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BARRIERS TO HOSPICE CARE: ARE WE SHORTCHANGING DYING PATIENTS

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BEFORE THE

SPECIAL COMMITTEE ON AGING UNITED STATES SENATE

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BARRIERS TO HOSPICE CARE: ARE WE SHORTCHANGING DYING PATIENTS?

MONDAY, SEPTEMBER 18, 2000

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 1:36 p.m., in room SD–562, Dirksen Senate Office Building, Hon. Charles Grassley, (Chairman of the Committee) presiding.

Present: Senators Grassley, Collins, Breaux, Wyden, and Lincoln.

OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN

The CHAIRMAN. I want to thank all of you for attending today's hearing. Senator Breaux, our distinguished ranking member, will be with us shortly and at that point I will ask him to give a statement. He will be here just as soon as he can be.

Today's hearing is continuing the committee's focus on end-of-life care. In July, as you know, we held a hearing which highlighted the need for more education in this area. Well, it seems that the educational process has caught on. You have had an opportunity to see the PBS series last week, and end-of-life care is also on the cover of Time magazine right now. And I hope that we can keep up this great momentum to talk about something that Americans find very difficult to talk about, and that also means using our genius to make those the easiest days for people, or at least much easier than they otherwise would be.

While that educational effort continues, today we turn our attention to the role of government in end-of-life care, and one of the most far-sighted things that Congress has done for our Medicare beneficiaries was to add a hospice benefit. So it is my honor to have my friend, Senator Bob Dole, here today because he was instrumental in getting that initial job done.

Over the years, it also has been my honor to visit many hospice providers in my home State of Iowa. Hospice sets a standard for caring, coordinated, comprehensive services that I would like to see the rest of Medicare meet. But it has become clear to me that many Medicare beneficiaries are not getting the full benefit of hospice care.

The General Accounting Office report that will be presented today identifies the problem. While more and more Medicare beneficiaries are receiving the care, they are receiving it for shorter and shorter periods of time. The number who receive less than a week of hospice rose sharply during the 1990's.

Why is this a problem? Well, it is a problem for hospices because patients in their final week of life have very high costs and if they can't balance those patients against less expensive patients, the hospice can't break even. Even worse, short lengths of stay hurt patients and their families because they struggle for too long without the very valuable support that hospice can give. That is what I am referring to throughout this meeting when I use the term "shortchanged."

Having identified short stays as a key problem, next we want to understand the reason for this trend and what can be done to reverse it. As you will hear today, there are many barriers and I would like to focus on a few that are sure to come up. One is financing.

As Dr. Christakis notes, studies have found that hospice saves substantial amounts of money compared to traditional coverage. But many hospice providers assert that Medicare hospice payment rates are inadequate, especially given the dramatic increase in drug costs in recent years.

This year, the Medicare payment for a routine day of hospice care in the home is just under $100. In the year 2000, that doesn't seem like a lot of money to take care of someone who is dying. Unfortunately, hospices have only recently begun to report their costs to the Government, so the General Accounting Office will not be able to examine this issue until next year. But I do want to hear from our provider witnesses on their experiences on this issue.

Now, there is a second issue, Medicare's requirement that a physician must certify that a patient is likely to die within 6 months. One question is whether this rule makes sense in the first place, given the difficulty of predicting the course of an illness.

A second question is whether the Government has been reasonable in interpreting and in enforcing this rule. We have long heard complaints about confusion as to whether the 6-month period of time is a hard and fast limit. Of course, it isn't, and we have had some heavy-handed enforcement of that rule even though it isn't hard and fast. If such things are going on that would help explain why patients are admitted to hospice so late.

We have been hearing these concerns for years, but apparently the Health Care Financing Administration has now concluded that there is a problem. So on Thursday, the Health Care Financing Administration mailed out a clarification of this rule. This clarification probably would have been useful much sooner, but I welcome it now and thank the people who are behind it, and hope that it signals a renewed focus on improving Medicare hospice.

By the way, there are now several years of history of this committee's work under Senator Breaux' and my leadership spurring the executive branch into action. I would like to list a few of those instances.

In May 1999, at our hearing on the home health OASIS assessment, the Health Care Financing Administration announced that the OASIS requirement would be limited to Medicare and Medicaid patients.

The President announced a 21-point Nursing Home Initiative exactly one week before the first Aging Committee oversight hearing on nursing homes in July 1998. The Health Care Financing Administration modified its policies for nursing home complaints and enforcement in preparation for an Aging Committee hearing centered around the General Accounting Office report in these two areas in March 1999.

In July of this year, the Health Care Financing Administration released its report on nursing home staffing, just 2 days before our Aging Committee hearing on the topic of nursing home staffing shortages. And just this weekend, knowing that I was working on an initiative on nursing home staffing to be included in the upcoming Balanced Budget Act revisions, the President announced a legislative proposal in this area, and it is welcomed by all of us. At the July hearing, Administrator DeParle said that we would have to wait until completion of phase two of the study, approximately a year, before they could take action. So that makes the President's announcement a very welcome surprise.

I could cite other instances, and obviously we welcome today the Health Care Financing Administration's letter on hospice. And I thank Senator Breaux for working with me to move the bureaucracy along on each of these issues that we have been dealing with.

There are many issues to cover today, so I want to stop now. And before I introduce our first panel, as is the custom in my committee, I always give members who are present at the opening a chance to make opening remarks.

So would you start, Senator Wyden, and then Senator Collins.

STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. Thank you, Mr. Chairman. I very much appreciate your holding this hearing, and I also especially want to thank Senator Dole for joining us today. I was a junior Member of the House of Representatives serving on the Health Committee, and to have the Majority Leader of the U.S. Senate work with me at that time on health issues was an extraordinary compliment. I am so glad that Senator Dole is with us today. This is his law and we are going to talk a little bit about ways in which we can push the bureaucracy to make it more efficient in the future and we are very glad you are here.

Mr. Chairman, I think you know the reason I came to you and Senator Breaux and asked that the GAO look into these hospice issues is that we now have an agency that is far too rigid in terms of how they are handling these questions. As you know, with respect to the 6-month rule, it is truly bizarre to think that somehow the Federal Government would ask hospices to pay money back because somehow the patients were not dying on time. I don't know any other way to characterize that, other than bizarre.

That is certainly not what Senator Dole intended when he wrote the law, and it is not what you and Senator Breaux and others have wanted. There is no question that now HCFA is starting to move away from that approach. Frankly, I think this should only be the beginning of our efforts on a bipartisan basis to try to get this agency to be a bit more flexible in terms of how they approach the issue.

That is why I have introduced S. 3026. It is legislation that I hope that the Finance Committee will act on favorably this year to allow for some demonstration projects so that we can try out some models for providing a hospice benefit that more accurately reflect what hospice providers out in the field say that they need to care for patients.

Now, I want to give you an example. Recently, in Oregon, I heard over and over again concerns with respect to the use of nurse practitioners. These, of course, are the providers who in rural areas of my State are permitted to certify that a patient needs a hospice under State law, but they aren't allowed to do so under the Medicare rules of participation. That means someone in rural Oregon has to find a physician instead of the person who has been a primary caregiver, the nurse practitioner, to get them into a hospice.

My legislation, S. 3026, that would allow for some demonstration projects to build on the reforms that we are now getting in the 6-month rule and develop flexibility which seems to me to be very timely.

The fact is that the benefit design of this program really hasn't changed since it was put in place in 1982. The design was based on a model involving suffering cancer patients, which was appropriate then. But now we have many individuals with a variety of other health problems who also need and use this benefit.

My legislation also would allow in this demonstration projects, Mr. Chairman, to receive support and comfort care while deciding whether you should still seek curative treatment or are facing a situation where the person wants to go into a hospice program.

So I think this is a very important hearing. Public awareness is absolutely critical. To have Senator Dole with us today sends a very powerful message about how Congress can build on the important law that Bob Dole wrote. And as always, I look forward to working with you and our colleagues on a bipartisan basis.

The CHAIRMAN. Thank you, Senator Wyden.

Now, Senator Collins.

STATEMENT OF SENATOR SUSAN COLLINS

Senator COLLINS. Thank you very much, Mr. Chairman. I have an in-depth statement that I will submit for the record and I will just summarize my remarks.

The CHAIRMAN. It will be included.

Senator COLLINS. Thank you.

Let me thank you for holding this hearing on this very important issue, and welcome Senator Dole back to the Senate. We always benefit so greatly from his wisdom and experience, and his humor as well. So it is very nice to have him, as well as our other distinguished witnesses with us today.

Thanks in no small part to Bill and Judith Moyers and their television series "On Their Own Terms," there has been increased and much-needed attention focused lately on how we care for people at the end of their lives. Advancements in medicine, public health, and technology have enabled more and more of us to live longer and healthier lives. However, when medical treatment can no longer promise a continuation of life, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is inconsistent with their values or wishes.

We know that most people would rather die at home surrounded by family. In fact, surveys show that 80 percent of us have that preference. Yet, the vast majority of us will die in institutions, subject to high-tech interventions that may needlessly prolong suffering. That is one reason that I am such a proponent of hospice care. I know from my experience in talking with hospice workers and physicians in the State of Maine, that families who have experienced hospice care generally have far better experiences in dealing with the death of a loved one than those who do not.

In Maine, however, we have a very low rate of physician referral for hospice care. And when I have talked to physicians about why that is so, inevitably the 6-month rule comes up and the fear of referring people who may ironically live too long and thus not be qualified. Obviously, with many diseases it is difficult for any physician to predict with certainty when death will occur. So, I think we need to take a look at having more flexibility in the program, as both the chairman and Senator Wyden have mentioned.

It is interesting to note that—and I think it is directly because of the fears that physicians have about exceeding the 6-month rule—that half of Medicare hospice patients are enrolled for only 19 days—nowhere even close to 6 months—and many have service periods of just a week or less. That, unfortunately, is really not enough time to fully take advantage in most cases of the wonderful and comforting services provided by hospices.

To help address some of these problems, I have joined with Senator Jay Rockefeller in introducing the Advance Planning and Compassionate Care Act. Like the bill that Senator Wyden has described, it also provides for demonstration projects to develop models for end-of-life care for our senior citizens. It would also make it easier for pain medications to be reimbursable even if they are administered in a home setting. So I think there is a lot of work we need to do in this area.

In closing, Mr. Chairman, I just want to say that I think that a lot of the drive to allow for assisted suicide in this country would recede or even evaporate if we did a better job of caring for people at the end of their lives. I think that a lot of times the desire for assisted suicide is driven by fear and pain and worry of emotional stress for families. And if we could do a better job with palliative care and with taking care of people at the end of their lives, I think we would see the desire for assisted suicide evaporate. So for that reason, as well, I think it is really important that this hearing be held and that we start doing a better job in this area.

Thank you, Mr. Chairman.

[The prepared statement of Senator Collins follows:]

PREPARED STATEMENT OF SENATOR COLLINS

Mr. Chairman, thank you for holding this hearing this afternoon to examine the Medicare hospice benefit to determine whether there are barriers that are preventing some seniors who would benefit greatly from receiving hospice services.

Thanks in no small part to Bill and Judith Moyers and their television series, "On Our Own Terms," increased and much-needed attention has been focused in recent weeks on how we care for people at the end of their lives in this country. Advancements in medicine, public health, and technology have enabled more of us to live longer and healthier lives. However, when medical treatment can no longer promise a continuation of life, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is inconsistent with their values or wishes.

Discussions about appropriate end-of-life care are particularly timely in light of the current debate on physician-assisted suicide. The desire for assisted suicide is generally driven by the fear of prolonged pain, loss of dignity, and emotional strain on family members. Such worries would recede and support for assisted suicide would evaporate if better palliative care and more effective pain management were widely available.

Unfortunately, most patients and their physicians do not currently discuss death or routinely make advance plans for end-of-life care. As a consequence, about one-fourth of Medicare funds are spent on care at the end of life that is geared toward expensive, high technology interventions and "rescue" care. Moreover, while most Americans say they would prefer to die at home, studies show that almost 80 percent die in institutions where they may be alone or in pain, and where they may also be subjected to high-tech treatments that merely prolong suffering.

Clearly, there is more that we can do to relive suffering, respect personal choice and dignity and provide opportunities for people to find meaning and comfort at life's conclusion.

Hospice care can offer tremendous advantages over traditional, hospital-based end-of-life care. It enables dying patients to remain in the comfort of their own homes, free from unnecessary pain and surrounded by friends and families. Moreover, hospice not only improves the quality of life for both the patient and their family, but it has also been shown to be less costly than the alternative ways of caring for the terminally ill.

Unfortunately, as we will hear from our witnesses this afternoon, there currently are barriers that may be preventing many Medicare patients with terminal illnesses from receiving appropriate hospice care. Currently, in order for a Medicare patient to qualify for the hospice benefit, their physician must certify that they have a life expectancy of six months or less. Many doctors, however, are reluctant to do this, particularly for patients with diseases like congestive heart failure, where it is difficult to predict life expectancy with any certainty. Others are concerned that referrals will prompt scrutiny by HCFA, which has actually ordered investigations of hospices whose patients have lived longer than 6 months. As a consequence, half of Medicare hospice patients are only enrolled for 19 days or fewer, and service periods of one week or less are common. This is simply not enough time for patients and families to take advantage of hospice's unique services.

To help address some of these problems, I have joined with Senator Rockefeller in introducing the Advance Planning and Compassionate Care Act, which authorizes the Department of Health and Human Services to study end-of-life for Medicare and Medicaid patients and to develop demonstration projects to develop models for end-of-life for Medicare beneficiaries who may not qualify for the hospice benefit, but who still have chronic debilitating and ultimately fatal illnesses. I also introduced an amendment to the Patients Bill of Rights, which was approved by the Senate, to require a comprehensive study into the appropriate thresholds, costs and quality implications of moving away from the current narrow definition in Medicare of who is terminally ill and toward a definition that better identifies those with "serious and complex" illnesses. This study will help us to provide better care for that broader category of patients who are terminally ill and have a need for more coordinated care, but who will probably live for another year or two.

Mr. Chairman, the fact is that dying is a universal experience, and these are critical issues that, at some point, will confront each and every one of us. This afternoon's hearing will be extremely helpful in our effort to improve care of the dying in this country, and I look forward to hearing the testimony from our witnesses.

The CHAIRMAN. Thank you, Senator Collins.

It is my opportunity now to introduce our first panel, and I want to start with a friend of mine, Senator Bob Dole. I don't know how you introduce a person who has served his country so honorably during World War II and since, and is still serving his country well. His presence here at this committee meeting today is a perfect example of continuing public service.

But the importance of Senator Dole related to this issue is that as chairman of the Senate Finance Committee during the 1982 timeframe, before he became Senate Republican Leader, he was gun behind this movement toward hospice being covered by Medicare.

I was a freshman member of the Finance Committee at the time he was chairman of the Finance Committee and he helped me a lot during that period of time. He was a dear friend during that time and still is, and so Senator Dole is with us.

Before Senator Dole speaks, I want to take an opportunity so I don't have to interrupt the panel, to introduce, Ms. Ruby Tooks, of Carol City, FL. Ms. Tooks' mother, Louise Tharpe, who was a hospice patient, passed away just a few weeks ago. Ms. Tooks will describe what hospice has meant to her family in the last year. After she speaks, we will see a brief videotape of her late mother. Ms. Tooks is accompanied at the witness table by Ms. Marly Hernandez, the hospice nurse who cared for her mother.

Ms. Tooks, you are doing a real public service, as I told you privately, by coming here to be with us.

So, Senator Dole, would you start, please?

STATEMENT OF ROBERT DOLE, FORMER U.S. SENATOR FROM THE STATE OF KANSAS

Mr. DOLE. Well, first, I would ask that my statement be made a part of the record. I will do as Senator Collins did, sort of summarize, because I know you have a number of panels.

I would also note the bipartisanship, and it has been my experience all the time I was in the Senate that any legislation that was worth anything had bipartisan support. Very few pieces of legislation pass on a party-line basis that really have a major impact on Americans everywhere, and I think that is certainly true in this instance.

I must say, going back to the time that Senator Grassley just alluded to, there was strong bipartisan support. I get maybe the credit because I happened to be the chairman, but I remember working with Senator Ribicoff and others. It was sort of an effort that people recognized the time had come. And, of course, it all started in Great Britain and we learned from Great Britain the value of this kind of care, and it seemed to us to be a very reasonable thing to do.

We have other witnesses here today who are going to tell you the real impact, how it affected their mother, how it affected their father. But it is certainly a proper role for Medicare and a proper role for Government. So I would just talk a few minutes on sort of the genesis of the hospice benefit and a couple of things that you have already touched on in the eligibility area, the length of stay, and the fear that doctors have that they are going to be prosecuted for fraud or something worse. That is why the number of referrals have been decreasing, and you said, "What, 19 days?" And I think in your case it was even less. Well, anyway, she will get to that.

This issue has been important to me for many years, and I had a chance to see some of Bill Moyers' reporting just yesterday. I watched part of it. And I think it is important and I think we understand the importance, and it is widespread. I think if people learn more about the program, the more participation you will have.

Medicare, as we all know, initially centered on acute care and favored institutional care mostly in the hospital. And it was focused mostly on curative care, which made a lot of sense at the time. Yet, all those facing death hope to die with dignity, and once they come to terms with their diagnosis their care needs shift from curative care to palliative care, again, as we all know.

It seemed to those of us on the committee 20 years ago, as I said, in both parties that it was time to do something and we made this initial effort. As a result of the addition of the hospice benefit, today hospice provides the most significant care for Medicare beneficiaries who are terminally ill.

This benefit was a unique addition to the fee-for-service Medicare program. It introduced a new choice, specifically for terminally ill individuals. Hospice provided comprehensive care tailored to meet individual needs. It also introduced flexibility to enhance the benefit package and provide homemaker services, counseling, prescription drugs, and utilized a multi-specialty team of health care providers to assure a better quality of life for terminally ill patients. It also embraced family life by supporting and educating a Medicare beneficiary's family to care for their family member in their home, and providing bereavement counseling to family members following death.

So it has grown over the past 20 years and it is serving more and more beneficiaries. Throughout the first decade of the hospice program, people were very slow to participate, but most hospices serve Medicare patients today. In fact, Medicare patients represent two-thirds of hospice patients. I think this growth is good news. You know, 20 years; it is a fairly new benefit. Also, these increases now provide a comprehensive analysis regarding access to hospice services.

I think if you are going to review the access, you have to also look at the difficulty of assessing how many patients should be in hospice and may not be, for whatever reason. Nearly 2 million Medicare beneficiaries die each year. Yet, not all of them may be appropriate for hospice, and not all of them may be comfortable foregoing curative therapy and accepting their impending death.

For some, there may be cultural issues that discourage this care choice. When you think of access to hospice care, these are not populations you worry about. Rather, it is those patients who can benefit from hospice care and who would elect the hospice benefits but may not have enough knowledge of the benefit to make an informed choice. I think, as Senator Wyden said, we need more outreach. More people need to know about the program and know about the benefits.

Some may not learn about it from their physician, or may not have a hospice provider in their area. In addition, access may be less than optimal for those individuals with complex medical problems, multiple diseases, complicated care, greater social service needs due to impairments, and higher-cost medical needs. In other words, access issues in hospice do not easily reveal themselves. They are very difficult to determine. They are complex. They involve perceptions, individual benefits and, of course, the ability to accept death.

I would just touch on a couple of areas in eligibility where I think it should be clarified. I would say we didn't know we were setting up barriers when we passed the law. We thought we were providing a benefit. What we thought we were doing at the time, as I recall, seems to have been—I don't know; maybe it is some distortion or lack of understanding. Maybe we didn't make a good history. Maybe there wasn't enough discussion of it in the committee.

At the time the benefit was established, 6 months represented the general practice within the hospice industry. It was not a topic of debate, nor did we discuss how difficult this assessment would be for physicians. Although physicians are expected to certify that a patient's life expectancy is 6 months or less, by no means are they expected to be certain of that timeframe.

I was just talking to a doctor who is going to testify later who said it is better to get a 6-month sentence from a doctor than a judge because there is some flexibility. The doctor has some flexibility. He will be speaking to you later.

Over the years, this issue has been revisited. Ten years ago, HCFA clarified that the physician was only expected to base this judgment on the general knowledge of the course of the illness. In addition, Congress has revisited this issue and attempted to provide assurance by, first, revising and then eliminating in 1997 the lifetime benefit limit of hospice.

The bottom line is that Medicare beneficiaries may live longer than 6 months and still be terminally ill and eligible for hospice. Unfortunately, perceptions persist that this is a limited benefit and that it is fraudulent to refer patients that may live longer. Ironically, this is the only benefit in the Medicare program to be frowned upon if it provides positive health outcomes, such as improved quality of life, the ability to enjoy a day out of bed with the family, or stabilized health status.

Finally, I would just say that as you review access to the Medicare hospice benefit, please consider the decreasing length of service indicative of late referrals. Last year, MedPAC wrote, and I quote, "Because of a recent investigation by the Office of Inspector General examining long hospice stays, physicians may be reluctant to make 6-month diagnoses in all but the clearest cases to avoid any perception of fraud. In such cases, the patient may be admitted to the hospice either after hospice services may be of optimal value or not at all." These aren't my words. These are the words of MedPAC, and I find that part of the statement very disturbing. So they be coming in very late, receiving very few of the benefits.

I would just say that I appreciate this opportunity to share my thoughts with you. We have certainly come a long way in 20 years to treat and take care of the needs of terminally ill Medicare patients. But I am certain this committee is doing the right thing. People are going to appreciate it. They may never know of the existence of this committee, but it is going to make a difference in what you suggest and what the Finance Committee and the House Ways and Means Committee, or the appropriate committee in the House, and Congress finally does.

Again, I thank my colleagues, and wish you every success as you deal with this very, very important problem.

[The prepared statement of Mr. Dole follows:]

Statement of Senator Bob Dole

U.S. Senate, Special Committee on Aging

Monday, September 18, 2000

Mr. Chairman, Senator Breaux, and other members of the Committee, thank you for inviting me to testify regarding hospice care. I commend you for dedicating a hearing to this topic, which accounts for only about 2% of Medicare's total outlays, and especially to delve into the issue of access to Medicare hospice services. Indeed, the government must play a role in assuring appropriate access to Medicare services and I look forward to hearing from the other witnesses to gain their perspective on what more can be done.

My remarks will focus on the genesis of the hospice benefit and on those issues that I believe you may want to look more closely at to achieve improved access to hospice care for terminally ill Medicare beneficiaries.

The issue of end-of-life care has been important to me for many years. Nearly twenty years ago, I introduced legislation to establish the Medicare hospice benefit. The goal of hospice care, which was initiated in Great Britain, is to assist terminally ill patients in preserving as normal a life as possible, while remaining in their home, surrounded and cared for by their family. At the time, this was an unmet need of millions of Medicare beneficiaries and their families. As you know, the Medicare program initially centered on acute care and favored institutional care – mostly in the hospital. As a result, the Medicare program was focused, and mostly still is, on curative care. Yet, those facing death hope to die with dignity and once they come to terms with their diagnosis, their care needs shift from curative care to palliative care. Twenty years ago, people needed more than what was available to them in the Medicare program and hospice was uniquely qualified to deliver comprehensive care at the end of life. As a result of the addition of the hospice benefit; today, hospice provides the most significant care for Medicare beneficiaries who are terminally ill.

The hospice benefit was a unique addition to the fee-for-service Medicare program. It introduced a new choice specifically for terminally ill individuals. Hospice provided comprehensive care tailored to meet individual needs. It introduced flexibility to enhance the benefit package and provide homemaker services, counseling and prescription drugs, and it utilized a multi-speciality team of health care providers to assure a better quality of life for a terminally ill individual. Also, the hospice benefit embraced family life by supporting and educating a Medicare beneficiary's family to care for their family member in the home and by providing bereavement counseling to family members following death.

The hospice program has grown over the past 20 years to serve increasing numbers of Medicare beneficiaries. Throughout the first decade of the Medicare Hospice Benefit, hospices were slow to participate in the Medicare program. Luckily, today, most hospices serve Medicare patients and, in fact, Medicare patients represent two-thirds of hospice patients. This growth is good news. I urge you to remember that this is a relatively young benefit and the increase in patients and participating providers is most welcome. Also, these increases do not provide a comprehensive analysis regarding access to hospice services.

Inherent in a review of access to hospice, is the difficulty of assessing how many patients should be in hospice, but for whatever reasons are not. Nearly 2 million Medicare beneficiaries die each year. Yet, not all of them may be appropriate for hospice and not all of them may be comfortable foregoing curative therapy and accepting their impending death. For some, there may be cultural issues that discourage this care choice. When you think of access to hospice care, these are not the populations you worry about. Rather, it is those patients who can benefit from hospice care and who would elect the hospice benefit, but may not have enough knowledge of the benefit to make an informed choice, may not learn about hospice care from their physician, or may not have a hospice provider in their area. In addition, access may be less than optimal for those individuals with complex medical problems, multiple diseases complicating care, greater social service needs due to impairments and higher cost medical needs. In other words, access issues in hospice do not easily reveal themselves. They are complex, involve perceptions, individual beliefs and an ability to accept death.

As you seek to improve access to hospice care, I urge you to review the current program with the goal to secure the future viability of the hospice benefit. Some areas you may wish to examine in particular include:

<u>ELIGIBILITY</u> –

There is merit in clarifying eligibility, specifically, that Congress never meant for the definition of terminally ill to serve as a barrier to access the benefit, but rather as a reasonable measure of when a person could be expected to come to terms with impending death. At the time the benefit was established, 6 months represented the general practice within the hospice industry. It was not a topic of debate, nor did we discuss how difficult this assessment would be for physicians. Although physicians are expected to certify that a patient's life expectancy is 6 months or less, by no means are they expected to be certain of that time-frame. Over the years, this issue has been revisisted. HCFA revised its regulations ten years ago to clarify that the physician was only expected to base this judgment on the general knowledge of the course of the illness. In addition, Congress has revisited this issue and attempted to provide assurance by first revising, and then eliminating in 1997, the lifetime benefit limit of hospice. Bottom line, Medicare beneficiaries may live longer than 6 months and still be terminally ill and eligible for hospice. Unfortunately, the perceptions persist that this is a limited benefit and that it is fraudulent to refer a patient that may live longer. Ironically, this is the only benefit in the Medicare program to be frowned upon if it provides positive health outcomes, such as improved quality of life, ability to enjoy a day out of bed with the family, or stabilized health status.

DECREASING LENGTHS OF SERVICE:

As you review access to the Medicare Hospice Benefit, I urge you to consider the decreasing length of service indicative of late referrals. Last year, MedPAC wrote, "because of recent investigations by the Office of Inspector General examining long hospice stays, physicians may be reluctant to make six-month diagnoses in all but the clearest cases to avoid any perception of fraud. In such instances, <u>the patient may be admitted to the hospice either after hospice services may be of optimal value, or not at all</u>." I find the latter part of that statement very disturbing. Medicare beneficiaries may be accessing hospice, but they and their families are missing out on the benefit. This population of patients is choosing hospice and is eligible for hospice. Yet, I regret that many hospices report that patients are coming to them within days of death. Regardless of the reason for dramatic decreases in the length of service, it points to an access problem. Personally, I suspect there are a combination of reasons for the decreased length of service, including recent OIG activities, the need for improved discussion and education regarding this option, and physicians', especially those who may not refer many patients to hospice, uncertainty regarding the certification requirements or a misunderstanding of their role in a hospice environment.

Again, I greatly appreciate the opportunity to share my thoughts with you. We've come a long way in meeting the needs of terminally-ill Medicare patients. However, there is much to do to assure improved access. I hope that your continued attention to improve this benefit will result in a strong, viable hospice benefit for many years to come.

The CHAIRMAN. Thank you, Senator Dole.

Now, Ms. Tooks, please go ahead.

STATEMENT OF RUBY TOOKS, CAROL CITY, FL; ACCOMPANIED BY MARLY HERNANDEZ

Ms. TOOKS. Good afternoon. I would like to thank the chairman and the committee for allowing me to share the special end-of-life story about my mother, Louise Tharpe. If you remember one thing about this short visit today, I hope you will understand the dramatic difference that hospice care has made in my life and my mother's, and all the incredible support from a special group of health care professionals.

Less than one month ago, August 20, my mother, my best friend, passed away on her own terms. Hospice care provided by VITAS Healthcare Corporation, Dade County, FL, has made all the difference in my family and how I have accepted the loss of not one, but both of my parents. Yes, both of my parents. My father also died 8 months ago in hospice care.

Today, it is because of hospice support that I can reflect on the many precious moments I shared with my mother during her final days. Because of these fond memories, I have the strength to be here today before you talking about what hospice means to me.

To each person in this room, hospice may have a different meaning to them. But to me, when someone asks what hospice means to me, I say it simply is the answer. It is the answer because if it wasn't for hospice being there for me, for my mother when she needed it most when I was unable to give her the care that she needed, hospice was there. All I had to do was just call them when the pain got too bad. They were there, whether it was morning, noon, or night. That is what you need when your loved one is at the end of their life, because family members might say they are going to be there, but they are not going to be there. They have somewhere else to be when you need them. So when you have hospice for your loved ones, they are going to be there.

Hospice was a godsend for myself and my family, plus it was important to my mother. Mother loved her hospice caregivers. She loved the control she maintained in her life until the end. It was hospice that it made it possible for her to spend most of her time when she was at home surrounded by her family and her friends. By that time, she was truly blessed, and I know she would want me to thank VITAS and all of you for the benefits that made it possible.

I doubt that, alone, my family would have been able to accomplish my mother's last wish because it would have taken all of our family resources to do this, and that still probably wouldn't have been enough. I am so grateful that we were able to have hospice with us for more than a couple of days. With the care of hospice, I was able to give back to the woman who sat with me at night when I was sick, kissed my bumps and bruises and made them better, and made me know that the world would not always be fair.

The early involvement of hospice in both of my parents' lives would allow me extra time to develop a special trust and confidence in the hospice staff. Everyone on the hospice care team was so wonderful. Whenever a physician was needed, Dr. Gomez would come to my home in Carol City, FL. The nurse and the nurses aides helped me with the day-to-day care of my mother so I could focus my attention on my husband, who was also suffering from chronic diabetes and on dialysis. The chaplain and the social worker also helped us with the stress and uncertainty that comes with terminal illness. All of them provided great comfort and support to both myself and my mother. For that, I am also grateful.

Assistance was given and is currently ongoing for my family because now I can go through the bereavement classes that I need because when my father died 8 months ago and my mother a few weeks ago, I didn't get a chance to grieve. So hospice is still helping my family.

The support of hospice and my church have made all the difference. Hospice care helped us appreciate that my mother was with me each day, and in the end this spared not only my mother pain, but softened our loss. As you can tell, I believe in hospice. Hospice is wonderful. It allows me to appreciate each day in a special way.

The new understanding that I have gotten since I have been with hospice has helped my family, and I plan on volunteering to help VITAS with their wonderful work in the future. Because they gave so much to my mother and my father, I want to give something back.

More people should know about hospice because when I talk to people in the community, they think you can only qualify for hospice if you have cancer and you are dying of cancer. Not true. I told them that hospice will help you if you have any terminal illness, like they said, from 3 to 6 months, 1 to 6 months. But you can't say that because only God Almighty knows how long you are going to be here. If it is terminal, you can say terminal, but you can't tell if a patient is going to die in 3 months or 3 days. But they will be there for you and they will not turn their back on you. If your parent or your loved one doesn't expire, hospice doesn't walk away and just leave you. They are there until the end.

I think my mother lived longer because hospice managed not only her physical pain, but also her emotional care. Regardless of outcome and the timeframe, hospice workers are committed until the end because hospice is a special way of caring. Hospice is about dying well.

Thank you for letting me share my story.

[The prepared statement of Ms. Tooks follows:]

U.S. Senate Special Committee on Aging

Testimony for Ruby Tooks

On

September 18, 2000

Good afternoon. I would like to thank the chairman and committee for allowing me to share the special "end of life" story of my mother Louise Tharpe. If you remember one thing from my short visit with you today, I hope you will understand the dramatic difference hospice care has made in my life, that of my mother and the incredible support of a special group of healthcare professionals.

Less than one month ago, on August 20th, my mother -- and my best friend -- passed away on her own terms. Hospice care provided by VITAS Healthcare Corp. in Dade County, Florida, has made all the difference in how my family and I have accepted the loss of not one but both my parents. Yes, BOTH of my parents. My father also died eight months ago on hospice care. Today, it is because of hospice's support that I can reflect on the many precious moments I shared with my mother during her final days. Because of those fond memories, I have the strength to be here today before you talking about what hospice means to me.

To each person in this room, hospice may have a different meaning. To me, when asked, "what is hospice care," I simply say it is "the answer." It is the answer to care at the end of a loved one's life. When all control is gone and final decisions have to be made, there is hospice to support you and your family.

Hospice was a "god send" for myself, my family and most important, my mother. Mother loved her hospice caregivers. She loved the control she maintained in her life up until the very end. It was hospice that made it possible for her to spend more time than expected at home surrounded by her family and friends. For that time, she was truly blessed and I know she would want me to thank VITAS and all of you for the benefit that made it possible.

Alone, I doubt my family would have been able to accomplish her last wishes. It would have taken all of my family's resources, and still most likely not been enough. I am so grateful that we were able to have hospice with us for more than a couple of days. With the care of hospice, I was able to give back to the woman who sat up with me at night when I was sick, kissed my bumps and bruises to make them better and soothed my heartache when the world seemed unfair.

The early involvement of hospice in both my parents' lives allowed us the extra time to develop a special trust and confidence in the hospice staff. Everyone on the hospice care team was so wonderful. Whenever needed, the hospice physician, Dr. Gomez, actually visited my mother at home in Carol City, Florida. The nurse and nursing aides helped me with the day-to-day care of my mother so I could focus the needed attention on my husband who suffers from chronic diabetes and needs dialysis treatments. The chaplain and social worker also helped us with the stress and uncertainty that comes with a terminal illness. All of this provided great comfort and support to both myself and my mother. And for that, I am truly grateful.

The assistance that was given – and is currently ongoing – for my family is wonderful. Many times in life, my mother was my strength and I was glad I could support her up until the end. The support of hospice and my church has made all the difference. Hospice care helped us appreciate each day that mother was with us. And in the end, they spared not only my mother's pain but softened our loss.

As you can tell, I believe hospice is wonderful. It allows me to live and appreciate each day in a special way. In fact, with my new understanding of hospice, I plan on volunteering to assist VITAS with their wonderful work in the future. Hospice is the answer to end-of-life care and dying on your own terms. More people should know about hospice. Hospice isn't just for cancer patients. And hospice workers won't turn their back on you if you live longer than predicted. I think my mother lived longer because hospice managed not only her physical pain but also her emotional care so well. Regardless of the outcome and time frame, hospice workers are committed until the end because hospice is a special way of caring. Hospice is about dying well.

Thank you for letting me share my story.

The CHAIRMAN. Before questions, I announced that we were going to see a videotape associated with Ruby Tooks' case here. So could we have that video now and then we will ask questions?

[Videotape shown.]

Thank you, Ms. Tooks, for sharing those last days of your mother with us and the country as an example of what hospice care is all about. We thank you very much.

I just have one question. I don't have any of Senator Dole, except to thank him once again for the public policy interest that he maintains even after being in the Senate by being with us, particularly viewing this legislation as something that he helped get passed, and for consulting with us on the original intent and what can be done to improve it.

Ms. Tooks, I have already thanked you. You have had to deal with a lot, with your parents passing away this past year and your husband being on dialysis. I think it is wonderful that even after all that, you still wanted to be here today and to be a hospice volunteer in the future to help make things better for those who come after all of us. Family caregivers like you are America's everyday heroes. Again, thank you.

I understand that after your father passed away, you took advantage of the respite care that Medicare offers after your mother's passing. Would you tell us about that, please? That is the only question I have of you.

I would also ask Ms. Hernandez if there is anything she wants to give us from her experience. I would be glad to have you offer anything you want to, Ms. Hernandez.

Would you please go ahead, Ms. Tooks?

Ms. TOOKS. My mother was first in hospice, and after I saw how well they were treating my mom—my father was sick and he was also in the hospital. The doctor said he was not going to make it; he was terminal. So they asked me what I was going to do, so I said I wanted to put him in hospice, also, because I knew I couldn't be there with mom. He lived in Broward County and I lived in Dade County, so I couldn't be with both of them. So I put him in hospice, so that way I knew he was in good hands.

So this is why I am saying if we don't have hospice, a lot of aging people are going to die because some of them don't have family. My mother was fortunate to have me. There are some people with children who still don't take care of their family. So with hospice, I knew the days they were going to be with my mom and I knew that I could focus on my husband's illness because I knew mom would be in good hands. So this is why hospice is so important.

And when my dad died, I couldn't be with mom, so they put her in respite care and the hospital and they kept her there for 5 days so that I could make funeral arrangements and do what I had to do for him. Then I came back and got her out of the hospital. So hospice is good all the way around because, like I said, you don't have family members who are willing to take care of a terminally ill person for 5 days; not even one day would they want to be bothered.

So without hospice and all the benefits that they give us—we need it, and people like me more especially because we don't have the resources to pay someone to come in and take care of your loved ones. We can't afford it.

The CHAIRMAN. Thank you very much.

Do you want to say anything?

Ms. HERNANDEZ. I don't know what to say. She has just been a great witness.

The CHAIRMAN. Thank you.

I will call on, in order, Senator Wyden, Senator Collins, and then Senator Lincoln.

Senator WYDEN. Thank you, Mr. Chairman. I am going to ask Senator Dole a question only because I know that he really is knowledgeable about these health care issues. As he knows, often we have colleagues who come on in and they read a statement or something, but really don't know all that they might about some of these issues.

The CHAIRMAN. Don't tell our secrets. [Laughter.]

Senator WYDEN. The word is going to get out.

The question I have, Senator Dole, is what is your sense about why it has been so hard to get the word out about hospice and its potential. I think we all know that it has just not penetrated really the way we would like. And as you study these health care and talk to folks in the health care field, what is your sense about why it has been hard to get the word out?

Mr. DOLE. Well, I think some of it is cultural and some people can't face the fact that it is the end of life. They don't want to hear it, they don't want to listen. They probably turn off the Moyers show because it is pretty heavy stuff. Then as Ruby indicated, some people may have the misimpression that it only covers one disease or cancer or whatever it maybe, which is not the case.

And maybe we haven't done a very good job on outreach. I remember working for years with Senator McGovern and Senator Humphrey on food stamp legislation, and we still have people in rural areas particularly whom you don't reach with those programs, particularly food stamps and some of the other programs for seniors.

I think there is still this reluctance—pride, call it what you will—of people not wanting help, and particularly where there are no children around. I mean, there are a lot times that they don't—you know, there are some people who probably go through life and never hear a spoken word maybe for a week. Nobody ever says hello or good-bye for a day, 2 days, or a week. So it sort of indicates how far we need to go.

I was on a panel on how to age gracefully. I am not sure it is going to work, but they had a group of us—Art Linkletter, who is 89, and Jane Russell, who is 70-some, and Barbara, the genie who came out of the bottle.

Ms. TOOKS. Barbara Eden.

Mr. DOLE. But, anyway, we were talking about the same thing, how do you get people to do these things, go to the doctor and learn about long-term care and hospice care. And these are fairly sophisticated people and they didn't have the answers.

But I think this committee hearing helps a little, and there will be some coverage of it and it helps a little. And I assume members are having town meetings, and maybe a seminar in each State and each district on hospice care would be helpful, too.

Senator WYDEN. I think, Mr. Chairman, Senator Dole is making an important point. In a sense, I think what he has said is that the folks who need it the most are often the most isolated and essentially have no kind of network. And I think as we work on these programs—we have got the Older Americans Act coming up again—we ought to look at some innovative approaches to reach those people. I happen to think that at some point you have got to have some folks actually knock on the door of these people.

Mr. DOLE. There are still people dying in some areas unattended. They find them a week or 2 weeks after they have died of natural causes.

Senator WYDEN. Thank you for your leadership. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Collins.

Senator COLLINS. Thank you, Mr. Chairman.

Ms. Hernandez, if you could move the mike up close to you, I do have a question for you. I think that Senator Dole and Ms. Tooks have put their finger on a very important issue, and that is how do we make sure that elderly people who are dying of a terminal illness who are all alone in the world learn about hospice care.

Ms. Tooks knew about it, and I am going to ask her a question about how she first learned about it with her father. But she was pretty knowledgeable and a lot of us who are lucky enough to come from large families have less to worry about in that regard. But what about that elderly terminally ill person who is all alone in the world? Are we doing a good job of making sure that doctors reach those people? I can see people in the audience shaking their heads, no, that we are not.

What has been your experience?

Ms. HERNANDEZ. I agree with those people who are shaking their heads that are saying, no, we are not doing too good a job regarding that to send the message out, trying to get early referrals out there to physicians. Physicians, as indicated by Senator Dole, are very fearful regarding referrals because of a certain perception that they may have regarding fraud, and what not.

So I think the answer is education and educating the consumer regarding their rights regarding hospice and Medicare guidelines and regulations. So I think you are making the key point right now, today.

Senator COLLINS. I think that our medical schools need to do a better job in this area, also.

Ms. HERNANDEZ. And nursing schools, too.

Senator COLLINS. Nursing schools, too. Good point.

Ms. HERNANDEZ. They do not have that as a criteria in the curriculum. In nursing school, they have psych, they have ob/gyn, but they do not have hospice, palliative care.

Senator COLLINS. I think that is an excellent point that we need to encourage the schools training health care providers to put more emphasis on end-of-life care, palliative care, and make them more aware of it. I think that our whole health system has been so geared toward curative care that we have really slighted palliative and end-of-life care.

Ms. HERNANDEZ. I concur.

Mr. DOLE. It may already be done, but we mail out 30-some-million Social Security checks every month, and maybe some are wired directly to the bank, but even a little notice in with the check for somebody to contact if somebody in your family—I mean, there are a lot of things that we can do to get the word out, particularly when you have got the Social Security program already in place. Maybe there is some prohibition against putting enclosures in with the check, but as long as they are non-partisan information——

Senator COLLINS. I think that is a good idea. Given the amount of mailings that my doctors tell me they get from HCFA, I think they could afford to put in one on end-of-life care.

Ms. Tooks, just one comment for you. I know how painful it was to watch your mother, but I hope you take great comfort and peace in knowing that you did all you could, working with hospice workers, to give her a very peaceful death. So I hope you take comfort in that. And I know that was hard for you, but it was wonderful to hear your mother's words in her own voice.

I am curious how you first found out about hospice care.

Ms. TOOKS. Well, I read a lot, but then I had a relative who died in hospice and I saw how well they did with her. And the family couldn't be there for her, but they were there, and that is what made me know that if I ever needed it, they would be there for me. So this is why I suggested to the doctor when they told my mother she had to leave the hospital and they were going to have put her in a nursing home—I told her PC doctor, no, she won't go in a nursing home, because mom never wanted to go in a nursing home. She said, "I know as long as you live, you will take care of me, and that was the bargain she and I made."

So when they said she had to go in a nursing home, I told the doctor, I said, no, put her in hospice. So he said, Ruby, she is terminal, but we don't know how long. I said it doesn't matter. She is terminally ill. It is for people who have a terminal illness, I said, so put her in hospice, put her at home with me, so then I can help with her treatment. I said as long as I get some help from hospice to come in and help me some, I can manage it.

So he said, but you can't do her IVs and all the medication that she needs. I said that is for hospice to come in. I saw it with my cousin. They came in and they administered the IVs and all the medicine. I said, then when she gets over that stage, I can handle it.

Senator COLLINS. Isn't that interesting, you essentially educated your doctor.

Ms. TOOKS. Yes.

Senator COLLINS. Rather than your mother's physician telling you about this option, you were the one who told him, it sounds like.

Ms. TOOKS. I worked with the doctor on it, and I talked with him and educated him about it. But that is how she got in hospice.

Senator COLLINS. Well, I think, Mr. Chairman, that that story says it all about the better job that health care providers need to do, because not everyone would have been as forthright as you were in making sure your mother got the kind of care that she deserved and wanted. So good for you.

Ms. TOOKS. One other thing. We need to go to AARP meetings and things. That is where we need to meet our seniors who are in there. They don't know about hospice. They don't know that it is a place for their loved ones in there by themselves, living in these homes by themselves, because we have a lot of people in my area who live alone and are very sick. So we need to go around to the meetings and things and try to educate them, and tell the doctors if a person is deemed terminal, try to put them somewhere so someone can be there for them, because they need some help when they know they are dying. And people know when they are dying. My mother knew she was dying, and I know that is why she said be sure to tell them and thank them for what they did for me.

Senator COLLINS. Thank you all very much for your testimony.

The CHAIRMAN. Your question may be the key question about the deficiency we have in medical training.

Senator Lincoln.

STATEMENT OF SENATOR LINCOLN

Senator LINCOLN. Thank you, Mr. Chairman. It is interesting because before the previous hearing you held on end-of-life care, I asked my husband, who is a physician, about the kind of training he got in medical school in regards to end-of-life care. It is amazing to me that general medical school lacks education in end-of-life care.

Mr. Chairman, I am very pleased that you are continuing this committee's discussion on end of life care by focusing on the Medicare hospice benefit today. I want to thank all of you all on the panel for sharing your experiences.

Senator Dole, you have been so instrumental in bringing about the Medicare hospice benefit. I think you bring up a great point, about educating individuals about end-of-life care because when you get to the end of life, you are frightened. I have seen that with my parents, and certainly with their contemporaries. They lack the capability to communicate with one another about this issue because it is the unknown to some degree and it is very, very frightening.

We have an opportunity in this Nation to also begin to educate the Baby Boomer generation, my generation, as we are dealing with our parents at their end of lives. We also must prepare for and learn about what is available to us.

According to a recent Time-CNN poll, 7 out of 10 Americans say they want to die in the comfort of their own homes. Yet, three-fourths of us die in medical institutions. Furthermore, nearly half of us die in pain, surrounded not by our families but by strangers.

Despite the growth of hospice care, which was designed to allow people to die with dignity in their own homes, too many people are going without it. Hospice is not only more attentive to patients than traditional care, but it is noticeably less expensive. And for those of us who are working to make Medicare solvent through the next millennium and effective in continuing longevity, that is an important part of the equation.

I have met with hospices in my home State of Arkansas several times, and hospice faces many challenges in serving their patients. As the GAO report indicates, the average length of stay for hospice users has plummeted in recent years. These short hospice stays may not fully meet the needs of the dying patients, and place an extra financial burden on hospices, particularly those in rural areas. Senator Dole mentioned a little about that.

Rural hospitals like those in my home State of Arkansas are already financially strained, in that caregivers must often travel several hours a day to serve their patients. Short stays are most often the result of doctors being afraid to refer their patients to hospice care for fear that their patients will outlive the 6-month certification for eligibility rule. Ms. Tooks mentioned that her doctor was reluctant at first. We need to examine this rule further and possibly clarify what it means.

My question is Senator Dole, was medical training regarding prognosis an issue as Congress discussed adding the hospice benefit to Medicare? Was it talked about?

Mr. DOLE. I would have to go back and check the record, but as I recall, I think everybody supported the idea and we probably didn't have hearings to the extent we should have had to look into prognosis and what would be an appropriate time. Six months was sort of the accepted period of time. It wasn't meant to be a barrier or a limit. It was sort of a guideline.

I think through different administrations, HCFA obviously wants to do the right thing, but there have been some problems. I think Senator Grassley indicated there had been another clarification just in the last week. Is that correct?

The CHAIRMAN. Yes.

Mr. DOLE. So all of these things will be helpful. I think that is another reason these hearings are helpful to get the agencies to focus on what is happening. Again, I think it is reaching out to people particularly in rural areas, where people are isolated in Arkansas, Kansas, Florida, or wherever, because sometimes the message doesn't get out that far.

But this will be a great program for the chairman and others of you to be on with Larry King or somebody that has a pretty good audience. And he is always looking for some way to reach out to people who are very vulnerable, and this is certainly a very vulnerable group.

Senator LINCOLN. Well, I certainly thank you for all of the work that you have done on this issue. I hope that you will continue to allow us to call on you to be helpful.

Mr. DOLE. This is an example of compassionate conservatism. [Laughter.]

Senator LINCOLN. And a special thanks to you, Ms. Tooks, for your insight, and certainly your willingness to share with us. I do think your suggestion of reaching out to the AARP, RSVP, and some of the other areas—I have a seniors advisory committee in my State that I work with and I certainly appreciate the public service announcements that we could do to get the word out. Senator Dole's suggestion of including something in the Social Security mailing is a great idea. We certainly should take advantage of every possibility of getting that message out.

Thank you all. Thanks, Mr. Chairman.

The CHAIRMAN. We have been joined by our distinguished ranking member, Senator Breaux.

STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Thank you very much, Mr. Chairman, and I thank the panel. I apologize. I just got in from Louisiana and I wanted to get here as quickly as I could because this is a very important subject.

I was catching a little bit of Senator Lincoln's comments when I came in and she was talking about life and the very serious subject of death, and I looked over here at Senator Dole and could see that there is life after politics. That is for sure.

We are delighted to have you with us, and it has got to be a real thrill for you, in particular, to come back after you have served and to see evidence of the good work and the wisdom that you exhibited back in the early 1980's in saying that hospice was going to be something that Medicare should cover.

The ironic thing is, 18 years later, we are still having an act of Congress to determine what Medicare covers and what Medicare doesn't cover. We shouldn't have to do that, but thank goodness that you did it and had the wisdom to do it.

Just a short comment—I don't really have a question—is the fact that it seems to me that we train doctors and physicians, Senator Lincoln, who is married to one, to extend one and to do everything they can to keep people alive as long as they can. It is my understanding that there are only three medical teaching hospitals in the country that really teach physicians how to deal with the end of life, because everything they are taught is to try and keep people alive as long as they can and do as good a job as they possibly can.

So there is a disconnect with most physicians, who are not trained to recommend hospice, but rather recommend continuing treatment and rehabilitation, when I think every bit of medical science tells us that we should be looking toward how that person is going to end their life and make sure that it is done with dignity and quality and as pain-free as we possibly can.

So I think if you see people getting into these programs for shorter and shorter periods, it is perhaps because not enough medical professionals are recommending it when they need to. Most people don't find out from a doctor about the existence of hospice. They find out from a friend or from someone in their family or someone else's family.

We have used it twice for my mother and for my father-in-law. It is a terrific service. I am on the board with the people back home in Louisiana and have helped them raise money. It is a wonderful, wonderful, and very important service, and thank God for Senator Dole for making sure that Medicare covered it. We appreciate that.

Thank you.

Mr. DOLE. I will just make a point that, as I said earlier, nothing ever happens that is really worthwhile up here unless it is bipartisan. Of course, I just happened to be the chairman, but there was broad support on both sides of the aisle. That is the way things should work.

Senator BREAUX. It helps to be the chairman, though.

Mr. DOLE. As I recall. [Laughter.]

Senator BREAUX. Thank you.

The CHAIRMAN. Any other questions from the members? I don't have any.

I want to thank Senator Dole and Ms. Tooks and Ms. Hernandez for participating in this hearing and helping us establish a record that will lead to congressional consideration of modernization or more explicit definitions of what hospice can do or not do. Hopefully we serve more people and help the institution of hospice be very, very viable.

Thank you all very much.

Mr. DOLE. You are probably going to need a little extra funding, too.

The CHAIRMAN. Yes, yes. I will make some announcement on that very shortly.

Mr. DOLE. Should I wait? [Laughter.]

The CHAIRMAN. I would say go home and turn on your television set.

I would like to now move to the second panel, so would the people who are on the second panel come and be seated while I am introducing you?

We once again have Dr. Scanlon, and it may be redundant for me to always say that he is a wonderful resource for our committee, representing the General Accounting Office as their Director of Health Financing and Public Health Issues. We draw on him almost every hearing we have, and so we thank him for returning to represent his very good agency that has done a new study on hospice benefits, already referred to by Senator Wyden.

Then our next witness is Dr. Nicholas Christakis, Associate Professor of Medicine and Sociology at the University of Chicago. He will be presenting results from his research into barriers to the use of hospice care, focusing I believe especially on problems of prognosis.

We will then hear from three hospice directors: one, my own constituent, Frances Hoffman, Hospice of North Iowa, in Mason City. Then we will hear from one of Senator Breaux' constituents, Kathryn Grigsby, Hospice of Baton Rouge, and finally from Karen Bell, Providence Health Systems, Portland, OR, a constituent of Senator Wyden's.

So we will start as I introduced you, Dr. Scanlon, Dr. Christakis, from left to right.

STATEMENT OF WILLIAM J. SCANLON, DIRECTOR HEALTH FINANCING AND PUBLIC HEALTH ISSUES, HEALTH, EDUCATION, AND HUMAN SERVICES DIVISION, UNITED STATES GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Dr. SCANLON. Thank you very much, Mr. Chairman and members of the committee. I am pleased to be here again today, particularly since you are dealing with such an important topic as hospice care and the potential barriers to its use.

At the request of the chairman and Senator Breaux and Senator Wyden, we have examined the use of the hospice benefit over the last decade, and have issued a report that is being released today on that subject. I would like to summarize briefly the findings of our work.

Since 1992, the number of Medicare beneficiaries choosing hospice services has grown dramatically. Nearly 360,000 beneficiaries enrolled in 1998, more than twice as many as in 1992. About 1 in 5 beneficiaries who died in 1998 used hospice, compared to 1 in 12 in 1992.

Despite this experience, concerns exist that the hospice benefit is underutilized. Cited most frequently as evidence of this underuse are declining lengths of stay. From 1992 to 1998, the average declined by a fifth, from 10½ weeks to 8½ weeks. Half of Medicare hospice users are enrolled for less than 3 weeks, and stays of less than a week are common.

A variety of factors are seen as influencing decisions about whether and when to begin hospice services, and we have heard many of them discussed already. Physician and patient knowledge and attitudes are keys. Physicians may be unaware of the benefits and the services hospice offer or the conditions for hospice use. They may be unwilling to stop curative care or be uncomfortable discussing end-of-life care options.

Similarly, some patients may also choose to continue curative or life-extending treatments. Others may reject or delay enrolling in hospice because it requires acceptance that death is near. In some cases, beneficiary circumstances may complicate the use of hospice services. For example, because hospice is designed to allow patients to remain at home, some programs limit participation to those with a caregiver at home.

Federal oversight of compliance with Medicare's eligibility requirements has also been a concern of the hospice industry, and it may affect use. In 1995 and 1996, the Health and Human Services Office of the Inspector General investigated cases where beneficiaries had received hospice services for longer than 6 months and found that some were patients whose original condition would not have justified making a prognosis of 6 months to live.

These investigations have been widely publicized and to some extent misconstrued to mean that if a patient survives for 6 months or longer, they weren't eligible for hospice care. This is not correct. The eligibility criterion, as we have heard, as specified in the original statute, is having a prognosis of 6 months to live. These prognoses are predictions made at admission or recertification based on information available at the time. What happens subsequently is irrelevant. Making a prognosis, however, is difficult. Well-trained clinicians can differ in their judgments regarding particular patients.

Some believe that as a result of the IG's scrutiny, referring physicians and hospice providers are more cautious about enrolling beneficiaries, particularly those with non-cancer diagnoses, because for these conditions it is more difficult to certify a 6-month prognosis. It is also felt that referrals, when made, are made much later, reducing the number of days of care before a patient dies.

We found, however, that hospice use grew most dramatically for patients with diagnoses other than cancer. This growth did slow somewhat after 1995, falling to 20 percent per year, instead of 36 percent per year. It is difficult to know how much of this slowdown is attributable to the effect of Federal scrutiny or the limited likelihood of being able to maintain a 36-percent growth rate indefinitely. We also found that the trend toward fewer average days of hospice use began before the period of Federal scrutiny.

Last week's announcement by the HCFA Administrator which you referenced, Mr. Chairman, included an announcement to begin a voluntary program for intermediaries to make eligibility determinations prospectively. This may reduce some of the concern over review of claims. Even though current reviews are to be based on information available when the prognosis is made, since they are done retrospectively, suspicions may arise that additional information, such as a patient's survival, can influence reviewers' judgments. Prospective determinations will not, however, make prognoses easier, so it would be desirable to consider development of alternative criteria that rely on more objective, measurable clinical factors.

Cost pressures have also been reported as a factor affecting access for certain patients. Shorter stays mean fewer days to spread the higher cost of admitting a patient or the higher costs of the care in the days immediately preceding death. Changes in the mix of services due to increased use of chemotherapy or radiation for palliative purposes or the substitution of more effective but more expensive pain medications adds to these pressures.

Assessing how much these changes impact costs and the adequacy of Medicare payment is impossible without adequate information on the provision of the full array of hospice services and their underlying costs. The Balanced Budget Act did require HCFA to collect hospice cost data. While that effort is underway, audited hospice cost data will not be available until late next year.

In conclusion, let me note while we have seen a considerable increase in the use of the hospice benefit, we should be sensitive to barriers to access for additional patients who might benefit. Because use of hospice is influenced by many factors and potential demand is difficult to determine, the extent to which the Medicare hospice benefit may be underused remains unclear. We can focus, though, on what seem to be unreasonable and unnecessary barriers, and consider how to ameliorate them.

Thank you very much, Mr. Chairman and members of the committee. I would be happy to answer any questions that you have.

[The prepared statement of Mr. Scanlon follows:]

United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging, U.S. Senate

For Release on Delivery
Expected at 1:30 p.m.
Monday, September 18, 2000

MEDICARE

More Beneficiaries Use Hospice; Many Factors Contribute to Shorter Periods of Use

Statement of William J. Scanlon, Director
Health Financing and Public Health Issues
Health, Education and Human Services Division

GAO
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Mr. Chairman and Members of the Committee:

I am pleased to be here today as you discuss issues related to the use of the Medicare hospice benefit. The twenty-first century will bring new challenges to the provision of palliative care to older people. Palliative care is changing, as are notions of a decent or "good" death free from unnecessary suffering for patients, families, and caregivers. New medical technologies and treatments are expected to result in better management of symptoms of chronic conditions and at the same time will blur the lines between curative care and palliative care.

Hospice care is an option available to Medicare beneficiaries who are expected to have 6 months or less to live and who choose to receive palliative care and supportive services, rather than traditional curative-focused medical care, to manage their terminal illness. Medicare-certified hospices provide a range of services to control pain and provide comfort, primarily to individuals in their own homes. Some patient advocates, hospice providers, and others contend that certain Medicare beneficiaries for whom hospice care is appropriate may have difficulty in gaining access to care or receiving services in a timely manner. However, officials of the Health Care Financing Administration (HCFA) and others assert that the hospice benefit is basically working as intended and meeting the needs of those who choose to use it. At your request, we examined the use of the hospice benefit during the past decade. Accordingly, my remarks will focus on (1) the patterns and trends in hospice use by Medicare beneficiaries, (2) factors that affect the use of the hospice benefit, and (3) the availability of hospice providers. Our report on this work is being released today, and it provides more detailed information on these issues.[1]

In summary, the number of Medicare beneficiaries choosing hospice services has grown substantially during the past decade—nearly 360,000 beneficiaries enrolled in 1998, more than twice the number that elected hospice in 1992. Cancer patients account for more than half of Medicare hospice users, but the most dramatic growth in use is among persons with other terminal conditions, such as heart disease, lung disease, stroke, or Alzheimer's disease. Although more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of 1 week or less are common. Many factors influence decisions about whether and when to begin hospice services, including physician practices, patient preferences and circumstances, and general awareness of the benefit among professionals and the public. Along with these factors, federal oversight of compliance with Medicare eligibility requirements may also have affected hospice use. Growth in the number of Medicare hospice providers in both urban and rural areas and in almost every state suggests that hospice services are more widely available to program beneficiaries than in the past. At the same time, hospice officials report increased cost pressures from shorter patient enrollment periods and the use of more expensive forms of palliative care. Because data on provider costs are not available, however, the effect

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[1] Medicare: More Beneficiaries Use Hospice, But For Fewer Days of Care (GAO/HEHS-00-182, Sept. 18, 2000).

of these factors on the overall financial condition of hospice providers is uncertain. HCFA is beginning to gather information from hospice providers about their costs, which should allow the adequacy of Medicare hospice payment rates to be evaluated in the relatively near future.

BACKGROUND

The Medicare hospice benefit, authorized in 1982 under part A of the Medicare program, covers medical and palliative care services for terminally ill beneficiaries. A Medicare-certified hospice provides physician services, nursing care, physical and occupational therapy, home health aide services, medical supplies and equipment, and short-term care in the hospital (for procedures necessary for pain control and symptom management). In addition, the hospice benefit provides coverage for several services not generally available under the regular fee-for-service Medicare benefit. These include drugs for symptom control and pain relief, inpatient respite care, and bereavement counseling for the patient's family. For each day a beneficiary is enrolled, the hospice provider is paid an all-inclusive, prospectively determined rate, depending on the level of care that is provided.[2]

Beneficiaries who elect hospice are required to waive Medicare coverage of care related to their terminal illness that is provided outside the hospice, although they retain coverage for services unrelated to their terminal illness. A beneficiary can cancel his or her election of hospice benefits at any time, return to regular Medicare, and reselect hospice coverage later. To be eligible for hospice services, a beneficiary's physician and the hospice medical director (or other physician affiliated with the hospice) must certify that the his or her prognosis is for a life expectancy of 6 months or less, if the terminal illness runs its normal course. This eligibility requirement has been a concern among patient advocates and providers, who assert that it deters referrals to hospice. Research has shown that it can be difficult for physicians to accurately predict whether or not a patient is likely to die within 6 months. It is particularly difficult to estimate life expectancy for persons with noncancer diagnoses because the course of their disease is often uneven.

THE NUMBER OF BENEFICIARIES USING HOSPICE HAS GROWN AS AVERAGE DAYS OF USE HAVE DECLINED

Our analysis of Medicare claims data indicates significant growth in hospice use. The number of beneficiaries electing hospice care more than doubled from 1992 to 1998, from about 143,000 to nearly 360,000 people annually. (See fig. 1.) In 1992, hospice users represented 1 in 12 Medicare beneficiaries who died that year. By 1998, this proportion grew to 1 in 5, with wide variation across states. However, this measure understates the proportion of Medicare beneficiaries who choose hospice care among those for whom the benefit was intended. According to a former president of the National Hospice

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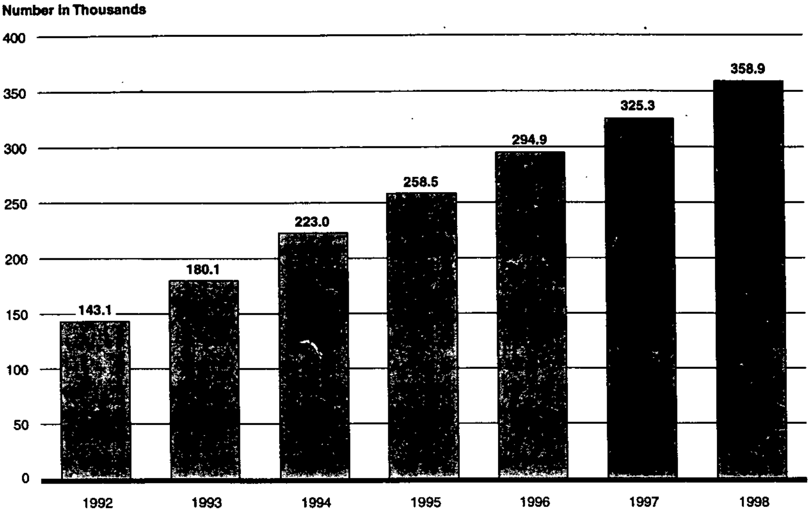
[2] The four levels of hospice care are routine home care, continuous home care, inpatient respite, and general inpatient care.

Organization, "when the number of deaths nationwide is adjusted to reflect only those that are likely to be appropriate for hospice care, the percentage of dying patients cared for in hospice care is probably about 40 percent."[3]

Figure 1: The Number of Medicare Hospice Benefit Users Has Grown Steadily, 1992-98



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Given concerns about the difficulty of establishing a 6-month prognosis for beneficiaries with noncancer diagnoses, we took a closer look at their use of hospice services. Although the majority of beneficiaries electing hospice have a diagnosis of cancer, the use of hospice services by beneficiaries with noncancer diagnoses has increased dramatically. From 1992 to 1998, hospice enrollment by beneficiaries with cancer increased 91 percent, while enrollment among beneficiaries with all other conditions increased 338 percent. By 1998, about 43 percent of Medicare beneficiaries electing hospice had noncancer diagnoses, compared with about 24 percent in 1992. Table 1 shows the distribution of new hospice users by primary diagnosis in 1992 and 1998.

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[3] John J. Mahoney, "The Medicare Hospice Benefit—15 Years of Success," Journal of Palliative Medicine, Vol. 1, No. 2 (1998), pp. 139-46.

Table 1: Noncancer Patients are a Growing Share of Hospice Enrollees, 1992 and 1998

Primary diagnosis[a]	1992		1998	
	Number	Percent	Number	Percent
All cancer	**108,232**	**75.6**	**206,190**	**57.4**
Lung	29,966	20.9	57,841	16.1
Prostate	10,052	7.0	15,494	4.3
Breast	7,602	5.3	13,093	3.6
Colon	6,697	4.7	13,278	3.7
Pancreatic	6,359	4.4	12,116	3.4
Other	41,141	28.7	84,846	23.6
All noncancer	**34,878**	**24.4**	**152,759**	**42.6**
Congestive heart failure	6,141	4.3	24,248	6.8
Chronic obstructive pulmonary disease	4,112	2.9	15,765	4.4
Stroke	2,140	1.5	13,282	3.7
Alzheimer's disease	1,591	1.1	11,836	3.3
"Ill-defined conditions"	888	0.6	7,599	2.1
Other	20,006	14.0	80,029	22.3
Total	**143,110**	**100.0**	**358,949**	**100.0**

[a] Patients entering hospice may have more than one terminal condition or diagnosis. The data presented include only the first, or principal, diagnosis listed for each patient.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

Beneficiaries who die of cancer are likely to receive hospice services during the course of their illness, more so than those with other conditions. In 1997, hospice users accounted for nearly half of all cancer deaths among Medicare beneficiaries aged 65 or older. For the most prevalent types of cancer in the hospice population, rates of use ranged from about 75 percent of deaths from brain or liver cancer to 31 percent for those with colon cancer. In comparison, hospice users represented 9 percent of people aged 65 and older who died from all noncancer causes in 1997.[4]

Although more Medicare beneficiaries are receiving hospice services, on average, they are receiving fewer days of care than did beneficiaries in the past. From 1992 to 1998, average length of stay declined 20 percent (from 74 to 59 days), while median length of stay declined 27 percent (from 26 to 19 days). (See fig. 2.) This overall decline appears to have been driven by both (1) a reduction in the proportion of beneficiaries with very long hospice stays and (2) an increase in the share of users with very short stays.[5]

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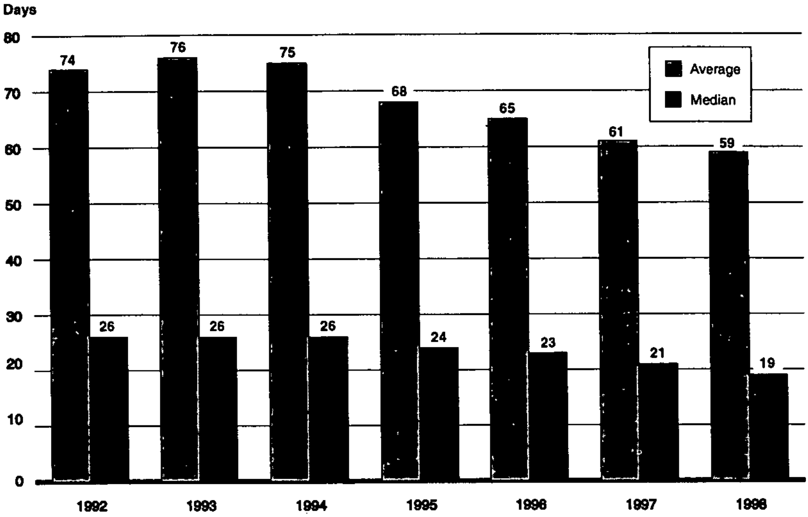
[4] The denominator used for calculating noncancer use rates includes people who died unexpectedly (for example, from a first heart attack or injuries sustained during an automobile accident, and thus are not candidates for hospice care).

[5] The small proportion of beneficiaries with very long periods of enrollment skews the average length of hospice service. Although 97 to 98 percent of all those electing hospice complete their hospice use by the

Beneficiaries using hospice care for one week or less accounted for 28 percent of all users in 1998, compared with 21 percent in 1992. While 9 percent of beneficiaries received hospice services for more than 6 months in 1992, this share decreased to 7 percent in 1998.

Figure 2: Average and Median Hospice Lengths of Service Have Declined, 1992-98



Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

The decline in the average number of hospice days used has been especially dramatic among patients with a primary diagnosis other than cancer. While these beneficiaries historically had used many more days of care, the average number of days used declined 38 percent between 1992 and 1998. In comparison, average days used by hospice beneficiaries diagnosed with cancer declined by 14 percent. As a result, differences in length of stay across diagnosis categories have narrowed considerably. By 1998, cancer patients used 54 days, on average, while noncancer patients used 68 days.

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end of the year following their initial enrollment, our data for 1992 and 1993 show that some of the remaining 2 to 3 percent of beneficiaries may receive services for as many as 6 or 7 years.

MULTIPLE FACTORS INFLUENCE THE USE OF HOSPICE BENEFITS

Several factors influence a beneficiary's choice about whether and when to use hospice care. These include physician preferences and referral practices, individual patient choice and circumstances, and general awareness of the benefit among the public and professional communities. In addition, recent federal oversight of compliance with patient eligibility requirements may have affected certain beneficiaries' use of the hospice benefit.

Physician Practices, Patient Preferences, and Public Awareness Affect Hospice Use

Physicians initiate most referrals to hospice, and they may continue to care for their patients after enrollment as part of the hospice team. Because patients and their families rely heavily on physician recommendations for treatment, including recommendations for end-of-life care, physicians are an influential factor in a patient's entry into hospice. However, the research literature indicates that not all physicians are comfortable discussing end-of-life care, and some may hesitate to suggest hospice care for other reasons. Specifically, research has shown that many physicians are poorly trained in care of the dying and are often uncomfortable discussing options for end-of-life care or the cessation of curative treatment. In addition, some physicians may not be aware that they can continue to provide services after the beneficiary has entered hospice and may delay referral out of concern about losing control of the patient's care.

Even when the issue has been broached, some beneficiaries choose instead to continue curative or life-extending treatments. Medicare beneficiaries' use of hospice services requires acceptance that death is near. Once a patient is enrolled, no other services related to the patient's terminal condition are covered under Medicare. Beneficiaries who do not consider hospice care may be unwilling to confront the terminal nature of their illness. The Institute of Medicine (IOM) noted that patients in the United States are influenced by the general American unwillingness to accept limits of all types, including those of aging and death.[6] A Gallup poll in 1996 found that although a majority of people expressed interest in hospice care, most also said they would still seek curative care.

Beneficiary circumstances may complicate the initiation of hospice services. For example, because hospice is designed to allow the beneficiary to remain at home, some hospice programs limit participation to beneficiaries who have a caregiver at home. Improvements in cancer care and the addition of new treatment options for other common chronic conditions may be prompting some beneficiaries to pursue new curative options until very shortly before death, thus contributing to the trend of shorter hospice stays.

Public and professional awareness of hospice also influences the use of the Medicare benefit. The need for greater public and professional knowledge and awareness of

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[6] Institute of Medicine, Approaching Death: Improving Care at the End of Life (Washington, D.C.: National Academy Press, 1997).

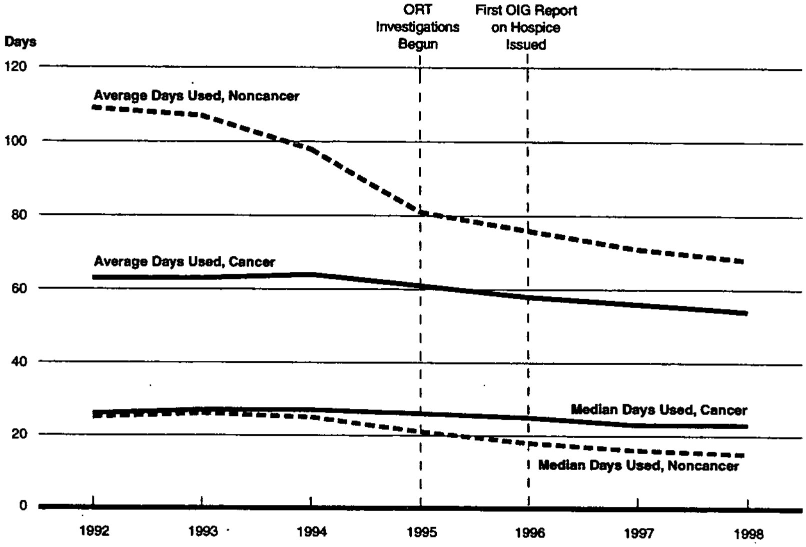
options for end-of-life care—including hospice—has been highlighted recently by the IOM, in recent congressional hearings, and in several other public forums. Patient advocacy groups, medical societies, and others have initiated a range of educational efforts designed to increase awareness of hospice care and its benefits. For example, the American Medical Association is developing a core curriculum for educating physicians in end-of-life care. The Medicare Rights Center, a consumer advocacy and education organization, is conducting a national campaign to increase awareness of the Medicare hospice benefit among health professionals. Also, the National Hospice and Palliative Care Organization has published a variety of materials on public education and outreach strategies for its members.

Federal Oversight of Eligibility May Have Had an Effect on Beneficiaries' Use of Services

In 1995 and 1996, the Department of Health and Human Services' (HHS) Office of the Inspector General (OIG) investigated the eligibility status of Medicare beneficiaries receiving hospice services, as part of a larger investigation of fraud and abuse in Medicare. Patient advocacy groups and the hospice industry assert that this federal scrutiny of compliance with the 6-month eligibility rule has had a chilling effect on entry into hospice for noncancer beneficiaries, for whom it may be more difficult to establish a 6-month prognosis with confidence. They contend that hospice providers are more cautious about admitting beneficiaries with noncancer diagnoses as a result, leading to delays in hospice entry for those wishing to use the benefit.

Although the percentage increases in beneficiaries electing hospice slowed somewhat from 1995 through 1998 compared with earlier years, it is difficult to know how much of this slower growth is attributable to the effect of federal scrutiny and how much is attributable to other factors, such as the larger base of beneficiaries already using hospice. Importantly, the trend toward fewer average days of hospice use began before the period of federal scrutiny, as shown in figure 3.

Figure 3: Decline in Days of Hospice Care Began Before Federal Scrutiny Increased



Note: Operation Restore Trust (ORT) was a joint initiative between HCFA, the Office of Inspector General, and the Administration on Aging designed to identify vulnerabilities in the Medicare program.

Source: GAO analysis of claims data from the Medicare Hospice Standard Analytic File.

While the OIG reviews were under way, the National Hospice Organization developed guidelines to assist physicians and hospices in determining a 6-month prognosis for patients with selected noncancer diagnoses. These included amyotrophic lateral sclerosis (ALS), dementia, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), heart disease, pulmonary disease, liver disease, stroke and coma, and kidney disease. In order to enhance accuracy and uniformity in the claims review process, HCFA distributed these guidelines to the intermediaries that process hospice claims for Medicare.[7] The intermediaries have since adapted them for use as formal local medical review policies, which specify clinical criteria for

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[7] Intermediaries contract with HCFA for paying providers for services provided to Medicare beneficiaries. They review all hospice claims for accuracy and completeness before payment and review a sample of claims to confirm that beneficiaries were eligible for the hospice services provided.

establishing a patient's 6-month prognosis.[8] Intermediaries report that they allow for variation in individual cases. For example, one medical review policy for heart disease states that "some patients may not meet the criteria, yet still be appropriate for hospice care, because of other comorbidities or rapid decline."

HCFA instructed the intermediaries to begin medical review of hospice claims in 1995. Prior to that year, a very small proportion of claims were reviewed. Four of the 5 intermediaries reported that, by 1999, review rates ranged from 0.8 to 4.2 percent of all hospice claims processed.[9] They noted that claims are selected for medical review based on a variety of factors, including beneficiary length of stay, beneficiary diagnosis, and provider use of hospice continuous home care or inpatient care.

HOSPICE CARE IS MORE WIDELY AVAILABLE, BUT PROVIDERS REPORT COST CONCERNS

Sustained growth in the number of hospice providers participating in Medicare and in their distribution throughout the country suggests that hospice services are now more widely available to program beneficiaries. While all sectors of the hospice industry have grown over the past decade, recent growth has been particularly strong in the for-profit sector and among large hospice programs. At the same time, hospice industry officials report growing cost pressures from shorter patient stays and changes in the practice of palliative care. However, because data on provider costs are not available, it is not clear how these cost factors affect providers and beneficiaries.

Until recently, the number of hospices participating in Medicare had grown each year. As shown in figure 4, the number of Medicare-certified hospice providers nationwide grew by 82 percent, from 1,208 in 1992 to 2,196 in 1999.[10] Each year during this period, additional hospice programs became certified for Medicare, although the number of new entrants declined from 274 in 1994 to 46 in 1999, and the number of hospices leaving Medicare exceeded the new entrants in 1999. (Many of those leaving were based in home health agencies which may have closed because of changes in home health agency payments enacted in the Balanced Budget Act of 1997.) The higher number of providers reflects not only new hospices but also growing participation in Medicare. In 1989, we estimated that about 35 percent of the approximately 1,700 hospice providers nationwide participated in Medicare. By 1998, the National Hospice and Palliative Care Organization estimated that 80 percent of hospices were certified to serve Medicare patients.

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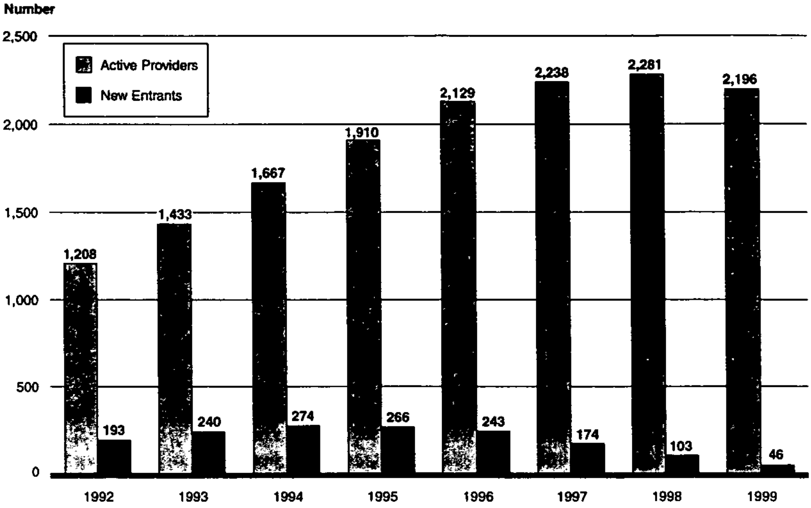
[8] Local medical review policies are medical criteria, specific to a service or diagnosis, that may assist in determining compliance with program eligibility requirements.

[9] One fiscal intermediary did not provide data on rates of medical review.

[10] The total number of Medicare hospice providers peaked at 2,281 in 1998. In 1998 and 1999, hospice program closures (195) exceeded new program entrants (149) for the first time. A disproportionate number of hospice closures were among those based in home health agencies. Although HHA-based hospices represent approximately one-third of all hospices, they accounted for 43 percent of those that closed over the 2-year period. As we reported in Medicare Home Health Agencies: Closures Continue, With Little Evidence Beneficiary Access Is Impaired, (GAO/HEHS-99-120, May 5, 1999), 14 percent of home health agencies closed between October 1997 and January 1999.

Figure 4: Growth in the Number of Medicare Hospices and New Entrants, 1992-99



Source: GAO analysis of annual Medicare Provider of Service Files.

Over this period, all types of hospice providers grew, in rural and urban areas, and in almost every state. From 1992 to 1999, the rate of growth was greatest among for-profit providers and those in rural areas. Also, large providers accounted for an increasing share of the services delivered. (See table 2.) The number of for-profit providers increased nearly fourfold and the number of large hospice programs (those serving 500 or more patients per year) more than tripled over the period. In addition, the number of rural providers increased 116 percent while the number of urban-based providers increased 64 percent. Even with high growth in these sectors of the industry, the majority of hospices are small programs (with fewer than 100 patients per year), organized as not-for-profit, and located in urban areas.

Table 2: Growth in Medicare Hospice Programs by Provider Characteristics, 1992 and 1999

Characteristic	Number of hospices		Percent change 1992-99
	1992	1999	
All hospices	1,208	2,196	82
Type			
Freestanding	466	877	88
Hospital-based	327	553	69
HHA-Based	403	730	81
Control			
For-profit	151	593	293
Not-for-profit	957	1,365	43
Government	63	146	132
Other	36	75	108
Location			
Urban	823	1,350	64
Rural	384	829	116
Size[a]			
Small	795	1,244	56
Medium	370	816	121
Large	43	136	216

[a] We categorized hospices as small if they served fewer than 100 Medicare beneficiaries a year, medium if they served 100 to 499 patients a year, and large if they served 500 or more beneficiaries a year.

Source: GAO analysis of annual Medicare Provider of Service Files.

Even as the hospice industry has grown, changes in the use of the hospice benefit and the delivery of hospice care have raised cost concerns among providers. Industry representatives point out several areas of change that they contend are adversely affecting the financial condition of providers. Specifically,

- Under Medicare's per diem payment system for hospice care, hospices have traditionally offset the higher cost days that occur at admission and during the period immediately preceding death with lower cost days of less intensive care.[11] For example, costs for admitting and assessing a new patient, establishing a care plan, and delivering medical equipment are incurred during the first few days of enrollment and do not vary with the patient's period of service. As enrollment periods have declined, hospices have fewer

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[11] Hospice representatives we interviewed reported that the hours of nursing, social work, and administrative time the typical patient requires are nearly twice as great during the first and last weeks of a patient's care as they are during the intervening weeks.

days over which they can spread the higher costs associated with the start and end of a patient's stay.

- As more patients enter hospice later in the course of their terminal illness, they enter with higher levels of impairment and in need of more intensive services. In addition, the shift in the mix of patients by diagnosis may have increased the average service needs for the overall hospice population. According to the most recent National Home and Hospice Care Survey, hospice patients with noncancer diagnoses are somewhat more likely than those with cancer to be functionally impaired and thus may require more services on a regular basis from hospice agencies.[12]

- Physicians and patients are calling on hospice programs to provide a broader array of palliative services than in the past. Costly treatments such as chemotherapy and radiation—traditionally used for curative purposes—are increasingly used in the hospice setting to manage pain and other symptoms. Furthermore, some new palliative care treatment options, such as the transdermal administration of narcotic pain medication, may offer better symptom control for some patients but often at greater expense.

Data to assess how declining patient stays and changes in palliative care have affected overall provider costs are not available. While specific, more expensive services may be provided more frequently, the share that these services currently represent of total costs is unknown. Furthermore, we do not know the extent to which providing more expensive medications or treatments to hospice patients may reduce the need for other services such as nursing visits. HCFA, in response to the Balanced Budget Act requirements, has begun collecting hospice cost data to use for evaluating the adequacy of current levels of Medicare reimbursement. Officials anticipate that audited hospice cost data will be available beginning in late 2001.

CONCLUSIONS

Trends in the use of the Medicare hospice benefit during the 1990s indicate that beneficiaries with all types of terminal diseases are making use of hospice services in greater numbers every year. In particular, the types of patients selecting hospice have expanded broadly—from mostly beneficiaries with cancer to a nearly even split among those with cancer and those with other chronic conditions. In spite of these trends in use and the widespread availability of hospice providers, patient advocates and the industry are concerned that the Medicare hospice benefit is underused. Because many factors influence the use of hospice care, however, potential demand is difficult to determine. The goal remains that the program ensure that beneficiaries understand their rights and options and receive appropriate care that is tailored to their needs and preferences at the end of life.

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[12] National Center for Health Statistics, The National Home and Hospice Care Survey: 1996.

Mr. Chairman, this concludes my statement. I would be happy to answer any questions from you and other members of the Committee.

GAO CONTACT AND ACKNOWLEDGMENTS

For future contacts regarding this testimony, please call Janet Heinrich, Associate Director, Health Financing and Public Health, at (202) 512-7119. Others who made key contributions include Rosamond Katz, Assistant Director; Eric Anderson; Jenny Grover; and Wayne Turowski.

(201100)

The CHAIRMAN. Thank you, Dr. Scanlon.

Now, Dr. Christakis.

STATEMENT OF NICHOLAS CHRISTAKIS, M.D., ASSOCIATE PROFESSOR OF MEDICINE AND SOCIOLOGY, UNIVERSITY OF CHICAGO, CHICAGO, IL

Dr. CHRISTAKIS. There are only two things in life that are certain, the saying goes, death and taxes, and I certainly am grateful to be here today to speak about the former.

To my eye, there could be no more vulnerable population than the terminally ill. Facing their own imminent death, this group of Americans has limited opportunities to find a political voice and to advocate effectively for its own interests. I therefore greatly respect and admire the attention that this committee is giving to end-of-life care, and I thank Chairman Grassley and Senator Breaux for their leadership, and Senator Wyden for suggesting me as a speaker.

I was asked to comment on three topics—general barriers to hospice use, the particular problem posed by prognostication, and the cost-effectiveness of hospice care. I feel qualified to comment on these since I am an internist who cares for the terminally ill and since I have spent the last 10 years investigating these topics. Much of my work has been funded by the National Institute on Aging.

Of the 1.6 million people older than 65 who die annually in the United States, approximately 15 percent receive some hospice care prior to their death. Unfortunately, those Americans who do avail themselves of hospice tend to do so late in the course of their illness, as we have been hearing in rich detail today.

Patients nowadays typically are referred for hospice care only 2 or 3 weeks before they die. Such late referral to hospice is concerning because it means that patients and families do not have the opportunity to derive all the benefits of hospice that they deserve.

Barriers to hospice can affect both the percentage of patients dying using hospice and the timing of referral of those patients who do use it. These barriers exist at four levels—the patient and family level, the physician level, the hospice provider level, and the market level. This afternoon, I will focus on the physician-level problem of prognostication. More detail on the other issues is provided in my written testimony.

Last month, I was to take care of an elderly patient with AIDS. He had been sick with his disease for about a decade and had deteriorated substantially over the year prior to our considering him for admission, and very substantially over the two preceding months, to the point where he was very clearly dying.

He was initially evaluated by our hospice program on August 2, when his physician finally suspected that the patient was about to die. However, the patient appeared unaware of the seriousness of his condition and refused hospice enrollment. On August 14, we were recontacted regarding admitting the patient for hospice care, and we did formally admit him on August 15.

Our nurses started to pay him daily visits to provide the kind of care that they do, alleviating the patient's pain and bringing his other symptoms under control. I called the patient on August 18, to schedule a home visit for the next day, but the patient died at 6 p.m. that night, having had only 3 days of hospice care and having missed the opportunity to have me visit him.

In this case, as in countless other cases like it, our hospice simply did not have enough time to do what we do best, to provide the kind of terminal care most Americans say they want. And I wondered why, after 10 years of a very serious illness and 2 months of very substantial deterioration, we did not receive this referral until 3 days before the patient died. Was it not possible for his doctors to formulate a reliable prognosis any earlier in the patient's course? Is it not possible to design a system that affords better and prompter terminal care for manifestly dying patients?

Part of the problem when it comes to hospice referral is indeed that physicians do not like to prognosticate, and as it turns out, are not very good at it either. For example, one of our recent studies found that only 20 percent of predictions that physicians privately formulate, let alone the ones they communicate to patients—that is, the predictions that they form in their own minds—less than 20 percent of those predictions are accurate by a very liberal standard of accuracy. In general, physicians overestimate survival by more than a factor of five. So we had in this study hundreds of patients that the doctors thought would live 3 to 6 months, and every one of them died within a week of hospice referral. This is a substantial rate of error, and suggests that physicians' predictions are not a good basis for hospice care policy and law.

Let me briefly turn to the issue of the cost-effectiveness of hospice which Chairman Grassley also alluded to in his opening remarks. Most research has concluded that hospice care saves money compared to alternative ways of caring for the terminally ill. Indeed, the estimate of cost saving is about $1.20 saved for every $1.00 spent.

The only debate is about over what time horizon hospice might save money, and our best estimates about this are that hospice can save between 25 and 40 percent of health care costs during the last month of life, 10 to 17 percent of health care costs in the last 6 months of life, and 0 to 10 percent over the last 12 months of life. Regardless of whether hospice costs more or less than standard terminal care, however, hospices probably provide better care for the dying, care that Americans deserve.

Now, evidence suggests that Americans are using hospice for about a third as much as they could or should. Some other work that we have done has suggested that the ideal amount of time that patients should get hospice is about 3 months, and so we might want to triple the amount of days that hospice is used. We might also want to increase the proportion of decedents that are using hospice. We might do things and also save money while doing so. Such improvements would enhance the quality of care given to Americans at the end of their lives.

Thank you.

[The prepared statement of Dr. Christakis follows:]

BARRIERS TO THE USE OF HOSPICE CARE AT THE END OF LIFE

Testimony before the U.S. Senate Special Committee on Aging
September 18, 2000

Nicholas Christakis, MD, PhD, MPH
University of Chicago

There are only two things in life that are certain, the saying goes: death and taxes. And I certainly am grateful to be here today to talk about the former since I know nothing about the latter.

It is fashionable to be concerned with so-called "vulnerable populations" in medicine as well as in policy-making and law-making, but, to my eye, there could be no more vulnerable a population than the terminally ill. Facing their own imminent death, this group of Americans has limited opportunities to find a political voice and advocate effectively for its interests. I therefore greatly admire and respect the attention the Senate Special Committee on Aging is giving to this issue, and I thank Chairman Grassley and Senator Breaux for their leadership, and Senator Wyden for suggesting me as a speaker. Surely, an important measure of our civilization is the care we give to those among us who are dying.

I was asked to comment on three items in my testimony today: 1) barriers to hospice use in general, 2) the problem of prognosis in particular, and 3) the cost-effectiveness of hospice care. I feel qualified to comment on these matters since I am an internist and sociologist who conducts research on the delivery and outcomes of medical care. I have doctoral-level training in medicine, sociology, and public health and am currently Associate Professor of Medicine, Department of Medicine, and Associate Professor of Sociology, Department of Sociology, at the University of Chicago. I have spent the last ten years studying ways to improve the care of the dying in our society, with a special emphasis on the role of prognosis in medical care and on the use of hospice. My clinical practice, at Horizon Hospice in Chicago, consists of providing home-based hospice care to primarily poor patients dying on the South Side of Chicago. My testimony today is based on my clinical experience, on the published work of other investigators, and on more than a dozen studies conducted by my own research group [1-11] (some of which are appended in their entirety to this testimony [12,13]). Much of my own work that I will discuss today has been funded over the past five years under grants from the National Institute on Aging.

Hospice Use in the United States Today

Hospice is a form of terminal care that emphasizes relief of patients' physical and emotional pain and suffering more than the treatment of the underlying disease. More than 80 percent of the time, hospice care in the U.S. is provided by visiting nurses and other staff in patients' own homes.

It is important to emphasize at the outset that several studies have shown that hospice care does not shorten life.[14,15] Yet, hospice offers several advantages over traditional, hospital-based terminal care: it facilitates at-home death;[16-18] it optimizes pain relief;[19] it increases patient and family satisfaction;[20-24] and it is cost-effective.[25-29]

In 1982, Congress introduced the Medicare hospice benefit, and, at present, Medicare pays for virtually all people older than 65 who receive hospice care, spending more than $1.5 billion annually.[30] The number of patients using the benefit has consistently grown 10-20 percent per year.[31] This increasing use is matched by positive attitudes towards hospice, as documented in at least one national survey of the general public [32] as well as in many samples of the terminally ill and their families.[33-36] Of the 1.6 million people older than 65 who die annually in the U.S., approximately 15 percent receive some hospice care, a percentage that is approximately equivalent to the percentage of Americans who die under nursing home care. And hospice is used by a broad cross-section of Americans; a demographic profile, based on a complete enumeration of 184,843 Medicare hospice users in 1993, is provided in Table 1. Hospice is thus an important source of end-of-life care today. And its special features seem perfectly suited to providing the kind of death most Americans say they want: free of pain, surrounded by loved ones, and not subject to needless technological interventions.[37]

In this sizable population of dying Americans, how is this important form of care currently being employed? When in the course of illness do patients use hospice, how long before death? To what extent do patient, physician, hospice, and market factors act as barriers to the optimal timing of hospice enrollment? Are these barriers interfering with increased use of hospice both in terms of percentage of dying patients using hospice and not just in terms of the duration of use? And how do patterns of hospice use compare to physicians' stated ideals? These are some of the questions I will address today.

Duration of Hospice Use and Timing of Hospice Referral

One survey of a national sample of internists showed that physicians recommend that hospice be used for about three months before death.[38] However, numerous studies have shown that patients typically receive hospice care for less than one-third of this amount of time, that is, for only about two to four weeks.

Studies of patients admitted to single hospices have revealed median survival times of 22 days,[39] 25 days,[40] 29 days,[41] and 62 days,[42] while studies that have reported data from multiple hospices have found median survival times of 26 days,[43] 30 days,[44] 35 days,[45] and 36 days.[46] The most recent and comprehensive study of hospice patients was one we ourselves conducted, and it involved a complete enumeration of all 184,843 Medicare hospice patients newly admitted to hospices in the U.S. in 1993 and followed until late 1996. This study found that median survival was 30 days, that 20 percent of patients die within a week of admission to hospice, and that 80 percent die within three months.[47] At the other extreme, however, there was a minority of patients (less than 15%) which lived for more than six months after hospice enrollment. But, in sum, enrollment in hospice tends to be very late in the course of seriously ill patients' care.

There is evidence that, over the course of the 1990's, patients have been enrolled progressively later in the course of their illness. For example, a representative cohort of patients admitted to hospices in the U.S. in 1990 had a median survival of 36 days;[48] in 1993, a different cohort had a median survival of 30 days;[49] and in 1996, still another cohort had a median survival of 24 days.[50] Anecdotal reports from numerous hospices, and my own clinical experience, confirm this trend, and also its ongoing evolution, to the point were at my hospice today 50% of patients are currently enrolled within about two weeks of their death.

Consequences of Sub-Optimal Timing of Hospice Referral

To reap the maximum benefit from hospice care, the decision to refer a patient should be properly timed. Unnecessarily long or short stays -- which might arise from unduly early or late referral, respectively -- should be avoided. Such short or long stays may have adverse clinical implications for patients and adverse economic implications for payers.

"Early" death due to unduly late referral provides several reasons for concern. For patients, early death may reflect an inadequate use of what many patients and caregivers consider to be a desirable mode of terminal care. For such patients, a longer stay in hospice would make their experience of terminal illness more humane and more clinically appropriate. Late referral often means that hospice professionals have inadequate time to become familiar with the patient, to evaluate properly the patient and the home situation, and to develop and implement a comprehensive care plan. In addition, late transfer of a patient to hospice results in a discontinuity at a critical point in the patient's illness, and may be undesirable because death might have been managed just as well by the referring hospital or doctor, avoiding the need to establish new caregiver-patient relationships. For hospices, the extensive work typically necessary at the beginning of the care of a new patient is organizationally disruptive and possibly financially burdensome.[51,52] Finally, early death may mean that the patient received costly and possibly unnecessarily aggressive care for too long prior to referral.

Of course, some early deaths at hospice may be both unavoidable and quite appropriate. For example, a patient might become terminally ill suddenly, be immediately referred to hospice, and then die rapidly (or "early"). In such a situation, the physician would not have had an opportunity to refer earlier. However, such cases account for a small minority of late referrals, given the pattern of illness seen in studies of patients referred to hospices.

"Late" death due to unduly early referral also can provide some reasons for concern. In some situations where death occurs very late after referral, the patient may actually have been more suited to, and have derived greater benefit from, long-term nursing care or rehabilitative care rather than hospice care. Premature referral to hospice may thus have adverse clinical implications. In addition, such an extended stay in a constant state of anticipation of death may be demoralizing to the patient and may oblige hospice nurses to deliver a type of routine nursing care which is inconsistent with their specialized training. To the extent that a lengthy stay results in the needless use of hospice resources, it may result in cost inefficiencies.[53]

BARRIERS TO HOSPICE USE

Barriers to hospice care can occur at many levels: (1) the patient/family level, (2) the physician level, (3) the hospice level, and (4) the market level. At several of these levels, provisions of Medicare regulations may contribute or interact with these barriers.

These barriers can operate on two distinct but interconnected levels: (1) particular factors may affect *whether* patients use hospice at all, and (2) the same or different factors may affect *when* in the course of their illness they use hospice (if they indeed use it). This distinction is illustrated by the following example: it may be the case that poor people are less likely to use hospice care at all (they may be under-represented in hospice rolls), but, when they do use it, they may use it *earlier* in the course of their illness. So, paradoxically, poverty may act as a *barrier* to hospice use in one sense, but act as a *facilitator* to hospice use in another. Surprisingly, much less is known about *whether* hospice is used than about *when* it is used. While these problems are distinct, they are nevertheless related, and so I will mostly focus on the latter here.

The Problem of Physician Prognostication

The need for a prognosis, and the presence of inaccuracy in any prognosis that might be made, is one of the most important barriers to hospice use, both practically for physicians and psychologically for patients. According to Medicare regulations, a beneficiary is eligible for the hospice benefit only if the patient's doctor and the hospice medical director both certify that the patient is "terminally ill," which is defined as having "a medical prognosis that the individual's life expectancy is six months or less."[54] Physicians have difficulty interpreting or applying this standard, however.[55,56] Indeed, commentators have noted that physicians typically make poor judgments about intermediate term survival in terminally ill outpatients and that unduly "optimistic" prognoses (with consequent late referral to hospice) and unduly "pessimistic" prognoses (with early referral) have adverse implications.[57-59] Some editorialists, concerned especially with the problem of late referral, remarked as far back as 1984 that "in the absence of objective criteria, the only patients referred to the hospice may be those who are so obviously close to death that the hospice's palliative care will be offered too late."[60] This prescient concern has proven to be largely true given the way Americans use hospice today.

On more than one occasion, I have seen the avoidance of prognostication altogether, or needlessly incorrect prognoses, harm patients by interfering with their timely use of palliative or hospice care. For example, one bereaved wife poignantly noted:

> The Thursday before my husband died, I thought he was dying and he thought he was dying. But the doctor was talking about aggressive chemotherapy. I asked if this was palliative, and he said that he still hoped for a cure. [But my husband died three days later.] I was with him at the time of his death, but the room was filled with eight other people hanging bags of blood and monitoring vital signs. It was about as horrifying as anything that could have happened. I don't think the [doctors] were trying to mislead us. They thought he might be the one case that would have a positive outcome. [But if I had been told the truth,] we could have spent days with the children, together, not filled with painful regimens in the hospital.[61]

The failure to predict this patient's death -- in the sense of not thinking about the prognosis clearly, in the sense of not articulating it, and in the sense of having an unduly optimistic expectation -- was harmful. Such a failure can contribute to a therapeutic imperative that prevents families from taking steps to prepare for death as they might wish and from availing themselves of hospice care. The physicians in this case did not want to conclude that the therapy would not result in the desired outcome. They did not want to predict that the patient was about to die. And they did not want to take action, such as limiting therapy or referring to hospice, based on those predictions. But if doctors were to think more cogently about the outcomes of their actions, if they were to develop prognoses more consciously (even in all their uncertainty), and if they were to share their prognostic estimates sensitively with patients, it would help them to avoid such outcomes. My feeling is that the problem in this case, and countless other cases like it, arises more from errors in prognosis than from errors in therapy. In our rush not to abandon patients therapeutically at the end of life, we abandon them prognostically.

I see this kind of problem every week in my practice. For example, last month, I was to take care of an elderly patient with AIDS. He had been sick with this disease for more than a decade, and had deteriorated substantially over the previous two months, to the point where he was clearly dying. He was initially evaluated by our hospice program on August 2, when his physician finally suspected that the patient was about to die. However, the patient appeared unaware of the seriousness of his condition and refused hospice enrollment. On August 14, we were re-contacted regarding admitting the patient for hospice care, and, after some planning, we formally admitted the patient on August 15. Our nurses started to pay him daily visits to help get his pain, shortness of breath, and diarrhea under control, as well as sort out his complicated psychosocial issues. I called the patient on August 18 to schedule a home visit for the next day, but the patient died at 6:00 pm that night, having had only three days of hospice care, and having missed the opportunity to have me visit him. We simply did not have enough time to do what we do best, to do what the patient, I am sure, would have wanted us to do. And I am wondering why, after ten years of a very serious illness, and two moths of substantial deterioration, we did not receive this admission until three days before the patient died. Was it not possible for his doctors to formulate a reliable prognosis any earlier in his course? Is it not possible to design a system of health care that affords better and prompter terminal care for dying patients?

Part of the problem when it comes to hospice referral is in fact that physicians do not like to prognosticate. This aversion to prognostication has numerous sources. Neither medical training [62,63] nor research [64,65] treat prognostication as important. Lacking training, physicians find prognostication difficult and stressful. The "difficulty" and "stress" in rendering prognoses are both technical (in the sense of how complicated it is to formulate them) and operational (in the sense of how emotionally and professionally unsettling it is to communicate them). Moreover, physicians feel that patients expect too much certainty and that both patients and (to a lesser extent) colleagues will judge them adversely for prognostic errors. For these and many other reasons -- including a belief in self-fulfilling prophecy -- physicians feel that they should accentuate the positive in making predictions and avoid making them altogether.

Quite beyond their aversion to prognostication, contemporary physicians are not very accurate when it comes to prognosticating. [66-71] One of our recent studies was a prospective cohort study of terminally ill patients directed at evaluating the extent and determinants of prognostic error. This study involved a cohort of 504 patients referred to five outpatient hospice programs in Chicago by 365 physicians during 130 consecutive days in 1996. We contacted the physicians at the time the patients was referred to the hospice and asked them to make a prognosis about how long the patient had to live. Then we followed the patients forward to see how long they lived, and we compared the predicted to the observed survival. This allowed us to quantify the extent of prognostic error and to evaluate its possible dependence on attributes of patients, physicians, or the physician/patient relationship.

Figure 1 illustrates the extent of the error. The median observed patient survival was 24 days. The mean ratio of predicted to observed survival was 5.3. Defining an "accurate" prediction as between 0.67 and 1.33 times the actual survival, only 20% of predictions were accurate; 63% were optimistic errors and 17% pessimistic errors. Defining an "accurate" prediction as between 0.50 and 2.0 times the actual survival, 34% of predictions were accurate; 55% were optimistic errors and 11% pessimistic. Death occurred within one month of the predicted date for 42% of patients, occurred at least one month before the predicted date in 46%, and occurred at least one month after the predicted date in 12% of patients. These are substantial rates of error by any measure and speak to the unreliability of physicians' predictions (at least, as they currently practice).

Careful examination of physician and patient attributes revealed that most physician and patient attributes were *not* associated with prognostic error. That is, all types of physicians are prone to error, in all types of patients. However, the tendency of physicians to make prognostic errors was lower among experienced physicians. Moreover, the better the doctor knew the patient -- as measured, for example, by the length and recency of their contact -- the *more* likely the doctor was to err.

I need to stress that the prognoses examined above were physicians' best guesses about their patients' survival prospects (objectively communicated to the investigators) and *not* the prognoses the physicians might or might not have communicated to the patients themselves.

These findings have several implications. First, undue optimism about survival prospects may contribute to late referral for hospice care, with negative implications for patients.[72,73] Indeed, as mentioned above, while physicians state that patients should ideally receive hospice care for three months before death,[74] patients typically receive only one month of such care.[75] The fact that physicians have unduly optimistic ideas about how long patients have to live may partly explain this discrepancy. Doctors who do not realize how little time is left may miss the chance to devote more of it to improving the quality of patients' remaining life. Second, to the extent that physicians' implicit or explicit communication of prognostic information affects patients' own conceptions of their future, physicians may contribute to patients making choices that are counter-productive. Indeed, one study found that terminally ill cancer patients who hold unduly optimistic assessments of their survival prospects often request futile, aggressive care rather than perhaps more beneficial palliative care.[76] Third, this work hints at corrective techniques that might be employed to counteract prognostic error. Disinterested physicians, with less contact with the patient, may render more accurate prognoses, perhaps because they have less personal investment in the outcome.[77] Clinicians may therefore wish to seek "second opinions" regarding prognoses, and our work suggests that experienced physicians may be a particularly good source of opinion. Finally, our work suggests that prognostic error in terminally ill patients is rather uniformly distributed. This finding has implications for physicians' training and self-assessment since it suggests that there is not one type of doctor who is prone to error, nor is there one type of patient in whom doctors are wont to err.

I believe that the medical profession can do better, and that the science of prognostication can be vastly improved. A key response to contemporary defects in prognostication is to try to enhance the science or prognosis (e.g., through more research).

In the meantime, however, given physicians' poor training in prognosis, their aversion to it, and their present levels of inaccuracy, a useful policy response to the problem would be to decrease the reliance on prognosis as a criterion for hospice use. Alternatives in the setting of hospice referral include:

- switch to performance-status-based criteria for hospice entry rather than prognosis-based criteria (e.g., a patient with one of a list of serious illnesses and who is bedridden more than 50% of the time would be deemed suitable for enrollment, by definition);

- switch to probabilistic based measures of prognosis (e.g., elicit the prognoses from physicians in terms of units of probability rather than units of time, thus modifying the criterion for hospice use from "the patient is expected to die within six months" to, say, "the patient has more than a 50% chance of dying within four months");

- switch to a reliance on objective prognostic standards and algorithms, along the lines of those recently promulgated by the National Hospice Organization (NHO), in which patients meeting certain clinical standards are felt to have poor prognoses (though the particular system currently promulgated by the NHO has recently had its reliability called seriously into question and would need improvement [78]).

Other Physician-Level Barriers to Hospice Care

Most physicians (89%) report feeling that hospice is "an appropriate mode of care for most terminally ill patients." And a majority of physicians (84%) refer at least one patient to hospice in any given year; the median number of patients referred is five.[79] This experience varies substantially with specialty, however. For example, in this study, the median general internist reported having referred five patients to hospice; the median pulmonologist/critical care physician referred ten patients; and the median hematologist/oncologist referred 38 patients to hospice.

Despite these favorable attitudes towards hospice and despite this frequent use, there are a number of physician-level barriers to optimizing the use of hospice in our society, in addition to the problem of whether and how well physicians prognosticate, as discussed above. These include:

- aversion to prognosis
- difficulty making accurate prognoses
- fear of facing death
- poor skills in communicating with patients regarding death, prognosis, and hospice referral
- stigmatized views of hospice (e.g., hospice seen as failure by physicians)
- misunderstanding about hospice care (e.g., misperception that hospice is only for cancer patients)
- concern about loss of control of the patient
- concern about loss of income
- specialty-specific practice patterns (e.g., more favorable attitudes of generalist physicians than of specialist towards hospice)
- attitudes towards patient traits (e.g., preferential referral by physicians of patients with certain socioeconomic traits or diagnoses).

Difficulties with communication are likely an important barrier to increasing hospice use, and physicians, who understandably have difficulty breaking bad news, often avoid discussing the fact that the illness has entered its terminal phase.[80]

There may be a lack of knowledge about hospice availability on the part of both physicians and patients, particularly in non-cancer diagnoses,[81] or physicians may simply have unfavorable attitudes towards hospice.[82,83]

Physicians may also worry that they will lose control of, or contact with, their patients if they refer them to hospice. In fact, however, this concern is mostly unfounded, in that patients can still see their own doctors (the doctors can even bill for the visits) and virtually all hospices update their referring physicians as often as they desire. (There is, however, an issue having to do with hospitalizations which can interfere with the doctor/patient relationship and which is discussed below.) Physicians may also resist hospice referral in order to preserve the ability to bill for curative services (such as chemotherapy) that are not covered by the hospice benefit. Many observers believe that this is a widespread phenomenon, but I am not familiar with any published research documenting it.

In prior work, we have investigated the specific variation in physicians' preferences regarding the timing of hospice enrollment. In one study, we asked a random sample of American internists the following question: "If you knew exactly when a patient was going to die, how many weeks before death would you refer the patient for home-based hospice care, if you felt that hospice care was appropriate?"[84] The range of responses to this question is shown in Figure 2. The average so-called "*lead time preference*" was 12.1 ± 8.5 weeks (that is, physicians, on average, prefer for patients to be referred to hospice about three months before death). At the extremes, only 2.0 percent would prefer for their patients to spend a week or less in hospice, and only 3.6 percent would prefer for their patient to spend more than twenty-six weeks. Responses varied from one to 52 weeks and the pattern of responses was bimodal. That is, as shown in Figure 2, 73 percent had a lead time preference of less than 16 weeks to live, with a peak at about 13 weeks; and 27 percent thought it meant having 16 or more weeks to live, with a peak at about 25 weeks. Lead time preference was not associated with years in practice, amount of time in patient care, gender, or board certification. But adjusting for these factors, physicians who thought hospice was an appropriate mode of terminal care were 3.7 times as likely to have a lead time of 16 weeks or more, and generalists were 1.7 times as likely as specialists to have such a preference.

All of the foregoing barriers to hospice referral have at least two consequences. First, an unnecessarily small fraction of terminally ill patients might be referred to hospice. And second, referral, when it occurs, might be delayed.

Hospice-Level Barriers to Hospice Care

Hospice provider factors can affect whether and when hospice is used. Such factors include:

- referral constraints
- poor relations with referral base (physicians, hospitals, social workers, etc.)
- inefficiency of intake mechanisms
- organizational features

"Referral constraints" encompasses a number of barriers. One obvious (but, I think, infrequent) problem, is when institutional or managed care arrangements interfere with the physician being able to use a particular hospice. A more problematic barrier, however -- and one which might be ameliorated by legislation -- is as follows: hospices are obliged to be able to provide inpatient hospitalizations for patients if needed (e.g., to stabilize the patient's pain, to provide respite for the family). They typically contract with particular hospitals for these services to fix the cost at the Medicare-specified amount. So, for example, my hospice, which serves patients all over Chicago, has relationships with several north Chicago hospitals. Physicians tend to refer patients to hospices according to where the patient resides (since hospices also tend to have geographic catchement areas). Thus, a patient residing on the north side of Chicago who sees a doctor at the University of Chicago (on the south side of the city) could be referred to my hospice for care. But, should that patient require hospitalization, my hospice would not admit them to the hospital at which the referring physician has admitting privileges (the University of Chicago), but rather to the hospital with which we have an arrangement. As a consequence, the referring physician might justifiably fear that his relationship with the patient might be compromised since his patient, in case of hospital admission, would not necessarily go back to him.

Barriers to the timely use of hospice can also arise when hospices themselves provide poor quality service or otherwise alienate their physician referral base; as a consequence, patients residing in the catchement area of that hospice might be deprived of the opportunity to get hospice care if physicians justly conclude that they do not want to use the hospice. Hospices might also have inefficient intake mechanisms which delay hospice enrollment after the referral has been made; for example, it may take them several days to send a nurse to evaluate the patient for admission. This is primarily a problem of resource constraints or of geography (e.g., a hospice nurse in rural northern Wisconsin once told me that she sometimes can only see two patients a day in the middle of winter since physically getting to them requires driving across icy lakes in a tractor with tire chains).

Finally, our research has shown that a number of organizational features of hospices are associated with the timing of referral of patients: freestanding hospices get patients earlier than hospital-based hospices; smaller hospices get patients earlier; newer hospices get patients earlier; and for-profit hospices get patients earlier.[85] How are for-profit hospices able to achieve earlier enrollment of patients? Because the survival of patients after enrollment is short, because evaluating newly admitted patients is expensive, and because payment is on a per diem basis, this observation suggest that such hospices may foster the early enrollment of patients in order to recoup the high up-front costs associated with patient admission. Do for-profit hospices have efficient outreach programs or fewer barriers to enrollment? Do they offer care in such a way that patients, families, and physicians are willing to consider earlier enrollment? Or do they inappropriately admit patients they expect with certainty to die years after enrollment? Conversely, do they refuse referrals that are "late"? If so, how do they identify such patients? These questions are the subject of ongoing research.

Market-Level Barriers to Hospice Care

Attributes of the health care market in which patients reside and hospices operate are also important. Such attributes include:

- medical infrastructure (e.g., number of hospital beds in the area, HMO market penetration)
- for-profit hospice market penetration
- specialty mix of physicians in the area
- local customs (e.g., there is substantial geographic variation in hospice use)

For example, in our study of 184,843 Medicare hospice patients enrolled in 1993, we found that certain market factors were meaningfully associated with the timing of enrollment.[86] An increase in the number of hospital beds (but not of nursing home beds) per 1,000 people over 65 was associated with relatively earlier enrollment. An increase in the number of hospice patients per 1,000 people over 65 newly admitted to hospice in the local county was also associated with earlier enrollment. An increase in population density or in for-profit hospice market penetration (but not in HMO market penetration) was associated with later enrollment. The number of physicians per capita was not associated with timing of hospice enrollment, but an increase in the percentage of generalist physicians was associated with earlier enrollment. If a market with a structure conducive to *late* enrollment (*e.g.*, hospital beds *per capita* of 17.2 per 1,000 people over 65, nursing home beds of 30.1, and hospice patients of 5.1 -- all values at about the 25th percentile for each variable) was compared to a market with values of these variables conducive to *early* enrollment (*e.g.*, hospital beds of 34.6, nursing home beds of 56.8, and hospice patients of 9.4 -- all values at about the 75th percentile for each variable), then the difference in median survival between patients enrolled in favorable and unfavorable markets, even holding constant individual and hospice provider attributes and other market traits, would be only 29 compared to 32 days.

Thus, certain features of local health care markets are associated with duration of survival after hospice enrollment. In the case of hospital beds specifically, this may have been because, at the individual patient level, discharge from a hospital to a hospice may be a way to decrease costs for a hospital caring for a seriously ill patient. This specific finding is perplexing, however, and it appears to run counter to work on the impact of hospital bed capacity on home death.[87] It is possible that hospital bed capacity is associated with a low likelihood of using hospice, but also with an earlier enrollment of patients when they are actually enrolled; more research will be required to sort out such complex effects. While the number of doctors *per capita* was *not* associated with timing of referral, a higher proportion of generalists was associated with earlier referral, a finding in keeping with other work that suggests that, compared with specialists, generalists favor earlier hospice referral, perhaps because they are more willing to cease aggressively curative efforts.[88] The effect of for-profit hospice market penetration, while appreciable and associated with later enrollment, is somewhat harder to account for. One possible explanation is that markets with higher for-profit hospice penetration are more competitive, driving all hospices to accept "marginal" patients with what might prove to be short survivals.

In keeping with some past work on market variation in health care use,[89] we found in this study that the measured role of market factors was *smaller* than the role of patient-level factors.

While market-to-market variation in survival after enrollment remains meaningful even after adjustment for multiple patient and hospice provider attributes, it seems quantitatively less important than each of the several individual-level patient traits we considered. This may reflect, in part, the nationwide uniformity of the Medicare hospice benefit.

In other work we have done, which we have not yet published, we have examined the geographic variation in hospice use by closely examining variation in whether and when hospice is used at the level of the approximately 3, 000 counties in the U.S.. In terms of whether hospice is used, we found that counties can vary enormously in the percentage of decedents who use hospice -- from 0% to 39%. That is, some counties in Florida, for example, have very high levels of hospice use and some counties in Indiana have very low levels of use. In terms of when hospice is used, we found somewhat less geographic variation, with fewer obvious patterns; however, at the county level, median survival could range from 20 to 60 days. Thus, in most counties in Kentucky, for examples, large percentages of patients use hospice, and they tend to do so earlier in the course of their illness.

Patient- and Family-Level Barriers to Hospice Care

Finally, it is important to note that some of the problems encountered in optimizing hospice use originate in patients and their families. These include:

- fear of death
- misconceptions about the purpose of hospice
- aversion to home death
- age, race, gender, marital status, income, education, etc.
- attributes of the illness (e.g., its duration or type)
- home structure (e.g., whether the patient is living alone or not, how sick the patient's spouse is)

Patients and their families may resist referral, typically out of a fear of managing death at home, a fear of stopping curative therapy, or a misplaced fear of being abandoned by the medical establishment. Clearly, patients and families need help in understanding the purposes of hospice care and its benefits. Certainly, it is difficult to face one's own death or the death of a loved one, regardless of whether one in fact realizes that hospice care might offer advantages in terms of achieving a "good death." Some patients have misconceptions about hospice care, thinking it somehow means that "nothing is being done for the patient" or that the patient is obliged to die at home (whereas, in fact, hospices can, to the extent it is possible to predict this, admit patients to a hospital for the actual act of death , if this is what the family wants).

Certain attributes of patients can also affect whether or when they use hospice care. For example, Table 1 gives the adjusted median survival in days, according to certain patient attributes in a sample of 184, 843 hospice patients. At the median, non-white patients were enrolled in hospice four days (13%) earlier prior to death compared to whites; women were enrolled in hospice five days (17%) earlier prior to death compared to men; older people were enrolled one day (3%) earlier prior to death than younger people (comparing 84-year-olds to 73-year-olds); and those with substance abuse, psychiatric disease, or dementia were, on average and after adjustment for all other factors, enrolled three days (10%) earlier prior to death. After adjustment for the other covariates, income and education were *not* associated with the duration between hospice enrollment and death. The even greater impact of some of these variables in combination is also apparent; for example, after adjustment for all other measured factors, the median time prior to death that patients were referred to hospice was 26 days for white men versus 37 days for black women.

Our major finding in this research was thus that several variables ordinarily associated with *shorter* survival or *worse* health outcomes,[90-95] including, for example, non-white race, lower education, lower income, psychiatric history, substance abuse history, dementia history, and advanced age, were associated with *longer* survival after hospice enrollment. For most of these variables, this held true after adjustment for each other and for other clinical, provider, and market factors. As shown in Table 2, these factors, even taken individually, are of a potentially clinically significant magnitude (an up to 30% impact on the median survival, depending on the variable, and still more if variables are taken in combination). The existence of a pattern in the results, wherein the impact of being within any socioeconomically disadvantaged group had a similar effect, supports the supposition that such factors are associated with an earlier hospice enrollment rather than with some beneficial effect of these factors on survival after enrollment.

If certain groups are being enrolled in hospice earlier than others, why might this be occurring? This study did not permit definitive conclusions, but there are at least three possible explanations.

First, predictions of death or evaluation of symptoms may be more difficult in some patients (*e.g.*, in those with dementia or psychiatric disturbance) thereby complicating decisions about when to switch from traditional medical care to hospice care and thereby leading to earlier referral. Faced with prognostic or clinical indeterminacy near the end of life, for example, physicians may choose to refer such patients relatively early. However, most research suggests that, if anything, prognostic uncertainty results in postponement of hospice referral.[96-100]

Second, outside help may be brought in more quickly by family members, physicians, or other concerned parties for those patients likely to be difficult to care for at the end of life (*e.g.*, those with dementia, psychiatric disorders, or substance abuse problems) or those who usually fill the care-giving role and therefore possibly lack a caregiver themselves (*e.g.*, women). That is, the *preferences* of the members of the groups defined by our variables may be such as to *favor* earlier use of hospice care. However, some prior work examining the relevance of patients' social support for the timing of hospice enrollment has tended to show that, if anything, lack of social support delays enrollment in home-based hospice care.[101-103] Lack of social support (*e.g.*, being a widow) may indeed preclude hospice care altogether -- a contention suggested by the fact that women in our sample are less numerous (51.4%) than in the underlying Medicare population as a whole (59%).

A third possibility is that socially stigmatized groups may possibly be seen as less appropriate for the costly, aggressive, "curative" care that is ordinarily offered in the period preceding the use of hospice, and so might be referred to hospice relatively early, in a form of "turfing."[104-107] Disquieting support for some role for the fourth explanation comes from previous examinations of the role of race,[108-113] sex,[114] age,[115,116] education,[117] and psychiatric illness,[118] in access to and use of medical technology in general.

To sort out which of these explanations, if any, explain the patterns we observe will require further research. It is hard to determine whether patients or doctors or both are driving these observations about how certain attributes of patients are associated with their timing of hospice use. If poor patients are enrolling in hospice earlier, it may because they are electing to use hospice in this fashion (e.g., because they must rely on formal supports since they lack their own financial resources) or it may be because physicians are referring poor patients to hospice sooner. It is worth noting, however, that even if referral to hospice is occurring earlier in some patients than in others for reasons that are possibly inappropriate, this might not actually be harming such patients if hospice referral is occurring too late for patients in general. Indeed, hospice care appears to be used later in the course of illness than most physicians prefer.[119]

Attributes of the patients' illness may also affect whether and when hospice is used, as summarized in Table 3, which is based on unpublished data from a large-scale study we are presently conducting of 1.3 million seriously ill patients. As can be seen, depending on the type of cancer involved, from 16% to 35% of dying patients may use hospice (with patients with leukemia being much less likely to use hospice and patients with pancreatic cancer being much more likely to do so). In general, non-cancer diagnoses are much less likely to use hospice, with approximately 7-10% of decedents with heart attacks, strokes, hip fractures, and the like using hospice care.

THE COST-EFFECTIVENESS OF HOSPICE

There have been several studies published in the peer-reviewed literature concerning the cost-effectiveness of hospice care,[120-124] and several well conducted unpublished studies as well. My summary of this literature is as follows: Most studies agree that hospice care saves money compared to alternative ways of caring for the terminally ill. Indeed, estimates of cost saving run as high as $1.20 saved for every $1.00 spent. What is still unclear, however, is over what time horizon hospice saves money. That is, it is clear that hospice is cost-effective for the last 30 days (i.e., it is cheaper to provide care using hospice for the last 30 days than to use the standard type of hospital-based care otherwise prevalent in our society). It is also quite likely that hospice care is cost-saving for the last 90 days of life. What is less clear is whether hospice saves money over the last six or twelve months of life. Put another way, if we were to enroll all patients in hospice care six months prior to their deaths (assuming we were able to reliably prognosticate this), hospice care (as it is currently reimbursed) might be *more* expensive than the standard care currently being used in our society -- which typically includes a hospitalization or two in the last six months, a few doctor visits, and then a 1-2 week hospital stay before dying. If we added up all these costs, they might, in fact, be lower than the cost of a continuous six-month hospice enrollment.

Nevertheless, one thorough review of cost savings at the end of life concluded that existing data suggest that hospice and advance directives can save between 25% and 40% of health care costs during the last month of life, with savings decreasing to 10-17% over the last six months of life and decreasing further to 0-10% over the last 12 months of life.[125]

It would therefore seem prudent to try to implement changes in the Medicare hospice benefit that would enhance the use of hospice care, both because it is a valuable and desirable form of end-of-life care, and because it is cost-effective. Current patterns of use of hospice (with very short stays) coupled with current reimbursement mechanisms are making it difficult for hospices to provide care in a financially viable fashion and may be wasting Medicare funds. Interventions which result in earlier referral or which compensate hospices for the fact that they do not, under the current system, recover their costs for patients who live less than about two weeks after referral would be beneficial.

It is important to emphasize, however, that regardless of whether hospice costs more or less than standard terminal care, hospice is probably *better* care for the dying, care that Americans might well feel entitled to receive from our superb health care system. In other words, six months of hospice care might possibly be more expensive, but it might be worth it.

CONCLUSION

Responding to some of the barriers to increasing hospice use in our society -- both in terms of increasing the proportion of decedents who use hospice and in terms of increasing the duration of stay under hospice care for those patients that are referred -- will require a number of educational, policy, and legislative responses. Certain selected opportunities on the legislative front include:

- shifting away from the current prognostically based entry criterion for hospice (e.g., shifting to a criterion that patients who have certain specific diseases and who are bedridden a certain fraction of the day are perforce considered eligible for hospice care)

- providing funds to educate physicians and patients about the suitability of hospice and the need to use it earlier in the course of a patient's disease (e.g., three months before death); such educational initiatives might be conducted on a grass-roots level, by local hospices working with their local physician referral base; indeed such efforts could be mandated and compensated through Medicare

- changing the way that hospices are obliged to contract with hospitals for admission (e.g., by requiring hospitals receiving Medicare funds to admit hospice patients from any hospice program, and not just from specific ones, for a Medicare specified reimbursement; alternatively, it could be possible to change regulations to make it possible to provide respite care at home, with a higher reimbursement level than the usual *per diem*)

- provide additional reimbursement for hospices when they care for patients dying in their own homes all by themselves (i.e., without a spouse or other family caregiver), thus making it easier for independently living elderly people to die in their own homes, should they chose; similarly, extra payments may be appropriate for other challenging situations presented by particular types of patients, e.g., those residing in hard-to-reach rural areas or inner cities where it can be very hard to provide hospice care in a financially efficient manner under the current system

- moving to a system whereby hospices receive some kind of fixed initial payment for evaluating and admitting patients, thereby covering their high initial admission costs and making it easier for them to overcome any administrative barriers that delay hospice enrollment after the patients have been referred for evaluation

Health care decisions at the end of life are made at a time when patients are at their most vulnerable. In general, patients get only one chance to elect hospice care, and if the care is inadequate for any reason, it is unlikely they will have an opportunity to switch or improve on their choice. For these reasons, parties who contribute to the hospice enrollment process should act with the greatest probity. Since patients in general are enrolling in hospice late in the course of their illness, thought might be given to addressing some of the barriers to more timely referral. The apparent role of certain social and provider and market factors in the timing of hospice enrollment suggests that it is not merely the patient's clinical status, but other factors as well, that influence this important end-of-life transition in care. This in turn suggests that it may be possible to change the way hospice is used for the better of both dying patients and our society as a whole.

FIGURES AND TABLES

Table 1: Characteristics of the 1993 Medicare Hospice Patient Study Cohort (N=184,843)* (source: N.A. Christakis and T.J. Iwashyna, "The Impact of Individual and Market Factors on the Timing of Initiation of Hospice Terminal Care," Medical Care, 38(5): 528-541 (2000))

PATIENT ATTRIBUTES	
demographics	
mean age	79.0 ± 7.4 years
female sex	51.4%
non-white race	10.2%
mean income (annual)	$31,540 ± 11,580
mean education	12.8 ± 1.0 years
health care use measures	
had >0 hospitalizations in 365 days preceding hospice	76.0%
had >0 hospitalizations in 730 days preceding hospice	82.3%
mean days spent in hospital in 730 days preceding hospice	27.4 ± 36.3 days
mean number of hospitalizations in 730 days preceding hospice	2.5 ± 2.4 hospitalizations
mean days spent in hospital in 30 days preceding hospice	6.0 ± 8.3 days
mean days spent in ICU care in 730 days preceding hospice	2.3 ± 6.3 days
spent >0 days in ICU care in 730 days preceding hospice	32.7%
mean DRG expenditures in the 730 days preceding hospice	$14.860 ± 16,280
health measures	
serious co-morbidity (Charlson score ≥ 6)	41.6%
history of substance abuse	3.96%
history of psychiatric problem	7.80%
history of dementia as a co-morbid condition**	4.85%
diagnosis at enrollment into hospice	
neoplasms	
head and neck	1.64%
upper gastrointestinal tract	3.24%
colon and rectum	8.99%
hepatobiliary system	2.84%
pancreas	4.30%
lung	19.38%
skin	0.81%
breast	4.80%
female genital tract	2.97%
prostate	7.00%
urinary tract	3.26%
CNS	1.98%
lymphoma	1.90%
leukemia	2.63%
all other neoplasms	5.59%
non-neoplasms	
dementia	2.33%
Parkinson's disease	0.73%
stroke	3.12%
other neurological diseases	0.77%
congestive heart failure	5.51%
	table continues

other cardiovascular diseases	4.40%
COPD	4.22%
liver disease/failure	0.86%
renal disease/failure	1.96%
infections	0.71%
all other non-neoplastic diseases	4.07%
MARKET ATTRIBUTES***	
mean number of hospital beds/1000 people >65	27.1 ± 15.8 beds
mean number of nursing home beds/1000 people >65	46.5 ± 21.8 beds
mean number of SNF beds/1000 people >65	1.9 ± 4.1 beds
mean number of new hospice patients/1000 people >65	7.6 ± 11.5 patients
mean percentage of new hospice patients at for-profit hospices	18.1 ± 26.8
mean number of doctors/1000 people >65	20.5 ± 13.9 doctors
mean percentage of physicians who are generalists	30.7 ± 14.2
more than 25 percent of people in HMO's	25.8%
population density more than 1,000 people/square mile	37.7%
HOSPICE ATTRIBUTES***	
small size (<200 admissions/year)	41.4%
new hospice (<5 years since Medicare certification)	31.1%
change in ownership since certification	9.0%
for-profit	18.3%
operated by hospital	18.6%
operated by SNF	2.1%
operated by home health agency	30.3%
operated by free-standing hospice program	49.0%

*Descriptive statistics regarding patients and, on a patient level, markets in which these patients reside, are provided for the 151,410 members of the study cohort.

**This variable characterizes the presence of dementia as a co-morbidity in those 97.7 percent of cases for whom dementia is *not* the principal diagnosis.

***These variables are expressed at the *patient* level.

Table 2: Adjusted Median Survival after Enrollment in Hospice, in Days, According to Certain Patient Attributes *

(source: N.A. Christakis and T.J. Iwashyna, "The Impact of Individual and Market Factors on the Timing of Initiation of Hospice Terminal Care," Medical Care, 38(5): 528-541 (2000))

Attribute	Absent	Present
Nonwhite	30	34
Female	29	34
Advanced Age †	30	31
Low Income †	30	31
Low Education †	30	31
History of Substance Abuse	30	33
History of Psychiatric Disorders	30	33
History of Dementia	30	33

* All figures represent the effects of the variable in question, holding all other variables constant at their mean and adjusting for numerous other variables characterizing patients, their illness, their hospice, and the local health care market, such as those listed on Table 1. Except for income and education, all of these differences are statistically significant at the 0.05 level.

† This is a continuous variable, for which median adjusted survival was computed for the 25th percentile ("absent") and 75th percentile ("present") for age, and vice-versa for income and education.

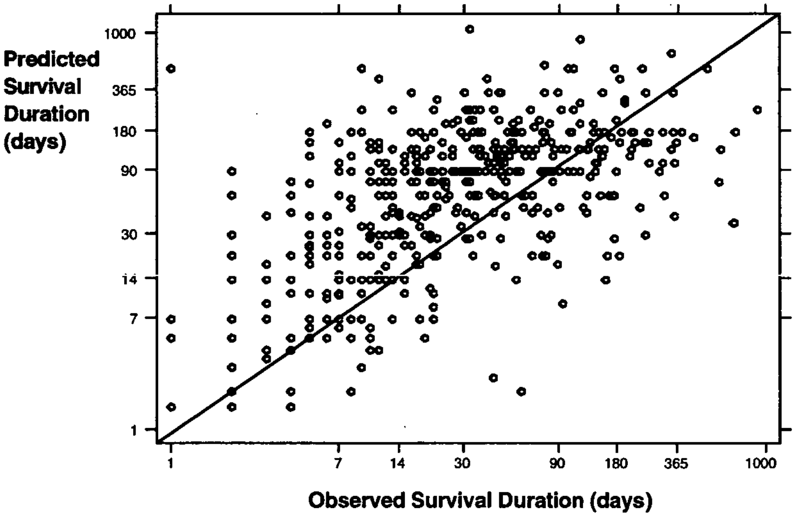
Table 3: Mortality and Hospice Use Outcomes in an Incidence Cohort of Seriously Ill Patients (the "COSI" cohort; N=1,343,295)

(source: unpublished data)

diagnosis	number in 1993 incidence cohort	% dead by 12/31/97	% enrolled in hospice by 12/31/97	% of dead patients who used hospice	median duration of hospice use in days (from: [126])
leukemia	22,017	79.6	13.0	16.3	25
lymphoma	34,327	78.7	16.9	21.5	22
head/neck cancer	11,428	72.2	19.0	26.3	30
urinary cancer	40,897	59.4	15.8	26.6	29
colon cancer	84,093	60.7	17.9	29.5	31
lung cancer	87,619	90.9	27.0	29.7	26
liver/biliary cancer	9,655	94.1	29.2	31.0	21
CNS cancer	6,276	93.3	32.4	34.7	31
pancreatic cancer	16,225	96.0	33.4	34.8	25
acute MI	256,183	58.0	4.1	7.1	41
stroke	268,222	65.0	5.6	8.6	29
CHF	277,676	69.5	6.4	9.2	38
hip fracture	228,677	60.0	5.8	9.7	NA

Figure 1: Predicted versus Observed Survival in 468 Terminally Ill Hospice Patients

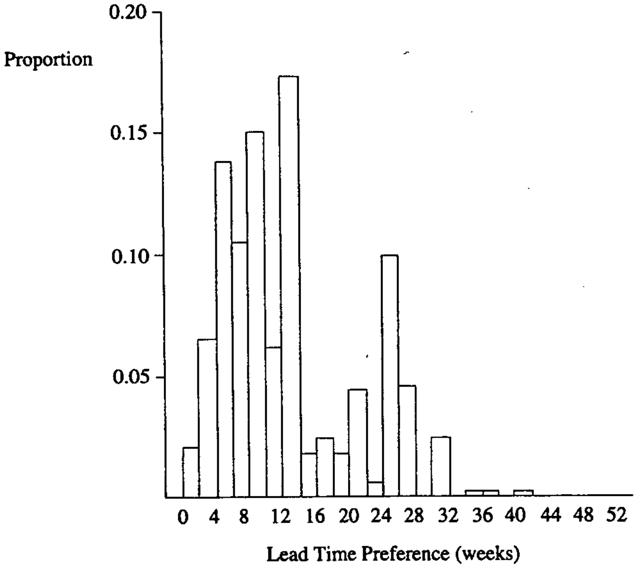
(Source: N.A. Christakis and E.B. Lamont, "Extent and Determinants of Error in Doctors' Prognoses for Terminally Ill Patients: Prospective Cohort Study," British Medical Journal, 320: 469-473 (2000))



Legend: The graph shows the predicted and actual survival, in days, for a cohort of 468 patients at the time of initiation of home-based hospice care. The predicted survival was elicited from referring physicians. Each point represents one patient. The diagonal line represents perfect prediction, where the patient lived for exactly as long as the physician predicted. Patients above the diagonal are ones in whom survival was overestimated; patients below the line are those in whom survival was underestimated. Prognostic error is very common, and, in most patients, quite substantial.

Figure 2: Distribution of "Lead Time Preference" with Respect to Hospice Referral in a National Sample of Internists

(Source: T.J. Iwashyna and N.A. Christakis, "Attitude and Self-Reported Practice Regarding Hospice Referral in a National Sample of Internists," Journal of Palliative Medicine 1(3): 241-248 (1998))



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The CHAIRMAN. Thank you, Dr. Christakis.

Now, Ms. Hoffman.

STATEMENT OF FRANCES HOFFMAN, EXECUTIVE DIRECTOR, HOSPICE OF NORTH IOWA, MASON CITY, IA

Ms. HOFFMAN. Mr. Chairman, ladies and gentlemen, thank you for the opportunity to come and speak with you today. My name is Frances Hoffman and I am the Executive Director of Hospice of North Iowa, which serves 16 counties in northern Iowa. Last year, we served 800 patients and families during a critical time in their lives.

I have been asked today to talk about barriers to the use of the Medicare hospice benefit. The first barrier I would like to talk about is the requirement that all hospice patients must have a 6-month prognosis from their physician. As Dr. Christakis has eloquently said, only about 20 percent of physicians are very accurate in their predictions, leaving 80 percent of predictions being wildly inaccurate and usually overestimates of survival. The result of this over-optimistic view of their patients' life spans is that physicians refer to hospice very late in an illness, when it is abundantly apparent that a patient's death is near.

Hospice services were designed to help a patient through the last 6 months of life. When patients come to hospice a few weeks or even days before they die, the benefit they and their families receive is significantly reduced. Admission criteria should be reviewed to encourage earlier admission to hospice care so that opportunities for physical, psychological, and spiritual support may not be missed for individuals at the end of life. I would encourage you to consider demonstration projects to test alternative eligibility criteria to the 6-month rule.

A second barrier is the short length of stay of many hospice patients, and you have been hearing that today. A hospice patient in my hospice now will average 39.5 days of care, a far cry from 6 months. Over 30 percent of our patients are with us less than a week. The quality of service we can provide is dramatically reduced when we have so little time with a patient.

Our financial picture is also greatly affected when our patients are with us only a matter of days. The Medicare hospice benefit was designed to balance the high cost of admission and the period immediately preceding death with somewhat lower costs of care for patients during non-crisis times. With very short lengths of stay, there are few non-crisis days any more. This results in growing financial pressures that are having a devastating effect on hospices.

In doing a review of typical patients who stayed with us a week or less, I found that we lost anywhere from $340 to $2,000 with these patients. We made no money on any of these patients. In the last 2 years, my hospice has lost $362,000. My annual budget is only $4 million. At the same time, my staff are working harder than they ever have and have instituted aggressive measures to reduce costs. We are not spendthrifts.

The problem is that reimbursement has not kept pace with the increased costs of providing care. The fiscal year 2000 Medicare routine home care rate for my hospice is $87.33. It costs twice that to spend a night in a Washington, DC., hotel. Yet, it is supposed to cover all costs related to a terminal illness, including physician oversight, nursing, counseling, spiritual support, bereavement counseling, medical equipment, drugs, home health aides, homemaker services, physical and occupational therapists, dietitians, and volunteers, for $87.33 a day.

Another aspect of the reimbursement issue is the significant changes that have taken place in care for the terminally ill. When Medicare set hospice payments in the 1980's, prescription drugs for hospice patients represented about $1.00 of the per diem reimbursement rate. These costs increased to approximately $16 per day by the late 1990's, an increase of 1,500 percent.

There is a drug, Epogen, being ordered by physicians for some of my patients that costs $250 per dose. One patient received three doses per week, which ate up my entire Medicare reimbursement. Outpatient procedures for relief of pain, like chemotherapy and radiation therapy, have also increased. At my hospice, these procedures have increased 46 percent in cost since 1996. My Medicare reimbursement has gone up 6 percent in that same timeframe.

Since over 85 percent of my patients each year are under Medicare, you can see what a problem I have in making ends meet. The only way I have found to continue to provide services is through the charity of people in the communities we serve. Of our $4 million budget, $500,000 comes from gifts and memorials each year. Without these gifts, Hospice of North Iowa would have to close its doors.

The Medicare hospice benefit is a wonderful service for Medicare beneficiaries, but reimbursement for this benefit must keep pace with the cost of providing care. It is critically important that hospice reimbursement rates are updated based on current costs of care.

Thank you.

[The prepared statement of Ms. Hoffman follows:]

Testimony of Frances Hoffman

Before the

Special Committee on Aging
United States Senate

Hearing on

Barriers to Use of the Medicare Hospice Benefit

September 18, 2000

Mr. Chairman, ladies and gentlemen, thank you for the opportunity to speak with you today.

My name is Frances Hoffman. I am the Executive Director of Hospice of North Iowa which serves sixteen counties in northern Iowa. Last year we served 800 patients and their families during a critical time in their lives.

When the National Hospice Foundation researched what people in the United States want at the end of their lives it found that they want the following:

- Someone to be sure that their wishes are enforced
- Ability to choose the type of services they want
- Emotional support for themselves and their families
- Control of pain
- Opportunity to get their lives in order
- Spiritual support for themselves and their families
- Care by a team of professionals
- Care in their own homes
- Continuity of care
- Relief of the burden on their families and friends

All of these elements are available through hospice care. If the Medicare Hospice Benefit is so wonderful, why am I here testifying? There are significant barriers to providing hospice care to all who might benefit from it.

The first barrier is the requirement that all hospice patients must have a six-month prognosis from their physician. As Dr. Christakis so eloquently presents in Death Foretold, his study on prognosis in medical care, physicians have a great deal of difficulty in foretelling how long a patient may have to live. In his work, Dr. Christakis cites a study where he "found that only 20 percent of predictions were 'accurate,' .....Of the remaining 80 percent of predictions, most (63 percent of the total) were overestimates of survival..." The result of this overoptimistic view of their patients' life span is that physicians refer to hospice very late in an illness--when it is abundantly apparent that a patient's death is near. Hospice services were designed to help a patient through the last six months of life. The reimbursement structure was designed based on this precept as well. When patients come to hospice a few weeks or even days before they die, the benefit they and their families receive is significantly reduced. I would encourage you to consider demonstration projects to test alternative eligibility criteria to the six-month rule.

A second barrier is the short length of stay of many hospice patients. A hospice patient in my hospice now will average 39.5 days of care. Over 30 percent of our patients are with us less than a week. Let me give you two examples of patients to give you an idea of the difference in what we can provide in care if we have the time to do it. These are actual patients of Hospice of North Iowa, although I have changed their names to protect their confidentiality.

"Larry" was an 85-year-old man with renal insufficiency, hypothyroidism, Alzheimers, diabetes, pneumonia, and a feeding tube. He was with us for two days. He lived in a nursing home and was referred to hospice as he was actively dying. The hospice nurse provided medications to ease the symptoms of dying for Larry and explained the dying process to Larry's family. The hospice social worker talked with the family about grief issues as Larry died. The hospice bereavement social worker provided follow up with the family for 12 months after Larry's death.

"Virginia" was with us for six months. She had ovarian cancer with metastases, a colostomy, a feeding tube, a central line, a large abdominal wound from surgery, an ileostomy, and a rash over much of her torso. She was an 82-year-old grandmother who had always been the strength of her family. Her husband and daughters were having a very difficult time accepting her critical illness. Virginia was admitted to hospice in the spring. She came to hospice from the hospital where she had had abdominal surgery. It appeared when she was admitted that her death was imminent. Virginia was taken to her home where a hospice nurse provided medications, wound dressings, and equipment to help her deal with her colostomy. A hospice home care aide provided baths and other care five days per week. The hospice social worker and chaplain worked with the family to help them adjust to Virginia's illness and to cope with the anxiety of caring for her at home. Virginia rallied after her first four days in hospice and she was able to go out for some drives with her husband during the summer months. The social worker worked with Virginia to help her address self-image issues that she had as a result of the many wounds and tubes she now had to deal with in addition to the loss of her hair. Virginia's husband and daughters were dealing with a great deal of anger at losing their support and "best friend". The social worker held several family conferences to help them work through these feelings. In late fall, Virginia began to decline rapidly. The hospice nurse arranged for oxygen for her and increased her pain medications. A hospital bed, trapeze grab bar for over the bed and an overbed table were provided. Virginia developed shingles and the hospice nurse provided medication to soothe this condition. After several weeks of increasing decline and weakness, Virginia died very quietly at home. Her family had come to accept her illness and death. The bereavement social worker from hospice continues to follow up with the family as they grieve the loss of the woman whom they had relied on to support them through the years.

Clearly, the quality of service we can provide is dramatically improved when we have some time with a patient. Our financial picture is also greatly affected when our patients are with us only a matter of days. The Medicare Hospice Benefit was designed to balance the high costs of admission and the period immediately preceding death with the somewhat lower costs of caring for patients during non-crisis times. With very short lengths of stay, there are few non-crisis days any more. This results in growing financial pressures that are having a devastating effect on hospices.

When the Hospice Medicare Benefit was implemented in 1982, the routine home care rate was set at $41.46 per day. The rate did not include an annual inflationary update. Instead, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, these increases have not kept pace with the expense of delivering specialized care to dying Americans. A report by Milliman & Robertson (M&R) states "the trend is clear that Medicare hospice per diem payments do not cover the costs of hospice care and result in significant financial losses to hospice programs throughout the country." The factors that M&R cites as contributing to hospice losses are "new technology, including breakthrough therapies and prescription drugs."

For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about $1 of the per diem reimbursement rate. These costs increased to approximately $16 per day by the late 1990s--an increase of about 1,500 percent. There is a drug, Epogen, being ordered by physicians for some of my patients that costs $250 per dose. One patient received three doses per week, which ate up my entire Medicare reimbursement. Duragesic, a commonly used pain reliever for cancer patients, can cost up to $36 per dose. Zofran, an effective anti-nausea drug, costs almost $100 per day--exceeding the entire routine home care rate paid by Medicare to the hospice provider.

Outpatient procedures for relief of pain, like chemotherapy and radiation therapy, have also increased. At my hospice, the increase in costs for these procedures has been 46 percent since 1996. My Medicare reimbursement has gone up 6% in that same time frame. Since between 85 and 90 percent of my patients each year are under Medicare, you can see what a problem I have in being able to make ends meet. The only way I have found to continue to provide services is through the charity of people in the communities we serve. Of our $4 million budget, $500,000 comes from gifts and memorials each year. Without these gifts, Hospice of North Iowa would have to close its doors.

In the last two years, my hospice has lost $362,400. My annual budget is only $4 million. At the same time, my staff are working harder than they ever have and have instituted aggressive measures to reduce costs. We are not spendthrifts. My staff work for hospice because they have a sense of mission. Any of them could get better paying jobs at any time--yet they stay with Hospice of North Iowa because they believe in what we are doing. Despite their lower pay rates, it is still costly to recruit, train, and retain staff. These costs are no less because we are located in a rural area, yet our reimbursement is reduced because of that fact. The routine home care rate paid for hospice care in an urban area is $98.96. The fiscal year 2000 Medicare routine home care rate for my hospice is $87.33. It costs twice that to spend a night in a Washington DC hotel room. Yet it is supposed to cover all costs related to a terminal illness, including physician oversight, nursing, counseling, spiritual support, bereavement counseling, medical equipment, drugs, home health aides, homemaker services, physical and occupational therapies, dietitians, and volunteers. Bereavement counseling and coordination of volunteers are Medicare mandated services that have been explicitly excluded from allowable costs in the new Hospice Medicare Cost Report.

Reimbursement has not kept pace with the increased costs of providing care. New drugs and other treatment modalities can greatly improve the quality of life for patients who are dying. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments forces us to seek other, less expensive and perhaps less effective alternatives. A Lewin study done in 1995 indicated that $1.52 could be saved by the Medicare program for every $1.00 spent on hospice care. There is room to increase hospice rates to more accurately reflect costs of care while still saving money for the Medicare system overall. As the Medicare Payment Advisory Commission has stated, "the gap between the care now given to dying beneficiaries and ideal care is wider than in probably any other area of medicine...closing this gap should be one of the highest priorities of the Medicare program."

It is important that fraud and abuse of the Medicare system be eliminated. However, aggressive efforts to discover and prosecute fraud and abuse has resulted in a great deal of attention to a very small percentage of hospice patients who outlive their six-month prognosis. This has created an environment of fear among referring physicians and hospices that has limited access to hospice care. I recently had a patient in my hospice program who was discharged because she had been with us some months and had reached a plateau for a short period of time. Staff were concerned that Medicare would refuse payment for her care--as, in fact, it did. This patient died just six weeks after her discharge from hospice. During that six weeks, she needed our services as her health dramatically declined. But this had happened before when she had been our patient and she had not died. So everyone was fearful of readmitting her because of the regulatory oversight that questions care in cases such as hers. She spent her final two days with us--when it was very apparent that she was actively dying.

The Medicare Hospice Benefit is a wonderful service for Medicare beneficiaries. But reimbursement for this benefit must keep pace with the cost of providing care. In addition, admission criteria should be reviewed to encourage earlier admission to hospice care so that opportunities for physical, psychological, and spiritual support may not be missed for individuals at the end of life. I strongly support an update of hospice reimbursement based on current costs of care. I also endorse a Medicare waiver for demonstration projects that test alternative eligibility criteria for the Medicare Hospice Benefit.

The CHAIRMAN. Thank you, Ms. Hoffman.

Ms. Grigsby, you are next.

STATEMENT OF KATHRYN GRIGSBY, EXECUTIVE DIRECTOR, HOSPICE OF BATON ROUGE, BATON ROUGE, LA

Ms. GRIGSBY. Thank you. I am honored to be here, and thank you, Senator Breaux, for the invitation.

Most of what I had written to say has already been covered. I will, I guess, reiterate the imperativeness and need for education, and I think that is with physicians, the consumer, and health care professionals. As Senator Breaux stated, in 1998, according to the AMA, there were 4 medical schools out of 126 who offered any training whatsoever on death and dying, hospice care, palliative care, or end-of-life care.

Physicians need to be educated. They need to understand. Unfortunately, the OIG and Operation Restore Trust has put a cloud upon them. They are much more reluctant to give referrals. You talked about the reluctance. I would like to read for you an actual statement from an attending physician. As part of the Medicare regs, we must have a signed statement that, in the best estimate of the physician, the patient has 6 months or less to live. The response to us was, "I do not authorize death in 6 months. I appreciate your help for my patient. Please do not ask me to predict his death. If I do, then at the end of 6 months I will have to kill him, which I will not do. Sincerely," signed by a medical physician in my community.

Also, one area that has not really been addressed is the lack of incentives for discontinuation of treatment. Pretty much, what we find in our community is that the patient goes where the reimbursement sources are, and that patients will be treated as long as there is a reimbursement source to be tapped. I believe that there are physicians who continue aggressive treatment long after hospice care would be appropriate and be in the best interest of the individual, and far more economical as well.

Recently, we received a referral on a patient with a non-cancer diagnosis. It was COPD, chronic obstructive pulmonary disease. The history and physical stated that the patient had a history of prostate cancer, skin cancer, a laryngectomy with tracheostomy, cervical soft tissue masses suspicious for recurrent tumor, and frequent pneumonia. And he had been hospitalized for a work-up for admission to a rehabilitation unit.

It was clear to me when I entered the patient's room that he was actively dying and there was no possibility of hospice providing care to this man. His wife said that she had heard of hospice, but thought it was a place. The man was clearly a hospice candidate. He was not a candidate for a rehabilitation unit, but he continued to receive aggressive treatment until the day before he died.

This is not an isolated incident. Our median length of stay in Baton Rouge is 20 days; the national is 29. This year, over half of our patients have died within 20 days of admit. Sixteen percent of our patients——die before we can contact them after receiving a referral.

Senator BREAUX. How many?

Ms. GRIGSBY. Twenty, within 20 days of admit. Sixteen percent die before we can ever get to them to make the first visit. We have a new term in our hospice and it is called DBA, "dead before admit." I was talking with Karen and they call theirs "drive-by." We get the referrals so late that the patients die either on our way or when we get there.

Unfortunately, the current reimbursement rate does not begin to cover the expenses incurred in delivering compassionate, specialized care to dying Americans. An interim report on the ongoing hospice cost study by Milliman and Robertson states that the trend is clear that Medicare hospice per diem rates do not cover the cost of hospice care and result in significant financial losses to hospice programs throughout the country.

According to the M&R study, new technology, including breakthrough therapies and prescription drugs, has increased hospice costs far beyond Medicare's annual market basket update. For example, when Medicare set payments in the 1980's, prescription drugs for hospice represented about $1.00 of the per diem rate. Today, these costs are 16 percent, and as Frances said, a 1,500-percent increase.

Drug costs have skyrocketed. Duragesic patches, which is one of the most commonly used pain relievers for cancer patients, can cost up to $36 per dose. Zofran, a very effective anti-nausea drug, costs almost $100 a day. We get a significant number of patients who are receiving Lupron, which is $900 per injection.

For a variety of reasons, more and more patients are being admitted later to hospice, when they require greater intensity and variety of services. The hospice care needs, including pain and symptom management and personal support, are often the greatest in the first few days of care. These very short lengths of stay and advances in clinical practices, both significant cost factors, were not anticipated at the time the original structure was formulated. We desperately need an increase in our reimbursement rate.

Smaller programs, particularly in the rural areas, are very handicapped because of the lack of economy of scale. It is not cost-efficient for me to send a nurse driving 2 hours to visit one patient an hour visit and return to the office 2 hours later. At the rate that we get, we simply can't afford to do it, so the rural community is without hospice services. A demonstration project could be considered. Their reimbursement rate is even lower than those of us in the city.

We need to find economical ways to provide hospice care to individuals without able or available caregivers. This is one of the biggest problems that we face. Imagine an 86-year-old man trying to care for his dying 83-year-old wife. I wish that we could explore a demonstration project which would provide some sort of reimbursement for residential care. It is very sad to see patients end up in nursing homes for the last month of life because the caregiver is physically unable to care for them.

All of our citizens need hospice care. I would like to simply read you a letter that I think summarizes what we do. "We would like to let you know how grateful we are. I never would have believed 7 years ago when my child was born that she would become terminally ill. It was an incredibly horrible experience to watch her die after a 2-year battle with brain tumor. She passed away in her room, in her bed, in our arms. Without the support of Hospice of Baton Rouge, I don't know how we could have managed."

I think people usually associate hospice with older people. It is important to know that babies, children, and their families need hospice, too. Every terminally ill American should have access to hospice care. There are barriers, but I am confident, particularly with your commitment, we can find answers.

[The prepared statement of Ms. Grigsby follows:]

Testimony of Kathryn Grigsby

On behalf of

Hospice of Baton Rouge

Before the

**Special Committee on Aging
United States Senate**

Hearing on

"The Barriers of Wider Utilization of Hospice in Medicare"

September 18, 2000

Mr. Chairman, Senator Breaux, members of the Committee and ladies and gentleman, I am honored to be here today.

My name is Kathryn Grigsby. I have served as Executive Director of Hospice of Baton Rouge for 12 years. Hospice of Baton Rouge is a non-profit, independent, United Way hospice provider with an average daily census of 65. We have been meeting the end-of-life care needs since 1984. I also serve as Vice President of the Louisiana Hospice Organization.

My special thanks to Senator Breaux of Louisiana for providing me with this opportunity to testify about issues confronting the terminally ill and their families as they seek a dignified and compassionate closure to their lives.

I am here today to talk about the barriers to hospice care for Medicare eligible individuals in Louisiana. The barriers I will address are not unique to Louisiana.

The modern day American hospice movement began in 1971 in Connecticut. The first freestanding hospice in this nation was the Connecticut Hospice in New Haven and it was founded on the model of care best identified with Dame Cicely Saunders, MD, who opened her now famous Saint Christopher's Hospice in 1967 in Sydenham, England. Her center became the model for comprehensive whole person and family care at the end of life (i.e., spiritual, psychological and medical team-driven care of the terminally ill patient and his/her family).

While hospice began as a grassroots movement in this country, it was institutionalized as part of the Medicare program in 1982. Since enactment, the

Benefit has afforded millions of terminally ill Americans and their families an avenue toward a death with dignity.

Simply defined, hospice is a philosophy of care that focuses on the whole person, not on the disease. It is not, as too often is thought, just a place to die. Hospice embraces these principles:

- Supports and cares for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible;
- Recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life;
- Exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them; and,
- Offers palliative care to terminally ill people and their families without regard for age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay. (NHPCO Standards of Hospice Program of Care, 1993)

Far too many patients die without ever being referred for hospice care. This is often the result of an unawareness of hospice and palliative care programs by patients and their families. This lack of knowledge or awareness of compassionate end of life care can lead to tragic and unnecessary pain and suffering – physical, emotional and spiritual -- for the patient and their families.

In order for terminally ill patients and their families to take advantage of hospice care, they must know that a compassionate and caring system exists and is accessible. This knowledge or awareness must come from different levels of information, but the first step in this process is to talk about death.

Only in America does the consumer consider "not dying" an option. There is the perception that there is always one more treatment to consider, one more specialist, usually 200 miles or more away to see. And only in America do health care professionals consider death a failure.

Conversations about our final wishes and how we want to be cared for at the end of life have to take place. It is ironic that we, as a society, celebrate and plan for other life events, like birth or marriage, but refuse to talk about death, until a crisis arises and we are at our worst to make decisions and resolve long standing issues. We, as individuals and families have spent a lifetime arriving at the edge of death, and need and deserve time to address lingering issues that will afford the dying patient, and their families, some better sense of closure and peace.

A recent television series by Bill and Judith Moyers, "On Our On Terms" aired last week. The four programs focused on issues facing dying Americans. In thoughtful and compassionate way, the subjects invited us to witness their struggle with accepting death and how the final months, weeks and days can be made better for the patient and their loved ones. Perhaps this program, and more like it can prompt our on citizens to start talking about death. Maybe when it appears on television, it becomes real for us.

We did a focus group with families of former patients. 90% had never heard of hospice until the physician told the family that hospice had been called. A survey done by the National Hospice Foundation in 1999 found that 80% of those surveyed did not know the meaning of hospice.

Obviously, to avail themselves of this form of care, they must know about it. Education is paramount. We must educate consumers, health care professionals and physicians. Most Americans rely on their health care professionals for information and advice. But, if those very highly educated and trained professionals don't know about, or don't care about quality end-of-life care, then they are failing their patients.

Physician education is essential. Most physicians practicing today have received no training on end-of-life care or communications. According to the AMA, in 1998 only 4 out of 126 medical schools in the U.S. had any formal training available on hospice care, death and dying, palliative care or end-of-life care. Other areas of medicine receive intensive training, but end-of-life care is a glaring example of an area needing more attention.

Once they know about hospice care, physicians must feel free to refer appropriate patients to hospice care. Unfortunately, many physicians are reluctant to refer patients to hospice. The activities of Operation Restore Trust and the Office of the Inspector General have exacerbated the problem resulting in even later referrals. Misperceptions about the actual eligibility requirements for the Medicare Hospice benefit are another problem confronting access to hospice. Congress, when they enacted the Benefit in 1982, recognized that predicting death was an inexact science and never intended the prognoses of patients to be a hard and fast requirement. Rather, the six month period was intended to be a guidepost, ensuring Americans access to end of life care, not some limiting factor.

As an example of this misperception, let me read you comments from one of our local physician's. These are direct quotes from our Physician's Order Sheet that we require the attending physicians to sign. "I do not authorize death in six months. This is not my opinion. I appreciate your help with my patient. Please do not ask me to predict death. If I do this then (at the end of six months) of six months, I will have to kill the patient, which I can't do."

There are no incentives for physicians to discontinue treatment. I believe some physicians continue to provide aggressive treatment when hospice care would be in the patient's best interest and more economical as well.

Recently we received a referral on a patient with a non-cancer diagnosis. The diagnosis was COPD (chronic obstructive pulmonary disease). The history and physical exam stated the patient had a history of prostate cancer, skin cancer, a layngectomy with tracheostomy (cancer related), cervical soft tissue mass suspicious for recurrent tumor and frequent pneumonia.

The patient had been hospitalized the week before to be "worked up for possible myopathy or neuropathy." According to the wife, the goal was to get him into a rehabilitation unit

The patient was clearly in the final stages of life. I explained our services to his wife and three adult children and said we could admit him whenever they made their decision. The wife stated that she had heard of hospice but thought it was a place.

Three days later he died in that same hospital room, a week before he was admitted to the hospital to be evaluated for the rehabilitation unit.

This man was clearly hospice appropriate. He was not a candidate for the rehabilitation unit, but he continued to receive "aggressive treatment" until days before his death.

This is not an isolated incident.

Our median length of stay is 20 days. Nationally the median length of stay is 29 days. This year half of our patients have died within 20 days of admission. 16% of the patients referred to Hospice of Baton Rouge die before we can make a visit.

Let me convey another story and tell you that these are not isolated incidents. They are routine, every day occurrences in hospices, large and small, across the country.

It was mid-June and a typical frantic Friday at HBR. The voice on the phone is that of a local physician whom I have known since high school. He said, "Kathryn, I need your help. My dad is 82. He has been in a coma for 3 weeks. He has a living will. He signed advanced directives upon entering the hospital and we want to take him home."

Then his voice began to crack. " I love my dad. I would never do anything to harm him. I only want to do what he asked me to do." There was a long pause.

He continued. " Mom wants to take Dad home. He has always told us he wants to die at home, but his doctor said that I might as well take a gun and put it to his head if we take him home without inserting a feeding tube. The neurologist has told us there is no hope for any recovery."

"I need your help. Please tell me what to do. My father's physician is a colleague of mine. I work with him all the time."

We discussed the situation. The dad had made his final wishes clear and all members of the family wanted to honor his wishes. I suggested that the family find another physician, and they did. With the help of HBR, Mr. Jones went home and died peacefully in his own bed, surrounded by his wife and children several days later.

Congress recognized the need for this kind of care in 1982 when it enacted the Medicare Hospice Benefit to provide compassionate and specialized care for the dying. While millions of terminally ill older Americans and their families have had the opportunity to experience more comfortable and dignified deaths, the reimbursement rate has not kept pace with the changes in end of life care -- especially due to increasing costs of prescription drugs and outpatient therapies, as well as decreasing lengths of service. Medicare Hospice Benefit reimbursement rates need to be increased if hospice programs are to continue to provide high quality care and related services that our nation's most vulnerable population needs and deserves.

Once a patient chooses hospice care, he or she is afforded the per diem reimbursement as the only Medicare payment for all costs related to the terminal illness, including physicians' oversight services, nursing care, counseling, spiritual support, bereavement counseling, medical appliances, drugs, home health aides, homemaker services, physical and occupational therapies, dietary advice, and volunteer assistance. An interdisciplinary team provides medical, social, psychological, emotional and spiritual services to the hospice patients and their loved ones.

In 1982, when hospice care was added as a Medicare benefit, the routine home care rate was set at $41.46 per day. When the benefit was established, the reimbursement rate did not include an annual inflationary update. Rather, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, the rate has not kept pace with the growing cost of delivering care to terminally ill Medicare beneficiaries. The fiscal year 2000 routine home care rate, at which more than 95% of all Medicare hospice patients are billed, is $98.96.

Unfortunately, the current reimbursement rate does not begin to cover the expenses incurred in delivering compassionate and specialized care to dying Americans. An interim report of an ongoing hospice cost study by Milliman & Robertson (M&R) states, *"the trend is clear that Medicare hospice per diem payments do not cover the costs of hospice care and result in significant financial losses to hospice programs throughout the country."* M&R notes several other factors driving the losses that hospices are experiencing today.

According to the M&R study, *"new technology; including breakthrough therapies and prescription drugs, has increased hospice costs far beyond Medicare's annual market basket update. For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about $1 of the per diem reimbursement rate. M&R noted that these costs increased to approximately $16 per day by the late 1990s (an increase of about 1,500%)."* Drug costs have skyrocketed, making pain relief and symptom management, cornerstones of hospice care, much more expensive. Many of the most effective and widely used drugs for relief of cancer patients' discomfort are shockingly expensive. Duragesic, one of the most commonly used pain relievers for cancer patients, can cost up to $36 per dose. Zofran, an effective anti-nausea drug, costs almost $100 per day – exceeding the entire routine home care rate paid by Medicare to the hospice provider.

We had a patient whose blood products and transfusion costs alone were in excess of $25,000.00. Our total reimbursement from Medicare for all of her care was $9,960.63.

But escalating drug costs are not the only problem facing hospices.

For a variety of reasons, more and more patients are being admitted to hospice programs very late in their illness, when they require a greater intensity and variety of services. Their hospice care needs, including pain and symptom management and personal support, are often the greatest in the first few days following admission and in the final days and hours before death.

The Medicare Hospice Benefit was designed to balance the high costs associated with admission and the period immediately preceding death with the somewhat lower costs associated with periods of non-crisis care. However, the median length of service for hospice patients has fallen rapidly in recent years leaving fewer "non-crisis" days. The very short lengths of service and advances in clinical practices, both significant cost factors, were not anticipated at the time the original rate structure was formulated. These added financial pressures are having a devastating impact on hospices.

In the longer-term, Congress needs to undertake a review of the assumptions under which hospice reimbursements are made. New drug treatment modalities and types of medications have come to establish new areas of medical practice, and we need to have them available to the hospice practitioner and other health professionals. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments force us to seek other less expensive and perhaps less effective alternatives. In fact, the vast majority of the nation's hospices resort to public fundraising to supplement their operational and capital costs. Within the context of the Medicare Hospice Benefit, we need a dramatic increase in our reimbursement rates. We need these changes now.

Routine regulatory reviews and investigations are having a substantial, and presumably unintended, adverse impact on end of life care and access to hospice. Such reviews should be undertaken with the goal of assuring quality patient care and compliance to the intent of the regulations. Unfortunately, many of the regulatory actions deal with technical interpretations of the regulations and they are neither focused on nor related to good patient care. The investigations, on the other hand, may have the unintended effect of creating a chilling environment for attending physicians and hospice providers, fearful of government review and possible prosecution.

According to the Medicare Payment Advisory Commission, "[t] he gap between the care now given to dying beneficiaries and ideal care is wider than in probably any other area of medicine... closing this gap should be one of the highest priorities of the Medicare program."

By adopting the Medicare Hospice Benefit in 1982, Congress took an important step in changing a deeply embedded aspect of our culture, one that denies the inevitability of death and ignores the value of the end of life. We continue to believe today, that hospice care is our best response to caring for people at the end of life.

Yet, there are any numbers of obstacles to ensuring access to hospice care for individuals in this country. In fact, we are witnessing an alarming decline in the lengths of service for hospice patients, which is turning hospice into a "brink of death" benefit. The National Hospice and Palliative Care Organization's data show that the number of hospice patients has steadily increased, totaling over 700,000 individuals last year. In 1998, their median length of service fell to just 25 days, which represents a 26% decline since 1992. This means that over one half of all hospice patients – 50% of men, women and children in hospice care – die within one month of admission. This is happening at a time when access to hospice care should be deepening and broadening, not contracting.

According to a study done by Lewin-VHI in 1995, for every $1.00 spent on the Hospice Medicare Benefit HCFA saves a $1.52. "The 1995 study also showed that in the last year of life, hospice patients incurred $2,737.00 less in costs than those not on the Medicare Hospice Benefit. These savings totaled $3,192.00 in the last month of life because hospice home-care days often substitute for expensive hospitalizations."

All Americans should have hospice available to them, but reaching rural patients and families is difficult. Smaller hospice programs are hindered by higher costs and lack of economies of scale. At the same time, existing reimbursement rates do not take into consideration distance or drive times, patients in rural areas are frequently denied hospice With the current reimbursement rate, which is only 80% of the routine home care rate, hospices cannot afford to provide services to patients who live long distances from the office. The rural "floor" needs to be raised so that everyone has a chance to have a dignified and comfortable death.

We need to find economical ways to provide hospice care to individuals without able or available caregivers. Imagine an 86 year-old man trying to care for his 83 year-old wife. As a contemporary of mine said recently, "If my mother needs hospice, I will have to make a decision whether to put her in a nursing home or leave my job. Financially we cannot afford to pay sitters." Today there are 40 million senior citizens. How many of them can afford to pay for sitter assistance?

And it is not just our older citizens who need hospice care. Let me read you another letter from one of our families.

> *We would like to let you know how grateful we are... I never would have believed seven years ago when my child was born the she would become terminally ill. It was an incredibly horrible experience to watch her die after a two-year battle with a brain tumor. She passed away in her room, in her bed, in our arms. Without the support of Hospice of Baton Rouge, I don't know how we could have managed.... I think people usually associate hospice with older people. It is important to know that babies, children and their families need hospice, too...."*

Every terminally ill American should have access to hospice care. There are many barriers but I am confident that there are as many solutions. With your help we can find ways to provide hospice care to the young and old alike in America.

Thank you.

The CHAIRMAN. Thank you, Ms. Grigsby.
Now, Ms. Bell.

STATEMENT OF KAREN WOOD BELL, DIRECTOR, PROVIDENCE HEALTH SYSTEM HOSPICE PROGRAMS, PORTLAND, OR

Ms. BELL. Thank you. On behalf of the Oregon Hospice Association and Oregon hospices, I want to thank you for the opportunity to speak to you today on the important issue of barriers to hospice care.

The continuation of a Medicare hospice benefit is vital to individuals with life-threatening illnesses, but the economic reality is if this benefit is not modernized, Medicare patients may no longer have access to hospice care. Oregon hospices are reporting a significant decline in the length of stay for patients admitted for care. This has had a devastating effect on every hospice, from the smallest rural program to the largest metropolitan.

None of us can continue to sustain the significant cost of short-term patient care when the average break-even point is estimated at 31 days. Moreover, the current reimbursement for hospice care does not take into consideration the added burden borne by rural hospices. Even though their volume of patients is small, their territory or service area is very large, and yet their reimbursement is less than in the metropolitan areas.

All 56 hospices in the State of Oregon have had an opportunity to make contributions to this testimony. The consensus of all these groups is that there are six barriers to hospice care in Oregon.

First, in all parts of Oregon, and more frequently in the rural communities, the primary health care provider is a nurse practitioner. Nurse practitioners can admit patients to the hospital, they can manage care in private practices, they can sign orders, they can order narcotics, and they can make changes in the patient's plan of care without a physician's co-signature, but they cannot admit a patient to hospice.

Second, the current conditions of participation require a member of the core team be a social worker, be it a BSW or MSW. In many parts of Oregon, and again in the more rural communities, this can be a challenge. Qualified social workers are simply not available in all of our counties, or it may take months for a social worker to be recruited for a hospice program.

Third, there is the question of time. It is difficult for a patient and a family to learn that there are no other further treatment options available to them. What the physician can offer to them is hospice care to ensure that the end of their life has quality, dignity, and their final wishes will be respected.

Even for the most skilled physician, a discussion on end-of-life care takes time, using more time than the physician has available during a routine office visit. Physicians have an average of 7 minutes allocated for an office visit for a patient.

It is very appropriate that the physician broach this topic with their patient. However, physicians need to be able to offer to the patient a personal visit with a hospice professional to review the concept of hospice care and provide more information on what the Medicare hospice benefits can offer.

As you are all very well aware, seniors are very protective and concerned about their Medicare benefit. A hospice professional that understands the intricacies of this benefit and can provide informed answers is in the best position to have this discussion, and can assure that eligible seniors do not forgo this vital benefit out of misguided fear or simple confusion.

Fourth, short-stay patients, defined by most hospice programs as under–14-day length of stay, are very costly for hospices. Recognition that the patient may have a very short stay usually results in an increased frequency of visits for most, if not all, members of the hospice team. The current Medicare benefit reimburses hospices for each day the patient is enrolled, making no provision for the intensity of services provided or the increased costs associated with this care.

Fifth, under the current conditions of participation a hospice is required to contract for inpatient respite care with a facility that has a 24-hour registered nurse on duty. This requirement hurts those patients who live in communities, again mostly the rural communities, that do not have skilled nursing facilities or where respite beds are not available.

Sixth, patients with a limited life expectancy may continue to receive active treatment, the primary goal being to extend their lives; for example, chemotherapy, blood transfusions, radiation therapy, all of which may be very appropriate for the patient's condition but which disqualify them from hospice care. Some of these treatment decisions, however, are inconsistent with what they say they would want at the end of life.

Acceptance of a poor prognosis and coming to terms with the fact that you have a terminal diagnosis is not simple. Many people need time and support to work through their conflicting emotions, and time to consider and evaluate the benefit and the burden of treatment options. At such time as their treatment options become palliative, they could then be transitioned into a Medicare hospice program.

In conclusion, I have not spoken with a single hospice provider or family in Oregon who does not applaud these proposed changes. The current Medicare benefit has stood the test of time, but it has not kept pace with the changes in how hospice care is delivered. We in Oregon are very proud of our contributions to hospice care. We have worked together to establish hospice benefits for almost all of our insurance providers, and now we have joined in support of this demonstration project. We believe the Hospice Program Improvement Act of 2000 will remove many of the barriers that currently exist, and that Medicare beneficiaries will be able to receive the care and the services they are entitled to.

Thank you.

[The prepared statement of Ms. Bell follows:]

SENATE SPECIAL COMMITTEE ON AGING
CHARLES E. GRASSLEY, IOWA, CHAIRMAN

TESTIMONY ON BARRIERS TO WIDER UTILIZATION OF HOSPICE CARE
SEPTEMBER 18, 2000

PRESENTED BY:

KAREN WOOD BELL, RN, BSN, MBA
DIRECTOR, PROVIDENCE HEALTH SYSTEM HOSPICE PROGRAMS
PORTLAND, OREGON

ON BEHALF OF OREGON HOSPICES

Good Day Senators.

On behalf of the Oregon Hospice Association and Providence Health System, I want to thank you for the opportunity to speak to you today on the important issue of barriers to hospice care.

First a brief introduction. My name is Karen Bell. I am a nurse with 37 years of nursing experience, the past 24 years in home health and hospice. Currently, I am Director of Hospice for the Providence Health System, in Portland, Oregon. Providence is a Catholic health care organization with facilities and programs in five Western states. (Oregon, Washington, Alaska, California, and Montana.)

Oregon hospices, along with other hospices in the United States, recognize an urgent need for changes in the Medicare hospice benefit. At the same time, however, we wish to honor the vision that created this benefit for the Medicare population.

When the current Medicare benefit was proposed as a demonstration project in 1979, it represented forward thinking and creativity

In 1980 Providence Medical Center in Portland was selected as one of the demonstration sites for the Medicare Benefit.

The continuation of a Medicare hospice benefit is vital to individuals with a life-threatening illness, but the economic reality is, if this benefit is not modernized, Medicare patients will no longer have access to hospice care.

This must be prevented. It is time to update this program!

Oregon hospices are reporting significant decline in the length of stay of patients admitted for care.

This has had a devastating effect for every hospice, from the smallest rural hospice to the largest metropolitan programs. None of us can continue to sustain the significant cost of short-term patient care when the average break-even point is estimated at more than 31 days.

Moreover, the current reimbursement for hospice care does not take into consideration the added burden borne by

Grant County, in Eastern Oregon, is 4,528 square miles, with a population of 8,000. It is not uncommon for Hospice staff to drive 75 miles to visit one patient.

rural hospices. Even though their volume of patients is small, their territory or service area they must cover is large, and yet their reimbursement is less than in larger metropolitan areas.

All 56 hospices in the State Of Oregon have had the opportunity to make contributions to the "Hospice Program Improvement Act of 2000". Input on the proposal has also been received from other health care professionals: physicians, pharmacists, case managers, home health providers and the community.

The consensus of all these groups is that there are six key barriers to hospice care in Oregon.

In all parts of Oregon, and frequently in the more rural counties, the primary health care provider is a nurse practitioner. These individuals currently work under the umbrella of a physician, but in many cases the physician has not seen the patient, doesn't know the patient and may even live and work in a different community. To ask this physician to sign the documents citing the patient as having a limited life expectancy and any subsequent orders is unjust and unreasonable. However, under the current Medicare Conditions of Participation, the medical doctor must sign the document or the patient cannot be accepted into hospice. A barrier is created that precludes them from accessing the hospice Medicare entitlement program.

Vicki Collister, ANP works for House Calls in Portland, Oregon. Under the current conditions of participation Ms. Collister cannot make a hospice referral or give orders for her patient to a hospice nurse. She must ask the physician she works with to sign all the paperwork. This cumbersome, labor-intensive process is a financial hardship on their small practice as well as resulting in a delay for a patient being referred to hospice.

Nurse practitioners can admit patients to the hospital, they can manage their care in private practices, sign orders and make changes to the patient's plan of care without a physician co-signing, but they cannot admit patients to hospice.

Also, it is noteworthy that the metropolitan areas of Oregon experience the same challenges and must cope with the frustration of Nurse Practitioners who are primary care providers for a patient and yet cannot make a referral to hospice.

Second, the current Conditions of Participation require a member of the core team be a social worker (BSW or MSW). In many parts of Oregon, this can be a challenge. Qualified social workers are simply not available in all counties, or it may take months for a social worker to be recruited for a hospice. Currently the hospice program Conditions of Participation dictate that no hospice program could be developed or remain operational without a social worker as an employee of the hospice program.

A small hospice on the Coast of Oregon went for 9 months "borrowing" a social worker from a Portland hospital. The social worker drove to the Coast twice a week, and then was available by telephone. A creative solution, but one that did not adequately meet the needs of the hospice patients or families.

Third, there is the question of time. It is difficult for a patient and family to learn that there are no further treatment options available to them. What the physician *can* offer to them is hospice care to ensure that the end of their life has quality, dignity and that their final wishes will be respected. Even for the most skilled physician, a discussion on end of life care takes time, usually more time than the physician has available during a routine office visit.

Physicians have an average of 7 minutes allocated for an office visit. Physicians report they are reluctant to even broach end of life discussions with patients due to their limited time. One physician said to me, "You get the patient to ask for hospice care and I will order it."

It is very appropriate that the physician broach this topic with their patient. However, physicians need to be able to offer to the patient a personal visit with a hospice professional to review the concept of hospice care and provide more information on what the Medicare hospice benefit can offer.

A hospice professional is also the best person to explain the complexities of the Medicare hospice benefit. The Medicare hospice benefit can be difficult to understand and, to add to the complexity, if the patient is enrolled in a Medicare HMO they will remain in the HMO for all care not related to their terminal diagnosis but revert to the non-HMO Medicare benefit for hospice care.

As you are well aware, seniors are very protective and concerned about their Medicare benefit. A hospice professional that understands the intricacies of this benefit and can provide informed answers is in the best position to have this discussion and can ensure that eligible seniors do not forego this vital benefit out of misguided fear or simple confusion.

Unfortunately, the current Benefit does not reimburse hospices for informational or consultative visits. This is a financial burden that few hospices can carry. We welcome the opportunity to explain hospice care and to permit patients and families to consider this option, but we need to be paid for our time and efforts.

Fourth, short stay patients, defined by most hospices as under 14-day length of stay, are very costly for hospice programs. The admission visit may involve not only the hospice nurse but also a social worker. The first days after admission to hospice are intense; the hospice team evaluates the patient and family needs and a plan of care is established. Frequently, durable medical equipment, such as a hospital bed, commode, or wheel chair, is needed to aid in the provision of care; also pain and symptom management frequently necessitates changes in the medication regime.

- *In Oregon, the mean length of stay has decreased from 56 days (1993) to 41 days (1999).*
- *More significantly, the median length of stay has decreased from 22 days to 16 days in 1999.*

Recognition that the patient may have a fairly short length of stay usually results in an increased frequency of visits from most, if not all members of the hospice team. The current Medicare benefit reimburses hospices for each day the patient is enrolled, making no provision for intensity of the services provided or the increased costs associated with these services. Because the patient is on service for a short period of time, the hospice team must try to condense the support, education and training to the family into fewer, but lengthier visits. Hospice programs report the reimbursement for the majority of short stay patients' falls far short of the cost of the care provided.

If a patient has another care provider, such as home health, the decision may be made to not admit the patient to hospice care. Few, if any, hospice programs want to acknowledge that they may make the decision not to admit the patient due to concern for inadequate reimbursement, but it is a factor that each program must consider. Resources in hospice are not unlimited, and hospices must make their admission decision based on <u>their program's</u> long-term survival so they can continue to provide hospice care to other seniors.

Hospices in Oregon report that while they are reluctant to acknowledge they make decisions to not admit a patient based on the risks of the patient's care being expensive, they do report, "We are careful who we admit onto the program because we could be wiped out".

The minimum payment for 14 days of care, regardless of the length of service for the hospice patient as proposed in the "Hospice Program Improvement Act of 2000" would provide much needed stability to the hospice program. This would also ensure access for Medicare beneficiaries seeking the benefit, particularly in rural areas of the country.

<u>Fifth</u>, under the current Conditions of Participation a hospice is required to contract for inpatient respite care with a facility that has 24-hour registered nurses on-site. This requirement hurts those patients who live in communities that do not have a skilled nursing facility, or where respite beds are not available.

A rural hospice in Eastern Oregon can not offer respite care to their hospice patients, as the only nursing home in their County does not have a Registered Nurse on duty 24 hours a day.

Under the Conditions of Participation, the hospice program is in charge of the patient's plan of care and hospice nurses must be available 24 hours per day, seven days of the week.

Sixth, patients with a limited life expectancy may continue to receive active treatment, the primary goal being to extend their life. For example, chemotherapy, blood transfusion, radiation therapy, all of which may be appropriate for the patient's condition but which disqualify them from hospice care. Some of these treatment decisions, however, are inconsistent with what they say they would want at the end of life.

A south Coast hospice program reports only 43% of their patients have a cancer diagnosis, a drop from 75% five years ago.

Acceptance of a poor prognosis, and coming to terms with the fact that you have a terminal diagnosis is not simple. Many people need time and support to work through their conflicting emotions, and time to consider and evaluate the benefit/burden of the treatment options.

The supportive and comfort care benefit in the "Hospice Program Improvement Act of 2000" would provide these patients with guidance while they are still making decisions about treatment options and with the support and services of hospice-trained staff while they are undergoing active treatment to extend their life. At such time as their treatment options become palliative, their care can be transitioned into the Medicare hospice benefit.

In conclusion, I have not spoken with a single hospice provider or family in Oregon who does not applaud these proposed changes. The current Medicare benefit has stood the test of time, but it has not kept pace with the changes in how hospice care is delivered. We in Oregon are proud of our contributions to hospice care. We have worked together to establish hospice benefits for all most all of our insurance providers and now we have joined in support of this demonstration project. We believe the "Hospice Program Improvement Act of 2000" will remove many of the barriers that currently exist and the Medicare beneficiaries will be able to receive the care and services they are entitled to.

Thank you.

OREGON HOSPICE ASSOCIATION, INC.

2000 FACT SHEET: Hospice in Oregon

◆ There are 62 hospices on the State of Oregon's Hospice Registry.

All of Oregon's operating hospice programs provide a full range of comprehensive and interdisciplinary care, including medical, social, psychological, volunteer and bereavement services, and are accredited by OHA or JCAHO or certified by Medicare, as required by Oregon law.

55 programs are home care programs, delivering their services in the patient's home or place of residence; 1 program delivers its hospice services in a specialty inpatient hospice care facility.

56 programs are operational, providing hospice services, 1 is developing new services.

54 are certified by Medicare, 15 accredited by OHA, 23 accredited by JCAHO.

16 are free-standing community-based, 31 hospital-based, and 7 home health agency-based. 43 are non-profit, 1 state, 3 county, and 8 for-profit.

7 programs serving Oregon patients are located in Washington, Idaho, or California. 4 Oregon programs provide services to residents in Washington, Idaho, or California.

◆ Oregon's hospices provided care to about 10,000 patients in 1999.

Approximate Number of Patients Served in 1988: 2,000; 1989: 2,200; 1990: 2,800; 1991: 3,300; 1992: 4,400; 1993: 5,500; 1994; 6,000; 1995: 7,200; 1996: 8,100; 1997: 8,500; 1998: 9,400.

◆ Hospice penetration rate in Oregon, the number of hospice deaths compared with total deaths, is estimated at 35 percent. The penetration rate in Oregon in 1998 was 32 percent, compared to a national rate of 20 percent, and estimated to be second highest in the nation.

◆ More than 99 percent of Oregonians have access to hospice in their community. Hospice services are available in all but one county in Oregon, where services are now being developed.

◆ Demographics

Mean age was 74.4. 49 percent were men, 51 percent women.

57 percent were diagnosed with cancer, 1 percent HIV-AIDS, 13 percent heart-related or stroke, 7 percent respiratory disease, 4 percent neurological disease, 4 percent kidney or liver disease, 14 percent other. Oregon's hospice programs care for more than 75 percent of all patients who die of cancer each year, and more than 50 percent of AIDS patients.

Average mean-length of stay is 41 days, the median 16 days. Sixty days is optimum; and patients are eligible when their life expectancy is six months or less. More than 97 percent die at home or place of residence.

Hospice Programs at High Financial Risk When Caring for the Uninsured

OREGON HOSPICES WITH <125 DEATHS ANNUALLY

Hospice	Location	Est. # Deaths/Year[1]
Sutter Coast Home Health and Hospice	Brookings	11
Newberry Hospice	La Pine	12
Harney County Hospice	Burns	15
Pioneer Memorial Home Health	Heppner	17[2]
Wallowa County Hospice	Enterprise	18
Lower Umpqua Hospice	Reedsport	23
St. Elizabeth Home Health/Hospice	Baker City	25
Lake District Hospital Hospice	Lakeview	31[2]
Mountain View Hospice	Madras	27
Vange John Memorial Hospice	Hermiston	34
Pioneer Memorial Hospice	Prineville	36
XL Hospice, Inc.	Fruitland, Idaho	37
Grande Ronde Hospital Hospice	La Grande	40
Hospice of St. Anthony Hospital	Pendleton	44
North Lincoln Hospice	Lincoln City	48
Curry County Home Health/Hospice	Gold Beach Brookings Port Orford	55
Peace Harbor Hospice	Florence	56
Hospice Services of Tillamook County	Tillamook	68
Pacific Communities Hospice	Newport	70
Douglas Home Care and Hospice	Roseburg	72
Lower Columbia Hospice	Astoria	75
Home Health/Hospice of LCH	Lebanon	78
Klamath Hospice	Klamath Falls	107
Pathway Hospice, Inc.	Ontario Baker City	117
Benton Hospice Service, Inc.	Corvallis	119
McKenzie-Willamette Hospice	Springfield	122
Central Oregon Hospice	Bend	123
Hospice of Redmond, Sisters, and Grant County	Redmond Sisters Prairie City	126
Washington County Hospice	Hillsboro	132
Hopewell House Hospice Center *(inpatient)*	Portland	143

A small hospice risks financial peril with just one uninsured patient

[1] *Data provided by Oregon Hospice Association*

[2] *New or developing hospice*

Hospice Programs at Lower Financial Risk When Caring for the Uninsured

OREGON HOSPICES WITH >126 DEATHS ANNUALLY

Hospice	Location	Est. # Deaths/Year[1]
Oregon State Penitentiary Hospice	Salem Pendleton	63
Walla Walla Community Hospice	Walla Walla, Washington Milton-Freewater	128
Hospice of the Gorge	Hood River The Dalles	158
Health Dynamics Hospice	McMinnville	167
Evergreen Hospice	Albany	169
Adventist Health Hospice	Portland	175
Willamette Falls Hospice	Oregon City	182
Hospice of Bend - La Pine	Bend	190
Asante Home Care & Hospice Services	Medford	209
Mercy Hospice	Roseburg	216
South Coast Hospice	Coos Bay	223
Lovejoy Hospice	Grants Pass	226
Mt. Hood Hospice	Sandy	230
Hospice of Providence	Medford	331
Community Home Health/Hospice	Longview, Washington Scappoose	357
Willamette Valley Hospice	Salem	470
Hospice of Sacred Heart	Eugene	499
Kaiser Permanente Hospice	Portland	697
Legacy VNA Hospice	Portland	805
Providence Medical Center Hospice	Portland	1,300
Providence St. Vincent Hospice	Portland	
Providence Hospice	Newberg	

Economies of scale mean that a larger hospice may experience less adverse impact when caring for an uninsured patient

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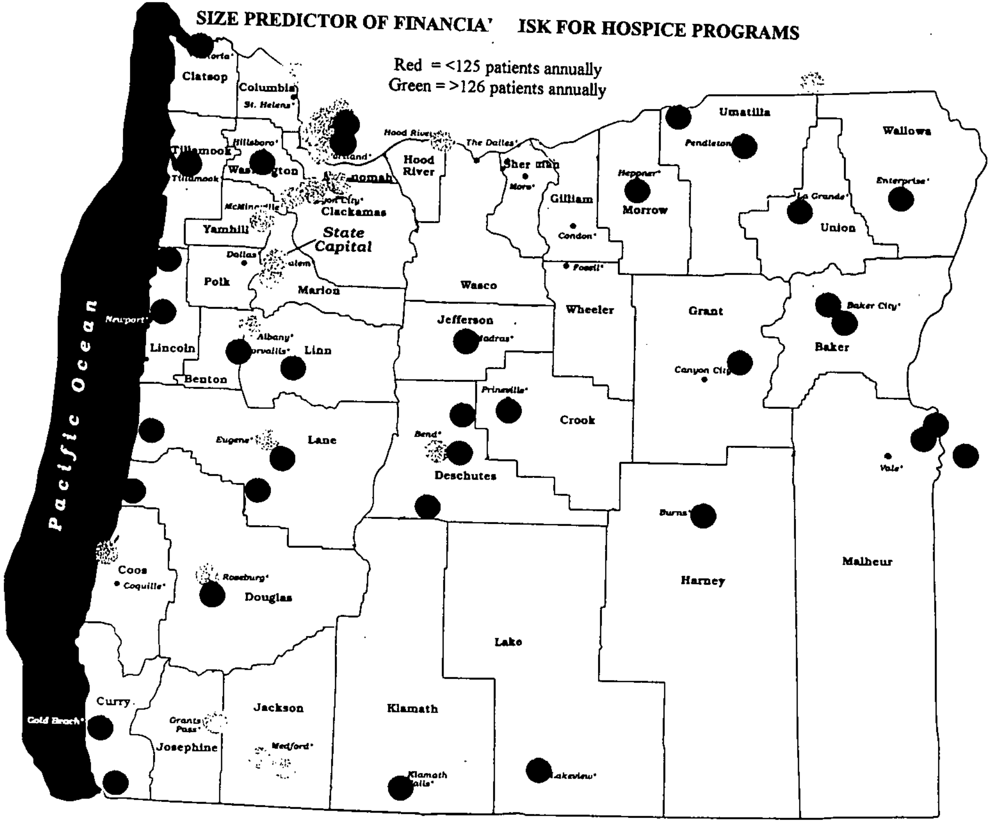
[1] *Data provided by Oregon Hospice Association*

SIZE PREDICTOR OF FINANCIA' ISK FOR HOSPICE PROGRAMS

Red = <125 patients annually
Green = >126 patients annually



Estimated Costs: Improving Access to Hospice in Oregon

COST COMPARISON

Hospice[1]

$98.40 = Cost per patient per day

44 days = Average mean length of stay (LOS)

$4,330 = Cost per patient for 44 days

14 days = Predicted median length of stay (LOS)

$1,340 = COST PER PATIENT FOR 14 DAYS IN HOSPICE CARE

Hospital[2]

$1,383 = COST PER PATIENT PER DAY IN HOSPITAL
(cancer patients dying in hospitals)

3.84 days = Average length of hospital admission prior to death

$5,311 = Cost per patient for 3.84 days

Hospices provide 14 days of care for the same cost as hospitals provide 1 day of care

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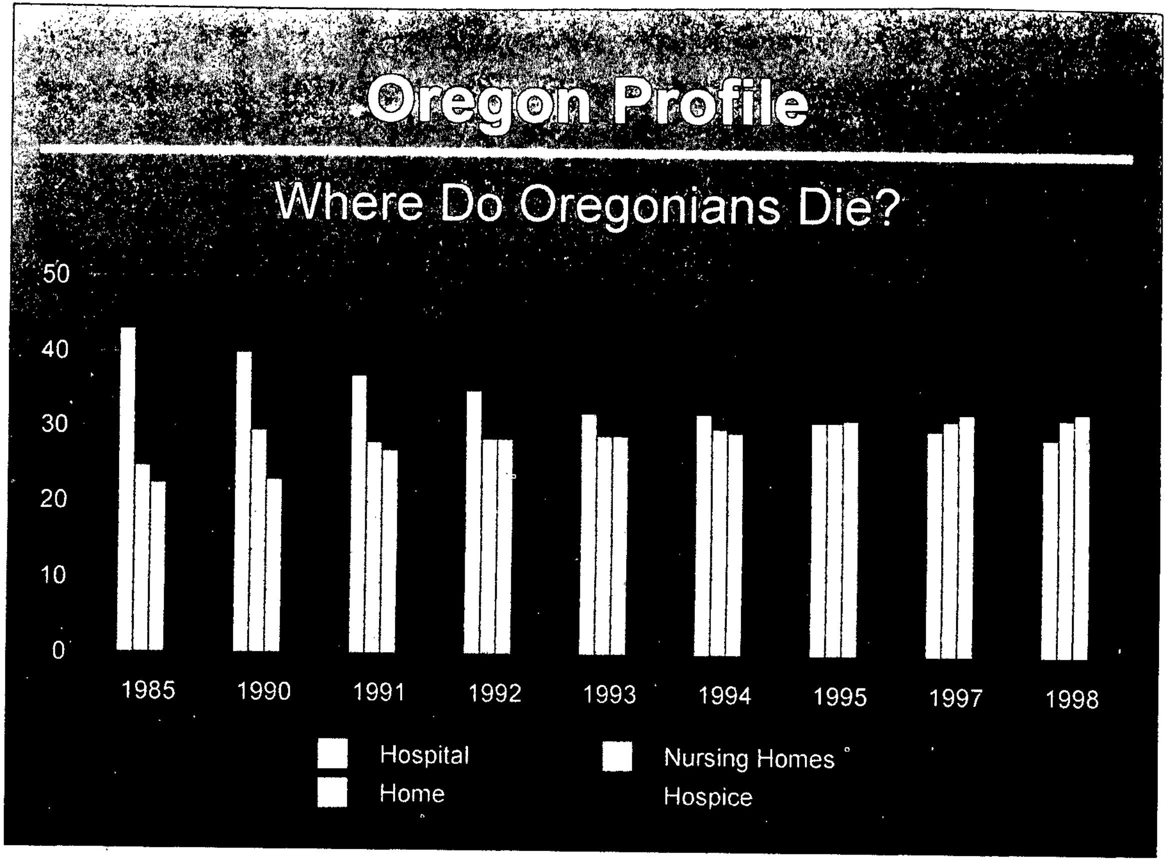
[1] *Data provided by Oregon Hospice Association*

[2] *Data provided by Oregon Association of Hospitals and Health Systems*

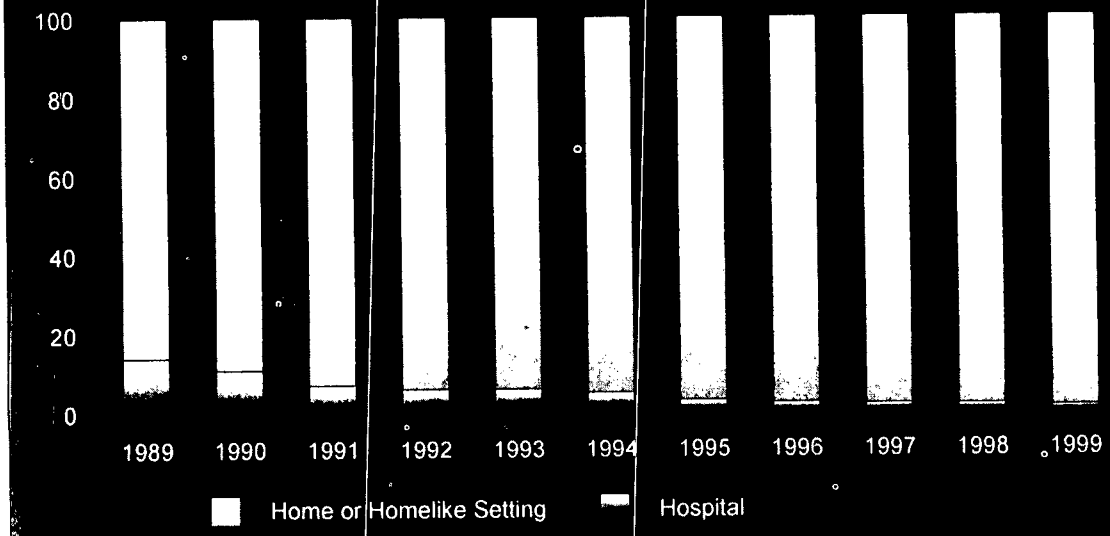


Oregon Profile

Where Do Oregonians Die?

Oregon Profile

Percent of Hospice Patient Deaths in Hospital [1]



The CHAIRMAN. Thank you, Ms. Bell.

By the way, we will have 5-minute turns.

I have an initial comment because all five witnesses have touched on the issue of short hospital stays. What I have heard today reinforces my impression that we need to address that issue so patients will get the care that they need, and also so that hospices can remain economically viable institutions.

I will start with you, Ms. Hoffman. I am sure that you have had a chance to read HCFA's recent letter clarifying the existing 6-month rule. I would like to hear your reactions to it, and from anybody else that would like to react to it.

Ms. HOFFMAN. I am extremely pleased to have them issue that rule. I think it is information that has been critically needed in the public arena so that people are clear about the fact that they aren't going to be penalized if they live too long under a hospice benefit. I am extremely grateful that they have finally issued that. It is, I think, going to be very beneficial for us. I hope that it is widely publicized.

The CHAIRMAN. Does anybody else want to comment before I move on to my next question? [No response.]

Dr. Scanlon, I know that you share the frustration that the audited cost data for hospice care won't be available for another year. That leaves us here in Congress in the position of making some sort of educated guess, and so I would like to ask you to make the same sort of educated guess.

Two of our provider witnesses described large increases in both the cost and the intensity of use of pain relief drugs. They also mentioned the rising cost of maintaining all the staff needed to provide hospice care. In my other work, rising Medicare drug costs and rising labor costs have very much been an issue across the board of provider care.

If you are able to comment, Dr. Scanlon, does it make sense that they are also realities in the hospice context, and is it plausible that they would create the kind of cost pressures on hospices that were described?

Dr. SCANLON. Mr. Chairman, I do think that we have heard a lot about areas that would increase the cost pressure on hospices, areas like the extraordinary cost of particular drugs, the issue of rising labor costs, the difficulty of operating in rural areas, the extra costs associated with transportation in those areas. All of these are similar to cost pressures on some other providers, and hospices are experiencing them as well.

I am extremely frustrated because I think without that cost data, we don't really know how to restructure the payment system for hospices. I think we have had a lot of indications that the current system is not necessarily appropriate because of extraordinary costs of individual patients who either are short-stayers or individuals who use extraordinarily expensive items. I think that we need to think about how to restructure payment, as well as potentially increase payment.

The CHAIRMAN. Can I ask you, Dr. Christakis, the same thing, but from your point of view of being a hospice physician?

Dr. CHRISTAKIS. I think that clearly to the extent that we would be able to, on average, increase the median length of stay—that is to say, to the extent we were able to change practice patterns so that more patients got in earlier, we could amortize the cost over a greater number of days and greater number of patients, so some of these problems would decrease.

Part of the problem is that some of the drugs, the particularly expensive ones that were alluded to, are better than the existing drugs but the existing drugs are much cheaper. So it becomes a little bit of a willingness to pay issue; that is to say, is the marginal benefit of one particular drug that decreases nausea worth the substantially increased cost?

I think as Dr. Scanlon just said, maybe some fixed, up-front admission monies that could go on a per-admission basis to help defray the cost of the short-stayers would be good, which is a different kind of problem than the problem of higher costs of care regardless of length of stay. The latter problem is harder to sort out, particularly since the intent behind the benefit is to kind of create a risk pool of terminally ill patients. So if all of a sudden you start paying on a fee-for-service basis, you have a completely different kind of vision of terminal care.

So very quickly, to summarize what I just said, the problem of patients not living long enough or being referred late could perhaps be addressed by some kind of fixed payment upon admission. But the problem of the costs of care going up is a more difficult problem to assess and probably would require a more radical change.

The CHAIRMAN. Dr. Christakis, I want to ask you, based upon your experience as well as your research, your view on what the General Accounting Office reports, saying that the physician groups that the General Accounting Office has spoken with did not cite concern about beneficiary eligibility as a primary barrier for referring patients to hospice.

Dr. CHRISTAKIS. You mean eligibility vis-a-vis does a patient have Medicare or not, or do you mean vis-a-vis the Operation Restore Trust issue?

The CHAIRMAN. Within Medicare.

Dr. CHRISTAKIS. I would actually strongly agree with what Dr. Scanlon said. I think that the declining length of stay largely preceded and probably is largely, although not wholly, independent of the OIG investigation, if that is the question you are asking.

The CHAIRMAN. Yes.

Dr. CHRISTAKIS. I think that it did have some effect, but I think there are other broader factors at play that are contributing to the declining lengths of stay over the last 10 years.

The CHAIRMAN. Again for you, Dr. Christakis, in your view, does Medicare do enough to educate health professionals about hospice care, and what is your perception of HCFA's current efforts and how do you think that they could improve upon that?

Dr. CHRISTAKIS. I don't think that enough has been done. I was very taken by Ms. Tooks' story at the beginning about how she had to educate her own doctor. Certainly, anecdotally, I have seen the same kinds of things where the patient will say, "you know, doctor, maybe I should go to hospice," and the doctor will say, "no, no, no, you are not that sick yet." And when I look at the case, it is transparent, like the case that you were talking about, that this patient is going to die very soon.

So I think a better job of education could be done. Senator Dole's suggestion about somehow using the patients as a leverage point, I think, was an excellent one. Again, I don't know whether that would be a possible thing to do. So, to summarize, I think that more could be done to educate physicians, but I couldn't quickly enumerate all the various things today.

The CHAIRMAN. Now, my two colleagues, I am going to step out for just a minute, so take your turns.

Senator BREAUX. Well, I thank the panel very much. It has been very helpful, I think. There are a number of issues that I think are out there that need to be discussed. I think the training of doctors is one. I think most people find out about hospice not from the doctor, but from other people.

Ms. Hoffman, Ms. Grigsby, and Ms. Bell, can you comment on where your patients or their families find out about hospice services?

Ms. HOFFMAN. By and large, our patients find out from other members of the community. And we have, I think, pretty good physicians in our community in terms of referring to hospice, but where our patients hear about it first is almost always other family members, other members of the community. They knew somebody who had had hospice. It is that kind of a referral.

Senator BREAUX. Ms. Grigsby, how about the Baton Rouge area?

Ms. GRIGSBY. In Baton Rouge, it is primarily through the physicians. We did a market study last year through LSU, and 90 percent of the families surveyed had never heard of hospice prior to the physician saying it was time for hospice.

Unfortunately, what happens predominantly in our community is when the reimbursement cost for the patient exceeds what is collectible is when they are referred to hospice, if that is making any sense. Once they get to be costly, then they are referred to hospice.

A contemporary of mine who is a physician called me one afternoon and said, Kathryn, I really need your help. Dad is 83. He has been in a coma for 3 weeks. There is no hope for recovery. We want to take him home. He has got a living will, advance directives, and the attending physician has told me that I might as well put a gun to his head if I take him home without a feeding tube. So what do I do?

Physician education. Consumer-driven is great, but it has got to be both.

Senator BREAUX. Ms. Bell, how about you?

Ms. BELL. Well, I think in the Portland area, and certainly in Oregon, I think many of the physicians are very supportive of hospice care, but it does come down to a matter of time, as I alluded to. I have had more than one physician say to me, if you can get the family to ask for hospice care, I will order it. But for them to bring it up in the context of an office visit, they simply don't have the time.

That is one of the reasons why in the proposal that Senator Wyden has put forth we would be reimbursed for an informational visit that a hospice staff member could make. We have done that without reimbursement in some cases and it is amazing the effect it has on the patient and family. They don't understand the benefit, they don't understand what their care is, and physicians quite frankly don't have the time to bring it up.

Senator BREAUX. It is a very difficult decision obviously for families to make because it is really an acknowledgement that there is no hope that the treatment is going to be successful in curing the illness or curing the patient. It is a very difficult thing to say, all right, we are going to send mom, dad, or whoever, to a hospice installation because of the fact that it is a recognition that that is it.

Ms. BELL. I think a lot of families and the patient need time to assess what their values are, what is going to have meaning to them when they do come to the realization that their life is coming to a close. This is what takes time. This has to be explored with them because that is something they are not going to think about.

Senator BREAUX. I think hospice does a great job in helping in those cases.

Dr. Christakis.

Dr. CHRISTAKIS. This business about hope is very important. You have hit on a key issue I think part of what needs to happen when we think about providing better end-of-life care is that there still is hope when we send patients to hospice. It is just that the object of hope has changed.

While we no longer might hope that the patient will be cured of their condition, we still might hope that they would have a good death, that they would have really terrific care delivered to them by their doctors, that they would have a meaningful few months before they died. And a key part of referral for hospice needs to be the realization that there is much that patients still have to hope for, even if they cannot hope for cure of their illness. So I personally try not to regard hospice and hope as kind of opposites. I try to tie them together and think of them as still being hope in hospice just a different kind of hope.

Senator BREAUX. Has the recent letter from Nancy Ann De Parle from HCFA on the 6-month guideline stating, "Let me be clear. In no way are hospice beneficiaries restricted to 6 months of coverage," basically saying that doctors have to merely certify that the patient will likely die within 6 months—has that helped the potential problem on the 6 months for your operation, Ms. Hoffman?

Ms. HOFFMAN. Not as yet. I am hopeful that it will be helpful. Part of the problem is getting the word out. Part of the problem is convincing people that, in fact, 3 weeks from now that will continue to be the stand that will be taken by HCFA, because everyone is accustomed to regulations changing rapidly and rules that were effective this week maybe 3 weeks from now aren't. But we are hopeful that that will help in our education with physicians to get them to understand that they are OK if they can't absolutely prognosticate their patient's death.

Senator BREAUX. Ms. Grigsby, is that helpful?

Ms. GRIGSBY. I hope the letter went to the physicians. I guess in an expansion of what Karen said, I do think it is very difficult. We had a focus group with our main referring physicians, and basically what they said is that they count on us to help the families understand that this is the end, that treatment is stopped, that they are indeed dying, and that they simply don't have the time to do that.

Unfortunately, with the current Medicare structure, that is a non-reimbursable cost for a hospice. You may spend several days, weeks, even months talking with families and patients prior to ever admitting them with trained professionals before you collect that first dollar from the Medicare reimbursement. I am optimistic that it may make a difference.

Senator BREAUX. My understanding is that it did not go to the medical doctors, but to 2,000 hospice organizations, which I take it would hopefully communicate it to the doctors that refer patients to them.

Ms. Bell, what is your comment on Ms. De Parle's position?

Ms. BELL. Well, I think it is a positive one. We have had ADRs for additional medical review from HCFA on patients who lived 2 days, and even had a denial on one from our intermediary saying the patient was not terminally ill. Now, we did go through the process of appealing that, but that took time and attention away from what we were trying to do to provide patient care. So I am cautiously optimistic. Let's put it that way.

Senator BREAUX. Thank you very much, Dr. Scanlon, Dr. Christakis, and our three people with hospice. Thank you for what you do. It is laudable, it is very important, and hopefully we can make it a lot easier.

Thank you.

The CHAIRMAN. Thank you, Senator Breaux.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman.

All of you have been excellent, and I like to think that you have really made the case for S. 3026, the hospice improvement program that I have introduced. We have gotten the support of the national hospice organization.

I think more than anything what we have been able to do today is to identify a variety of key barriers to hospice care, and that is what we are seeking to do in the demonstration project legislation is to try to test out a handful of these models and see what we can do to really expand coverage.

A couple of questions that I had. Dr. Christakis, you, of course, are one of the leading scholars in this area and I wonder what you think of the idea of moving toward a severity index rather than a 6-month standard. That is something that I put in the demonstration project legislation because we heard about it across Oregon. We heard about it from hospice providers all across the country. It seems to me that the severity index kind of approach allows you to move away from the rigidity of what the Health Care Financing Administration is offering up today and would really give us a chance to be responsive to the patients.

Dr. CHRISTAKIS. I think that is an excellent idea. I mean, the idea here, of course, is to say, look, you know, doctors are just not willing or able to prognosticate adequately. Whether we could perfect the science of prognostication is another whole topic, but let's just say it is broken now, it is not going to work. Let's do away with the prognostically based criterion for admitting patients to hospice, and instead let's replace it, as you are suggesting, with a performance status-based criterion which would say something like if the patient has one of a number of conditions—and we could list them legislatively, I presume—these are the conditions: you have to have colon cancer, you have to have pancreatic cancer, you have to have Lou Gehrig's disease, you have to have COPD, or whatever.

And if the patient, let's say, spends more than 50 percent of their time in bed, or more than 80 percent of their time in bed, and if the patient is unable to do the following activities, that is the criterion for entry into hospice. Just eliminate the prognostic standard. I think that would be tremendously helpful, for a variety of practical and legislative reasons.

One of the practical reasons is it would help to destigmatize the referral because now it would no longer be that the doctor has made any kind of prognostic assessment. Some kind of descriptive statement has been made about the patient's status. So I think that is a very good suggestion.

Senator Wyden. Well, I thank you. I just think as we read the GAO report and listened to all of you, as much as anything we need to breathe some flexibility into this area. Of course, Oregon has wrestled with a variety of issues in this area. It is hard to get the word out—physicians' attitudes. The under-treatment of pain today is a documented public health crisis. That is not in dispute.

We have got to address the barriers that you all are talking about, and I guess what I would like to do—Ms. Grigsby, Senator Breaux has let us all know of your expertise. You and Ms. Hoffman, if you could wave your wand on these demonstration projects, that are in my legislation to test out a handful of approaches that all of you out there in the field who are really wrestling with this think are most important—if you could wave your wand, Ms. Grigsby, what would you like to see examined in a demonstration project initiative?

Ms. Grigsby. I think in our area I would like to see possibly one with some solution to the residential situation. We have so very many patients who do not have able, available caregivers. I mean, as a good friend of mine said to me over the weekend, Kathryn, if mama has lung cancer, I have got two options. I quit my job or I put her in a nursing home, because I can't afford to pay the sitters to provide the care.

And I think it is terribly sad to think that what we are doing is forcing individuals to become impoverished and end up in Medicaid beds in nursing homes. I think there are other options out there, and I would love to see something of that form in a demonstration project.

Also, I think that we have got to figure out some way to balance. I guess the main thing that I see is we are never good with balance. We go from one extreme to another. The focused medical review, as Karen said, having denials on patients that died within 2 days—this does not make sense.

I really don't understand your demonstration project, so I really can't comment on that.

Ms. Hoffman. If I had the choice, I would allow us to provide a hospice style of care to patients who require some palliative care but don't qualify for home care and don't qualify for hospice. They are probably out a little bit. They are seriously, chronically ill. They are not being served right now.

I think what we would discover is that that would not only provide better care for those patients, I personally think it would reduce costs to the overall health care system because I think it would reduce exacerbations of their serious chronic illnesses and it wouldn't be spending a lot of time in acute inpatient settings and in ERs. But I also think it would bring patients to hospice sooner. I think they would be able to come to understand what hospice has to offer, and that we would thereby bring them a better death and spend a little less time on the very expensive and not always helpful intensive care kinds of situations that many people experience at the end of life.

Senator WYDEN. You are being too logical, heaven forbid. Of course, that is the heart of the problem. The way this system was set up was built around a lot of boxes that lent themselves to be administered by various personnel, but really weren't family and consumer-driven. So your suggestion is a good one.

Ms. Grigsby, yours about the number of caregivers, of course, is extremely important. We lack personnel in every field of geriatrics.

One question for you, Mr. Scanlon. What is your sense, based on the research you all have done, of what seems to be driving the problem of getting the word out in the minority communities? It seems that we are having some special problems in getting minority Americans aware of this benefit. What can you tell us in terms of your research that would be helpful here this afternoon?

Dr. SCANLON. Well, I think in this instance we did not find anything different with respect to this service as opposed to other services. One of the problems for minorities is information and access to services, and part of it is potentially related to economics, the fact that more are lower-income, reliant on Medicaid. And providers to serve a Medicaid population, or even a dually eligible population, are more limited than those that are serving a Medicare-only population. But I do think it is a combination of information and economics.

Senator WYDEN. All of you have been excellent. With a little luck, we will get S. 3026 a part of this year's final budget. One of the reasons I try to stay in the good graces of these two sitting next to me is Senator Breaux and Senator Grassley are always in the room when those bills are written. They, of course, have been incredibly supportive of hospice and these issues, and we just really appreciate your coming, and especially to your organizations for all the help you gave me in drafting this legislation.

I thank you, Mr. Chairman.

The CHAIRMAN. Thank you all very much. I am going to just have three questions. They won't take a lot of discussion. We are just about done. I am going to ask any one or all of you, depending on how many of you want to respond, about something Dr. Christakis offered as one possible change in the hospice benefit, increasing payments for hospice patients that may have special circumstances, such as living alone or living in a rural area or an inner city.

Assuming that the total amount of money in the system stays the same, do you think that this would be wise, or are we better off sticking with the current approach of paying basically the same for all patients?

Ms. HOFFMAN. I would think if we have to stay budget-neutral, I am not sure that that would help us. I think we would find ourselves fighting an urban versus rural kind of thing, which we have seen in health care already, and I don't know that that is beneficial.

The CHAIRMAN. The same for all of you. I will go on, then, to Dr. Scanlon, if you want to speak.

Ms. BELL. But we are not all paid the same right now. I mean, what I am paid in Portland, OR, is different than what they are paid in eastern Oregon. So there is not the same reimbursement. Maybe if there was, that would be a more equitable situation.

The CHAIRMAN. Well, I have legislation in that deals with the wage index that would take care of what you are talking about there. But we are still talking about people that would have a possible situation where you would give special attention to special needs.

I will go to Dr. Scanlon. You point out that the extent to which hospice may be underutilized remains unclear. Do you have any suggestions on how to improve the ability to review access issues in the future?

Dr. SCANLON. I think one of the things that we can do potentially is to try and identify information about the attitudes of physicians and beneficiaries in areas that may contribute to the variation that we see. That is probably, as we have heard today, one of the most significant factors affecting utilization. We then may have a better basis for looking at areas that appear to be under using the benefit and assess what fuller use of the benefit would be.

The CHAIRMAN. Ms. Grigsby and Ms. Hoffman, I would like to have you address the idea of a larger up-front payment for hospice patients, or possibly a minimum payment, because we had both Ms. Bell and Dr. Christakis suggest that this is a way to compensate providers for the very costly initial days of hospice care.

Your thoughts?

Ms. HOFFMAN. I think that would be extremely helpful. Many of our patients—I said 30 percent of mine—are coming in at 7 days or less. A substantial number of those are with us 2 days, and there is just as much paperwork to do as there is for a patient who is with us longer. It would be extremely helpful to us to have an up-front cost for all patients that recognized that admission expense.

The CHAIRMAN. Do you have anything to add to that?

Ms. GRIGSBY. I think in an ideal world the solution is to get them earlier, but I think it would be a tremendous help because as my statistics indicated, we have them for such short lengths of time. Last year alone, my agency would have been over $325,000 in the red without the charitable dollars that we raised, and our budget is $2 million. So, you know, percentage-wise it is quite significant and it is driven by that shortened length of stay.

The CHAIRMAN. I thank all of you for your attention. I want to draw some conclusions based upon our hearing, as well as some of the research that went into this before we even put the hearing together, and thank Senator Wyden for his suggestion of the General Accounting Office study.

We have about a $2 billion program here, and this is a relatively small piece of Medicare, but I think we have heard that there are a lot of complex problems that affect this small piece of the Medicare pie. If we are going to have better end-of-life care, we are going to have to deal with them. For you folks who are in the business, it is your life, but I mean compared to everything else in Medicare it is relatively small. So I think we need to deal with it.

So one of the things that I thought about is that I don't think that until we do an overall Medicare reform that we can wait until next year to give some relief for Medicare payments in these areas. We probably should have better data that we can't get because the General Accounting Office doesn't have the base to work from yet. We are getting that, but we have to make decisions on the information we have.

I think an increase in the base hospice rate should be a part of this year's Medicare package. I plan to communicate to Chairman Roth that aspect of it, and I would invite Senator Breaux to do that with me, if he would be inclined. This isn't something I have had a chance to visit with him about.

Senator BREAUX. I will join with you.

The CHAIRMAN. Thank you. I am sorry I didn't have a chance to visit with you about that beforehand.

Then on a second point, we do have HCFA acknowledging, very significantly, the need to improve hospice in Medicare. I don't know if Congress will address any hospice issues other than financing in the short term available this year, but I would definitely like to see it be part of a broader effort of strengthening Medicare next year.

So I would like to write to HCFA, and again hopefully with Senator Breaux helping me do this, urging a review of the hospice benefit, and asking for them to make to us concrete, serious legislative recommendations early enough in the new year to be useful in the Medicare discussion. I have an open mind on the timing, but just for some sort of a deadline, maybe 6 months from now, which would be March 18, 2001, as maybe a target date.

This would give, I hope, HCFA staff time to develop proposals, and the incoming administration time to make final decisions. I would urge HCFA to listen to input from hospice providers, patients, and caregivers, advocates, and policy experts. And I am certainly willing to have our staff of the Aging Committee be involved with that, as well, and any of the colleagues beyond Senator Breaux who would like to be involved in that to be involved in it.

Some questions that I would ask for possible discussion and consideration by HCFA: in light of prognosis issues, should a new eligibility criterion replace the 6-month rule? If we retain the 6-month rule, is statutory language needed to clarify it once and for all? Does Medicare need to undertake a professional and public education campaign on the hospice benefit? Should Medicare payments be adjusted to reflect special challenges posed by individual patients, like those who have no family caregivers or those that we have just talked about, rural or inner-city areas?

Is the current Medicare reimbursement adequate? Is the requirement that a patient electing hospice surrender all rights to curative care still appropriate now, 18 years after we set it up? Should providers serving rural areas be relieved of some regulatory burdens because of special constraints?

These are all questions that I would ask HCFA to consider, and a lot of others that they might think about. But I would hope that we could all agree that review is needed, and that when HCFA does it that they will make use of today's committee hearing record because I think that our hearing today has been most helpful, and each of the Senators present have said the same thing.

So I thank all of you witnesses. Thank you very much.

The committee meeting is adjourned. Thank you.

[Whereupon, at 3:43 p.m., the committee was adjourned.]

APPENDIX

ONCOLOGY NURSING SOCIETY
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THE ONCOLOGY NURSING SOCIETY

STATEMENT TO THE

SENATE SPECIAL COMMITTEE ON AGING

ON HOSPICE CARE

September 18, 2000
Senate Dirksen Building

The Oncology Nursing Society (ONS) is the largest professional oncology group in the United States composed of over 29,000 nurses and other health care professionals dedicated to improving the care of oncology patients and oncology health services. We wish to submit our comments to the Senate Special Committee on Aging of our concerns about the quality of care and access for hospice patients and current problems encountered by hospice organizations.

ONS, as outlined in our position statement regarding end-of-life care, supports policies that allow people with fatal illnesses and their caregivers to receive reliable, skillful, and supportive care. Oncology nurses strive to improve the care of dying patients by identifying and relieving symptoms associated with end-of-life experiences. This includes the use of prescription drugs, therapy, and a wide variety of other means that effectively treat the diverse experiences that patients encounter at the end of their lives.

Specifically, ONS has the following concerns related to hospice care and access to care:

- ONS is concerned that due to the "six-month" eligibility rule (that a patient must have no longer than six months to live for admission to a hospice) many patients are being denied access to hospice, lose their benefits if they do not die within six months, or do not receive quality hospice care due to the fact that patients and their families are already late into their illness when finally admitted for care.

- ONS is concerned that patients requiring hospice may have their access to care denied due to fiscal restraints due to benefit policies that result in patients being selected for care based on financial considerations rather than the need for care considerations.

- ONS is concerned that patients who live in rural areas are being denied access to hospices or full benefits due to reimbursement structures that narrow admission eligibilities.

- ONS is concerned that current benefits for hospice patients do not adequately cover medication and pain medication requirements. This coverage is crucial for quality of care for hospice patients requiring supportive care and pain management.

ENTRY DIFFICULTIES AND QUALITY OF CARE

Although the intent may not have been this, the "six-month" rule has prevented many individuals from being admitted into hospice. Many physicians are fearful of referring individuals due to the misinterpretation of the intent of this law, as well as the history of denials by HCFA for patients who do not die within six months.

Because patients are not being referred to hospice or referred very late in their illness, many hospices play "catch up" with the care that is needed by patients. This does not assist in the quality of care that should be available for patients.

Hospices are experiencing financial difficulties due to the reduced average length of stay for patients. When the hospice program was originally created, it was assumed that patients would enter the program early in their illness and require less care and expense at the beginning of treatment. Cost could be recouped at the end of their care when more services would be needed. In essence, the lower costs at the beginning of care would balance out the higher costs at the end. Unfortunately, this is not the case at present.

Today, as stated earlier, patients are entering hospices much later into their illnesses. As a result, costs for care are high from the onset of treatment because patients enter when they are extremely ill and require a great deal of supportive care. In addition, time spent in hospice is relatively short, with resulting financial loses to hospice programs across the country. In fact, many hospices are being forced to fund a substantial portion of their services with money from other sources. This includes money collected through charitable measures which would otherwise go to help those who have no medical coverage and cannot afford quality care.

REIMBURSEMENT CONSIDERATIONS AND QUALITY OF CARE

Upon the enactment of the Hospice Medicare Benefit in 1982, the routine home care rate was set at $41.46 per day. This rate, however, did not include an annual inflationary update. Instead, Congress periodically increased the rate and has now tied the hospice reimbursement rate to the hospital market basket in an attempt to provide for inflation increases. In FY 2000 the routine home care rate was set at $98.96 dollars per day. This was the only reimbursement payment which Medicare provided and it was expected to cover all the costs related to the terminal illness.

This rate does not even begin to cover the costs incurred in delivering adequate care to end-of-life patients. Not only have prescription drugs and out-patient therapy costs increased drastically, hospices have also been faced with a greater amount of patients who come to the program late in their illnesses, which puts an even greater financial burden on hospice organizations. As a result, hospice's ability to care for terminally ill patients has been extensively eroded.

This has also resulted in hospice programs not having the funds available to offer competitive wages for their employees. As a result, hospices are having increasing difficulty recruiting quality staff and are in desperate need of qualified nurses. Some hospices, especially in rural areas, are becoming extremely selective of the patients they accept because they do not have the resources necessary to help everyone that requires the service. This greatly affects the access of care for patients needing hospice care. The end result is that patients are not receiving appropriate care for end of life treatment.

Hospice provides care for terminally ill patients through palliative health care management, which focuses on the pain and the symptoms of patients in order to help to improve the quality of their lives. Prescription drugs and other medical technology have an extremely important role in this type of health care management. Many of these interventions are expensive. One drug used typically for hospice patients can be $100.00 per day. That is more than the total per diem drug reimbursement currently allowed by Medicare. This presents tremendous problems for many patients for the services they can receive.

In addition, coverage of prescriptions or medications remains at too low of a level to realistically coverage medications used today. Many oral pain medications are much more expensive. For instance, fentanyl patches can be hundreds of dollars to thousands of dollars depending on the dosage. Oral pain medications allow an individual to have more freedom of movement, rather than requiring intravenous medications. Intravenous medications require a higher level of maintenance, can produce site infections, and restrict movement. Reimbursement for oral pain medications, medications for nausea and other typically used drugs needs to be re-assessed for the hospice patient.

Because the majority of hospice patients today require more intensive therapies from the time of their admissions, their care is more expensive. As one can see from the above problems that have been outlined, many hospices must restrict the number of patients that they can accept, simply due to financial considerations. Many of the hospice organizations that are currently fiscally sound are the larger, national organizations due to economies of scale. The smaller hospices and those operating in rural areas are beginning to have a more difficult time maintaining their programs, providing needed services and accepting patients. ONS is very concerned that a large majority of patients in the United States who live in rural areas do not have access to adequate care or do not have access at all to hospice services. These patients must then be admitted into home care settings or in-patient hospital settings. Both of these alternatives are more costly and do not provide the type of care needed by the terminally ill.

As reiterated earlier, because of fiscal restraints, many hospices are becoming increasingly unable to hire appropriate staff that are well-educated and experienced in the care of the terminally ill. This has a tremendous impact on the quality of care being provided patients at the end of their life.

ONS commends the Senate Special Committee on Aging for holding a hearing on this important subject for terminally ill patients. We look forward to working with the Committee in the future on these important reimbursement issues and quality of care. Thank you.

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