover, the movement has been so decentralized, pluralistic, and diverse that there is still much ambiguity about what hospices are, what they should be, or even how many there are.

Most hospices claimed that the new Medicare benefit will have a significant impact on how many hospices will exist, who will run them and how they will operate. In general, providers were pleased that the hospice idea has now been officially recognized and they expected the hospice movement to gain legitimacy and public acceptance as a result. The majority, however, expressed deep reservations about the particulars and the timing of the benefit.

- A variety of respondents said the new benefit has come too soon. For some, this statement emerged out of a belief that the demonstration hospice data were incomplete, inappropriate, and inapplicable. In other cases, however, the comment reflected a concern that the movement is still at a very early stage in the development of quality assurance standards and therefore is not yet ready for the greater public scrutiny this new benefit will attract.

- In the view of many respondents, the legislation prescribes an organizational structure and a way of doing business which are inflexible, expensive, and foreign to the way the majority of hospices operate. Some providers feel that presenting a "one right hospice" model at the very least implies that some kinds of hospices are more "correct" than others and ultimately could bureaucratize and institutionalize what heretofore has been a pluralistic, community-based movement.

- There is some concern that hospices which do not seek certification will be the "fall guys." Publicity regarding the program is increasing public expectations, raising "false hopes", but hospices have the job of telling patients the benefit is unavailable in their city.

B. Regional and Community Impact

Although hospices everywhere will experience some of the political and organizational repercussions of the new benefit, the direct practical effects will be in cities where one or more providers will be certified. In many regions of the country, particularly in rural areas, hospices will conduct "business as usual" because nobody will be seeking certification. In areas with one or more certified hospices, however, many non-certified providers expect to experience one or more of the following effects:

- The increase in overhead costs will motivate certified hospices to expand the number of patients they serve. With a good marketing plan, these hospices may take potential patients away from non-certified hospices. This could effectively eliminate some of the smaller providers.
- In a few instances, hospitals are absorbing or affiliating with the local home health agencies in order to be able to meet the core services requirement. If the home health agency is unwilling to be absorbed, some hospitals are forming their own competing home health units, thereby leading to the establishment of "parallel services" or to the "freezing out" of home health providers.
- Another significant side effect of the Act and regulations in some states has been the fostering of state licensure laws which reflect the federal requirements. This may cause some hospice programs to "go underground" by abandoning the hospice label for designations such as "palliative care" units.

VI. Implications of the Hospice Benefit for Access and Cost

- By the end of FY '85, it is predicted that 23% or less of the Medicare patients receiving hospice services will have their care paid for under the new benefit. (This represents less than 5% of all Medicare cancer deaths.) It is predicted that the remaining 77% will have the eligible hospice care services they receive reimbursed under the conventional Medicare benefit.

- At the projected rate of participation, pay out under the new benefit during the first two fiscal years will be less than previously anticipated; less than $22 million in FY '84 and $104 million in FY '85. It is unclear whether the new Medicare hospice benefit will result in a net savings or loss to the Medicare trust funds.

Hospice care as a philosophy or concept has gained acceptance by many patients and providers because it is seen as a humane and sensible alternative to the impersonal technological intervention that often accompanies the last days of life for some terminally ill patients. The Medicare hospice benefit was adopted both to improve access to hospice services and because such services were presented as a less costly alternative to traditional medical care.

Whether access is improved and/or cost savings achieved as the result of the new Medicare benefit is largely dependent on the anticipated behavior of hospices under the program. In particular, questions must be raised not only about how many hospices intend to seek certification, but also regarding: 1) the number and service volumes of those providers likely to actually be certified, 2) which patients they intend to serve, 3) which patients they intend to serve under the new benefit, 4) when patients are admitted to hospice care under the new benefit and 5) how hospices will bill for care given to the Medicare patients they serve.

Figure 2 provides a graphic representation of the certification and billing choices available to hospice care providers. Included in each box is an estimate of the percentage of hospices which fall in that category and an estimate of the percentage of Medicare hospice patients to be served. Solid lines between boxes indicate the pattern and direction of choice. Broken lines between boxes indicate the Medicare benefit that would be billed for hospice care.

In Section III above, it was reported that 20% of the hospices plan to seek certification, 18% were undecided and 62% plan not to apply. It was estimated that hospices served about 58,800 Medicare patients in the last 12 months and in the next 12 months would increase their Medicare volume about 18% to serve 69,420 patients.

A review of the general characteristics and responses given by the undecided hospices indicates that for the most part, the majority of them are unlikely to apply for certification in the next 12 months. These undecided hospices have therefore been allocated to the "Will Not" (B_1) and "Will Seek" (B_2) categories on the ratio of 75/25. The percent of patients served by these providers has been allocated on the same basis. As a result, it is estimated that 75% of the hospices (serving 66% of the Medicare hospice patients over the next 12 months) will not seek certification. All of the eligible Medicare services provided to the patients of these non-certified hospices will have to be billed to the conventional Medicare Parts A and B. There may be some reduction of Medicare costs because of the anticipated increase in hospice care provided by these non-certified hospices. But this would have occurred even without the new benefit. Hospices that will seek certification would now equal 25% of the hospice providers and 34% of the anticipated Medicare hospice volume.

HCFA reports have indicated that about 20% of the hospices that seek certification are either denied or have asked to be put on hold. In addition, discussions with hospices contacted during the field visits indicated that there are several which will not participate even if they are certified. Allocating the "Will Seek" (B_2) hospices and patients to "Will Hold, etc." (C_1) and "Will Be Certified" (C_2) on a 20/80 ratio results in an additional 5% of the hospices (serving 7% of the patients) that can only seek reimbursement from the conventional Medicare Part A and B benefits.

A. Hospice Decisions Regarding Patient Admissions and Billing

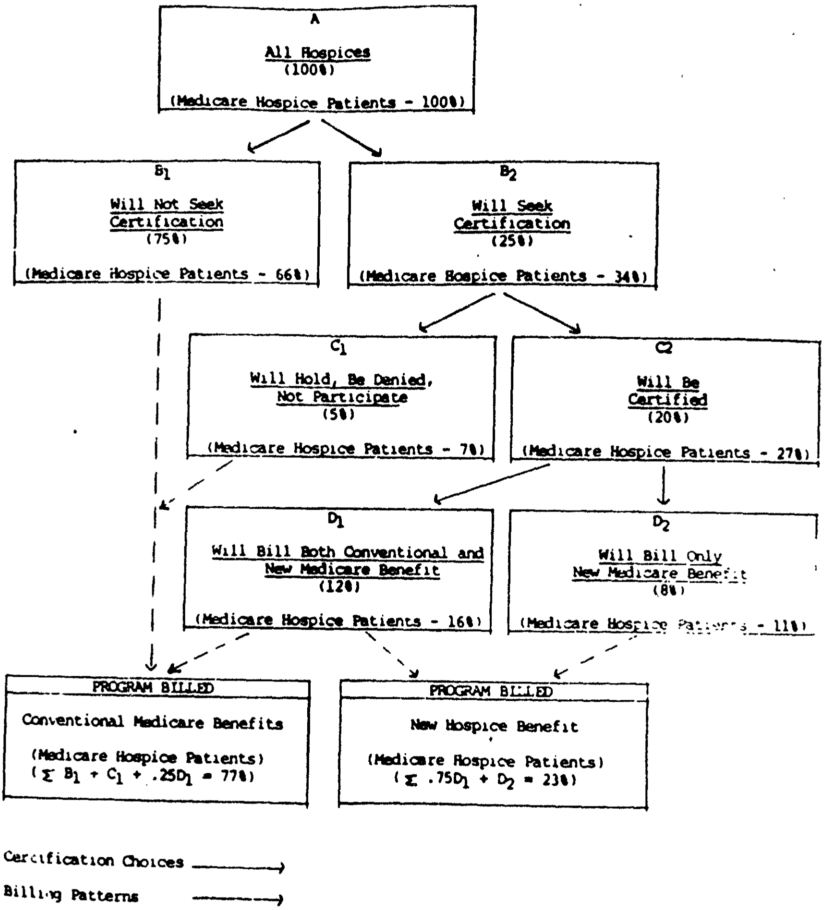
Those hospices (C_2) that do become certified and participate in the benefit will have to make a number of decisions relating to how or to what extent they select patients and structure billing practices in ways which will maximize their income or at least stabilize revenues and reduce losses to their programs. As indicated above in Section IV, almost all hospices in both the telephone sample and in the group that were visited on site had serious concerns about the reimbursement levels for various types of services, as well as the risk aspects of the program associated with the cap and the 20% limitation on inpatient days. They were worried about the start up costs (much of which had been covered in the reimbursement of the demo projects) and the fixed overhead they believed associated with operating the program model required by the new hospice benefit.

A number of options were presented by the hospices which might be used to protect their organization from perceived financial disaster. These involved both screening patients who would be admitted to the hospice program and the timing of their admissions. Included were:

- Setting strict standards for the availability of a primary care giver in the home.
- Rejecting or discouraging formal adoption of the hospice benefit for patients whose length of stay or resource demands would be unpredictable.
- Rejecting or discouraging patients for whom resource use, particularly inpatient utilization, would likely be extensive or expensive.

Figure 2

Certification Choices and Billing Patterns for Hospices



- Optimizing time of admission to the hospice program so that length of stay will generate maximum routine care revenues, but not so long as to approach the cap. Short lengths of stay that might risk a greater than 20/80 ratio of inpatient use would be avoided.
- Possibly counseling out of the hospice benefit patients whose length of stay or physical needs place extreme demands on the hospice budget, including those whose benefit had run out.

These types of decisions force the hospices into making moral choices which many groups find difficult. During the discussions, hospices would often indicate they would continue to serve a broad range of patient types and needs. But when discussing financial realities, they would come back to the above kinds of issues. Although the full extent of such screening can not be predicted, it is safe to assume that the net effect would be to encourage most of the less expensive patients to select the new hospice benefit and some of the more expensive patients to remain partially or wholly under the conventional Medicare benefit.

Hospices which are part of, or affiliated with, organizations (such as hospitals and home health agencies) which have a separate billing capability, have greater flexibility in providing services to higher risk patients. These organizations can still provide a variety of hospice type services to high risk persons. But by counseling them not to formally adopt the new hospice benefit, or having them enter the hospice program under the new benefit at an optimal time period, they can bill for these expensive patients under the conventional Medicare hospice benefit. The telephone discussions indicated 60% of the hospices that intend to seek certification will serve some patients who have not formally adopted the new hospice benefit and will bill under both the conventional and the new benefit depending on which option the patient has selected. Such an approach can be used both to optimize the time of formal admission to the hospice program as well as to provide some hospice care for a portion of the terminally ill patients throughout their course of illness. Although hospice care provided under the conventional Medicare benefit may moderate patient demand for some expensive services, it would likely be the more costly patient that was counseled to use this approach.

Allocating the "Will Be Certified" (C_2) hospices to the "Will Bill Both" (D_1) and "Will Bill Only New" (D_2) categories on a 60/40 ratio results in an estimate that only 8% of all hospice care providers (serving 11% of the Medicare patients) will participate solely in the new benefit while 11% will bill both. If the hospices which bill both programs (D_1) adjust admissions or timing of admissions so that 25% of the hospice care they provide is billed to the conventional Medicare benefit and 75% to the new hospice benefit, the final result would be that 77% of the hospice care provided over the next 12 months to Medicare patients would in fact be billed to the conventional benefit ($\Sigma B_1 + C_1 + .25D_1$) and 23% under the new benefit ($\Sigma .75D_1 + D_2$). This probably overstates the volume of services billed under the new benefit during FY '84 because of the time it would take for these newly participating hospices to complete certification and begin operating under the new billing system.

B. Entry of New Providers to the Market

One question not yet considered is whether there will be new hospices entering the market (which were not reflected in the sample) which will increase the number of patients served under the new benefit. There has been some publicity given to the emergence of one proprietary hospice corporation which intends to start new programs in several parts of the South and Southwest. But apart from the few cities where this corporation indicates it will start programs, there was no indication that major proprietary groups would, in the near future, establish any significant new hospice capacity. Discussions with other proprietary groups which operate home health agencies indicated little or no interest in moving into hospice care at this time.

There was evidence that some hospitals may have increasing interest in providing hospice care in the future, but this would be more likely to be on the basis of acquisition or affiliation with existing programs or as a later expansion of a home health care program. Hospital based hospices, as a group, were not particularly interested in certification at this time. Therefore, any expansion of the volume of services by these providers would most likely be provided under the conventional Medicare hospice benefit. There may be some other growth of hospice care related to new voluntary groups starting programs. But the time it would take to achieve an organizational structure and volume sufficient to make participation under the new benefit attractive would mean little impact on the increased availability of services under the new benefit in the near future.

C. Impact of the New Benefit on Medicare Pay Out

Because of the slower than anticipated start up of the certification process and because it will take time for hospices undecided and/or not yet certified to begin serving patients under the new benefit, the impact of the new benefit will be felt gradually. If it is assumed that:

A. As estimated above, only 23% of the hospice services for Medicare patients will eventually be billed under the new benefit.

B. In FY '84, only 25% of the volume of hospice services anticipated to be billed under the new benefit will actually be delivered.

C. Hospices served 58,800 Medicare patients last year.

D. Hospices will serve 69,420 Medicare patients in the coming year.

E. All Medicare hospice patients served under the new benefit will use $6500 in services.

Then, the anticipated number of Medicare patients served in hospices and billed under the new benefit in FY '84 =

A x B x C = .23 x .25 x 58,800 = 3381 patients.

Total pay out under the new benefit in FY '84 would =

E x 3381 = $6,500 x 3381 = $21.98 million.

The anticipated number of Medicare patients served in hospices and billed under the new benefit in FY '85 =

A x D = .23 x 69,420 = 15,967 patients.

Total pay out under the new benefit in FY '85 would =

E x 15,967 = $6,500 x 15,967 = $103.79 million.

It is not yet clear whether the new Medicare hospice benefit will in fact result in either a net savings or loss to the Medicare trust fund. Most studies report that hospice care is a substitute for more expensive conventional care during the last days of life. The restrictions included in the Medicare hospice legislation and regulations (including the cap, reimbursement rates, and 20/80 restriction on inpatient hospital use) would appear to make it difficult for a hospice to run up extensive bills paid under the new Medicare benefit. But estimates of savings would also have to consider the cost of hospice care provided under the new benefit in relation to the cost of hospice services provided under conventional Medicare coverage. A scenario where every patient served under the new benefit costs $500 more than would have been spent if eligible services had been billed under the conventional Medicare benefit, would result in only about $1.69 million in increased cost in FY '84 (3381 patients x $500) or less than $7.99 million in increased cost in FY '85 (15,967 patients x $500). Savings at the same levels are also possible.

VII. Quality of Care, Abuse and Fraud

A. Quality

During the discussions, hospice representatives made frequent reference to the history of the hospice movement and how it had been founded upon a strong committment to providing the terminally ill patient "a better way of dying." In reaction to the perceived impersonalization of the highly technical medical care delivery system, hospices were established to provide medical and social care with "differing qualities" as well as "quality care." All respondents expressed a strong belief that their organizations were providing a high level of medical and social services and that most of their counterparts were doing so also. But they indicated that the new Medicare benefit created certain tensions that had implications for quality.

- Many hospices felt that the new benefit essentially requires one model of organization and hospices which wish to participate and do not fit that model are forced to significantly change their emphases and direction.

- Those hospices which in the past have stressed the psycho-social aspects of hospice care, were often concerned that these issues were being overshadowed by an increased emphasis on the medical/technical aspects of care.

- Frequently, home health and hospital based hospices, which had grown out of the more traditional medical care delivery system, were worried about the level of professional and technical competence of some other hospice organizations. They cited the lack of professional standards for nursing staff and unfamiliarity with the most recent advances in pain control and other aspects of palliative care. They were also concerned about smaller hospices not having sufficient documentation for the care they provided.

- Hospitals were concerned about the hospice responsibility for managing inpatient care and the potential conflict between hospice and hospital protocols and standards.

- Concrete suggestions for improving quality included: utilizing existing peer review systems; developing a standard regarding frequency of visits and other elements in the plan of care; developing criteria regarding the qualifications of nurses and other professionals providing hospice care; developing standards for the use and training of volunteers; and ensuring that State and Fiscal Intermediary personnel are sufficiently knowledgeable about hospice operations to enforce standards.

B. Abuse and Fraud

There is a strong relationship between the issue of quality and the potential for program abuse and even fraud. According to many respondents, the new benefit structure builds in a powerful "incentive to underserve". Because the income of certified hospices heavily depends on length of service, rather than the number or nature of the services provided, the interests of the patient and those of the provider may not always coincide. While some conflict of this sort is inherent in any prospective payment system, the respondents indicated that the reimbursement rates, cap, 20/80 restriction, and core services requirement may force some certified providers to consider providing something less than the optimum level of services at all times. Technically, underserving the patient is a "quality assurance" issue but serious deterioration in quality crosses the line into the realm of fraud and abuse.

Issues which the respondents raised that will require ongoing consideration and review include:

- Are hospices providing an appropriate number of services? Are they making home visits and providing necessary drugs and durable medical equipment? Are they continuing to provide necessary inpatient care even after the hospice reaches a 20% utilization rate? Are they employing qualified personnel to serve the patient? Are providers dropping their level of services to patients who are costing too much? What standards should be used to evaluate these issues?
- Are hospices misrepresenting the services they are providing? For example, are they claiming to make two home visits a week but in fact visiting only once?
- Are hospices providing higher levels of services in order to increase their reimbursement? For example, are they providing continuous home care to patients who need only routine home care? Is inpatient hospital care used to provide respite care?
- How realistic is the requirement that representatives of the Fiscal Intermediaries make home visits to hospice patients and their family? Will such visits be made and would they have any significant impact on the level or quality of services which hospices provide?
- Are hospices transferring cost to the Medicare Part B benefits by encouraging patients to seek services from their attending physician that the hospice should provide? Are hospice patients receiving curative treatments under Part B that they have waived under the hospice benefit?

- How will hospices use the recertification process at the beginning of each new election period? Will it be employed as a way to screen out patients who could still benefit from hospice services but have become "unprofitable" in terms of the Medicare benefit? After patients have used their 210 benefit days, will hospices pressure them to opt out of their program?

VIII. Recommendations

A. For purposes of analysis and evaluation, consider the new hospice benefit as a demonstration program in a market setting.

Under current conditions, the projected number of certified providers and the number of patients served will be so small that the benefit will have little immediate impact on costs and a gradual impact on other providers. The factors affecting participation are so numerous and interrelated that any effort to tinker with the system before 1986 would be premature and would have unpredictable consequences on costs, quality, abuse, and the hospice movement as a whole. The legislation requires HCFA to prepare a report to Congress on the cost and impact of the benefit, as well as an evaluation of the core services requirement, and this can be best done in the context of a stable program. For these reasons it is recommmended we should:

- Keep the current program as it is until the legislation expires in September 1986.
- Re-examine the premises and implications of the current conditions of participation and the current benefit structure. In particular, re-examine the need for a core services requirement by comparing the costs and quality of care delivered by hospices which do and do not provide core services.
- Continue the dialogue with representatives of all hospice models and other providers regarding the form a hospice benefit should take.

B. Develop standards and systems for evaluating and monitoring quality and abuse under this or any subsequent hospice benefit.

- Develop standards that would enable the Department and its contractors to assess quality care regardless of the hospice model. Since there are few experts in quality assurance in the hospice movement, the Department might consider letting a contract for this purpose.
- Continue and enhance the training of state surveyors and particularly personnel in fiscal intermediaries so that they become

even more knowledgeable about issues related to the delivery of quality medical care in a hospice setting.

- Examine ways proprietary hospices create operating efficiencies in order to determine possible implications for the delivery of hospice care.

C. Publicize hospice as an option.

The number of hospice care programs in the United States has grown rapidly in recent years because this approach is seen by many as a valid, humane and potentially cost effective means of dealing with terminal illness. The Department should initiate a campaign to inform Medicare beneficiaries and their families about the potential implications and advantages of hospice care as an alternative to conventional medical care. Such an approach could be similar to that of previous Departmental efforts, e.g. the publicity about HMOs. To the extent that hospice care produces a Medicare cost savings, such savings are likely to occur in both certified and non-certified hospices. Care should be taken to ensure that information which is disseminated regarding hospice care does not imply that services provided by non-certified hospices are necessarily inferior.

Appendix

Telephone Discussions

The numbers and quantitative estimates included in this report are primarily derived from telephone discussions held with a randomly selected group of hospice care providers in March 1984. HCFA Regional Offices provided lists totaling 1461 names of persons or organizations to which preliminary information had been sent about the new Medicare hospice benefit. Although the HCFA Regional Offices had varying means of compiling these lists, their intent was to send information to every operating hospice in the United States. A cross check with other available sources indicated that the HCFA lists were very complete.

One hundred and sixty-seven names were randomly selected for telephone contact. Some of these turned out to be trade associations, interest groups, health care providers and private parties which were not hospices. Where a diligent search could not turn up a telephone listing for a person or organization included in the sample, it was assumed they were also not a hospice. One hundred and twenty-two hospices were identified of which 114 are now providing hospice care and 8 will be operational in the near future. Only 3 hospices declined to participate in the study.

The telephone discussions usually lasted between 15 to 20 minutes. Respondents were asked whether they were (or would be in the next 12 months) providing hospice services and whether they were intending to seek certification for participation in the new Medicare hospice benefit. There was an open ended discussion about what factors went into their decision to seek or not seek certification, their sources of funding hospice care and their overall perceptions about the entry of other hospice care providers into the market in their communities. A limited set of other data was collected on the size of their programs, current and projected Medicare case loads, and type of organizations.

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