

IMPROVING CARE AT THE END OF LIFE WITH COMPLEMENTARY MEDICINE

HEARING BEFORE THE COMMITTEE ON GOVERNMENT REFORM HOUSE OF REPRESENTATIVES ONE HUNDRED SIXTH CONGRESS

FIRST SESSION

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IMPROVING CARE AT THE END OF LIFE WITH COMPLEMENTARY MEDICINE

TUESDAY, OCTOBER 19, 1999

HOUSE OF REPRESENTATIVES,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The committee met, pursuant to notice, at 1:05 p.m., in room 2154, Rayburn House Office Building, Hon. Dan Burton (chairman of the committee) presiding.

Present: Representatives Burton, Morella, Horn, McIntosh, Ose, Waxman, Mink, Norton, Cummings, Kucinich, and Schakowsky.

Staff present: Kevin Binger, staff director; James C. Wilson, chief counsel; David A. Kass, deputy counsel and parliamentarian; John Williams, deputy communications director; S. Elizabeth Clay, professional staff member; Robin Butler, office manager; Corinne Zaccagnini, systems administrator; Carla J. Martin, chief clerk; Lisa Smith-Arafune, deputy chief clerk; Nicole Petrosino and Heather Bailey, legislative aides; Robert Briggs, staff assistant; Phil Schiliro, minority staff director; Phil Barnett, minority chief counsel; Kristin Amerling and Sarah Despres, minority counsels; Ellen Rayner, minority chief clerk; and Jean Gosa, minority staff assistant.

Mr. BURTON. A quorum being present, the Committee on Government Reform will come to order, and I ask unanimous consent that all Members' and witnesses' written opening statements be included in the record, and without objection so ordered.

[The prepared statement of Hon. Elijah E. Cummings follows:]

Congressman Elijah E. Cummings
Statement
Government Reform Full Committee Hearing
on
"Improving Care at the End of Life with Complementary Medicine?"

Tuesday, October 19, 1999

1 Thank you, Mr. Chairman.

2

3 We come today to examine the status of care provided for
4 individuals who are dying. Ecclesiastes 3:1 in part states "To every
5 thing there is a season, and a time to every purpose under the
6 heaven; a time to be born, and a time to die ..."

7

8 It is important that we make the final days of our loved ones as
9 peaceful and painless as possible. Hospice care provides such an
10 environment. According to the National Hospice Organization,
11 hospice is an "emphasis on pain and symptom control, so that a
12 person may live the last days of life fully, with dignity and comfort."

13

1 Complementary and alternative medicine, (CAM), is another
2 way to achieve this goal. The use of complementary medicine has
3 become very popular in the United States. In fact in my hometown
4 of Baltimore, the Complementary Medicine Program (CMP) at the
5 University of Maryland School of Medicine was founded in 1991. The
6 school is dedicated to investigating complementary and alternative
7 therapies and evaluating their contribution to the care of patients.
8 Also, Dr. Brian M. Berman, director of the Complementary Medicine
9 Program in Baltimore, currently serves as U.S. editor for the journal
10 *Complementary Therapies in Medicine*.

11
12 Extensive research is essential and should be one of our main
13 areas of focus. Research is important because it offers patients
14 access to a variety of treatments. Patients need to understand their
15 options and physicians need to be able to discuss these options.

16
17 I look forward to hearing from our witnesses this afternoon.

Mr. BURTON. I want to start off by saying that I appreciate the hard work that a lot of people have done on this hearing. Beth Clay was very insistent that we have the hearing today. We had a lot of other pressing business, but because she was beating me over the head with a ball and bat, we went ahead and decided to do it.

After reading some of the background information on this and understanding the issue more thoroughly, I think this is a hearing that is truly important, much more important than I thought initially. Today we are going to broach a topic that is not easy for some of us to talk about—dying. Everyone in this room that has lost someone they loved is concerned about that. While the topic of end-of-life care may be emotionally charged and difficult to face, it is a topic that we must have the courage to face, all of us. We can and must improve end-of-life care and we can do this in several ways. The most recognized issue in the end-of-life care is pain management, and I am painfully aware of that because last September and October my mother and stepfather died. Watching them go through the kind of pain that they endured was very difficult, and had it not been for a medical assistant that was there administering pain relief, it could have been a lot worse.

In today's world, with such a wide range of drugs for pain management, why is it that pain is not properly treated? Dr. Ira Byock, a leader in the field of end-of-life care and the author of the book "Dying Well," will share with us his observations about pain management and ways to improve end-of-life care including the role of complementary medicine.

Dr. Ming Tian, a physician and licensed acupuncturist, will share with us his experience as the doctor the National Institutes of Health has called on for almost 10 years to treat intractable pain for patients at the Clinical Center. He will also share insights about the role of traditional Chinese medicine.

Family members are often faced with daunting challenges: providing care at home, making treatment decisions, working through the myriad issues of insurance and Medicare, all at a time that they deal with the emotions surrounding the imminent loss of a loved one.

Mrs. Carolene Marks recovered from cancer by using alternative medicine. After her experience, she used what she learned to begin helping other women dealing with cancer. She served 4 years in the National Institutes of Health's Alternative Medicine Program Advisory Council. She continues to work with academic institutions in the San Francisco area to hold alternative medicine conferences to make information available to women who are facing breast cancer. She is also the wife of the late Milton Marks, who served for many years in the California State Senate. Today, she will share with us her personal insights, including complementary therapies in her husband's care.

Typically, when one thinks of end-of-life care, one thinks of the hospice program. Elizabeth Kubler-Ross made "hospice" a household word with the publication of her book, "On Death and Dying." In her book, she lambasted the medical community for its lack of compassion and inability to care for the dying patient appropriately. The importance of compassionate care is immeasurable.

Has that changed since the publication of her book back in the 1960's?

Hospice care is a special kind of care designed to provide comfort and support to patients and their families in the final stages of a terminal illness. Hospice care seeks to enable patients to live their remaining days in an alert and pain-free manner, with symptoms under control, so that those last days may be spent with dignity, at home or in a home-like setting surrounded by people who love them. Hospice care neither speeds up, nor slows down, the dying process. It does not prolong life and it does not hasten death. It merely provides a caring presence and specialized knowledge of medical care, psychological care, and emotional and spiritual support during the dying process in an environment that includes the home, the family and friends. Hospice services are provided by a team of trained professionals, doctors, nurses, counselors, chaplains, therapists, social workers, aides and volunteers, who provide medical care and support services not only to the patient, but to the patient's family and caregivers. Bereavement care is critical to supporting surviving family members and friends. A key component of the hospice team is the hospice volunteer. These individuals receive special training and assist medical professionals by visiting the terminally ill, providing respite for family members, and by simply being a compassionate, loving presence.

Mr. Dannon Brinkley is the chairman of the Board of Compassion in Action, an organization that trains hospice volunteers as well as provides community and professional education about death and dying issues. Mr. Brinkley has served tirelessly for over 20 years recruiting, and now training, hospice volunteers. As the author of two international bestsellers, "Saved by the Light" and "At Peace in the Light," and as a motivational speaker, Mr. Brinkley travels the world sharing his personal story and helping others overcome their fear of death. He has been credited over the years with recruiting over 20,000 volunteers. Through his own personal experiences and research, Mr. Brinkley has become an advocate for integrating complementary and alternative therapies into our health care system. Compassion in Action provides hospice volunteers to veterans' hospitals across the country.

Of particular focus today will be the end-of-life care for our veterans. As we grapple with veterans' issues like Agent Orange and Gulf War Syndrome, we must also remember those who served in the World Wars earlier in this century. These heroes are the ones that stormed the Normandy Beaches on D-Day and raised the flag atop Mount Suribachi on the island of Iwo Jima, and deserve quality care as they face their last days.

This is something that just amazed me: 134 World War II veterans will die during the time it takes to hold this hearing today. Did you know that? Just in the time we are going to hold this hearing, 134 of them are going to die. Thousands die every month and I think you are going to talk about that, Mr. Brinkley.

Is the Veterans Health Administration providing adequate care? Is there a difference in the quality of care a veteran would receive from a local hospice or the veterans end-of-life program? Dr. Thomas Holohan from the Veterans Health Administration is here to tes-

tify about these programs and is accompanied by Dr. Judith Salerno.

Mrs. Kathy Buto will present information about Medicare coverage for hospice programs on behalf of the Health Care Financing Administration.

In March 1998, the National Institute of Nursing Research issued a report on managing symptoms at the end-of-life. Dr. Patricia Grady, Director of the Nursing Institute, will testify about the research funded by the National Institutes of Health on palliative medicine and end-of-life care including complementary therapies. She will also discuss treatment and stress management options made available to Clinical Center patients and their families.

There are many complementary therapies that can be extremely helpful for end-of-life care. They include music therapy, acupuncture, aromatherapy, massage, and guided imagery, and today we will learn more about these important complements to end-of-life care.

This week in Congress, we are scheduled to vote on H.R. 2260, the Pain Relief Promotion Act of 1999. I am proud to be an original cosponsor of that bill. This bill recognizes the importance of good pain management and the necessary and legitimate use of controlled substances in pain management and other care. The passage of this bill will require the Department of Health and Human Services to develop and advance the scientific understanding of palliative care, the development of practice guidelines, and better education on these issues. Through increased research and education, we can find better and more compassionate ways of relieving pain for those in terminal conditions, including complementary therapies.

It is my hope that this hearing will broaden our understanding of these very important issues and I now recognize my colleague, Mr. Waxman, for his opening statement.

[The prepared statement of Hon. Dan Burton follows:]

Opening Statement

Chairman Dan Burton

**Government Reform Committee
U.S. House of Representatives**

Hearing

**“Improving Care and the End-of-Life with
Complementary Medicine”**

October 19, 1999

1:00 pm

**2154 Rayburn House Office Building
Washington, D.C.**

Today we are going to broach a topic that is not easy for some of us to talk about – Dying. Everyone in this room that has lost someone they loved. While the topic of end-of-life care may be emotionally charged and difficult to face, it is a topic that we must have the courage to face. We can and must improve end-of-life care! And we can do this in several ways. The most recognized issue in end-of-life care is pain management. In today's world, with such a wide range of drugs for pain management, why is it that pain is not properly treated?

Dr. Ira Byock, a leader in the field of end-of-life care and the author of the book, *Dying Well*, will share with us his observations about pain management and ways to improve end-of-life care, including the role of complementary medicine.

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A key component of the hospice team is the hospice volunteer. These individuals receive special training and assist medical professionals by visiting the terminally ill, providing respite for family members, and by simply being a compassionate loving presence.

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Is the Veterans Health Administration providing adequate care? Is there a difference in the quality of care a veteran would receive from a local hospice or the Veterans end-of-life program?

Dr. Thomas Holohan from the Veterans Health Administration is here to testify about these programs and is accompanied by Dr. Judy Salerno.

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It is my hope that this hearing will broaden our understanding of these very important issues.

Mr. WAXMAN. Thank you very much, Mr. Chairman. I am pleased you are holding this hearing. Individuals who are at the end of their lives deserve the same level of attention and care as do individuals who have longer life expectancies. Our country is a world leader in medical research and technology, and with every day, we achieve advances in treatments for terminal diseases. Nevertheless, many people in this country are not able to obtain the quality of life and care, that they and their families should expect, in the last stages of their lives.

Many people have been working to increase our understanding of steps that policymakers, health professionals, volunteers, family members, and others can take to help improve the quality of life for individuals at the end of their lives. Today's hearing provides an opportunity to continue this effort. Some of today's witnesses are caregivers who will share their personal experiences and insights regarding the end-of-life care. We will also hear from government representatives about ongoing efforts at the Veterans Health Administration, the National Institutes of Health, and Health Care Financing Administration to research and support end-of-life care.

This discussion will provide valuable insights regarding the status of end-of-life care in this country and efforts and initiatives we should continue to explore. I join my colleagues in welcoming these witnesses and I look forward to their testimony.

I would also like to comment on the bill, Mr. Chairman, that you referenced that is going to be on the House floor this week. That bill came out of the Commerce Committee where I sit as a member on the Health and Environment Subcommittee. One of the great concerns I have with that bill, is that it would leave to the Drug Enforcement Agency the determination of whether the use of any particular drugs might hasten the end-of-life even though they are intended for use for palliative care. And I worry, as do many health professionals, that they will be intimidated and refuse to use drugs that will ease the pain that terminally ill patients are suffering from, for fear that they may be prosecuted for violating the law.

We have to be very careful about that. I think most Members, at this point, do not realize that there is that provision in there that is so troublesome to most of the health professionals who have looked at this legislation. We need to make clear, as that legislation tried to do, that Congress need not endorse assisted suicide in order to make sure that we provide all that is necessary to afford people palliative care.

In fact, it is quite inconsistent to talk about wanting to prevent suicides and then not give people the ability to control their pain because that is the major reason why people despair and contemplate, if not, in fact, take actions to end their lives. I also want to note that two of the witnesses today, Mr. Dannion Brinkley and Mrs. Carolene Marks, are from my home State of California and I want to welcome them to the hearing today. I want to thank them for making the trip to Washington.

As so often happens, we have our schedules in conflict, so I am not going to be able to be here for the whole hearing. I will be in and out. But the testimony that we will receive will be in the record and we will be able to share it with all of our colleagues. We have, of course, the written statements in advance, but the re-

sponses to questions I think will be very, very helpful for our colleagues to understand this issue.

I do not know that any committee has ever held a hearing on this subject so I am pleased, Mr. Chairman, that you have taken this issue on so that we could give a public airing to what I think are very, very important matters. Might I ask, our colleague, Congressman Pete Stark, asked me to see if he could insert a statement into the record?

Mr. BURTON. Yes, without objection, so ordered.

[The prepared statement of Hon. Pete Stark follows:]

FORTNEY PETE STARK
THIRTEENTH DISTRICT, CALIFORNIA

CONGRESS OF THE UNITED STATES
HOUSE OF REPRESENTATIVES
WASHINGTON, D.C. 20515

COMMITTEES:
WAYS AND MEANS
JOINT ECONOMIC

Statement of Congressman Pete Stark
End of Life Care Hearing
House Government Reform Committee
Tuesday, October 19, 1999

Mr. Chairman and Members of the Committee:

I commend the Committee for holding this hearing on this important and often neglected subject. Issues surrounding end of life care touch the lives of every American. The experience of both the patient and family at the end of life can be marked by dignity and meaning. We need to improve our understanding of the needs of the terminally ill as well as their loved ones. We also must assure that high quality services including supportive care, pain management and counseling are readily available to those who are in need.

A recent study published in the New England Journal of Medicine (September 23, 1999) evaluated the types of assistance that terminally ill patients receive. The study revealed that patients with terminal illnesses other than cancer are more likely to receive end-of-life care from family members than from a hospice program and that the bulk of care of all terminally ill patients is provided by women. This data underscores the need for further study of the needs of the terminally ill, with focus on the differences that exist amongst diagnostic groupings as well as the impact of end of life care on family members, and particularly, women.

Congressman Ed Markey and I have introduced the Omnibus Long-Term Health Care Act, H.R. 2691, to respond to the needs of those with both chronic and terminal illness. Three provisions specifically encourage the

provision of hospice care. The National Hospice Organization estimates that only 2 out of 7 dying Americans who could benefit from hospice actually receive it. Improved access to hospice care can be accomplished with improved education for patients, family members and health care providers. The first provision assures that terminally ill patients receive counseling and information about hospice benefits at the time of hospital discharge when the diagnosis (DRG) indicates serious, chronic and eventually terminal illness. End of life counseling should be a routine component of discharge planning following hospitalization.

A second provision of the Omnibus Long-Term Care Improvement Act would encourage physician education in hospice care. Information about the services of the hospice program are not generally included in medical education curricula. Many physicians are not aware of the range of services provided by hospice including pain management, the provision of needed drugs and medical supplies, advising the family on how to care for the patient as well as counseling and bereavement care. Our bill requires that hospice care be an integral part of physician training to encourage physicians to consult with hospice when caring for terminally ill patients.

In addition, this bill establishes hospice care as a covered service within the Federal Employees Health Benefits Program. All of these provisions would improve access to the hospice care program which is an important and established resource of both knowledge and services at the end of life. In acknowledgement of the importance of high quality care for the terminally ill. I am also urging Chairman Bill Thomas to add provisions to the Medicare Balanced Budget Refinement Act to reduce the BBA cutbacks to hospice.

Again I congratulate the committee on holding a hearing to discuss end of life issues. Open discussions about the needs of the terminally ill will assist us in transforming our concept of this natural period of life and improve our ability to enhance the quality of end-of-life.

Mr. BURTON. Mrs. Mink, did you have an opening statement or any comments?

Mrs. MINK. If I might make just a brief rejoinder to my ranking member.

Mr. BURTON. Sure.

Mrs. MINK. I would like to concur with his sentiments, particularly in reference to the bill referred to as the pain management bill that is coming up on the floor. I agree totally with his remarks. I have very, very grave concerns that we are emphasizing again the law enforcement end of this problem rather than really paying attention to the needs of the patients in terms of pain amelioration. We are now going to put once again the Drug Enforcement people in charge of the end-of-life and I have very, very grave reservations about voting for such a bill. Thank you, Mr. Chairman.

Mr. BURTON. Thank you, Mrs. Mink. I would just like to share with the folks who are listening a conversation I just had with Mr. Waxman. After having experienced this just last year with my mother and father, I hope that there is not some ambiguity in the bill that can't be corrected because without that pain management, unless you have gone through it and seen somebody dying, you do not realize how important that is. Let's work together to see if we can't do something about that, and I will be happy to work with you in that regard.

Mr. WAXMAN. I welcome that. Thank you very much.

Mr. BURTON. Would our first panel come forward, Dr. Byock, Dr. Tian, Mrs. Marks, and Mr. Brinkley? As is customary, we swear in our witnesses.

[Witnesses sworn.]

Mr. BURTON. We will start with you, Dr. Byock.

STATEMENTS OF IRA BYOCK, M.D., DIRECTOR, THE PALLIATIVE CARE CENTER, MISSOULA, MT; DANNION H. BRINKLEY, CHAIRMAN OF THE BOARD, COMPASSION IN ACTION; CAROLENE MARKS, SAN FRANCISCO, CA; AND XIAO MING TIAN, M.D., LAC, WILDWOOD ACUPUNCTURE CENTER, BETHESDA, MD

Dr. BYOCK. Thank you, Mr. Chairman. Mr. Chairman, Congressman Waxman, thank you for inviting me to give testimony about improving end-of-life care. I am testifying today as an individual, not on behalf of any institution or organization. I have worked as a physician in the field of hospice and palliative care since 1978 and have over those years served on numerous committees including the ethics committees and task forces of national hospice and palliative care organizations and I am a past president of the American Academy of Hospice and Palliative Medicine.

I am currently a research professor of philosophy at the University of Montana and a member of the Practical Ethics Center there and principal investigator for the Missoula Demonstration Project, a long-term community-based effort to improve the quality of end-of-life care, as an example of what might be possible in communities nationally.

There is no greater urgency facing American society than relieving the crisis that surrounds dying and care for the dying in our country. The Institute of Medicine's landmark report, *Approaching*

Death, details the severity and pervasive nature of this crisis. Dying patients and their families have known this for a long time. Even within otherwise excellent medical institutions, pain and physical suffering among dying Americans remains inadequately controlled, and if we are honest, inadequately addressed.

In addition, most Americans still die in institutions, approximately 60 percent in hospitals, and some 20 to 25 percent in nursing homes, though all Americans state on surveys that they would like to die at home. Patients' preferences for care still often go unhonored even when those choices are clearly conveyed. As if all that were not bad enough, our current health care system routinely pauperizes people and their families for being chronically ill and not dying quickly enough.

Cultural denial marks the confused and conflicted way our society approaches life's end. We are terrified of being ill, being physically dependent on others, and being in pain. We worry about being a burden to those we love. There is a deep resulting fear and deep frustration and anger that has arisen that fueled the assisted suicide movement. Unable to face the stark reality of the end-of-life crisis, many people in our country have embraced legal assisted suicide as a quick fix that would allow us to avoid the dark and twisted roots of this crisis.

There is actually a precedent from the history of pediatrics that is pertinent here. In the late 1940's, our Nation awakened to a silent epidemic of pediatric failure to thrive. Rene Spitz and his colleagues studied foundling homes in which orphans were cared for and found that mortality was alarmingly high, up to 80 percent in some institutions, and profound development retardation universal. Babies were being fed, cleansed, swaddled and they lay untouched until it was the next time to be fed or have their diapers changed.

The key deficiency was the lack of human interaction. Spitz described the blank, listless stares of infants. The expressionless faces of too many elderly residents in America's long-term care facilities call these studies to mind. They too, are often untouched unless they are wet or it is time to be fed. We have an epidemic today of geriatric failure to thrive in America. The public is only now beginning to grasp the nature of the problem or its breadth. Nevertheless, the problem grows daily.

Just as another example, today's aides in America's home health and long-term care industries are woefully underpaid and overworked. The graying of America will accelerate dramatically during the years 2010 to 2030 as the baby boomers turn 65. By the year 2030, 75 million Americans will be over the age of 65, almost 20 percent of the population. In addition, there are currently 40 million Americans living with chronic illness and some disability. Some estimates have that figure tripling by the middle of the next century.

Meanwhile, private caregiving resources within our own individual networks of relatives and close friends is rapidly falling. Social trends including geographic mobility, smaller families, and two working adult families, have all contributed to this decline. Already families struggle to provide the sort of day-to-day, hour-to-hour, minute-to-minute care that we all want for our loved ones.

I shudder to think of how hard it will be when it is my generation's turn to be cared for and our children's turn to provide care. Today, family caregiving represents the unrecognized backbone of health care in America. It is an enormous resource that must be supported and expanded as we grapple with this crisis. Currently, it is estimated that almost 26 million Americans spend an average of 18 hours per week caring for frail relatives. The economic impact is estimated to be \$196 billion per year, more than formal home health care and nursing home care combined.

Seventy-three percent of these caregivers are women. Most of them give care for an average of 4½ years, but some as many as 10 or more years. Many report significant physical and emotional stress from caregiving. These well-documented facts compel us to look beyond formal medical care to the care given by family members and provided by the ill person's community.

Hospice is a bright spot in this otherwise gloomy landscape, a hopeful beacon that exemplifies what we can achieve. Excellent hospice programs have provided us with a best practice standard, a benchmark against which to gauge the outcomes of our clinical and policy efforts. But hospice is wrestling with problems itself. Only 20 percent of dying Americans receive hospice care and for a rapidly diminishing period of time.

The Medicare eligibility criteria has severely limited access to persons whose diseases such as congestive heart failure or emphysema or Alzheimer's and other senile dementias are characterized by a prolonged or stuttering disease trajectory.

More recently, the Office of the Inspector General's Operation Restore Trust has sent a chill through the American hospice programs. Hospice administrators and medical directors are worried, and with good reason, that if they admit patients whose slowly progressive, though ultimately terminal, illness, caused them to live beyond a few months, the program may be investigated for fraud for having admitted the patient at all.

Many programs now feel compelled to discharge patients who have become relatively stable under the comprehensive care that hospice provides and yet away from hospice care these same patients decline more rapidly and often die shortly thereafter. This is ethically and socially troubling and unnecessary.

It is worth recalling that in 1989 OBRA legislation, Congress added an unlimited fourth benefit period to the Medicare hospice benefit and the 6-month prognostic criteria was softened with statutory language that added "if the disease runs its normal course." Both actions were taken in recognition of the medical uncertainty regarding prognostication and in an attempt to address the reluctance of physicians to refer to hospice or the tendency to refer far too late. Instances of fraud and abuse should be vigorously pursued and prosecuted, but oversight programs must be conducted with an awareness of the social context and potential unintended consequences of these actions.

Government programs to uncover abuse and responsibly administer public funds must also preserve fair and equitable access to critically needed services by dying people. The most maddening aspect of this crisis in end-of-life care is that it need not exist. Dying is inherently hard but it need not be horrible. What we currently

lack is a firm commitment on the part of the health care system to bring the power of medicine to bear in service of comfort and quality of life.

Palliative care can be provided earlier in the course of a person's illness. By managing symptoms and helping people address difficult but normal psychosocial and spiritual concerns and assisting with the coordination of medical and supportive services, palliative care can dramatically improve the quality of life for persons and families.

Beyond assurance of relative comfort, people need not die alone. Many times the calm and caring presence of another person can soothe a dying person's anxiety and distress. But comfort and companionship are still not all there is. Over the years patients and families have taught me a surprising truth: that this stage of life holds remarkable possibilities. When people are relatively comfortable and know that they will not be abandoned and will not be allowed to become too heavy a burden on their families, they frequently use the time to strengthen bonds and complete relationships with the people that they love and create moments of profound meaning.

With basic good care, complementary therapies have a wonderful contribution to make. The one that I most often use is simply eliciting and listening to people's stories. In the process of life review, people often achieve a better sense of meaning about their own life, their struggles and regrets, their triumphs and joys, and also attain a deeper sense of the meaning of life in general.

A number of complementary therapies represent resources for inner growth. A person's culture, values, beliefs, and temperament will all influence which if any of these practices will be helpful.

This one national crisis has a solution that need not cost more money. When the basics of good medical and supportive care are provided, families are able to take care of their loved ones at home. That is what both families and patients want. Because dying people are by definition the sickest patients in our health care system, their care will never be inexpensive. Indeed, as comprehensive as it is, we can serve dying patients and their families and our country through the expanded use of hospice care which is significantly less expensive than care in its absence.

This high tech curative care that we provide is quite expensive. As people are confident that they can receive hospice care if we were to remove the terrible choice that is currently imposed by the eligibility criteria, people are more able to accept that they are dying, and stay at home. The either/or approach to the current Medicare reimbursement for hospice is built on an untested assumption: that providing life prolonging and palliative care together would be too costly.

The experience in Canada and Britain would strongly challenge this assumption. The field of palliative care has advanced dramatically in recent years, and as you will hear, is continuing to advance rapidly. Reimbursement structures and government policies have not kept pace. Government has a role in this crisis, has a role in resolving this crisis.

First, the formal audit of prevailing statutory limitations and regulatory policies regarding access to needed services and quality of care for people who are dying is urgently needed.

Second, creative models of delivering care have been developed and are ready for further testing. Demonstration projects such as those provided in Senators Rockefeller and Collins' Advance Planning and Compassionate Care Act of 1999 would be a major start.

Third, government can help by ensuring that medical education includes sufficient content in symptom management and the core skills of communication and ethical decisionmaking. These are not elective subjects.

Fourth, the compensation of aides in our Nation's home health and long-term care programs must provide them with a living wage and their own health benefits. Staffing must be improved so that aides have the time to care for residents.

Fifth, America's families are already giving their fair share in caring for their loved ones. Many are doing so at the cost of their own health. They deserve our support. Government can provide tax breaks for caregivers as they care for their loved ones, and as one of the Nation's major employers, can model flexible workplace and health benefit policies, setting an example for the industry.

As someone who has actively opposed the legalization of physician assisted suicide for years, I can tell you that opposition to legalization of physician assisted suicides sounds shallow and insincere unless it is wedded to a constructive program of caring that includes increasing the number of health care professionals who are able to provide skilled care.

While government does have a role to play, ultimately this is one national crisis that cannot be fixed by government alone. The communities of our Nation's neighborhoods, workplaces, schools, and our faith communities, all have critical roles to play. Each of us, as friends, coworkers, and neighbors, can reach out to those we know who are dying and to their families we know are struggling to provide care.

We can reach out to strangers as well. Compassion in Action's Twilight Brigade of Volunteers, which we will hear about, is an excellent example of what can be achieved. Stephen's Ministry, Parish nursing programs, the Care Team Networks offer American faith communities and workplace communities and neighborhoods examples of strategies that work.

In conclusion, we are in the midst of a real crisis in end-of-life care. But we have an opportunity to transform the way American society approaches the inevitable end of life. Before we allow our society to recognize a so-called right to preemptive death, we must honor a basic human right—to die in relative comfort, in the presence of caring people, and in a clean, dry bed. The real solution to the crisis of care for the dying ultimately will emerge one person at a time, by treating people in medically competent, genuinely caring, and even loving ways, allowing them to feel wanted, worthy, and dignified even in their terminal frailty and their physical dependence. Thank you, Mr. Chairman, for the opportunity to give testimony today on this most important topic.

[The prepared statement of Dr. Byock follows:]

**Testimony before the
Congress of the United States
House of Representatives
Committee on Government Reform**

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Director of the Palliative Care Service
and
Principal Investigator for the Missoula Demonstration Project
Missoula, Montana**

October 19, 1999

Mr. Chairman, members of the Committee, thank you for inviting me to give testimony about Improving Care at the End of Life with Complementary Medicine.

I am testifying today as an individual, not on behalf of any institution or organization. I've worked as a physician in hospice and palliative care since 1978. Over the years, I have written about the clinical and ethical aspects of end-of-life care including several articles opposing legalization of physician-assisted suicide. Some of these articles were cited in Amicus Briefs before the Supreme Court and one was cited by Justice Breyer in his concurring opinion.¹

I have served on numerous committees (including the ethics committees) and task forces of national hospice and palliative care organizations, and as a past president of the Academy of Hospice and Palliative Medicine. I am Chief Medical Consultant for Partnership for Caring, a recently formed consumer organization that advocates for expanded access to and quality of end-of-life care.

Currently, I am a Research Professor in the Department of Philosophy at the University of Montana and faculty member of the Practical Ethics Center. My central research interest is in measuring quality of life and quality of care in advanced illness. I am principal investigator for the Missoula Demonstration Project, a long term community-based effort to improve the quality of end-of-life care to demonstrate what may be possible in communities across the nation. I direct a national grant and technical assistance program for The Robert Wood Johnson Foundation entitled, Promoting Excellence in End of Life Care. I maintain a consulting and counseling practice in palliative care in Missoula, Montana.

Crises at the end of life: How people die in America

There is no greater urgency facing American society than relieving the crisis that surrounds dying and care for the dying in our country. The Institute of Medicine's report, *Approaching Death*, details the severity and pervasive nature of this crisis and concludes that there are serious deficiencies in medical education, health systems financing, attitudes and culture, and extensive errors of omission and commission in clinical practice.²

Dying patients and their families have known this for a long time. Even within otherwise excellent medical institutions, pain and physical suffering among dying Americans remains inadequately treated -- or even recognized. Up to 40% of dying patients receive grossly inadequate analgesia.^{3,4,5,6} Being of minority ethnicity, older than 80 or having dementia seriously increase the risk of having one's pain untreated. In addition, most Americans still die in institutions, approximately 60% in hospitals and 20% to 25% in nursing homes.

Patient's preferences for care often are not honored, even when those choices are clearly conveyed.⁷ As if that is not bad enough, our health care system routinely pauperizes people and their families for being chronically ill and not dying quickly enough. In the large SUPPORT study, one third of families of dying patients reported losing most or all of the family's major source of income; a third reported losing the family's life savings; and 20% said that a family member had to either move or delay their own medical care, education, or career to meet the basic needs of their dying loved one.⁸

Cultural denial marks the confused and conflicted way our society approaches life's end. Research and public opinion surveys demonstrate that it's not death so much as dying that we fear. We are terrified of becoming ill; being physically dependent and in pain, and we worry most about becoming a burden to others.⁹ However, although we all say we want control over the way we live and the way our lives end, only a small percentage of us fill out a living will or durable power of attorney for health care.¹⁰ Many people with far advanced illness refuse to talk about cardiopulmonary resuscitation or mechanical ventilation with their doctors.¹¹ Most people say they would prefer that their families make decisions for them if they become unable to speak for themselves,¹² but only a few of these people tell their families what kind of care they would want.

The resulting fear, deep frustration and anger fuel the assisted suicide movement. Unable to face the stark reality of this end-of-life crisis, many people have embraced legalizing physician-assisted suicide as a "quick fix" that would allow us to avoid the dark and twisted roots of the crisis.

Crises at the end of life: Care for the aged

In the late 1940's our nation awakened to a silent epidemic of pediatric failure to thrive. Rene Spitz and his colleagues studied foundling homes in which orphans were cared for and found the mortality was alarmingly high. Spitz determined that the key deficiency in the foundling homes was lack of human interaction. Babies would be fed, cleansed, swaddled and then lay untouched until it was the next time to be fed or have their diapers changed. He described the blank, listless stares of the infants.

The expressionless faces of too many elderly residents in America's long term care facilities call these studies to mind. They, too, are often untouched unless they are wet or it is time to be fed. We have an epidemic of geriatric failure to thrive in America today. The public is only now beginning to grasp the nature of the problem and has yet to grasp it's breadth. Nevertheless, the problem grows.

Today, aides in America's home health and long term care industries are over worked and woefully underpaid. These remain entry level jobs, often at minimum wage and without health benefits. It is no wonder that the annualized turnover rate among these people is over 100%. This level of churning in the

workforce inhibits meaningful training. And staffing is so short that aides rarely have time to spend simply listening to and visiting with elderly or ill residents.

The graying of America will accelerate dramatically between 2010 and 2030, as the baby boomers turn 65 years old. By the year 2030, 75 million Americans will be over 65, more than 20% of the population. In addition, there are 40 million Americans living now with chronic illness. Some estimates have that figure tripling by the middle of the 21st century.

While the graying of America accelerates, private caregiving resources within our individual networks of relatives and close friends are rapidly falling. Social trends, including geographic mobility, smaller families and families in which both adults are working have all contributed to this decline. Specifically, in 1970 there were 21 healthy adults representing potential caregivers for every person 85 years or older. In 2030 there will be just six such potential caregivers for the aged and just four by the middle of the next century.

Already families struggle to provide the sort of day to day, hour to hour, minute to minute care that we all want to give to our loved ones. I shudder to think of how hard it will be when it's my generation's turn to be cared for and our children's turn to provide care.

Crises at the end of life: The burden of family caregiving

Informal caregiving provided by relatives and close friends represents the unrecognized backbone of care in America. It is an enormous resource that can be supported and expanded as we grapple with the crisis of how badly Americans now die. A survey conducted in 1996 by the National Alliance for Caregiving and AARP found that nearly one quarter of households contained at least one caregiver.¹³ It is estimated that 25.8 million Americans spend an average of 18 hours per week caring for frail relatives. The economic impact of such care is extraordinary. It amounts to \$196 billion dollars per year, more than formal home health care (\$32 billion) and nursing home care (\$83 billion) combined.¹⁴

Among the most poignant characteristics of the caregivers revealed by the NAC/AARP study, are the fact that 73% of caregivers are women. These women devote an average of 4.5 years to caregiving, but often as many as ten or more. And 15% of all caregivers and 31% of those providing the highest levels of care report significant physical and emotional stress.¹³

Among the difficulties faced by caregivers are the profound needs of those for whom they care. Recently, researchers at the National Institutes of Health published an important study in the *New England Journal of Medicine* of caregiving needs among nearly 1,000 terminally ill patients living at home.¹⁵ Eighty-seven percent of the people needed help with things like transportation

(62%), homemaking services (55%), nursing care (29%) and personal care (26%).

These well documented facts must force American health policy makers and planners to expand the focus beyond the patient who is ill, including relatives and close friends who comprise a person's "family" in our planning. These facts also compelling us to look beyond the medical care to the care given by family and to the support provided by the persons community.

In summary, the existing data have cast a light on a very disturbing picture of end-of-life care in America. But the same light also illuminates potential avenues for constructive change.

Hospice Could Be One Answer

Hospice is a bright spot in this otherwise gloomy landscape, a hopeful beacon that exemplifies what we can achieve. Excellent hospice programs have provided us with a best practice standard, a benchmark against which to gauge the outcomes of our clinical and policy efforts.

But hospice is wrestling with problems as well. Hospices now care for barely 20% of dying Americans and do so for rapidly diminishing periods of time. Numbers of admissions to hospice have actually increased to a current high of approximately 540,000 a year, but lengths of stay have plummeted to an all time low.¹⁶ In most programs, many patients receive care for barely two weeks. Intended to provide end of life care, hospices are now scrambling to provide brink of death care.

The Medicare eligibility criteria of a six-month life expectancy has strongly and adversely influenced the delivery of hospice care in America, severely limiting access to persons whose diseases, such as congestive heart failure, emphysema or senile dementias, are characterized by a prolonged or stuttering disease trajectory. Implementation by Medicare fiscal intermediaries of strict prognostic guidelines and rigid eligibility criteria for hospice admission threaten to further limit access to palliative care by patients with non-cancer diagnoses.^{17,18,19} In addition, these trends toward later referrals and shorter and shorter lengths of hospice care have substantially worsened under the influence of the Office of the Inspector General's Operation Restore Trust.

Operation Restore Trust has sent a chill through American hospice programs. Hospice administrators and medical directors are worried -- with good reason -- that if they admit patients with slowly progressive, but ultimately terminal, illnesses who live beyond a few months, the program will be investigated for fraud for having admitted the patient. Death typically occurs suddenly and somewhat unpredictably for patients dying of chronic heart, lung or neurologic diseases, in the midst of slow, up and down decline. Thus, there is reluctance

to admit them until they are obviously dying -- too late for them to realize most of the benefits of hospice care. Also, many hospice programs feel compelled to discharge patients who have become relatively stable with the comprehensive care hospice provides. Away from hospice care, these patients, decline more rapidly and die shortly thereafter. This is ethically and socially troubling. And unnecessary.

In addition to preventing patients from receiving good hospice care, the Medicare intermediaries' Focal Medical Review procedures and Operation Restore Trust investigations entail huge administrative costs for hospice programs, often involve frozen payments and carry the risk of large recoupment. These events can threaten the very survival of a small or moderate sized community hospice program.

With this level of intense scrutiny one would expect that the problem being addressed in this tiny sector of our nation's health care industry would be proportionately large. Yet, the Office of Inspector General's own report concludes that instances of abuse in Medicare's two billion dollar hospice program are uncommon.²⁰

Is it necessary to be focusing such intense scrutiny on hospice programs? It is worth recalling that in the 1989 OBRA legislation, Congress added the unlimited fourth benefit period to the Medicare Hospice Benefit and the 6 month prognosis criteria was softened with statutory language adding, "if the disease runs its normal course." Both actions were taken in recognition of the medical uncertainty regarding prognostication and in an attempt to address the reluctance of physicians to refer to hospice, or the tendency to refer too late.

Instances of fraud and abuse should be vigorously pursued and prosecuted. But oversight programs must be conducted with an awareness of the social context and potential unintended consequences of the actions. Government programs to uncover abuse and responsibly administer public funds must also preserve fair and equitable access to critically needed services by suffering people.

It doesn't have to be this way

The most maddening aspect of the crisis in end-of-life care is that it need not exist. Dying is inherently hard, but it need not be horrible. We possess the medical expertise and more than enough resources to ensure that no one will die in physical agony. Pain and other distressing symptoms among dying persons *can always be alleviated*. Doctors and nurses may not be able to eliminate a person's pain, but we are always able to make it a little less severe, a bit more tolerable.

What we currently lack is a firm commitment on the part of the health care system to bring the power of medicine to bear in service of comfort and quality of life. Palliative care can be provided earlier in the course of a person's illness. By managing symptoms, helping people address the difficult, but normal, psychosocial and spiritual concerns they may have and assisting with coordination of medical care and support services, including transportation and housekeeping, palliative care can dramatically improve the quality of life for the patient and his or her family.

Beyond assurance of relative comfort, people need not die alone. Many times the caring presence of another person can soothe a dying person's anxiety and distress. But comfort and companionship are not all there is.

Over the years, patients and their families have taught me a surprising truth; this stage of life holds remarkable possibilities.^{21, 22} When people are relatively comfortable, know that they will not be abandoned or allowed to become too heavy a burden on their families, they frequently use the time to strengthen bonds and complete relationships with people they love and create moments of profound meaning.

People who are dying of a progressive illness have a chance to consider the question of what would be left undone if they died suddenly. In contrast to a sudden death, they can ask themselves what matters most and say and do many of the things that come in answer to those questions.

Complementary Therapies

When basic good care is provided, the complementary therapies have a wonderful contribution to make to people's comfort and quality of life. The "complementary therapy" that I most commonly employ is the simple practice of eliciting and listening to people's stories. In the process of life-review, people often achieve a better sense of the meaning of their own life; their struggles and regrets as well as their triumphs and joys. They also may attain a deeper sense of the meaning of life in general.

Obviously for many people approaching death, the spiritual aspects of life come to the fore. Spirituality and religion are not synonymous. Although many people cherish a felt connection to God, spirituality also exists in a felt connection to one's family that will live on for generations to come. And spiritual bonds can extend beyond family. Fatally injured soldiers may express a connection to their country which will survive partly through their sacrifice. In Montana, people I care for commonly express a sense of connection to the wilderness, the rivers and the mountains into which their body or ashes will go.

A number of alternative or complementary therapies represent resources for inner growth. Massage therapies can provide moments of peace and generate

positive physical memories to balance the pain of illness. Therapeutic touch, an increasingly accepted nursing technique, can alleviate patients' pain and anxiety. Relaxation training and meditation can help a person center swirling thoughts and calm emotions. Meditation and contemplative prayer can provide a place of safety and distance, not from, but *within*, the experience. This ability to remain centered and "well within oneself" in the middle of distraction, doubt, anxiety and bodily discomfort is recognized by many cultures and religious traditions as being critical preparation for the transition from life.

The techniques of dream work and guided imagery, skillfully practiced, can help people explore inner realms and uncover rich insights from their unconscious. Breath work can allow access to otherwise hidden domains of personal and transcendent experience.

A person's culture, values, beliefs and temperament will all influence which, if any, of these practices will be helpful. But a common element among these techniques and therapies is that they foster a sense of inner confidence and openness. By relaxing body and mind a person can become more open to and less fearful of the mystery that awaits.

Costs of Better Care

This is one national crisis whose solution need not cost more money. When the basics of good medical and supportive care are provided, families are able to care for their loved ones at home. It's what patients and families want to do.

Because dying people are, by definition, the sickest patients in the health care system, their care will never be inexpensive. However, home-based care of people with advanced illness, although not cheap, is much less costly than the institution-based, medically focused care dying people currently receive. Indeed, as comprehensive as it is, even full hospice care is significantly less expensive than the care that is provided in its absence.^{23,24}

Although hospice is less expensive than our "high-tech" curative care, statutory requirements that a person give up life-prolonging care as a requirement for hospice under Medicare erect a significant barrier to utilizing hospice. This requirement imposes a "terrible choice" on seriously ill patients and their families. They must acknowledge that the patient is officially "dying," an emotionally devastating milestone that no one wants to cross. They also may need to relinquish their relationship with their oncologist, cardiologist, neurologist or pulmonologist and give up access to the hospital or another round of chemotherapy. Expensive medications to build up blood counts or treat resistant cases of nausea and vomiting may not be available under hospice care. Is it any wonder that some people refuse to make that choice?

But, in fact, once admitted to hospice programs, the vast majority of patients and families are delighted with the care they receive. They become confident of being cared for, even in emergencies and as confidence builds, they tend to focus more on quality than absolute quantity of life. By providing a skilled and reliable home-based alternative to ambulance transports, emergency rooms, MRI's and ICU's, hospice experience shows that high levels of hands on care can be provided while remaining cost effective.

This either-or approach to Medicare reimbursement for hospice care is built on the untested assumption that providing life-prolonging and palliative care together would be too costly. The experience in Canada and Britain would strongly challenge this assumption. In both countries, care for patients with chronic, progressive illness is of higher quality and significantly less cost. Although both health care systems have their problems, hospice is widely available, and few people worry about leaving their family financially devastated as they die.

An important new model of affordable, enlightened long term care is provided by the Eden Alternative. Initially developed by Dr. William Thomas, the Eden Alternative has become a virtual movement within progressive segments of long term care, especially dementia care.²⁵ In Eden nursing homes, there is strong emphasis on "greening" the environment with plants and pets. Intergenerational activities between seniors and young children and pleasurable human interaction are also fostered. The impact of "edenizing" nursing homes on patients with dementia can be profound. People who have been withdrawn often brighten when interacting with a colorful bird, affectionate dog or cooing baby. Even having responsibility for a plant has been shown to have notable impact on a person's health.

Government's Role

The field of palliative care has advanced dramatically. Reimbursement structures and government policies have not kept pace. Unless bold and creative new solutions are helped to flourish, Americans won't achieve the goals they say they want; to live out their lives in comfort and at home.

Where do we start? First, a formal audit of the effects of prevailing statutory limitations and regulatory policies on access to needed services and quality of care for people who are dying is urgently needed.

Second, creative models for delivering care have been developed and are ready for further testing. Demonstration projects, such as those provided for in S.628, the *Advance Planning and Compassionate Care Act of 1999*, introduced by Senators Rockefeller and Collins, can document the impact of alternative models of advanced illness care on clinical care, quality of life, and utilization of health system resources. Alternative eligibility for hospice care, simultaneous provision

of hospice and life-prolonging care, wider application of PACE (Program of All-inclusive Care for the Elderly) and reimbursement models such as the Medicare proposal of the Center to Improve Care of the Dying all warrant formal study.

Third, government can help by ensuring that medical education includes sufficient content in symptom management and the core skills of communication and ethical decision making.

Fourth, compensation of aides in the nation's home health and long term care programs must provide them with a living wage and their own health benefits. Requirements for training and certification of aide level personnel must be raised. So, too, staffing levels must be raised, enabling aides in nursing homes the time to give adequate care to the residents. The costs of these "high touch" improvements would be modest and more than likely would be offset by a corresponding reduction in futile "high tech" care and emergency admissions to hospitals and intensive care units.

Fifth, America's families are already giving their fair share in caring for their loved ones -- in fact many are doing so at the cost of injury to their own health. They deserve support. Government can provide tax breaks for caregivers and, as one of the nation's major employers, can model flexible workplace and health benefit policies, setting an example for industry to follow.

As someone who has actively opposed the legalization of physician-assisted suicide, I can tell you that opposition to physician-assisted suicide is shallow and insincere unless it is wedded to a constructive program of caring that includes increasing the number of health care professionals who are able to offer skilled care.

Other Players:

Government can ensure equitable access to critically needed services such as hospice and home care. But ultimately, this national crisis is not one that can be fixed by government alone.

The communities of our nation's neighborhoods, workplaces, schools and the faith communities of our congregations also have critical roles to play. Each of us as friends, co-workers and neighbors can reach out to those we know as they are dying and to the families we know are struggling to provide care. We can even reach out to strangers in need. Compassion in Action's Twilight Brigade of volunteers is an excellent example of what can be achieved. The critical service they provide is to show up. In so doing they give tangible evidence that they care and that the person who is dying still matters to them.

Other programs around the country also provide us with valuable models of volunteer training and community-based support. The Stephen's Ministry programs, Parish nursing programs, Care Team Network programs in Texas and Alabama, among others, offer American faith communities, workplace communities and neighborhoods examples of strategies that work. We can and must build on these important examples.

Conclusion

In the midst of this crisis in end-of-life care, we have an opportunity to transform the way American society approaches the inevitable end of life. The root problems that comprise this crisis are many and deep, but every one can be addressed. We can build a future in which no one has to die alone or with their pain untreated. Congress can provide critical leadership in approaching this national crisis. Ultimately, the real solution to this national crisis lies in strengthening communities in which people share a sense of common life and look after one another, because to ignore each other's needs would be seem as unnatural as it is.

Before we allow our society to recognize a so-called "right" to preemptive death, we must honor a basic human right to die in relative comfort, in the presence of caring people and in a clean, dry bed.

Each of us can play an important role in realizing this goal, as legislators, as clinical professionals, but also as family members, friends and neighbors. We can see to it that people are cared for in a way that ensures relative comfort, prevents a sense of isolation but that also and honors people in their passing.

The real solution to the crisis of care for the dying ultimately will emerge *one person at a time* by treating people in a medically competent, genuinely caring and even *loving* manner, allowing them to feel wanted, worthy and dignified even in their terminal frailty and physical dependence.

Thank you for the opportunity to give testimony on this most important topic.

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The People

Whiskies from all areas of the community were on the work groups (Clark Foreest, and a many other people)

The Task Forces (current and future)

- Life Sciences
- Fifth Communities
- The Arts
- Advanced Care Planning
- Plan as a Fifth Vital Sign
- Complementary Therapies
- Wish Site
- Living Room Care
- Schools
- Future

Together we are embracing the challenges of living with honesty, caring, and commitment

An Invitation

To discover how you can be reached, for a referral to agencies in the community to share opportunities or to ask questions, please feel free to call, write, or stop in

Shoreline Community Center, 1000 N. 10th Street, Shoreline, WA 98148 or 206.251.1111 or 206.473.1111

A Vision of the Future

A future "generation of children will, most likely, not even comprehend that we had to write books on death and dying and had to start special institutions for the dying patients. They will not understand why there was this overwhelming fear of death, which we in doing covered up the fear of living."

Elizabeth Kubler-Ross, MD

Join us in this Dream



MSDF represents those people who work to improve the quality of life for all. We are committed to the future of our community and to the well-being of all who live here.

By: David J. Nelson, Executive Director, MSDF

Missoula Demonstration Project The Quality of Life's End



Building a Community Vision



Missoulian

APRIL 28, 1999

MISSOULA, MONTANA

MISSOULA DEMONSTRATION PROJECT

A loving death



Dying with dignity in Missoula can become the national metaphor

By IRA BYOCK

Jack Kevorkian is in prison, doing 10 to 25 years for murdering Thomas Youk. Yet when it comes to talking about dying in America, he remains in the driver's seat. Any discussion of end-of-life care invariably begins with the question, "What do you think about Kevorkian?" His peculiar perspective has captured and continues to frame America's view of life's end.

Except here. Something is happening in Missoula that sets us apart. With help of the Missoula Demonstration Project: The Quality of Life's End (MDP), Missoula is gaining a broader perspective and a sensitivity to the needs of people who are dying, their caregivers and grieving family.

Not that Missoula is a utopia. The many problems that plague dying in America are felt here as well: challenges of pain management, inconsistent respect for people's preferences for care, breakdowns in clinician-patient communication, financial stress, too little support for family caregivers, people feeling isolated and alone. These problems may be less severe in our community, but Missoula is the real world.

What is different here is that we have not allowed ourselves to be confined by the suffering-on-suicide dichotomy not mesmerized by Kevorkian's promise of a quick fix. Instead, we are taking a hard look at dying and grief and taking steps to improve the quality of life's end. We don't have all the answers, but we are asking critical questions: What individual and collective responsibility—and "response-ability"—do we have toward people who are dying—our family members, friends but also

our neighbors? What value is there in the last phase of life? Can there be any value in the process of dying? Missoulians are investigating what it means to live in a community with one another in ways that integrate dying and caregiving within the continuum of human life.

The Missoula Demonstration Project is a collaborative, communitywide effort to study and transform end-of-life experiences and care. Both local hospitals and every nursing home and home-health provider in Missoula are actively participating, along with many of our town's doctors and nurses, health-care aides, social workers and emergency medical technicians. So, too, are ministers, faith community members, artists, writers, educators and everyday people who are simply interested.

During its first few years MDP has focused on research. We've taken—and are now developing—a high-definition snapshot of end-of-life experience and care. The data will serve as a baseline for future research, including comparisons with two demographically similar communities in the Northwest.

Over the next few years MDP will employ these research findings to fuel ongoing discussions of how we can make things better. MDP's strategy is not to impose a specific vision or set of values, but to authentically involve people throughout our community in defining what success would look like and in working together to achieve success.

This process has already yielded tangible results:

- The project's Pain Task Force has conducted conferences and workshops in which hundreds of area doctors, nurses and pharmacists improved their knowledge and skills in controlling

pain. State-of-the-art pain assessment tools and treatment protocols are now available in every health-care setting in Missoula. St. Patrick Hospital recently added pain as a "vital sign" to its computerized clinical flow sheets, right alongside temperature, blood pressure, pulse and respiration. Similar efforts are under way in other health-care settings.

- The Advance Care Planning Task Force developed "My Choices," a user-friendly form that combines a living will and a power of attorney for health care. Every local health-care organization has endorsed its use, making Missoula the first city to have a consistent communitywide document for communicating preferences for care.

- The Faith Community Task Force is helping to expand the capacity of local ministers and congregations to support members who are confronting life's end and family members who are struggling to provide care. Just last week many faith community leaders came together for a full day to explore these issues.

- Life Stories Task Force has successfully raised local awareness of the precious nature of our collective memories. The task force is so successful, in fact, that a separate nonprofit community organization, Story Keepers Inc., has emerged to continue this nurturing work.

Plans are on the drawing board for new research initiatives, new task forces in education and caregiving, and new avenues for volunteer training and services to Missoula local families.

The work within MDP and throughout Missoula on these broad issues is for the good of us all. Many of us will age, become

caregivers, and eventually die right here, in the shadow of our mountains. But our efforts have importance far beyond the Five Valleys. Already we have attracted the attention of national foundations, academic institutions, policy makers in Washington, D.C., and national media. We've received inquiries from people in places like Bend, Ore., Akron, Ohio, and St. Joseph, Mo., all of whom are replicating one or more aspects of our community's efforts. Researchers from around the country are using our survey instruments and will be contributing data to expanded comparative studies.

As baby boomers age and the number of people living with chronic illness or advanced old age soars, issues regarding dying and caring for those who are dying will remain at the forefront of our national priorities. Missoula has an opportunity to serve our nation simply by caring for one another locally in ways that combine medical excellence with compassionate and unabashedly loving care. We can build creative community muscle for ensuring people are comfortable and feel wanted, worthy and dignified as they die.

Not too many years from now, when Kevorkian has become just a footnote, whether people are discussing end-of-life care in Peoria, Pensacola or Petaluma, you can be sure someone will ask, "Have you heard what they're doing in Missoula?"

In fact, many already are.

Ira Byock, M.D., is a faculty member at the University of Montana's Practical Ethics Center. He is co-founder and principal investigator for the Missoula Demonstration Project.

Mr. BURTON. Thank you, Dr. Byock. I appreciate your testimony and your entire statement will be included in the record and we will look at that. We will have some questions for you. If we could keep our comments close to 5 minutes, I would really appreciate it.

Mr. Brinkley.

Mr. BRINKLEY. Well, first, I would like to say I am from South Carolina, but I work in California. Everything that Ira said is exactly what I was going to say, so I have really nothing to say, and I will read through this briefly.

Good afternoon, Mr. Chairman and members of this committee. I am honored to be here to discuss improving care at the end of life for all Americans, but especially veterans. I appear before you today as the chairman of the Board of Compassion in Action and also appear before you today as an advocate of integrating alternative and complementary therapies.

Compassion in Action is a nonprofit organization. At the core of our mission statement is our conviction that no one need die alone. And to this end, we recruit and train volunteers to serve at the bedsides of those who are nearing the end of life. In addition, we respond to the needs of community and professional education on the subject of death and dying through lectures, workshops, and seminars.

We have volunteers serving in 17 cities, and I am happy to report that we are now fielding questions from countries all over the world. I have personally served as a hospice volunteer for over 20 years. I have been a part of the end-of-life care team for over 270 individuals, and personally held in my own arms 176 persons breathing their last breath, one of these my mother. So my heart goes out to you and my understanding, Mr. Chairman, exactly where you are and why I am really proud that we are able to come and face this at such a short time after your loss.

I can tell you that volunteers are an integral part of the vital part that the hospice circle of care takers. The Veterans Administration itself has over 350 volunteer service organizations, 110,000 volunteers. We are making the difference now in the VAs. With the issues that we are about to deal with, the volunteer can be there when professional staff cannot. The Compassion in Action team are comfortable with a broad range of emotional and spiritual issues from the most basic to the most profound.

Compassion in Action volunteers are carefully trained to be skilled listeners, much like Dr. Byock said, because listening is the greatest gift we can offer any other human being. Because they do not get paid for their services, it is very clear that they are there to serve for reasons of the heart. Did you know that over 32,000 World War II veterans will leave this world every month, and by the year 2001, the number will increase to over 40,000 per month, and that is just our World War II veterans?

Without volunteers, careful management and cost-effective measures, this system could be dangerously close to collapsing. Senator Thurman and Congressman Floyd Spence, leaders on the Veterans Administration appropriation on both sides of the Senate and the House, and old family members, are aware of these issues. But Compassion in Action volunteers can see things that they cannot.

With the help of my old friend, and my Congressman, Lindsey Graham, we are working very closely with these legislators to assist in developing appropriate programs to effectively bring forth the desired solutions in end-of-life care. The sad fact is too many veterans are dying alone. I find this totally unacceptable and I am dedicated to changing this. These men and women were there for us when we needed them. We must be there for them at this critical time.

For this reason, Compassion in Action established a partnership with the Veterans Administration and, in fact, our national headquarters are located on the campus of the West Los Angeles VA Administration. And that happens to be Congressman Waxman's district. Our volunteers are now serving in VAs in Chicago, Atlanta, Seattle, San Diego, Spokane, Sacramento, Palo Alto, and Los Angeles.

We are determined to create a volunteer corps, the Twilight Brigade, trained disciplined troops that will serve dying veterans across the country. Our veterans hospitals are filled with men and women who are facing death. Many have no family or friends to visit them. Imagine a veteran lying there, very near the end of life, so sick that he can no longer speak. His only visitor has been a Compassion in Action volunteer. One of those volunteers noticed that a brother and daughter, listed in his chart, with a notation that they have been estranged or pushed apart for over 15 years. Asking permission from the staff, the volunteer contacted the family member explaining the situation and asked if they would be willing to say a few words to this man in his desperate need. They both agree. Holding the phone to a patient's ear, the volunteer watched as tears slid down his cheeks, hearing healing words being spoken. Hours later he took his last breath and left in peace. This is reality and this happens everyday. It is where the volunteer truly serves, and I hate to say, volunteers and hospice are alternative and complementary medicine in our present medical system.

A lot of people wish and say, I just wish I had 5 more minutes. We are trying desperately in Compassion in Action to create the arena where just 5 more minutes becomes an institution. But the picture is not always as bright as this. Here are some things we have heard from volunteers across the country.

Because of frequent rotation of interns and residents, there is a serious discontinuity in patient care within the veteran facilities; pain management is less than optimal and there have been times when veterans have truly died unnecessarily. I have to agree with the two committee members about putting the DEA in control of the quality of end-of-life care. They cannot legislate legal control of a doctor's ability, and it takes a good critical care doctor to understand it—just what you went through. I am sorry that the DEA and law enforcement agencies get a little territorial in these issues, because it should be the health care professional's job, and I hope as you said earlier, Mr. Chairman, that these issues can be worked out.

The dying are kept in rooms where noise levels are so high, radios, televisions blaring, the individual cannot even die peacefully. Inadequate discharge planning often leaves veterans and their loved ones totally unsupported. Well intentioned nurses cannot

serve their patients adequately, due to serious understaffing and worst of all, patients that are moved either within the hospital or to a facility off the grounds of the hospital when they are actively dying. In some VAs, the nurse-patient ratio is completely unacceptable.

These are grave problems, and anyone concerned about the quality of end-of-life care of our veterans, must address them. Compassion in Action can play a part in this solution, and I am pleased that a new executive officer in Congressman Waxman's district, Phil Thomas, at the Greater Los Angeles VA, has ordered a focus group meeting with our volunteers to identify these problems and to seek viable solutions.

There are now many VA administrative chief executive officers that are reaching out and looking for these answers. I would like to mention some of the people who have helped me very, very much in the VA: James Delgado, the National Volunteer Coordinator; Bonnie Ryan, National VA Hospice Administrator; Beverly Fitzgerald of the West Los Angeles VA; and many other staffs in the other places we are working.

As a man who has been twice struck by lightning, survived heart failure, open heart surgery, three ruptured subdural hematomas, and brain surgery, and after that having a massive grand mal seizure, I have some idea of what the personal experience of end-of-life care that people go through. I am one of these people. I am one of the people who went into hospice, but by the grace of God and good medicine, both complementary and conventional, I sit before you today. I have a personal interest in this because I am one of these people.

I know it is as important to look up at that acoustical ceiling in a hospital as it is to look down at that person. And I wanted to let everyone know that what I have learned through these experiences, is death is not to be feared. However, sometimes the path there is a tortuous hell. Three years ago, as I lay again in a hospital intensive care unit, I became very much aware of the quality of end-of-life care, the noise, the inadequate pain management, and the problems that people are going through. We need healing, peaceful, relaxing environments, and wellness can be achieved even when dying. Emotional, spiritual and relationship understanding can be effectively used to improve end-of-life care.

Almost 10 years ago, I participated in the planning of the Office of Alternative Medicine at town meetings and then at Chantilly, VA for the leading alternative medical experts. As a result of this report, what is commonly known as the "Chantilly report," the National Institutes for Health outlined complementary and alternative advisory programs. I have also attended, all but two, advisory committees over the last 8 years. I missed one because of brain surgery and another because of a hurricane. I think that this has to be looked at more and more, and I find that the last 10 years of this has been woefully inadequate. More has to be placed upon this.

There are complementary and alternative therapies that can be very helpful. Acupuncture has been proven valid with chemotherapy nausea and pain management. A sense of calm is incorporated through things like music and aromatherapy. Therapeutic

touch and even prayer expressed by Dr. Larry Dossey, a two tour MASH combat veteran and a combat surgeon, and his wife, who is a doctor of nursing, doing research in alternative measures. The power of the human touch is invaluable. Just think how wonderful it would feel to know that someone would just hold your hand and listen, massage your feet, and the only other touch you ever get is somebody rolling you over administering some type of medicine.

Guided imagery and visualization are very helpful in pain reduction and stress reduction. Music therapy and guided imagery have been shown to be effective in trauma recovery and grief recovery, in rape and abuse cases. Surely it can help a family in stress. And I think probably the most important treatment is not a treatment at all. It is the life review. This is important for someone to review their life, talk about their childhood, marriage, birth of their children, their life as a veteran and also maybe some other not so important issues.

This is a time for people to have a healing path between relationships. Compassion in Action volunteers are carefully trained in closure technique. Closure is one of the most important complementary therapies for both the patient leaving this world, and those staying behind, and I cannot emphasize closure enough. I would like for people to really pay attention to the fact that these are going to be the issues over the next 4 and 5 years. This is where it is going to be, and that people who could not look at death, will look at death now, because it is their moms and dads, their brothers and sisters and their friends.

Look at No. 1 best selling books like "Tuesdays with Morrie," which is the study of a gentleman going back to his professor and reliving his life together. The fact that that book has stayed in the top 10 bestsellers list for the last year tells us we are looking at this. It was recently made into a television movie by the Oprah Winfrey Production Co. that will air on NBC. This shows us that this will be one of the campaign issues. This will be what we will look at.

Another thing that is very interesting is the time we are living in this country we are facing the turn of a century and the turn of a millennium. We have estimated that our health care costs are going to double by the year 2007. In the coming years, the geriatric population is going to outnumber those 18 and under. What this means, is that we are a Nation in need to prepare for when it will become our time for end-of-life care. No one wants to think about death, and doctors, typically, are not terribly comfortable discussing with the patient, that the time has come to change from aggressive curative measures to palliative measures.

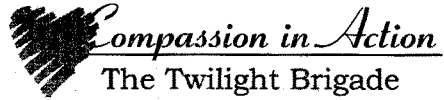
This is why many doctors wait until the last minute, sometimes only days prior to death. It is also a huge chunk of medical expenditures that come in the last 3 weeks. I think a study by the NIH of the opinions of critical care doctors and how they manage this burden could be very effective in changing this paradigm.

Over the last years, I have seen and been helped, by a lot of people in the NIH, in Congress, in the Office of Alternative Medicine, and just people looking to try to understand how to help each other. I am very grateful to you, Chairman Burton, for your courage in opening up this discussion. I am very thankful to you, Mr.

Waxman, for what you are doing. We must face our own mortality before we can help those whom we love and who have loved us face theirs.

I am truly thankful for this committee's historic act. By raising the awareness in Washington about these issues, we can find and begin to see the solutions. In the military, we are trained never to leave our wounded buddies on a battlefield. These World War II veterans never deserted this country in its time of need. We cannot desert them. I thank you.

[The prepared statement of Mr. Brinkley follows:]



Testimony of

Dannion H. Brinkley

**Chairman of the Board
Compassion in Action**

**Before the Government Reform Committee
United States House of Representatives**

Hearing

**"Improving Care at the End of Life
with
Complementary Medicine"**

**October 19, 1999
1:00 pm**

**2154 Rayburn House Office Building
Washington, D.C.**

<http://www.twilightbrigade.com>

Good afternoon, Mr. Chairman and Members of the Committee. I am honored to be here today to discuss improving care at the end of life for all Americans, but especially for Veterans. I appear before you today as Chairman of the Board of Compassion in Action. I also appear before you today as an advocate for the integration of alternative and complementary methods of healing.

Compassion in Action is a non-profit organization. At the core of our mission statement is our conviction that no one need die alone. To this end, we recruit and train volunteers to serve at the bedside of those nearing the end of life. In addition, we respond to the need for community and professional education on the subject of death and dying through lectures, workshops, and seminars. We have volunteers serving in 17 cities across the United States, and I am happy to report we are now fielding calls from other countries as well.

I personally have served as a hospice volunteer for over twenty years. I have been a part of the end of life care team of over 270 individuals and personally held over 176 persons as they breathed their last breath. One of those was my mother. I can tell you that volunteers are an integral and vital part of the hospice circle of care. The Veterans Administration has over 350 Volunteer Service Organizations with over 110,000 volunteers. Volunteers are there when the professional staff cannot be there. The Compassion in Action Volunteer Teams are comfortable with the broadest range of emotional and spiritual issues – from the most basic to the most profound. Compassion in Action Volunteers are carefully trained to be skilled listeners, because listening is the greatest gift we can offer another human being. Because they do not get paid for their services, it is clear that they are there to serve for reasons of the heart.

Did you know that over 32,000 World War II veterans leave this world every month? In 2001, that number will increase to over 40,000 per month. And that is just our Veterans from World War II. Without volunteers, careful management and cost-effective measures the system could be dangerously close to collapsing. Senator Strom Thurmond and Congressman Floyd Spence, leaders of Veterans Administration appropriations on the both the Senate and House Sides of Congress, and both old family friends, are aware of these issues. But the Compassion in Action volunteers see things they cannot. With the help of another old family friend, former Congressman Arthur Ravenel as well as my own Congressman Lindsey Graham, we are working very closely with these legislators to assist in developing appropriate programs to effectively bring forth the desired solutions.

The sad fact is that too many of our veterans are dying alone. I find this totally unacceptable and am dedicated to changing this. These men and women were there for us when we needed them, and we must be there for them now at this critical time.

For that reason, Compassion in Action has established a partnership with the Veterans Administration. In fact, our national headquarters are located on the campus of the West Los Angeles Veterans Administration. Our volunteers are now serving veterans in Chicago, Atlanta, Seattle, San Diego, Spokane, Palo Alto, Los Angeles and Sacramento.

We are determined to create a volunteer corps – the Twilight Brigade – trained and disciplined troops that will serve dying veterans around the country.

Our Veterans hospitals are filled with men and women who are facing death. Many have no family or friends to visit them. Imagine, a veteran lying in bed, very near the end of life, so sick that he can no longer speak. His only visitors have been Compassion in Action volunteers. One of the volunteers notices a brother and daughter listed in his chart, with a notation that he has been estranged from both for over 15 years. Asking permission from the staff, the volunteer contacts both family members, explaining the situation and asking if they would be willing to say a few words to a man in desperate need. They both agree. Holding the phone to the patient's ear, the volunteer watches as tears slide down his cheek. Healing words are being spoken. Hours later, he draws his last breath and dies in peace. This really happened. We were there. And we made a difference!

We later heard from both the brother and the daughter that they were very thankful they have had the chance to be in communication so they did not go through the rest of their life, with what I call the "If I had only had five more minutes" guilt burden. Closure is very important for family and loved ones.

But the picture is not always that bright. Here is what we have heard from our volunteers around the country:

- Because of the frequent rotation of interns and residents, there is a serious discontinuity in patient care within Veterans facilities.
- Pain management is less than optimal, and there have been times when veterans have died in unnecessary pain.
- The dying are kept in rooms where the noise level is so high – radios and televisions blaring – that these individuals cannot die peacefully.
- Inadequate discharge planning often leaves veterans and their loved ones totally unsupported.
- Well-intentioned nurses cannot serve their patients adequately due to serious understaffing.
- Worst of all, patients are moved either within the hospital or to a facility off the grounds of the hospital when they are actively dying.
- In some VA's the nurse-patient ratio is totally unacceptable.

These are grave problems and anyone concerned about quality of end of life care for our veterans must address these issues.

Compassion in Action can be part of the solution. I am pleased to report that the new Chief Executive Officer in Congressman Waxman's district, Philip Thomas, at the Greater Los Angeles Veterans Healthcare System, has ordered a focus group meeting with our volunteers to identify the problems and viable solutions. There are now many other Veterans Administration Chief Executive Officers that are reaching out looking for answers.

There are many dedicated and helpful individuals within the Veterans Administration. James Delgado, the National Volunteer Coordinator, Bonnie Ryan, National VA Hospice Administrator, Beverly Fitzgerald of the West Los Angeles facility, and the many other VA staff at West Los Angeles, Spokane, Sacramento, San Francisco, and that Peach of the South, Atlanta, Georgia.

As a man who has twice been struck by lightning, survived heart failure, open heart surgery, three ruptured subdural hematomas, and brain surgery, and a massive grand mal seizure, I have had much personal experience with end of life issues. I often tell my Dad that I have been successful at many things in my life, but dying is just not one of them!

What I learned from these experiences is that death is not to be feared. However, sometimes the path there is a torturous hell. Three years ago, as I once again lay in a hospital Intensive Care Unit, looking up at an acoustic ceiling, I listened to the sounds around me and what I heard was fear and agony. Hospitals, nursing homes, and hospices can and should be peaceful and healing environments. And yes, wellness can be achieved as one is dying – emotional, spiritual, and relationship understanding can be healing. I have dedicated my life to improving care, especially for those at the end of life.

I am not a scientist or a doctor. I am just an average guy who has had some rather extraordinary experiences. Because of the things that have happened to me, I know people are interested in this topic. I have written two international best sellers about death, palliative care, alternative therapy and transformation. I am very thankful to Harper Collins/Newscorp for their support in my efforts to improve end of life care. I would also like to thank Sumner Redstone, a World War II veteran, and his companies, Viacom/Paramount and Dreamworks for which Steven Spielberg produced *Saving Private Ryan* – a tribute to his father - for their continuous support in helping Compassion in Action make a difference in the lives of Veterans.

Almost ten years ago, I was asked to participate in the planning of the Office of Alternative Medicine at a series of town meetings and then a meeting in Chantilly, Virginia of the leading alternative medicine experts around the country. As a

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result of this meeting, a report commonly known as the "Chantilly Report" was issued to the National Institutes of Health outlining the complementary and alternative medicine issues. I understand that copies were delivered to every member of Congress in 1994 when it was published. I hope each of you has read it. I also have attended all but two of the Advisory Committee Meetings over the last eighth years -- being kept away once while in the hospital for brain surgery and the second time by a hurricane.

There are many complementary therapies that can be helpful for someone near the end of life. Acupuncture has been scientifically validated for chemotherapy nausea and can also be used for pain management. A sense of calm can be achieved by incorporating simple things like music and aromatherapies like lavender, rose, or sandalwood. Massage therapy can be very beneficial for muscular pain or tension. Therapeutic touch and prayer -- as expressed in the works of Dr. Larry Dossey, who wrote *Prayer is Good Medicine*, and has recently published the book, *Reinventing Medicine*, and his wife Barbara Dossey, a critical care nurse, who has taught and written extensively on compassionate caring in medical care -- have shown to be effective tools in end of life care.

The power of human touch is invaluable. Just think how wonderful it would feel for you to have some one hold your hand or massage your feet when no one ever touches you except to provide medical attention?

Guided imagery or visualization is helpful for someone who is dealing with pain or stress. These all can be helpful for patients and their loved ones. Family members are often under extraordinary stress and can benefit from meditation and breathing techniques. Keeping journals and art therapy have been shown to be very helpful also.

Music therapy and guided imagery/visualization have shown to be effective in trauma recovery and grief recovery, especially rape and sexual abuse cases. Surely it can help a family stressed during end of life care.

And then ladies and gentlemen, something that may not be of much interest to the person dealing with these issues, but to you, these techniques are cost-effective -- both in labor intensity and medical and drug therapy costs.

Probably the most important "treatment" is not a treatment at all. It is the life review. This is an opportunity for someone to review their life, talk about their childhood, their marriage, births of their children, all the "important" and not so "important" issues in life. This is a time when some people will let go of things that have caused tension or pain in their lives and in their relationships. Compassion in Action Volunteers are carefully trained in closure techniques. Closure is one of the most important complementary therapies for both the person leaving this world and those staying behind. I cannot emphasize enough

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the value of a volunteer for closure. One of our volunteers shared the following story:

"I had been a hospice volunteer for a number of years, but had gone through the Compassion in Action training because I had the opportunity to learn about the program from Dannion and had a great deal of respect for him and for the mission and values of the organization. I had previously learned all about universal precautions, how to change sheets with someone in the bed, and how to help someone in and out of a wheel chair, but had not felt completely trained in communication issues. This was an added bonus from the Compassion in Action training.

Every week for several months I visited a 96-year old man – the patriarch of his family - who was bedridden with stomach cancer. I usually spent Saturday afternoon with him so his granddaughter could take her toddlers to the park. We would usually sit and watch football and talk. One day, he held my hand and started talking about his life. He shared with me stories of growing up, leaving home, getting married, having a family. He talking about the sorrow of losing his first wife, the joy of remarrying years later and then losing yet another wife to cancer. I remember consciously thinking wow, he is doing a life review, and was careful to ask open-ended questions. He spent that afternoon sharing his life with me, talking about a few regrets and the achievements he was proud of including his military service. He did not need advice or judgement from me. He just needed someone to listen. After that conversation he was much more at peace – he had reviewed his life and let go of any regrets. He died a few weeks later. And I was a better person for having been there."

I hear stories like this all the time from our volunteers. They always tell me that it is a joy to serve others and that it oftentimes is a spiritual experience. I agree. I think it is important that we all take time to read the book *Tuesdays with Morrie* or if you don't have the time, watch the Oprah Winfrey produced movie on NBC of the same name.

We are at an interesting time in this country. We are facing the turn of a century and the turn of a millenium. We have estimates that our health care costs are going to double by 2007. In the coming years the geriatric population is going to outnumber the under 18 population. What that means is that we as a nation need to prepare for when it is our turn for end of life care. No one wants to think about dying. Doctors typically are not terribly comfortable discussing with a patient that the time has come to change from aggressive curative measures to palliative care. This is why

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many doctors wait until the very last minute, sometimes only days prior to death. It is also why a huge chunk of medical expenditures come in the last three weeks of life. I think a study by the NIH of the opinions of critical care doctors and how they manage this burden, could very effectively change this paradigm.

Oftentimes it is the patients themselves that tell the doctor that it is time to look at hospice. Medicare programs now cover up to six months of hospice care. There are many very good county-based hospices around the country that Compassion in Action sends volunteers to also. We all have a lot of work to do to improve care at the end of life.

Over the last twenty-three years, I have been blessed to learn from and want to thank a number of valuable experts -- Steven Halpern for sharing with me his landmark work in music therapy; Steven Segal in Buddhist, Tibetan Traditions and medicine; Dennis Franz and Tom Hanks for their support of Veterans and their ideals; Tom Brokaw for writing *The Greatest Generation* and Dr. James Gordon for *Manifesto for a New Medicine*. I also want to thank Franklyn Smith and Marilyn Winfield who taught me about guided visualization; Dr. Andrew Parfitt for helping me understand acupuncture, herbs and microbiology; Deepak Chopra in Ayurvedic medicine, Dr. Wayne Jonas for teaching so many of us about the research needs and accomplishments in anomalous areas of alternative medicine and to the countless others who have helped along the way. Art and Ramona Bell for their continuing support of our efforts. And maybe most important of all I want to thank Dr. Stephen Groft -- the Dream Weaver - the original acting Director of the Office of Alternative Medicine.

I would also like to thank Cheryl Birch, the dedicated volunteers of the Twilight Brigade, and all hospice volunteers around the world -- who give of themselves to meet the shared goal that no one need die alone.

I am grateful to you Chairman Burton for your courage in opening this discussion. We must face our own mortality before we can help those we love and those who have loved us face theirs. I am truly thankful to this Committee for this heroic act. By raising awareness in Washington about these issues, we can begin looking for solutions.

In the military we were trained never to leave our wounded buddies on the battlefield -- these World War II veterans never deserted this great country in our times of need -- we cannot desert them now!

Maybe a member of the minority from Indiana stated it best, "Caring for America's veterans is an ongoing cost of war. As a nation, if we fail in this obligation, how can we justify sending more and more young service

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members into harm's way? How might we expect our children and grandchildren to volunteer for military service in the future, if we are not prepared to keep our promises to disabled veterans today?" (Rep. Julia M. Carson, D-IN)

I ask that my testimony and materials be included in the record. I would be pleased to answer any questions.

Enclosures

Mr. BURTON. Thank you, Mr. Brinkley.

Mr. WAXMAN. Mr. Chairman.

Mr. BURTON. Yes.

Mr. WAXMAN. Before you call on Mrs. Marks, I am going to be called away to a meeting. I am going to stay here for your testimony, but I just want to say to you that Milton was a good friend of mine, as you know. We served together in Sacramento and we had many talks, and I realize what a support you were to him while he was doing his job as a legislator. I read your testimony and he had you there with him caring about him to the very end. I just want to tell you how pleased I am that you are here to share your insights with us. I wanted you to know that.

Mrs. MARKS. Thank you.

Mr. WAXMAN. Thank you, Mr. Chairman.

Mr. BURTON. Thank you, Mr. Waxman. Mrs. Marks, would you pull the microphone close so we can hear you?

Mrs. MARKS. I am smaller than the rest of them.

Mr. BURTON. Beg your pardon?

Mrs. MARKS. I am smaller than the rest of them but bigger in what I do.

Mr. BURTON. You are prettier, too.

Mrs. MARKS. It is a pleasure to be here with you, Mr. Chairman.

And I particularly wanted to mention you, Congressman Waxman, because my husband thought so highly of you and you shared many goals together and I am glad you are still here fighting. Thank you for the opportunity to speak about improving care at the end of life with complementary medicine. It is a subject that is close to my heart, since I have found it effective in monitoring my health and in preserving the length and the quality of life for my husband, Senator Milton Marks.

I give tribute to his courage which gave us strength. By making the choice to utilize complementary alternative medicine, which is called CAM, the patient and the family feel empowered, which is beneficial in itself. But there are questions that the medical profession and patients must ask. For example, does miso soup, a central part of the macrobiotic diet, really help stave off cancer? Do the phytoestrogens in soy truly benefit heart disease? Oftentimes if we think so, they do. Although some substantive studies are being undertaken, such as the one Dr. Debu Tripathy is spearheading at the University of California San Francisco, regarding effectiveness of Chinese and Tibetan medicine as well as others by the NIH and the National Foundation for Alternative Medicine, headed by your former colleague Berkley Bedell, there is, as yet, no scientific proof of complementary medicine's efficacy, but there is other proof.

Complementary indicates working with conventional mainstream medicine while providing other interventions. Increasing numbers of health care institutions are utilizing such methods of health delivery which patients are demanding. At least 42 percent of people in this country are incorporating CAM in their health care, spending almost \$30 billion out of pocket every year.

The number of visits to alternative practitioners exceeds total visits to primary care physicians according to the Journal of the American Medical Association which has also stated that prayer is

healing even when the patient, as was the case with my husband, does not know that prayer is offered.

For years, chemotherapy was unproven but utilized. Chemotherapy, one of the central cancer treatments, often is not effective. Then why would anybody reject alternative treatments that are effective and improve the quality of life? No one questions insurance coverage for chemotherapy, but there is resistance to coverage of all but a few modalities of complementary medicine. We are struggling to determine whether CAM is merely palliative in terms of symptoms or whether such interventions alter the biologic force of a disease.

I personally determined that it is effective in both ways in the last years of life when my husband was battling diabetes, heart and renal failure, as well as other major ills. When his internist said he was the sickest patient he had ever seen who was not hospitalized, and when his cardiologist despaired for his life, we maintained his life with quality, dignity, and incredible length. He received constant aggressive care from the best doctors in the world who respected our zest for complementary medicine and encouraged us to bring practitioners to his hospital bed.

They marveled that this treatment seemed to prolong his life. The medical system, while continuing incredible care, had given up hope. I am convinced that the complementary treatments gave the extra fillip to extend his life.

When he was admitted to the hospital in his next to last ordeal, the clinical nurse said coldly, Mrs. Marks, I had to let my mother go to the other side; you should let Senator Marks go, too. My response was that it was not my decision. It was up to God and my husband. She would not talk with me until his final admission when she indicated that we had proven her wrong.

My husband received regular acupuncture treatments, massages, visits to a healer, and Jin Shin Jytsu, Japanese acupressure. His diet was changed to avoid foods harmful to his condition. Before entering the hospital, he became part of a support group. He participated in the Dean Ornish program of stress reduction, exercise, and diet. He visualized that his health was improving, and explored aromatherapy and healing music, which gave constant healing in his hospital room thanks to Dannion Brinkley, and one of his friends, Steven Halpern.

He wore an appropriate crystal. He consumed quantities of nutritional supplements, strong antioxidants, and various Chinese herbs. But we have to bear in mind they are costly, thereby eliminating a large segment of society from benefiting. Insurance paid nothing for the supplements, but reimbursed for part of acupuncture and the Dean Ornish program, Ornish only after a long battle with the insurance company. When Milton broke his shoulder, western pain medication made him hallucinate. We substituted Chinese herbs. The pain vanished. The hallucination ceased.

We did not approve painful dangerous conventional procedures. The floor nurses applauded our approach. The home health care nurses were disparaging. They created many other problems which are an area for investigation. After he was hospitalized for 2½ months with numerous downs such as aspiration pneumonia, we organized a day of prayer throughout our city, prayer for his recov-

ery with an outpouring of healing and love in every church and synagogue. And what happened?

He was released from the hospital. He lived for another 3 months with continuing complementary care. He lived to enjoy our grandchildren's birthdays, to attend dinners honoring him, and to celebrate Thanksgiving with us. It was a miracle. The care did not cure him. Nothing could have. The combination of treatments maintained a life of quality and dignity without pain. We became even closer as a family rejoicing in his smiles, plateaus of strength, any improvement. We felt that our love, positive attitude, special nurturing, notes of encouragement under his pillow, and urging him to continue to live as normal a life as possible were key to even minor improvements.

I want to conclude with mention of myself, although I hope I am not in an end-of-life situation. I have followed the same regimen for 11 years concentrating on maintaining a strong immune system after thyroid cancer and breast cancer twice. In one instance, my oncologist found a new lump and advised me to see a surgeon. I visualized that the lump disappeared. It did. When I was undergoing radiation therapy, I suffered radiation burns. I went swimming daily and did Jin Shin Jytsu. Much to the radiologist's surprise, the burns disappeared, enabling me to continue the therapy.

There unfortunately comes a time when physical function declines, with death imminent. Even at this time, CAM is ameliorating for the patient and family. When we no longer have a cure, CAM can bring healing and peace, giving the patient an opportunity to grow as a whole person in contemplation of death, giving the family an appreciation for the process in which to come to terms with their fears, their anger that medicine cannot cure, and their realization that everything possible has been done. This results in a peace that is essential but unusual.

It resulted in Milton's awareness almost to the moment of his death. He controlled the removal of supports and died in peace with my being in bed with him while our children embraced us. What we did was so unusual that it was verbally applauded throughout the hospital.

While establishing the office, now Center for Complementary and Alternative Medicine at the NIH, was a forward step, the pace of exploring new modalities is agonizingly slow. This was frustrating to me and to others on the Alternative Medicine Program Council. That is why Berkley Bedell established the new foundation of which I am a trustee. That is why we need to consider accelerating the pace of studies and changing protocols. People are ill and dying. We must help them. The resources and results are there.

If we cannot get proof scientifically that CAM is effective, we can assemble data from patients who have found good results from these treatments. What we consider alternative is in many countries the basic standard of care which has cured ills or prevented them over thousands of years. Scientific proof, as we know it, may not be feasible although with cooperation through the World Health Organization, we can try to achieve international standards for herbs and other indigenous medicines. The lack of standards encouraged organization of a meeting of world leaders in which I

was privileged to participate in to begin the climb for uniformity in various categories.

The NIH and other research agencies can assemble data and must do so from patients and families that will corroborate what I discovered personally. We must proceed at a faster clip and reconsider our criteria for measuring success. Our Representatives and insurance companies must have the facts. They must understand that CAM is an integral part of today's medicine, that it improves health and will save money for them in prevention as well. I would be delighted to join with this committee in your good work. Complementary medicine does succeed.

[The prepared statement of Mrs. Marks follows:]

United States House of Representatives

Committee on Government Reform and Oversight Hearing:

Improving Care at the End of Life with Complementary Medicine

October 19, 1999

Testimony of:

Carolene Marks

Trustee National Foundation for Alternative Medicine

Four Year Member

Alternative Medicine Program Advisory Council (AMPAC)

Office of Alternative Medicine

National Institutes of Health

It is an honor to be here, especially with long time friends such as Congressmen Henry Waxman and Tom Lantos who shared goals with my husband in California over many years.

Thank you for the opportunity to speak about "Improving Care at the End of Life with Complementary Medicine", a subject close to my heart since I have found it effective in monitoring my health and in preserving length and quality of life for my husband, Senator Milton Marks. I give tribute to his courage which gave us strength. By making the choice to utilize Complementary Alternative Medicine (CAM), the patient and family feel empowered, which is beneficial in itself.

But there are questions that the medical profession and patients must ask.. For example, does miso soup, a central part of microbiotic diet, really help stave off cancer. Do the phytoestrogens in soy truly benefit heart disease? Are the endorphins that are released through exercise beneficial? Oftentimes if we think so they are.

Although some substantive studies are being undertaken, such as the one Dr. Debu Tripathy is spearheading at the University of California San Francisco regarding effectiveness of Chinese and Tibetan Medicine as well as others by the University of Texas relating to Co Enzyme Q10, NIH, and the National Foundation for Alternative Medicine headed by your former colleague Berkley Bedell, there is, as yet no scientific proof of complementary medicine's efficacy.

Its results are anecdotal.

Complementary indicates working with conventional mainstream medicine while providing other interventions. Increasing number of healthcare institutions are utilizing such methods of health delivery which patients are demanding. For example, the Stanford Faculty Development Program in end of life care is preparing a curriculum for end-of-life care. Conservatively speaking, at least 42% of people in this country are incorporating CAM in their health care, spending almost \$30 billion out-of-pocket. The number of visits to alternative practitioners exceeds total visits to primary care physicians, according to the Journal of the American Medical Association which has also stated that prayer is healing even when the patient, as was the case with my husband, does not know that prayer is offered.

We should bear in mind that for many years chemotherapy was unproven, but utilized. When you consider that chemotherapy, one of the central cancer treatments, often is not effective why would anyone

reject alternative treatments that are effective and improve the quality of life? No one questions insurance coverage for chemotherapy, but there is resistance to cover all but a few modalities of complementary medicine. We are struggling to determine whether CAM is merely palliative in terms of symptoms or whether such interventions alter the biologic course of a disease.

I personally determined that it is effective in both ways in the last years of life when my husband was battling diabetes, heart and renal failure as well as other major ills. When his internist said he was the sickest patient he had ever seen who was not hospitalized and when his cardiologist despaired for his life, he and we maintained it with quality, dignity and incredible length. He received constant, aggressive care from the best doctors in the world, who respected our zest for complementary medicine and encouraged us to bring practitioners to his hospital bed. They marveled that this treatment seemed to prolong his life. The medical system, while continuing incredible care, had given up hope. I am convinced that the complementary treatments gave the extra fillip to extend his life.

When he was admitted to the hospital in his next to last ordeal, the clinical nurse said coldly, "Mrs. Marks, I had to let my mother go to the other side, you should let Senator Marks go, too." My response was that it was not my decision. It was up to God and my husband. She would not talk with me until his final admission when she indicated that we had proven her wrong.

My husband received regular acupuncture treatments, massages, visits to a healer and Jin Shin Jytsu (Japanese acupressure). His diet was changed to avoid foods harmful to his condition. Before entering the hospital he became part of a support group. He participated in the Dean Ornish program of stress reduction, exercise and diet. He visualized that his health was improving and explored aromatherapy and healing music which gave constant healing in his hospital room. He wore an appropriate crystal. He consumed quantities of nutritional supplements such as Co Enzyme Q10, strong antioxidants and various Chinese herbs. They are costly, thereby eliminating a large segment of society from benefiting. Insurance paid nothing for the supplements but reimbursed for part of acupuncture and the Dean Ornish Program (Ornish only after a long battle with the insurance company). When Milton broke his shoulder, western pain medication made him hallucinate. We substituted Chinese herbs. The pain vanished. The hallucinations ceased.

We did not approve painful, dangerous conventional procedures. The floor nurses applauded our approach; the home health care nurses were disparaging. They also created many other problems for us.

After he was hospitalized for two and a half months with numerous downs such as aspiration pneumonia, we organized a day of prayer throughout our city, prayer for his recovery, with an outpouring of healing and love.

And what happened?

He was released from the hospital. He lived for another three months with continuing complementary care. He lived to enjoy our grandchildren's birthdays, to attend dinners honoring him, and to celebrate Thanksgiving with us. It was a miracle. The care did not cure him. Nothing could have. But the combination of treatments maintained a life of quality and dignity without pain. We became even closer as a family rejoicing in his smiles, plateaus of strength any improvement. We felt that our love, positive attitude, special nurturing, notes of encouragement under his pillow and urging him to continue to live as normal a life as possible were key to even minor improvements.

I want to conclude with mention of myself although, I am not at an end of life situation. I have followed the same regimen for 11 years concentrating on maintaining a strong immune system after thyroid cancer and my second diagnosis of breast cancer. In one instance my oncologist found a new lump and advised me to see a surgeon. I visualized that the lump disappeared. It did. When I was undergoing radiation therapy I suffered radiation burns. I went swimming daily and did Jin Shin Jyutsu. Much to the radiologist's surprise the burns disappeared, enabling me to continue the therapy. When I suffered from an irritating cough that doctors explored for years but could not rectify, a healer treated me for ten minutes and the cough was gone.

There unfortunately comes a time when physical function declines, with death imminent. Even at this time CAM is ameliorating for the patient and family. When we no longer have a cure, CAM can bring healing, and peace – giving the patient an opportunity to grow as a whole person in contemplation of death, giving the family an appreciation for the process in which to come to terms with their fears, their anger that medicine cannot cure and their realization that everything possible has been done. This results in a peace that is essential, but unusual. It resulted in Milton's awareness almost to the moment of his death. He controlled the removal of supports and died in peace with my being in bed with him while our children

embraced us. This was verbally applauded throughout the hospital. We were comforted by knowing that we were there for him in every way.

While establishing the Office, now Center for Complementary and Alternative Medicine, at the NIH was a forward step and good people are working on this agenda, the pace of exploring new modalities is agonizingly slow. This was frustrating to me and to others on the Alternative Medicine Advisory Programs Council. That is why Berkley Bedell established the new Foundation. That is why we need to consider accelerating the pace of studies and changing their protocols. There is great need. People are ill and dying. We must help them. The resources and results are there.

A friend, who is a Jin Shin therapist, was diagnosed with stage IV Non-Hodgkin's Lymphoma combined a bone marrow transplant with daily Jin Shin treatments. She left the hospital within three weeks, the most rapid discharge of any lymphoma bone marrow patient at Stanford. She is well. One of her physicians was perplexed that there is so much questioning about complementary medicine when the results are loud and clear.

If we cannot get proof scientifically that CAM is effective, we can surely assemble data from patients who have found good results and utilize those treatments. What we consider alternative, is in many countries the basic standard of care which has cured ill or prevented them over thousands of years. Scientific proof as we know it may not be feasible although with cooperation through the World Health Organization (WHO); we can try to achieve international standards for herbs and other indigenous medicines. The lack of standards encouraged organization of a meeting of world leaders in which I was privileged to participate to begin the climb for uniformity in various categories. The NIH and other research agencies can assemble data from patients and families that will corroborate what I discovered personally. We must proceed at a faster clip and reconsider our criteria for measuring success. Our representatives and insurance companies must have the facts. They must understand that CAM is an integral part of today's medicine, that it improves health, and will save money for them in prevention as well. I would be delighted to join with this committee in your good work.

Complementary medicine does succeed.

Mr. BURTON. Thank you very much, Mrs. Marks. I think you have given us a little different perspective on a lot of things. I appreciate it. Dr. Tian.

Dr. TIAN. Mr. Chairman, my name is Dr. Xiao Ming Tian and my medical training in China was at Beijing Medical University including western medicine and Chinese medicine. My postdoctoral training was at NIH and also Johns Hopkins. I have practiced acupuncture for more than 30 years in Beijing and in Maryland since 1986. I have served as a clinical consultant on acupuncture at NIH Clinical Center since 1991. Currently, I am also conducting an NIH sponsored clinical trial evaluating acupuncture in the treatment of fibromyalgia in conjunction with Dr. Daniel Clauw at Georgetown Medical School.

Traditional Chinese medicine has been used in China for more than 2,500 years and includes acupuncture, herbal medicine, herbal remedies, and Qi gong.

Acupuncture is a treatment using fine needles that are placed in certain body points, some of our 361 points. They are connected with various organ systems in our bodies. Acupuncture needles were FDA approved as medical instruments in March 1996. Acupuncture can balance and enhance the vital energy flow in our body system to normalize our body function. In November 1997, NIH panel reviewed research on acupuncture and positively supported its use as an effective, safe treatment for various disorders, including chronic pain, asthma, stroke, addiction, and nausea/vomiting induced by chemotherapy and so on.

The second important component of traditional Chinese medicine is herbal medicine and herbal remedies that are widely used throughout China and other Asian countries for the treatment and prevention for most disorders. There are more than 10,000 herbs. There are more than 650 recipes and formulas that have been documented and used as official medicines in the hospitals and the clinic. It is getting popular in the United States and people try herbal remedies. NIH is supporting a study on herbal medicine and the remedies.

No. 3 component is Qi gong, which is a form of a meditation with special movement that is used to balance or enhance the patient's energy. External Qi can be manipulated by an experienced instructor in treatment. Qi gong also can be taught to patients and used as a rehabilitative exercise. A patient can learn how to balance their mind and body in order to improve their health. It is even more beneficial when combined with acupuncture and herbal remedies.

At NIH, I have treated more than 300 patients suffering from cancer, HIV/AIDS, arthritis, fibromyalgia, peripheral neuropathy, chronic pain, and diabetes. Most of them did not respond completely to the conventional medicine and they were referred to me by the other physicians as the last hope. The treatment, acupuncture treatment, treats symptoms such as pain, nausea, vomiting, fatigue, depression associated with the disease, and also treats some conditions. Most patients made progress. Their symptoms and some conditions were considerably improved after treatment.

Acupuncture treatment is tailored for the individual patient. Treatment may include acupuncture and Qi gong at the NIH Clin-

ical Center. In my private practice, I have treated more than 5,000 patients for similar conditions, using acupuncture, Qi gong, and Chinese herbal remedies which are three major components of traditional Chinese medicine.

Most patients are happy with the satisfactory results. I have found these therapies especially effective for reducing pain, reducing pain medications, and other medications. Other scientists have found these treatments also act to enhance the immune system by increasing interleukin 2 and the activity of natural killer cells. The therapies of traditional Chinese medicine can increase the quality of life by decreasing fatigue, depression and anxiety, and so on. They can also improve sleeping disorders and enhance general well being. In my experience, some positive changes can be noted immediately after the first treatment. I would like to share my experience with a patient at NIH named Chuck. He had metastatic terminal cancer, and suffered from very severe abdominal pain with a 36 hour episode of hiccups. He had not responded to the conventional treatments given at the NIH Clinical Center. And so Dr. Mitchell Max called me. He is the clinical Director of the Pain Clinic at NIH. He called me and said, "Ming, come over here; you are our last hope. This is a challenge because we tried everything. And he failed all the conventional treatment and his condition was miserable . . ."

After examining him and making a diagnosis, I decided to use six needles to treat him and after 20 minutes he felt better. He said, "Doctors, please leave me alone, let me go to sleep." So after 12 treatments of acupuncture and with the care of the other physicians and nurses at NIH, his condition was greatly improved after 3 weeks.

So most often acupuncture can be integrated with conventional western treatment. There is currently great interest by patients and their doctors for using acupuncture as a joint treatment. In fact, over the past 10 years, the use of acupuncture has increased greatly in the United States because of its effectiveness, safety, and low cost. Acupuncture has become a very important component of complementary and alternative medicine.

Regarding insurance coverage, currently only a few insurance companies cover acupuncture. Medicare and many private insurance companies do not pay for this treatment, so many patients cannot take advantage of this treatment. I believe the health insurance industry should provide coverage for acupuncture treatment, especially Medicare. I also believe acupuncture should be considered a medical specialty in our health care system. It plays a very important role in treating so many disorders and improving care at the end of life.

Thank you for inviting me to testify. I will be very happy to answer any questions you may have.

[The prepared statement of Dr. Tian follows:]

**Xiao Ming Tian, M.D., LAC
Director, Wildwood Acupuncture Center
Director, Academy of Acupuncture
And Chinese Medicine
Clinical Consultant, National Institutes of Health**

*Testimony for the Congressional Committee on Government Reform
hearing on "Improving Care at the End of Life with Complementary
Medicine," October 19, 1999*

My name is Dr. Xiao Ming Tian. My medical training in China was at the Beijing Medical University and included studies in both Western Medicine and traditional Chinese Medicine. My postdoctoral research training was at the National Institutes of Health and at the Johns Hopkins Hospital. I have been practicing acupuncture for 30 years in Beijing and in Maryland since 1986. I have served as a clinical consultant on acupuncture at the NIH Clinical Center since 1991. I am currently conducting an NIH sponsored clinical trial evaluating acupuncture in the treatment of Fibromyalgia in conjunction with Dr. Daniel Clauw at Georgetown University Medical School.

Traditional Chinese Medicine, which has been used in China for more than 2500 years, includes acupuncture, herbal medicine, herbal remedies, and Qi gong.

ACUPUNCTURE is a treatment in which thin needles are placed in certain body points according to the 14 main Chinese acupuncture meridians and 361 points, which are connected with various organ systems in our bodies. These needles, which are now FDA approved medical devices, are manipulated so that they can balance and enhance vital energy flow in the body systems, to normalize body function. This vital energy, called Qi (Chee) in Chinese medicine. In November 1997, a NIH Panel reviewed the research on acupuncture and positively supported its use as an effective and safe treatment for various disorders, including chronic pain, asthma, strokes, addiction, and nausea/vomiting induced by chemotherapy, etc.

HERBAL MEDICINE AND REMEDIES are widely used throughout China and other Asian countries for the treatment and prevention of all medical disorders. There are more than 10,000 herbs and 650 patent or regular remedies that have been documented and used as official medicines in hospitals and clinics.

QI GONG is a form of meditation with special movement that is used to balance or enhance a patient's energy. External Qi can be manipulated by an experienced instructor in patient treatment. Qi gong can be taught to patients by a qualified instructor as a rehab exercise. Patient can learn how to balance their mind and body in order to improve their health. It is even more beneficial when combined with acupuncture or herbal remedies.

At NIH, I have treated more than 300 patients for a variety of conditions including cancer, HIV/AIDS, arthritis, fibromyalgia, peripheral neuropathy, chronic pain and diabetes. This treatment has encompassed both the primary disorder, and symptoms such as pain, nausea, vomiting, fatigue, and depression that could be associated with the disease and/or its treatment, such as chemotherapy or radiation therapy. My particular focus has been palliative care, pain management, and end-of life care.

Treatment is tailored for the individual patient and may include acupuncture and Qi gong at the NIH Clinical Center. In my private practice, I have treated more than 5000 patients for similar conditions using acupuncture, Qi gong, and Chinese herbal remedies, which are the three major components of Traditional Chinese Medicine.

I have found these therapies especially effective for reducing pain, resulting in lower doses or discontinuation of pain medicines. Other scientists have found that these treatments also act to enhance the immune system by increasing interleukin 2 and the activity of natural killer cells. The therapies of Traditional Chinese Medicine can increase the quality of life by decreasing fatigue, depression, and anxiety. They can also improve sleeping disorders and enhance

general well being. In my experience, some positive changes can be noted immediately after the first treatment. Gradual improvement in the over all condition is often seen after about 15 treatments over approximately 3 to 5 weeks. Most often Acupuncture treatment is integrated with conventional Western treatment.

There is currently great interest by both patients and their doctors for using acupuncture as an adjunct therapy. In fact, over the past 10 years, the use of acupuncture has increased greatly in the US because of its effectiveness, safety and low cost. Acupuncture has become a very important component of Complementary Medicine.

INSURANCE COVERAGE: Currently, only a few insurance companies reimburse for acupuncture treatment. Medicare and many private insurance companies do not yet pay for this treatment, so many patients cannot take advantage of this treatment. I believe that the health insurance industry should provide coverage for acupuncture treatment, especially Medicare. I also believe that acupuncture should be considered a medical specialty in our health care system. It plays a very important role in treating so many disorders and improving care at the end of life.

Thank you for inviting me to testify. I would be happy to answer any questions you may have.

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Mr. BURTON. Thank you, Dr. Tian. I will start with Dr. Byock. Doctor, how many patients should one nurse have responsibility for in a hospice or a nursing home unit?

Dr. BYOCK. Well, it differs. In a hospice program, optimally 10 patients per nurse often works fairly well. Their patients are often at home being cared for by family primarily with the nurse and the interdisciplinary hospice team coordinating and obviously supporting that care. In an inpatient facility, an inpatient hospice facility, again I would still have to say there is a range because there are different types of facilities. The one that we have in my town of Missoula, MT is a residential hospice facility where people are cared for as they would be in their own home. They simply need a place to be.

In some more interventional oriented hospice facilities, they should be considered basically intensive care units. Hospice care, when it is done correctly, is intensive care and nurses should really only have to be managing two, three, four patients at most. But aides are an important part of this system in both hospice and in nursing homes. In nursing homes right now, sometimes there is 1 RN on for 30, 60, more patients, and then at night sometimes no RN is on. There may be a licensed practical nurse on. The ratio of aides to people in nursing homes is really dramatically high or dramatically low—the aide/patient ratio needs to be improved.

At night, sometimes an aide has the responsibility of caring for over 20 residents. Just think how long that requires if somebody needs to be taken to the bathroom or is twisted up in their bed-sheets and needs help or needs pain medication. These are bedrock issues that we need to address. These days, many of us frankly are reluctant to do extensive teaching in nursing homes simply because the annualized turnover rate of the care providers there are so high that it is simply not cost effective for our time.

We really need not break the bank of America to raise that ratio. When I sit with aides in nursing homes, often they say that they are simply not, you know, they cannot make ends meet themselves. They are often on welfare and they are looking for other jobs. They say we could make more money waitressing. And when I ask them then why do you do this, the most consistent answer, almost without change, is they say we love these people. And yet we are not giving them the time to do the care that they can do.

Mr. BURTON. I think that that is absolutely correct. I know in the case of my mom and dad the people were doing it, I think, in large part because they really developed an affection for them.

Mr. BRINKLEY, you have trained what—20,000—you said?

Mr. BRINKLEY. I have trained probably 4,000, but I have recruited more than 20,000.

Mr. BURTON. Now are these people paid at all?

Mr. BRINKLEY. No way.

Mr. BURTON. They are all volunteers?

Mr. BRINKLEY. Everyone is a volunteer. I accept donations but everyone is a volunteer. Compassion in Action is completely volunteer based, and it just goes to show that out in this broad, wonderful country that we live in, the opportunity. Death is a really horrible thing for everyone to think to deal with, but there are people who have lost loved ones and who sincerely love to be in service.

They love it. I find it is one of the most rewarding things for me. If I had never gone through what we call "near death experiences," there are a lot of different explanations for this, but I found a spiritual context to my mental-physical life. I watch people who are looking for the same thing and that they can find a spiritual moment. When you are helping someone in transition and helping that family, you gain a certain sense and control of your life. You get a new perspective on your own destiny.

I am very adamant about hoping that every Congressman that runs and every Senator that runs spend some time in a VA and learns what people are going through and how much just their walking in the door and patting them on the hand, say how are you doing and spend 10 minutes means to them.

There are a lot of people out there who want to help and by bringing this awareness that you guys are really looking at this gives them a comfort and a security and also the possibility that if there was a day care center somewhere in a VA where older veterans could look after children and children look after veterans, then there are single parents and single parent women, which consist of 73 percent of most of our hospice volunteers, who would have no problem coming to a VA.

And, you know, service is service and I have been trying to figure out how to map these two together because if we have a lot of single parent families that don't have a male figure, then let the male figure be that their mother is taking care of a veteran and maybe those veterans can come downstairs with the kids and interact and we have begun a full circle look that an old soldier can find the value of his life and a young person can find service and value of their family.

Mr. BURTON. If you have a program on paper that you think might be something that we could look at, we could at least talk to some of the health agencies here in Washington about it. Let me just ask one more question and then I will yield to you, Mrs. Mink. Mrs. Marks, you were talking about alternative therapies as an adjunct to your husband's conventional medicine. You are very forceful in your statement and I just wish all my colleagues could hear that. There is no scientific evidence that some of those things work, but you just feel in your gut that it was really helpful to your husband?

Mrs. MARKS. The conventional medicine wasn't working. So we tried the other and it did work. So I feel more than in my gut, I feel that it really does work, and I have noticed that it works with me or has worked with me when I needed it.

Mr. BURTON. Yes. I am glad that Henry was here to hear your statement because Henry has had some different feelings from time to time on alternative CAM and alternative therapy so since your husband was very close to Henry, I hope you will continue your dialog with Henry because it could be very helpful.

Mrs. MARKS. I would be very glad to continue my dialog with all your committee and I would like to work with you because this is very, very important to me and to many Americans. I appreciate your interest and I appreciate that you are working with Beth Clay because she knows a great deal.

Mr. BURTON. Beth, does that mean you are going to ask for more money? [Laughter.]

Mrs. Mink.

Mrs. MINK. Thank you, Mr. Chairman. I certainly benefited from all of your testimony and agreed basically with all the sentiments and ideas that have been expressed this afternoon. Mrs. Marks, the concept that you expressed with reference to alternative ways in which to deal with people who are in terminal situations and needing pain amelioration or palliatives or other kinds of support mechanisms is very much a part of the alternative health methods that have been accepted and promoted in my State by the Native Hawaiian community. So I wanted to share that with you.

I have a general question to the panel and that is, NIH established, I believe, an Institute for Alternative Medicine not too many years ago and I wondered whether it is embracing some of the thoughts that you expressed today. Is there any sort of institutional acceptance of the end-of-life support mechanisms that need to be embraced by the National Institutes of Health? I don't consider health only the traditional methods of treating illness. Health has got to be the whole person. And so when NIH adopted this Institute of Alternative Medicine, my hope was that it would enlarge and impact on all the other disciplines that are included in the NIH and that through the acceptance of this alternative medicine notion that it would then embrace the methodologies that are used, the approaches that are encouraged by all the other disciplines in cancer and heart disease and so forth.

I wondered if that is a realistic hope for this NIH Institute or is there something more that we ought to be doing so that institutions like Medicare would not hesitate to compensate or pay or reimburse for acupuncture treatments that are providing such relief to thousands of people in the country? So somewhere along the line we still have a mismatch in terms of accepting the importance of this, not an exclusive jurisdiction but certainly the importance of it in terms of end-of-life considerations or just pain in the case of Dr. Tian. It is not end of life. It is just to make quality of life better by following a particular discipline. So are there any comments you would like to make on that objective?

Mr. BRINKLEY. I would like to make a comment and thank you very much for bringing it up. I followed the Office of Alternative Medicine from its very first day, from the town meetings all the way through the Chantilly report and have never missed a meeting or read anything that they produced. I find it woefully inadequate. I find it to be isolated and kept apart and I think of the people, and the thing that bothered me the most is from Chantilly until this year, you know, you are talking almost 10 years. I watched some of the people who are the leaders in this field in alternative and complementary medicine who are leaders, who have come and been a part of this program and the despair and the utter frustration that I have witnessed by talking to them, and some of them have remained good friends of mine, and these are people who have gone on to improve quality of care, who have gone on and used these techniques in many places that so far not a single program and not a single thing has ever been accepted by the NIH.

The research paradigms and the studies that are done are kept scientifically clinical. I think it is going to take more push from you guys to go over and push that bunch around so they loosen up enough to create quality in end-of-life care. When you have no other choice like we are discussing, look at the results. There is where, no matter if it is anecdotal or not, there is where you see the true keys.

Mrs. MINK. Somehow I get the impression that at NIH what they are pursuing is pure science and they do not look upon these other methods that are working so well as science. Somehow we have to find a way to break that mental block that so many of our medical researchers adhere to. Yes?

Dr. BYOCK. I couldn't agree with you more, and my own actual research work for strategic reasons has been in the area of the measurement of subjective quality of life. You said it yourself. We are talking about end-of-life care. People are not going to be physically healed. We already know that their time is short. But we can improve the quality of their lived experience for themselves and their family.

The infrastructure, the basic tools for measuring subjective human experience are not well developed. They exist and they can be developed. We have done this in so many other areas of human endeavor. This is a key sort of a wedge issue because NIH has said that quality of life assessment is an important outcome measure. It needs to be, but so far the methodology has continued to go back to objective measures: how big is the tumor; how long does somebody live; what is their functional status?

In fact, given the fact that we are all going to die and given the fact that the vast majority of us will die of a progressive illness, we know that functional status and physical deterioration is inevitable and we really need to develop the thermometers, the basic measurement tools to measure subjective quality of life. If we were able to do that and really hold NIH and the research community to that as an important outcome measure, things like complementary therapies would automatically be able to be measured and raised in their priorities. So we have some basic work to be done. There is wonderful stuff happening but it is to this point insufficient.

Mrs. MARKS. I think your question to me is in several parts. One, we would like to see Medicare get involved, but I think if we get Medicare involved, we have to somehow discover what is happening with Medicare and where the waste is. We could use them in the complementary medicine very surely. Second, complementary medicine, although we are speaking about end-of-life, is very important in maintaining wellness and can cut down much of the cost and suffering in this country of people maintaining their health.

Dr. McLanahan, who is here today, was the one who advised me on what I should give my husband. You can't just go out there and take herbs willy-nilly. You have to know what you are doing. So that is another part. But I do think the NIH and the Center for Complementary and Alternative Medicine need to be made more aware that the American public really wants to zero in on this and let us have some speed in this and let us not be bogged down in the old methods of researching it.

Mr. MCINTOSH [presiding]. Thank you, Mrs. Marks. Dennis, I also have a couple of questions. Are you going to come back after the vote?

Mr. KUCINICH. I hope to.

Mr. MCINTOSH. I was going to suggest that perhaps you and I could split about 7 or 8 minutes before the vote and then if you get a chance to, you can come back. I will not be able to.

Mr. KUCINICH. All right. How about if we both do 5?

Mr. MCINTOSH. Sounds good. Then the panel could be dismissed and we will go to the second panel after the vote. Let me ask you to be very specific and brief in your answers, but I really want to get through several questions for the record. Dr. Byock, what specific complementary therapies do you think Medicare should cover at this time that they do not?

Dr. BYOCK. I have no specific recommendations regarding that.

Mr. MCINTOSH. Mr. Brinkley?

Mr. BRINKLEY. I will take music therapy. Music therapy began in 1941 and 1942 in VAs before we knew what post-traumatic stress syndrome was. It was used between 1941 and 1947 as the exclusive method. It is noninvasive and it begins to show results. You can do serotonin levels. You can do endorphin levels, but you can watch a change in the quality of that person's comfort zone.

Mr. MCINTOSH. Have there been any studies that measured those?

Mr. BRINKLEY. Hundreds of them, but still no one will bring it in as an active test because it opens the door on just what we were talking about. It opens the door to acceptability.

Mr. MCINTOSH. Let me ask unanimous consent that we keep the record open for 10 days for additional material. And Mr. Brinkley, if you could submit maybe a summary of those tests that we could include in the record for the hearing?

Mr. BRINKLEY. Absolutely. It would be a pleasure, sir.

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Mr. MCINTOSH. Mrs. Marks, we recently lost my wife's mother to breast cancer and hospice was a wonderful experience for us. There was a book that we read called "Final Gifts" that helped explain exactly what the patient was going through. It talked about experiences similar to near-death experiences and that didn't happen with Sherry, my mother-in-law, but it was very helpful in terms of knowing how best to release somebody you love. I have a great deal of admiration for hospice and I appreciate all that you all have said. But what observations and recommendations can you offer regarding complementary and alternative medicine as you get to the end-of-life care? How did you pick which herb therapies to use and some of the different things? How did you go about finding that information?

Mrs. MARKS. I talked with various people. I talked with Dannion and I talked with Sandra and I talked with the acupuncturist and various people who are knowledgeable and have seen the results and then we tried one thing and then another and they seemed to work. You have to rely on the experiences of other people in this situation because the studies are not there. We do need more studies and I would like to respond also to the question of coverage.

I think there should be a national coverage of acupuncture. There is no doubt in my mind. That has been proven to be successful. I think that is one place to start.

Mr. MCINTOSH. Good.

Mr. BRINKLEY. I think that Chantilly report published in 1994 on the beginnings of the Office of Alternative Medicine, which everyone received, is the book. I mean it is one of the greatest books of this century and each Member received it. To read it will help you so much in finding what to target and who is the expert in that.

Mr. MCINTOSH. Appreciate that. Thank you. Dr. Tian, do you have specific recommendations on coverage?

Dr. TIAN. Acupuncture should be covered. I just want to mention that in 1994 FDA and NIH sponsored a workshop on acupuncture. There was a panel—I was one of the panelists who reviewed all the research papers worldwide. They showed that in the past 25 years, acupuncture, only six cases of malpractice in 25 years—which means very low risk. It is quite safe and effective. In 1997, NIH proved the positive and mentioned the conditions including cancer patients and as I mentioned in my talk.

Mr. MCINTOSH. So you were able to measure outcomes and demonstrate that it was beneficial?

Dr. TIAN. Yes, yes. They reviewed all the research papers and strongly recommended and supported acupuncture. So I have a problem understanding why Medicare does not cover acupuncture treatments because this is now—acupuncture is in mainstream health care. It is not something we don't understand.

Mr. MCINTOSH. Yes.

Mrs. MARKS. Because it is not western medicine.

Mr. MCINTOSH. There seems to be a real bias there. We ought to use scientific criteria and say when it works we will support the payment for it.

Mrs. MARKS. I would like to add something if I might. I would like to see some consideration being given to tax deductions in term of supplements, not just the ordinary vitamin you buy over the

counter, but in terms of supplements I think there could be a real study of that and it would help people to be able to include the cost of such supplements in their medical expenses.

Mr. MCINTOSH. Thank you. Let me finish my questioning and recognize Mr. Kucinich for 5 minutes.

Mr. KUCINICH. Thank you very much, Mr. McIntosh. First of all, I want to thank the panelists for coming before the Congress and this committee to present their views, which I appreciate and honor as well as your commitments. Mr. McIntosh raised an important question about what Medicare would cover. I would certainly be ready to advocate that Medicare covers the full range of complementary treatments, and as someone who understands the basic assumptions of allopathic medicine, it would appear that it is focused purely on the body and not even on the senses, by the way, but on the body itself, is almost a preoccupation.

It focuses a very narrow subject-object orientation, which really minimizes one's humanity. When you get outside of that sphere of practice or the philosophy which subsumes it, you get to a condition of understanding that there are other choices out there, some of which have been used for thousands of years in other cultures, other ways of looking at the world. What really we are challenged to do in this Congress is to assist allopathic practitioners in broadening their perspective and not to threaten to supplant that practice. The word is complementary. The word is adjunctive therapy. To find ways of giving people more choices about the way they live and the way they die and the testimony that I have had a chance to review of the witnesses, which speaks to options that deal with therapeutic touch and prayer.

Prayer, you are dealing with the spiritual condition of people. I mean if we are more than our bodies and we are mind, body, and spirit, and if we have integration, and you take a truly integrative approach, it is quite possible that people are not simply ushered from a physical to a nonphysical condition, but they are given an opportunity to give their lives more meaning. And when you do that, you not just prolong or bring about the possibility of a prolongation of life, but you do it with a sense and attribute to the quality of life, which I think helps to celebrate humanity. If there is one thing that our current medical practice despite its technological efficiency doesn't quite reach, it is a celebration of the humanity of the individual.

When I look at the work that is represented here by these practitioners and by these philosophers, and you look at life review, music therapy, guided imagery, visualization, human touch, prayer, these are a lot of things that people find that excite their interest in life itself.

Mr. BRINKLEY. Well, I mean I would like to say this about the VA. And I see this and I hear it from Ira. What I love about the VA right now is they give us the opportunity. They are the one true Government institution that allows us the freedom of movement to use these things. You know you think about guided imagery and music therapy. How many of us—and the other day someone says how do you think a bunch of soldiers can use guided imagery? Well, I made one to Mr. McIntosh, but you think of this. In the guided review, in the end-of-life review which we are all taught; we ask

them what their favorite song was. It will be a dance at a USO. It will be when they met their wife and when they start telling you that story and we go out and find the music and bring it back and let them listen to that era in their life, that is music therapy at its best.

The VA allows us, because I train my practitioners in therapeutic touch, aromatherapy, music therapy, and color therapy, noninvasive alternative and complementary techniques, and I love them because they will let me try anything that will help that patient. The other day someone said prayer? You are going to go into a VA and talk about prayer? And I said, pal, whether you know it or not, there ain't no atheist in a foxhole. Everybody knows about prayer right then and there and we are watching it work and trying to set up programs where that is happening.

Mr. KUCINICH. Thank you very much and I would like to tell Mr. McIntosh that I think this is an important function of the Congress because as we go to a new millennium, we have a chance not just to keep repeating those things that didn't work, but bring back those things that do work and try to introduce them into a more broadly accepted public policy. If there is one thing, one area that might help guide us to a new age of enlightenment in this world, I think it would be the area of complementary medicine. So thanks to all of you for your commitment. Thank you, Mr. Chairman. Thank you.

Mr. MCINTOSH. Thank you, Mr. Kucinich. I will now have the committee stand in recess at the call of the chair after this vote and I will leave it to the discretion of Chairman Burton whether he wants to continue with this panel, if that is all right. He may have some more questions that you didn't get to answer before he had to leave. The committee will stand in recess. Thank you.

Mr. BRINKLEY. Thank you, sir, and my heart goes out to you about your wife and the loss of her mom. Tell her I owe her a hug.

Mr. MCINTOSH. Thank you.

[Recess.]

Mr. HORN [presiding]. The committee will be reconvened. If panel one is still in the room, there are a few questions we would like to ask of panel one. So if you could take those seats again we will put some of these questions for the record. Sorry about the voting interruption. That is our life here. So those are the things we have to do, but we enjoy these.

OK. Let us start. Dr. Byock, you are here and would you give us an opinion as to how do the British and the Canadian health systems differ in offering hospice programs?

Dr. BYOCK. Very importantly, a person is not made to choose between continuing life prolonging therapy either with chemotherapy, if they have cancer, or hospital-based therapy for congestive heart failure, or those sorts of interventions in order to receive hospice care. I have spent some time in both countries actually studying the hospice delivery system and although neither of them are perfect by any means, by the way, people aren't provided with what I have come to term "the terrible choice," where you can either continue to get cancer therapy, for instance, or you can, you know, give up and get hospice care which is what they hear.

So in the decision whether to receive hospice care, families are often—they feel that they are being made to give up the opportunity to go back to the hospital, to give up the opportunity to have more chemotherapy, maybe an opportunity to use an intensive care unit if they need to. In fact, also, in many hospice programs these days because the hospice community is struggling with survival of their programs, programs can't provide, they cannot pay for certain very expensive pharmaceutical agents, for instance.

There is a pain medication called Duragesic which can cost as much as \$36 a dose. There is an anti-nausea medication. One is called Zofran that can cost \$100 a day. In order to receive those medications for comfort, people actually very often have to stay in the hospital. That is kind of an irony. Their care would be less expensive at home, but they have to be in the hospital. In Britain and in Canada, people simply can have both. They can have full service hospice care and continue to see their chemotherapist or go to the hospital when they need to.

In fact, when that happens, when people aren't forced to make that choice, their behavior changes. They have a confidence that they can be at home, that they will be cared for, that they will be comfortable, and as that confidence builds, because it is nice at home, you know, you want to live out your days at home, their behavior over time is that they don't tend to call the ambulance because there is a plan in place for when problems occur right there at home. They don't go back for their fourth or fifth round of chemotherapy often because, you know, they are focused on quality of life rather than the quantity of life.

So that what happens over the last year of life is in both systems even though the choice isn't imposed, in fact, the result is that people tend toward home care rather than using the hospital and the ICUs. It doesn't take many avoided hospitalizations or ambulance trips or ICU admissions to pay for a lot of high touch care in the home.

Mr. HORN. When you compare British and Canadian systems, are the therapies offered in each plan similar or are there differences between the plans?

Dr. BYOCK. There are differences, but they are fairly similar. And I want to say, you know, there are—certainly having spent time in both countries, there are certainly major advantages to the American health system when it comes to acute life saving illness and injury. I practiced emergency medicine for a number of years, and I would much rather practice that here than in the accident and injury departments in Britain.

At the end of life, however, when you are living with advanced chronic illness, frankly I would much rather be cared for in either of those two systems. Not only is the access to palliative and hospice care better, but rarely do people face the end of life worried that they are financially devastating their loved ones and that they have truly become a burden to the people they are leaving behind.

Mr. HORN. You are absolutely right. That is a major worry for every elderly person I have met.

Dr. BYOCK. It is.

Mr. HORN. Are there various therapies including complementary therapies that Medicare does not cover at this time that you feel could improve the end-of-life care?

Dr. BYOCK. Well, if we have access to adequate pain management and services like palliative and hospice care, the answer is yes. Simple things that provide comfort and pleasure for people such as massage therapies or aroma therapy, music therapy was mentioned, having the time to do life review with people, to just bring them back through their stories. In the hospice program I have been most recently associated with, we frequently use massage therapy as a way to not only alleviate muscle tension and physical pain, but actually as a gift of pleasure for somebody whose time is short. All of those things can be incorporated, frankly often within the comprehensive package of hospice care without dramatically increasing expenditures in any direction.

As I said, because we already spend an enormous amount of money during the last year of people's lives because they are so sick, simply by coordinating efforts with a consistent, cohesive vision of what good care should look like, we really can simply by redirecting resources achieve much, much better outcomes. And I think we really should have much higher expectations. I don't think that is going to require more money.

Mr. HORN. Well, I thank you for those answers and, Mr. Brinkley, you came in just in time. I once was president of a university where we had a very fine music therapy program, and my question to you is, what is the basis for why you think music therapy can be effective?

Mr. BRINKLEY. Well, when music therapy became a scientific modality was during World War II before we knew what post-traumatic stress syndrome was. We called it shell shock. Music therapy began to be a tool from 1941 to 1947 in VAs and then in its outgrowth it became to be a very comforting zone. Look at all of us where music therapy really works. How many have listened to gospel or spiritual? How many have a favorite song? And the other day when I mentioned just earlier someone said how do you bring music therapy into a VA? By simply sitting with a soldier and as he reviews his life, what is the favorite song? And it will be a song from a USO. It will be the song that he met his wife by.

And when you look at how advanced music therapy has been brought into play with handicap, with autism, and it is noninvasive. It only takes a tape recorder, music, and conversation. It is not labor intensive. It is not medical or therapeutic or drug-intensive and it is a quiet way to start. I have learned a lot about people listening to music as opposed to the static of the hallways and the rooms. And it worked with Carolene when we were going through this with her husband, the difference that music therapy made in a simple room.

I used to call her and threaten her about turning off the television. As soon as I would hear it, I would threaten her, turn the television off and play this kind of music. And Steven Halpern and I want to take things, after going through 10 years of alternative and complementary focus, and it never really goes anyway except in the school of nursing and in some small groups in the NIH, but

never out of the Office of Alternative Medicine, and take these things and show how they can impact.

And when you have guided imagery, which is music and a thought process to take a person through the relaxation and the comfort that all of us have seen work, and then we begin to really look at these things not from an intense medical perspective but from a mental, emotional, and spiritual perspective, and we have begun to help them go home safely.

Mr. HORN. On the point of music therapy, how do you use that to help the next generation not be afraid of death and dying and even more important to be like those from the Second World War where they made a great difference in their own lives for valor and many in service on the front line?

Mr. BRINKLEY. In what we call Education 2000, there was an initiative called "service learning." This service learning program, it was taking kids to keep from being dropped out. I work in South Carolina with an EH class, which is emotionally handicapped. I have looked at Minnesota, Ohio, and California, who are doing fabulous programs of taking kids, single parents or abused children, and by taking them and giving them service learning, giving them responsibility into the community, to go to a nursing home, to go to a VA, to go to these places with a sense of pride that they are service in the community and in their own homes.

You know when you are in a place that has children that, has seven children with three mothers, seven children, and no male figure, you know things are going to be a little rough. To take these kids and let them help an old soldier and old soldier tell them a story and say thank you, this is a way that the old and the young still have service. A young child finding an identity in a community and an old soldier doing one more job. And that blend I have watched be so tremendously effective on both of them that the guys, the little fellows, they come and sit with attention. They have less problems. The teacher has less problems because an old soldier talked to them and they helped someone.

We have to look at the emotional spiritual sides of us as individuals and by bringing those together we are going to improve the quality of the next generation with service, compassion, and caring. And we are going to give an old soldier a chance to make those last stands and helping people understand what he fought for, what this country is about, and to improve the quality of a community working together.

Mr. HORN. I think you are right on the mark. I had a psychology program for undergraduate and graduate students where they would go out and help mentor and spend time talking to senior citizens in various homes. And that was good for them and good for the senior citizens.

Mr. BRINKLEY. Yes, sir. Mentoring is a tremendous program that doesn't cost anything. Nothing I am talking about costs anything except maybe a \$9 cassette player and the ability for a community service related person to want to get involved. The Council on Aging is doing this and service learning is really a wonderful program when applied just like you are saying mentoring. There are a lot of vast resources in our elderly people that can really help once that interaction of helping and serving each other gets into

play. It helps me tremendously. I love people who are in their elder years. Why? Their sense of humor. They will tell you like it is.

Mr. HORN. Yes.

Mr. BRINKLEY. And they are the joy that helps us all learn to grow closer together.

Mr. HORN. Mrs. Marks, when you served on that advisory panel at NIH, did you feel the advice of the panel was being listened to?

Mrs. MARKS. No.

Mr. HORN. Would you like to elaborate on that?

Mrs. MARKS. I felt that there was something that was stopping the message from flowing where it should go. There were studies that went out in the field, but not much has come back. I hope that with its becoming the new Center for Complementary and Alternative Medicine that that philosophy will change. But it is very important for the Congress to put pressure, if you will pardon me—I know there is someone from the NIH here—to put pressure on the NIH to move forward because this is so key to wellness and health and illness.

I would like to expand upon what one of the gentlemen said. I think another area where Medicare could provide more coverage is in psychotherapy. There is some coverage but it is a little difficult to achieve the coverage, and I think that is very important in terms of wellness. I think it is also important to enable people to die at home. My mother died when my daughter was 14. She held her hand while she was dying and Carol said, “I am not afraid of dying, now.”

Mr. HORN. Well, on the point of the observations you have made, what recommendations could you offer us regarding complementary and alternative medicine research in the end-of-life care? Do you have some particular recommendations you would like to share with us?

Mrs. MARKS. I believe the record is being kept open for 10 days.

Mr. HORN. Right.

Mrs. MARKS. May I send that to you?

Mr. HORN. Certainly.

Mrs. MARKS. I think it is important right now to say that I think some of the actions that have taken place in communities and in organizations and such as the doctors here have observed, I think it is very important to start with that and move forward because there is a great deal of belief that this works. And I know it works. I have a friend who had non-Hodgkin’s lymphoma. She had a bone marrow transplant at Stanford. Her husband did Jin Shin Jytsu on her everyday and she left the hospital in 3 weeks, earlier than any other patient so treated had ever left. Now that is anecdotal, but we can build on the anecdotal. We don’t have to have the scientific reports. It happened.

Mr. HORN. Question for you, Mr. Tian. And this will be the last question unless Chairman Burton has one. Please, I will yield to you.

Mr. BURTON. Well, since you are talking to Dr. Tian, I want to learn more about acupuncture because I may be calling you myself. I have some problems once in awhile. But Mrs. Marks said—and thank you for yielding, Chairman Horn—I am concerned about you are on the advisory panel and you said that you felt like NIH

wasn't listening to you. You are not the only person that has said that.

When you were talking to them or when your compatriots were talking to them from the advisory panel, why do you guys feel like, why did you feel like they weren't responding or weren't paying any attention?

Mrs. MARKS. I think the results. I haven't seen the results that I would like to see achieved and it was a very slow pace. Now, it is a different operation, I hope, so I think we should look at that very carefully. I am no longer on the council. My term ended. I am on Berkley Bedell's Foundation on Alternative Medicine. I would recommend that we all talk with him, too, because he does have some procedures in place. But it just appeared to me and to some of the other people who are on the council that the pace was very slow and I would go to every meeting and say people are dying and people are ill and we have to move faster. The pace is slow. Let us try to improve the pace, speed it up.

Mr. BURTON. Well, I shall look forward to your response to what Chairman Horn was asking for awhile ago because we will have people from NIH up here on a regular basis and I think they are aware of that and we will do everything we can to get them to open up to some of these new ideas.

Mrs. MARKS. I don't mean to be disparaging of the NIH. I think it is going to be a different matter now. I am hoping.

Mr. BRINKLEY. I am not really sure that it will be, but I attended every meeting for 10 years. I looked at everything. I think it would behoove this group of gentlemen to take a good look at those who already sat on the boards for 10 years who are now scattered back into the mainstream who left or rotated off. You have probably 30 or 40 people. Go ask them. They can be located. Ask them to send you a report and let them tell you what they saw. You see such disheartening among these people who had such faith and hope in this and then you look at how the mechanism and the money was spent. You know I don't owe the NIH anything. All I care about is people in the end-of-life care and there are maybe 60 people that you can call upon to give you good scientific, medical perspectives of what they saw.

And that is \$96 million, Chairman Burton and Chairman Horn. That is \$96 million. What I could do with \$96 million or any of the rest of us in palliative and end-of-life care, we can't even comprehend that much money.

Mrs. MARKS. I can send you a list of some of the people when I send the material to you.

Mr. BURTON. We will look at that. Thank you, Mr. Horn.

Mr. HORN. Well, Dr. Byock, I think wanted to answer your question, too.

Dr. BYOCK. One minor point here. It is actually a major point that I want to kind of put in context. A recent study, a very important study from NIH researchers on care giving of people, terminally ill people, in their homes. One of the findings was that less than 3 percent of the care that they received was from volunteers. Now, you have seen today or heard testimony about how willing and ready people are across the country to step up and care. An unintended side-effect of our licensure and accreditation policies of

the health care system is that we have inadvertently built barriers for the community to come forward.

Now we have to reach back out and build programs or avenues where people can be trained and supervised, including being supported, in providing care as volunteers to other members of their community and we need to set an example as a national government for communities across the country. In my own community, I know that if you build those avenues, people come. They are ready and willing to provide care. They do it for free. It improves the quality of their life as volunteers and members of the community. This is a national resource that we can tap that will not expand the Federal budget and that is really unfortunately being largely untapped today.

So here is NIH research that I think casts a very bright light on a place that we need to expand the care resources in our country. Thank you.

Mr. BURTON. Thank you, Mr. Chairman.

Mr. HORN. Did you want to bring up the veterans question here?

Mr. BURTON. Well, I do not want to prolong the panel because they have been here for a long time. Mr. Waxman brought up the issue of the bill that we have got that is going to be pending before the House I think in the next few days regarding DEA and how they are going to have control over people getting medications that might ease their pain and suffering. Do you think that is going to be a big problem? And if so, what do you think we ought to do about that?

Dr. BYOCK. You know this is a very contentious bill. It has unfortunately increased the polarization in this country around these issues which I think is really unfortunate because I think that people on both sides of the issue of assisted suicide firmly believe that we need to improve end-of-life care. Having been introduced, I actually support the Pain Relief Promotion Act because from my perspective, lethal medications are already illegal and the DEA already has this authority. They already have this authority and so I don't see an expansion there except in the State of Oregon which we know is an exception. I don't see how it changes anything other than improves education of the DEA and local law enforcement in what is effective pain management.

From my perspective, if we are going to have a problem with physicians confusing effective pain management with euthanasia we have an even more serious problem in this country. As a physician who has practiced emergency medicine and hospice and palliative medicine, I can tell you that it isn't a subtle distinction between caring and killing. The medications we use are different. And I do think intention matters. So from my perspective, I think that intentionally killing a patient has no place in the health care system or the practice of medicine.

I have no problem with the Pain Relief Promotion Act. I understand, however, that it has become a symbol and that it is increasingly polarizing people who really need to talk to one another. I mentioned before I have for many years spoken ardently against the legalization of physician-assisted suicide. Frankly, during that time, I have come to be personal friends with a number of the people that I still argue with and debate from podiums. I know that

they are good people, that we seriously disagree on this matter, but that together we have a strong commitment to alleviate suffering and improve the quality of life for dying Americans. I think that this bill should not keep us from building that collaborative spirit and working together to alleviate suffering. I think that is an achievable goal.

Mr. BURTON. Congressman Waxman and I and others will try to work to clarify that when it goes to conference.

Dr. BYOCK. Thank you. Thank you very much.

Mr. BURTON. I think we should pass it through the House and then get to the Senate and get it in conference.

Dr. BYOCK. I would be happy to serve as a resource to you.

Mr. BURTON. Fine. Thank you, Mr. Chairman.

Mr. HORN. Thank you. We appreciate you asking those questions. I think all of us, the one worry we have if we are going to be hospitalized when you are in your 60's, 70's, 80's, whatever, we don't want to be a burden on our family.

Dr. BYOCK. Right.

Mr. HORN. And we didn't work for 50 years or 60 years, 7 days a week, to be then have that money flowing down to the hospitals.

Dr. BYOCK. That is right.

Mr. HORN. And as far as I am concerned, pull the plug on me because I don't want to damage my family and I don't want any small estate I might have to be going down the drain because of some idiotic new probe that they stick in me. So you are all under oath and I am under oath. So I feel very strongly on that problem and I think we have got too many loose screws in this society that haven't faced up to some of these issues.

Mr. BRINKLEY. I agree. And critical care doctors are a great resource for this, Chairman Horn. Critical care doctors are the ones left, whether you administer 40 milligrams of morphine in a slow controlled pain reduction or whether you give them 20 and then they go immediately. I mean a good physician knows what he is doing. Where I come into that issue is law enforcement has a place to control certain controlled substances, but law enforcement aren't at the bedsides, they are sitting in their towers and doing what they are doing and chasing whatever they are supposed to be doing, but they are not at the bedside like a doctor is. They are not watching the pain this person is in.

And that physician is frightened because he is at the maximum. I have a 48-year old veteran. He is paralyzed. He broke his neck. He got hit by a train. He cannot move. He is in paralysis. He has degenerative muscles and atrophy of his muscles. His spine, which is where most of your nerves are, is pushing against it. The doctors can give him no more medication because the DEA says he can't do it, and although I see this person literally every couple of days and he has been a friend of mine for 35 years, I get a little resentful because this doctor can give him something to relieve the pain. They have a pump, but then the pump has to be regulated by the DEA.

Then they go through a whole new deal where they drive him up and down the road between medical hospitals in a van. There is a point where, hey, guys, wait a minute. These are human beings and stay out of it, let the doctor do the job because he has kept

him alive for 7 years, you think he is going to kill him now? And I am like Ira. I am against assisted suicide. I am totally against euthanasia. I believe you choose to come and are chosen to come here, you have come to do your time, and whatever you messed up or what went wrong genetically, you still have your time here to do, and it is important that we keep that.

What I am worried about in the Veterans Administration, and I have people here, that there comes a time when it reaches, when you are losing 40,000 a month, and you guys will keep putting pressure that euthanasia, whether, no matter how it comes, will become almost necessary and that is why I want to make this something to be aware of today, that 3 years from now there will be choices being made by physicians and by staff members who are writing appropriations for VA and by collective little consortium group that we then will be euthanizing these guys and some against their own will and some happy about it, and that is what this bill is polarizing, and I don't mean to ramble on, but these are some really important issues that I am so proud the committee brought to focus today. Three years from now, it will be dead on your election trail, but now you have made the motion to move forward in it and this bill coming up, it has to find where Chairman Burton said, that middle ground—and you, Chairman Horn—that middle ground. It must be found.

Mr. HORN. Well, we thank you for those thoughts and Dr. Tian, I will ask you the last question for the panel. Why is it, do you think, that the NIH Clinical Center has been so progressive with providing acupuncture for their patients, even before there was an Office of Alternative Medicine?

Dr. TIAN. In 1986, it was the first time that I was invited to give a talk at NIH Clinical Center regarding Chinese medicine. Since then I have treated a lot of NIH physicians including their patients and families for 4 years. They referred all the tough cases to me as a last hope. So until 1990, they believed that we don't know too much about acupuncture and Chinese medicine. We know this guy was trained at the NIH. He knows science and he is good guy. Let us try acupuncture for Clinical Center patients. So the board of Clinical Center approved acupuncture first in May 1991 before the office—OAM—which was set up 1 year later.

I provided acupuncture almost everyday for in- and outpatients, including emergency patients. I believe also they reviewed a lot of the data, research papers, and there were a lot, more than a few hundred clinical trials on acupuncture. I want to share the experience with applying for research grants because I tried three times. The first two times I didn't get it because I was using the language, the Chinese language and Chinese medicine. And then I learned, I realized I must change this. So I am not going to say anything about how the skill, what kind of skill you enhance or reduce energy. I am talking about the "dosage" of each treatment. So the four groups of patients will be treated in different "dosages," stimulation, time, how am I manipulating the needles, and finally we passed the group. You know the group who reviewed the scientific grant is not from Alternative Medicine. It is from different institutions, for instance, arthritis or fibromyalgia, that is from Ar-

thrititis Institute, not from Alternative Medicine until recently they changed the system.

Now I believe the National Center for Alternative Medicine and Complementary Medicine can give a grant directly. So they would set up their own panel. It will be much easier. So I was joking with my colleagues at NIH. I said now I understand the system. OK. We want to study an apple. I said this is an apple, it is delicious, it is from China, let us study it. They say, "no, no, no. We are not interested in apple because the apple is not in regular shape; you have to cut." I say all right. How many cuts do you want? They said try to make six cuts. One, two, three, four, five, six. Now the apple is a square. Can we study it now? Yes. We can study. That is my experience of some skills needed to get a research grant. I want to share this. Maybe you want to follow this to get your research approved.

Mr. HORN. In 1981 I was in China at the Second Medical College in Shanghai and watching a brain operation with acupuncture and a mix with western ether of the 30's, shall we say, and it was fascinating to see that. There were about a dozen of us asked to go over and look at the various institutions the Chinese Government thought they might make some changes in. So I was fascinated by that and I am curious on your early venture into this.

Dr. TIAN. Thank you.

Mr. HORN. Thank you. Does the gentleman from Indiana, our esteemed chairman, have any further questions of this panel?

Ms. SCHAKOWSKY. Mr. Chairman.

Mr. HORN. Yes. Fine.

Ms. SCHAKOWSKY. Thank you, Mr. Chairman. I am sorry that I have been so in and out because this is an issue very dear to my heart. My father, who passed away in 1997, really taught all of us how to die. It was an incredibly uplifting experience. He lived in my home for 6 years and then at the end of his life we were really blessed with hospice care. And it was, well, I am really beyond words almost. It was just an incredible experience, one that I think was comforting and rewarding for all of us.

But I was concerned and you raised this, Dr. Byock, in your testimony that we had to somehow certify that he would be dead in 6 months, although the doctor said, you know, there is no sanction if he doesn't comply and die in the right amount of time, but that is certainly a barrier. And then the issue of relinquishing access to other kinds of services was definitely something that we as a family had to talk over and I think—is that what you had in mind when you were talking about the statutory limitations, et cetera, that we had to—

Dr. BYOCK. Yes, it is. And now there are repercussions if somebody is admitted to a hospice program and doesn't die quickly enough. Right now we have I think a national crisis just in the Medicare hospice benefit program. The median length of stay in hospice programs is right around 17 days. Congressional intent was that people have access to about 6 months of hospice care. Hospice providers want to do end-of-life care. That is what we are trained to do, but currently we are doing brink-of-death care. There is not a lot of time to do the life completion and life closure work and really nurture the family process when people are being admit-

ted right sometimes within hours of their death. This is unnecessary and frankly it is so ironic because it ends up costing the system more money, not less.

Ms. SCHAKOWSKY. I also just wanted to make the point, if you will allow me, Mr. Chairman, regarding how this interfaces with the whole issue of the so-called right to die and I got a fax today regarding an Oregon patient with dementia who was, in fact, the physician even though the physician knew that this person couldn't remember anything or really understand anything, including the names, could not remember recent events and people, including the names of her hospice nurse or her doctor. Was this already discussed in this hearing?

Dr. BYOCK. No.

Ms. SCHAKOWSKY. They made the decision, the go-ahead was given by Kaiser Permanente to end this person's life. I think what we are talking about here is a whole new ethic, a whole new approach, a whole different understanding about what end-of-life means, and that is so important, I think, to our whole society and what we are about as people. We must understand the value, the importance, the dignity, and the beauty of these last days, rather than seeking ways to cut it off earlier and particularly when we are robbing people who can't even make these decisions of their right to live.

Dr. BYOCK. It is very troubling. This case was in "The Oregonian" over the weekend and it talks about a patient with advanced cancer who also has dementia and can't remember the events of her diagnosis or treatment nor who her doctors are. The family felt that she wanted to be helped to a preemptive death. Her doctor disagreed. They got a mental health consultant who thought that she did not have decisionmaking capacity. So they got a new doctor who then got a new mental health consultant. This is all within the Kaiser Permanente system.

The second medical consultant felt, well, maybe she could and the ultimate decision went to a physician who is a Kaiser administrator and also a Kaiser shareholder who ultimately decided that it would be OK for this woman to receive her lethal prescriptions. Those of us who worry about the slippery slope in assisted suicide have been proven right in this case. The slope is not only slippery, it is a virtual precipice.

Ms. SCHAKOWSKY. Let me just make one final comment. For 5 years before I went into the State legislature, I was director of the Illinois State Council of Senior Citizens, so I can easily envision situations where frail elderly, women in particular, who are faced with the choice of and posed with the question, do you want to be a burden to your family?

Dr. BYOCK. Right, exactly.

Ms. SCHAKOWSKY. And to society.

Mr. BRINKLEY. It happens all the time.

Ms. SCHAKOWSKY. And wouldn't it be better for you and for everyone if you just opted out? We have so far to go to offer people at the end of life the option of living with dignity to now choose the right to die I think is—or so-called right to die—I think is such a serious mistake.

Dr. BYOCK. So many people that I speak with who are asking me for help in dying say that for them the choice seems to be one between suffering on the one hand and suicide on the other. If that is the choice that Americans face, it is no more a progressive extension of our personal freedoms than "Sophie's Choice" in William Styron's novel was an expression of self-determination.

Ms. SCHAKOWSKY. For low income people, that seems to be the choice, as you pointed out in your testimony, that low income people seem to have less access to pain medication and pain alleviation.

Mr. BRINKLEY. Burden on the family. The three major things—pain, insufficient pain management; the dignity at the end of life; or putting an unnecessary burden on the family—are the three reasons that we come across all the time why euthanasia or assisted suicide comes into play. None of those are necessary. We live in the greatest country in the world. We have the resources, the people, and the hearts and the souls in the legislature, in the government, to step up and handle this. Why I support Ira in what he does, he is out here with everything he has and just what you went through and just what you are seeing, when a person hits a place where they are going to burden their family, they have insufficient pain management, which I think is somewhat a conspiratorial nature, and they lose their dignity, and then Kaiser Permanente comes along with a great suggestion of how to end it all, and the person who is making that decision is a bean counter, he is not a doctor. A doctor knows what he is doing.

I watch this all the time, and I watch the struggle that critical care and palliative care doctors go through. I am just a guy. You know I don't have a—I don't have those mixed feelings about it. I am going to protect that person. We have to enlarge that scope for critical care and palliative care doctors that they can be responsible, they can make the right decisions, and they can stand up and fight for what a managed care or an HMO or PPA or PPW or whatever they are all called in making that decision, and we are capable. And why I am so proud to sit here today, and really proud, because Chairman Burton and Beth, and Chairman Horn and the rest of the committee, you are stepping up to the plate.

It is not going to stay in the closet. It is going to come out and be dealt with so 2 to 5 years from now or maybe 10 when it is us, we have opened the door for graciousness, complementary and alternative therapies, legislative action, and a safety net so people have a place to come. So thank you.

Ms. SCHAKOWSKY. Mr. Chairman, in honor of my father, if I could just say that the one thing I learned from him is that you don't lose your dignity unless you give it away.

Mr. BRINKLEY. You got it.

Ms. SCHAKOWSKY. And he taught us all that. Thank you.

Mr. HORN. I thank the gentle woman from Illinois on that very perceptive discussion and now I would ask does the distinguished woman from Maryland wish to get into this?

Mrs. MORELLA. Absolutely, Mr. Chairman, and I want to thank the panel and in advance the second panel because I think this is a very important issue. Speaking to the chairman of the full committee, it is too bad we just have so many committee hearings and

mark-ups going on at the very same time, so that we cannot stay with one committee throughout its entire duration to be able to fully relish and absorb and respond to what is being said.

I, like Ms. Schakowsky, and probably others on this panel, have experienced firsthand the difficulty with dying in the midst of a full life. My sister died in 1976 at the age of 40, and we took her six children into our family with our three. But she was fortunate or we were fortunate in that we were able to provide a home environment where she was at home and she was at home with the family, with the little children, and we all recognized that unless a miracle occurred, that life was going to be shortened and therefore I think it resounded in being as full of life and death with dignity and an understanding of what was going to happen in the future with her family.

With my mother, who died several years ago, hospice care came into play beautifully, beautifully, and in fact we had the contributions sent to our hospice society because they were just there providing the same kind of thing that family were able to provide for my sister. And so I know that the strides that have been made in treatment and technology have made American medical prowess the envy of the world and have lengthened the lives of many.

However, these advances have also created the unexpected consequence, the modern day medical nightmare, of a death alone, in pain, without dignity, tethered to expensive equipment and machines. Through our efforts, Mr. Chairman, Congress is addressing the nationwide outcry for alternative ways to relieve terminally ill patients' symptoms while comforting their spirits, supporting their loved ones, and instilling in their families the hope of a peaceful death.

With the support of the Life with Dignity Foundation, I became an original cosponsor of H.R. 1149, which is entitled, the Advanced Planning and Compassionate Care Act of 1999, to help Congress respond to the critical needs of the terminally ill and their caretakers during this very difficult and traumatic time. I am encouraged that the National Institutes of Health, located within my district, has founded projects in palliative and end-of-life care. I look forward to hearing from Dr. Patricia Grady, who will be on the next panel from NIH, and I was pleased to be able to hear Dr. Tian, who is also from my district. I am very honored to have you here, sir, and to have the other experts on this particular panel.

I know that from a Capitol Hill breakfast briefing on end-of-life care which took place in March 1998, Dr. Grady, as an example, the Director of the National Institute of Nursing Research, gave some detailed information on NINR's research over the past 10 years related to the end-of-life care. So I think it is an important issue. All Members of Congress should have access to the kind of information and experience that you give us and the work that you are doing. So I thank you.

I do not really have any questions. I was looking over the testimony and I was saying to the chairman I think that all of the things you say make sense including even music. I have always said I would really like to be listening to Puccini's—one of the operas—probably *La Boheme*, I think, maybe *Madame Butterfly*. I think that is a comforting factor, too, but we are talking about

making the end of life something as it should be and that is one with dignity. Thank you.

Mr. BRINKLEY. A celebration. And that it is a celebration.

Mrs. MARKS. I think I would like to underscore what Dr. Byock has said that you can't go into a hospice unless you give up the other treatment. I think that should be very seriously reconsidered, because we couldn't do that with my husband and he should have gone in earlier. It means you give up all the conventional treatments, and that is not good for the patient psychologically, and I also think we have to think about reshiftng our resources through Medicare and our finances, possibly to support other activities that are not being supported now and to decrease some of the others.

Mr. HORN. We thank all of you, each and every one of you, for the very fine statements you filed with us and for the questions and answers and the dialog we have had with you. So thank you very much for coming.

Mrs. MARKS. It was a pleasure.

Mr. HORN. We now dismiss the first panel and if panel two would come forward, we will swear you in. Dr. Thomas V. Holohan is accompanied by Dr. Judith Salerno; Kathy Buto; and Dr. Patricia Grady, Director of National Institute for Nursing Research, that Mrs. Morella mentioned. Do you have any of your staff that might well want to get into the dialog on some specific questions because I would like to swear in everybody at once. Just one big baptism rather than 10. I am used to the Pentagon and there are usually three rows. OK. If you will raise your right hands.

[Witnesses sworn.]

Mr. HORN. The clerk will note that the four witnesses and two that accompany the witnesses have been sworn in. So we will begin in the order on the agenda and that will be Dr. Thomas V. Holohan, the Chief of Patient Care Services for the Veterans Health Administration, and I might say to all of you automatically your full statement is put in the record when I call on you and we go down the line with all four witnesses before we question you. So we would like to get all out on the table with panel two and then we can go back and you can comment on some of the papers or thoughts some of your colleagues didn't agree with you on, and then we will have a discussion with the Members. So Dr. Holohan, it is all yours and welcome.

STATEMENTS OF THOMAS V. HOLOHAN, M.D., CHIEF, PATIENT CARE SERVICES, VETERANS HEALTH ADMINISTRATION, ACCOMPANIED BY JUDITH SALERNO, M.D., CHIEF CONSULTANT, GERIATRICS AND EXTENDED CARE STRATEGIC HEALTH CARE GROUP, VETERANS HEALTH ADMINISTRATION; KATHLEEN BUTO, DEPUTY DIRECTOR, CENTER FOR HEALTH PLANS AND PROVIDERS, HEALTH CARE FINANCING ADMINISTRATION; AND PATRICIA GRADY, PH.D., DIRECTOR, NATIONAL INSTITUTE FOR NURSING RESEARCH, NATIONAL INSTITUTES OF HEALTH

Dr. HOLOHAN. Thank you, Congressman. I should comment that I am also a constituent of Congresswoman Morella's and I remember we had many candidates appearing at our Metro Station prior to the last election day. The day after election day, very cold and

rainy, there was only one person there still shaking hands after the election and that was Congresswoman Morella.

We are pleased to be here today and have the opportunity to provide testimony and to answer any additional questions the committee may have regarding the provision of medical care in the Veterans Health Administration. I have previously testified with regard to the Veterans Administration and complementary and alternative medicine. Today Dr. Judith Salerno, my Chief Consultant for Geriatrics and Extended Care, will discuss a number of our programs and areas of interest to the committee. This will include care at end of life, palliative care, and pain management as well as a number of new initiatives to assist families and caregivers. In her presentation, Dr. Salerno will also address some uses of complementary or alternative practices as they relate to these programs. Following her testimony, we will both be happy to answer any questions that you may have. Judy.

Dr. SALERNO. Thank you, Dr. Holohan. VA has made a significant commitment to improving end-of-life care for our veteran patients. Because we are the largest integrated health care system in the country and because our veteran population is older and sicker than the general population, we recognize that VA had the opportunity to make inroads in improving care that ultimately will be for the benefit of all Americans.

In 1998, a national VA summit was held bringing together experts from across the Nation. From that summit came three goals. The first was that no dying veteran shall suffer from preventable pain. Second, every veteran with terminal illness shall have an individualized plan for palliative services that minimizes suffering and optimizes quality of life. And third, every veteran with a terminal illness shall have access to hospice care and/or palliative care services.

Based on these principles, VA has crafted and implemented innovations in end-of-life care, pioneered faculty development programs, and set performance standards to assure that our patients with terminal illnesses have comprehensive and coordinated care. While I am proud to say that VA's national performance, as measured by our palliative care index, improved from 52 percent to 94 percent systemwide in less than 2 years, it is but just a beginning.

With support from the Robert Wood Johnson Foundation, the VA faculty leaders in end-of-life care project identified and supported leaders at 30 medicine residency training programs, and are assisting them in implementing benchmark curricula for state-of-the-art care for patients at the end of life. A website has been developed as part of the project which is serving as a resource for all health care professionals, both within and outside of VA.

VA operates 59 inpatient hospices and nearly all of our facilities have hospice consultation teams. These teams work closely with community hospice providers to offer home hospice care. Our own home-based primary care program offers palliative care services in the home to veterans who are seriously and chronically ill, and their approach is that of an interdisciplinary team and often family caregivers and community volunteers are included as members of the health care team. This is especially important to terminally ill

individuals who would not otherwise choose traditional hospice care.

We have recently turned our attention to pain management. While pain management and palliative care are hallmarks of excellent care at the end of life, we have recognized the need to develop strategies for easing pain and suffering across all health care settings and at all times. In March, we launched a national policy that says no patient served by the VA health care system should suffer from preventable pain. That pain will be assessed as the fifth vital sign in all VA health care settings.

In the next year, we will closely monitor our progress in achieving this goal. We are quite excited about a national leadership conference scheduled for November 2–5, which will bring together experts, innovators, and direct care providers in both end-of-life care and pain management. It is our hope that this meeting will generate many new opportunities for networking, collaboration, and advancing the state-of-the-art in palliative care.

I would like to briefly address support of services and complementary therapies. In our view, palliative care affirms life and regards dying as a natural and profoundly personal process.

Any treatments that are supported by good evidence of safety and effectiveness should be available to our veterans. Complementary therapies that are offered at some VA medical centers include relaxation, visualization, music and art therapy, healing touch, aromatherapy, massage, Tai Chi, and reminiscence or life review therapy. The creative arts have been used in VA as a powerful means of expression to help veterans and with the participation of their families to reflect upon their lives.

Spiritual care and bereavement support is available to patients at all VA facilities through VA's active chaplaincy service and chaplains of all faiths function as key members of our interdisciplinary team. VA also supports and encourages attention to multicultural approaches to healing such as access to Native American healers.

Over the past 2 years, VA has made tremendous and measurable strides in improving care at the end of life for our veteran patients. There is much more for us to do to better serve the needs of our dying and suffering patients. The extraordinary attention that VA has received for its end-of-life and pain management activities comes from the recognition that VA can lead by example and effect change in the culture of health care. We remain steadfast in our goal to provide excellent care that affirms life and achieves the best possible quality of life through relief of suffering and compassionate care. Thank you.

[The prepared statement of Dr. Holohan and Dr. Salerno follows:]

Statement of
Thomas Holohan, M.D.
Chief Patient Care Services Officer
and
Judith A. Salerno, M.D., Chief Consultant
Geriatrics and Extended Care Strategic Healthcare Group
Veterans Health Administration
Department of Veterans Affairs
On
Improving Care at the End of Life
With Complementary Medicine
Before the
Committee on Government Reform
U. S. House of Representatives

October 19, 1999

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Mr. Chairman and members of the Committee, we are pleased to appear before you today to provide an overview of the Department of Veterans Affairs' (VA) experience and initiatives in improving end-of-life care for its veteran patients.

VA has made a significant commitment to improving care at the end of life for our veteran patients. There are several factors that make it important for the VA to focus on this crucial issue at this time:

- Serious, life-limiting illnesses are prevalent in the aging veteran population;

- VA is the nation's largest integrated healthcare system;
- VA has decades experience in geriatric and palliative care;
- VA's academic and educational affiliations provide an opportunity to influence the education of large numbers of physicians, nurses and other health care professionals in the area of end-of-life care; and
- VA's research capacity provides an opportunity to strengthen the knowledge base in end-of-life care.

VA has recognized that our resolve to confront these issues can offer leadership that will benefit not only veterans, but all Americans.

In 1997, VA initiated a national strategic effort to improve care at the end of life. A national summit was held in May 1998 for the purpose of developing a comprehensive, system-wide VA strategy for improving care of veterans at the end of life. The recommendations of the Institute of Medicine (IOM) Committee on Care at the End of Life published in the report, "Approaching Death: Improving Care at the End of Life" (1997) served as a framework for the strategy summit. It should be noted that VA is probably the only single health care system in the United States with the capacity to address each and every recommendation made by the IOM committee. The specific elements of VA's national strategy to improve care at the end of life include:

- identification and dissemination of state-of-the-art practices in care of the dying;
- improving systems and organizational processes to achieve reliable, excellent care for patients during the last phase of life;
- strengthening methods for measuring processes and outcomes of care for dying patients and their families;
- designing education for VA health professionals and affiliated trainees to assure that caregivers have the knowledge, skills and attitudes to care well for dying patients and their caregivers;

- empowering patients and their families through education about care at the end of life;
- collecting data on quality, access, cost and utilization to inform public policy; and
- collaborating with other national organizations and with health care providers that are similarly committed to improving the care of patients during the last phase of life.

The summit brought together individuals from across the VA health care system who have demonstrated interest, expertise and leadership in this area, along with non-VA experts and national opinion leaders. Three strategic goals were identified:

1. No dying veteran shall suffer from preventable pain while being cared for by the VA health care system.
2. Every veteran with a serious, life-limiting illness receiving care from VA shall have an individualized plan for comprehensive, coordinated, palliative care services that minimizes physical, psychological, social and spiritual suffering and optimizes the patient's quality of life.
3. Every veteran enrolled in the VA health care system who has a serious, life-limiting illness shall have access to hospice care and/or palliative care services and shall have an understanding about the availability of those services.

During the past two years, VA has made tremendous strides in developing and implementing programs for improving care at the end of life, based on these simple, direct, but profoundly important tenets. Programs and projects have been developed at the local, regional and national level. A brief overview of some of VA's activities is outlined below.

1. Network Directors Performance Measure: Palliative Care Index

In 1997, the VA initiated a national performance measure to assure that patients with incurable, life-limiting illnesses have an individualized, comprehensive plan for coordinated palliative care services. To meet the intent of the measure, the plan must include: discussion of care alternatives and treatment settings with the patient and/or family; discussion of advance directives (a patient's specific written instructions regarding future health care decisions); effective palliative symptom management; psychological, social and spiritual support for the patient; and continuity of care coordinated over a continuum of health care settings. National performance has improved from 52% compliance in the third quarter of FY 1997 to 94% in the second quarter of FY 1999, reflecting the enthusiasm with which VA health care providers have undertaken to improve end-of-life care for veterans.

2. VA Faculty Leaders Project for Improved Care at the End of Life

The VA Faculty Leaders in End-of-Life Care project was initiated in 1998 with support from the Robert Wood Johnson Foundation. The project has identified faculty leaders at 30 internal medicine residency training programs affiliated with VA throughout the nation. The Faculty Leaders are participating in a two-year project designed to assist them in developing and implementing benchmark curricula for state-of-the-art care for patients through the end of life. The Faculty Leaders have shared their progress at several national conferences. A web site has been developed as part of this project and has become a valuable resource on end-of-life care for physicians and other health care professionals both within and outside VA. The web site for the VA Faculty Leaders Project is <http://www.va.gov/oaa/flp>.

3. Breakthrough Collaborative on Improving Care for Patients Approaching the End of Life with Chronic Obstructive Pulmonary Disease (COPD) and Congestive Heart Failure (CHF)

VA recently co-sponsored a quality improvement initiative with The Institute for Health Improvement (IHI) and the Center to Improve Care of the Dying (CICD) that focused on devising systems for better care for patients approaching the end of life with CHF and COPD - common serious conditions found in VA patients as well as in all older populations. Seventeen VA sites participated in the nine-month collaborative, and a number of them achieved breakthrough improvements in care. Some of the innovations that were implemented during the collaborative included: improved continuity of care across settings, successful patient and family education; advance care planning; improved symptom management; and improved patient and family self care. Several participating VA sites significantly reduced the episodes of symptom exacerbation, which resulted in fewer emergency room visits and hospitalizations. Results of the collaborative were presented at a national conference in Atlanta in September 1999, and several of the improvements will be featured at the VA National Leadership Conference on Pain Management and End of Life Care, which will be held November 2 - 5, 1999, in Crystal City, VA.

4. VA National Pain Management Strategy

As an outgrowth of the VA's efforts in end-of-life care and the substantial attention given to pain management issues by VA's Anesthesiology Service, VA has implemented a national strategy to develop a system-wide approach to reduce pain and suffering for veteran patients across all VA health care settings. An expert coordinating committee has been appointed to oversee the development and implementation of the national strategy. In March 1999, VA initiated a national policy to assess pain as the "5th vital sign." The goal of this initiative is to assure that pain assessment is performed in a consistent manner, and throughout the VA healthcare system. The overall objectives of the VA national strategy for pain management are to:

- provide a system-wide VHA standard of care for pain management that will reduce suffering from preventable pain;

- assure that pain assessment is performed in a consistent manner;
- assure that pain treatment is prompt and appropriate;
- include patients and families as active participants in pain management;
- provide for continual monitoring and improvement in outcomes of pain treatment;
- provide for an interdisciplinary, multi-modal approach to pain management; and
- assure that clinicians practicing in the VA healthcare system are adequately prepared to assess and manage pain effectively.

The VA National Pain Management Strategy recognizes the need to take a long-term approach to improving pain management, and is committed to continual improvement in assessing and treating pain. The VA strategy also recognizes the importance of an interdisciplinary approach to pain management and the role of non-medical modalities for treating acute, chronic and cancer pain.

5. Alzheimer's CARED Project (Caregiver Assessment Regarding End-of-Life in Dementia):

In 1998, VA received support from the Alzheimer's Association for a year-long research project on end-of-life care for patients with Alzheimer's Disease. Through the CARED Project, based at the Bedford, Massachusetts VA Medical Center, VA is reviewing the current status of end-of-life care for patients with dementia and developing recommendations for an innovative home- and community-based service model. The Geriatric Research, Education and Clinical Center (GRECC) at Bedford, which is coordinating the CARED project, has accomplished cutting-edge research in care for patients with advanced dementia. Dr. Ladislav Volicer and Dr. Ann Hurley at the Bedford GRECC are nationally known as leaders in palliative care for patients with dementia. They co-authored

the book "Hospice Care for Patients with Advanced Progressive Dementia" published in 1998. One of the significant outcomes of Dr. Volicer's and Dr. Hurley's work is a unique model for advance surrogate decision-making that involves interdisciplinary team/family conferences.

6. Hospice Care

VA is working to increase access to hospice care for veterans who need and want to receive hospice services. Currently the VA has 59 inpatient hospice programs in VA medical facilities. Nearly all VA medical centers have hospice consultation teams, and most VA medical centers work closely with community-based hospices to provide home hospice care to veterans. Hospice care is one of the services included in the uniform benefits package that is available to all veterans enrolled in the VA healthcare system. Currently, VA is exploring ways to use our sharing and contracting authority to increase access to hospice care for veterans. For example, a pilot project being implemented this month at the VA medical center in Palo Alto expands the VA inpatient hospice capacity to provide reimbursable inpatient hospice care to community hospices with the proceeds substantially supporting additional hospice beds for veterans. A number of other VA facilities have been exploring the feasibility of entering into use-of-space agreements with community hospices to operate inpatient hospice units in unused VA inpatient space. We are optimistic that these efforts will increase access to hospice care, which has already increased 21% since 1995.

7. Palliative Care

There are many terminally ill individuals who would not choose traditional hospice care. VA has a number of excellent palliative care programs, including one of the few Alzheimer's palliative care units in the nation, which is a major initiative of the Bedford GRECC. In addition to inpatient palliative care, a number of VA facilities provide excellent palliative care in the home through their Home-Based Primary Care (HBPC) programs. The VA HBPC program is very similar to

hospice in that it provides an interdisciplinary, holistic approach to care and is specifically designed to serve long-term, seriously chronically ill patients. The advantage of the HBPC program is that, unlike the Medicare hospice benefit, the patient need not have a prognosis of six months or less to live. Many HBPC programs serve patients who are terminally ill with non-cancer diagnoses and for whom it would be difficult or impossible to predict whether they will live for six months. The unique advantage that the VA HBPC programs have over Medicare hospice is that they can offer a combined approach to care --good supportive care services along with excellent medical disease management. Patients are not forced to make an artificial choice between "palliative care" and "aggressive care," but rather can receive the care that is most appropriate for their individual needs. Several of the VA HBPC programs (Tampa, Tucson, Indianapolis) are piloting programs specifically designed for patients who are approaching the end of life with CHF and COPD. The interdisciplinary team approach to care in the home provides support for family caregivers. In addition, several HBPC programs are using community volunteers to provide additional caregiver support.

8. VA National Leadership Conference in Pain Management and End-of-Life Care

This national conference, scheduled for November 2-5, 1999, will bring together 300 experts, innovators, change agents and direct care providers from across the VA health care system. The goals of the conference are to:

- provide education on pain management and end-of-life care for health care providers of all disciplines and at all levels in the organization;
 - facilitate planning and problem-solving related to organizational systems;
 - feature state-of-the-art practices and innovations throughout the VA;
- and

- provide an opportunity for networking and collaboration and sharing of ideas.

Response to the call for participation for the conference has been enthusiastic across VA, with many impressive projects and programs from individual VA medical centers and networks being brought to the forefront. The conference is designed to be interdisciplinary and holistic, reflecting attention to the medical, social, and spiritual needs of patients. Spiritual and emotional support for patients, as well as non-medical modalities of care, will be the focus of several of the breakout sessions because we recognize the central role they play in planning for the needs of dying patients.

9. Supportive Services and Complimentary Therapies

VA national policy supports and encourages comprehensive management of the physical, psychological, social, spiritual and existential needs of patients with advanced, incurable illness. Palliative care affirms life and regards dying as a natural process that is profoundly personal for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal, cultural, and religious values, beliefs and practices. VA has taken the position that any treatments that are supported by good evidence of safety and effectiveness should be available to our patients, consonant with their risks and benefits as compared with other interventions. Complementary therapies that are available at some VA medical centers include relaxation, visualization, music therapy, art therapy, healing touch, aroma therapy, massage, Tai Chi Chuan (a Chinese exercise therapy), and reminiscence (life review) therapy. Spiritual care is available to patients at VA facilities through VA's active Chaplaincy Service. Chaplains of all faiths function as key members of the interdisciplinary VA team. Bereavement support for families and memorial services are part of many of VA's hospice and palliative care programs.

VA also supports and encourages attention to multi-cultural approaches to healing. For example, a number of VA medical centers that serve Native American veterans have made available sweat lodges and Native American healers who desire those services.

The power of arts is an important part of the palliative care supporting patients at the VA Nursing Home Care Unit in Washington, D.C. Patients are introduced to all of the creative arts through a program that provides a means of expression and helps veterans to reflect upon their lives. There is a literary arts as well as visual and performing arts component in which family members can participate. A poetry program has been very popular with nursing home patients, some of whom have been escorted to recite at poetry readings. An annual calendar created and published by and for the patients is a highlight of the unit's activities. VA supports evidence-based complementary therapies in concert with conventional therapies as part of a commitment to excellent care for veterans during the last phases of life.

Summary

Over the past two years, VA has made tremendous and measurable strides in improving care at the end of life for our veteran patients. We realize that these efforts have not fully matured. Indeed, there will always be more for us to do and fresh ideas to test about how to better serve the needs of our dying and suffering patients. The extraordinary attention that VA has received for its end-of-life and pain management activities comes from the recognition that no other major health care system has set its sights so high. The opportunities for VA to lead by example and effect change in the culture of health care are enormous. We have accepted that challenge and remain steadfast in our goal to provide our dying patients with care that affirms life, recognizes the right to self-determined life closure and achieves the best possible quality of life through relief of suffering and compassionate care.

Thank you, Mr. Chairman, for the opportunity to provide the Committee with information about VA's initiatives on end-of-life care. We will now be happy to answer any questions that you or other members of the Committee might have.

Mr. HORN. Thank you very much. Our next witness is Ms. Kathy Buto and she is the Deputy Director of the Center for Health Plans and Providers of the Health Care Financing Administration, part of the HHS empire. So Ms. Buto, we would like the witnesses since we have the statements to not read them but to summarize them in 5 minutes if you could do it and then we will have more time for questions.

Ms. BUTO. I hope it will even be shorter than 5 minutes.

Mr. HORN. Yes.

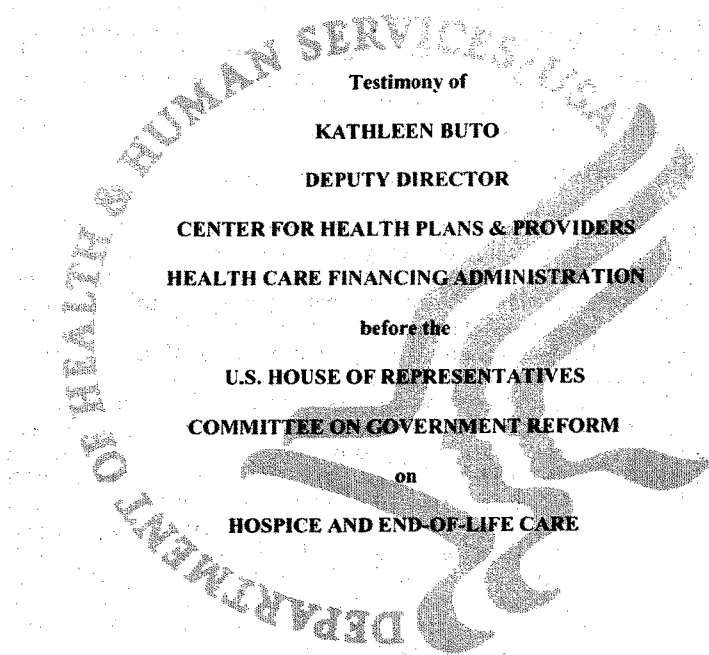
Ms. BUTO. Medicare and most Medicaid programs cover hospice for terminally ill beneficiaries as you have already heard from many of the previous panel members. We have seen a steady increase in the number of beneficiaries electing hospice and the number of certified hospices in Medicare since the benefit became covered more than 15 years ago. Nearly one in five Medicare beneficiaries now uses hospice services at the end of life.

The benefit is designed to give hospices great latitude in meeting patients' medical, psychosocial, and spiritual needs. Payment is a set prospective rate for different types of services, allowing hospices to use payment more flexibly. That means they can provide both traditional services such as physician services, nursing care, and drugs to control pain as well as social services, homemaker assistance, and other nonmedical services. At the discretion of each hospice and patient, hospices can use Medicare funds under this prospective system to provide complementary treatment such as acupuncture, massage therapy, music therapy, et cetera. So just to underscore that, the hospice has the flexibility to use funds in those ways.

The Balanced Budget Act made a number of important improvements to the hospice benefit. We ensure under the BBA, that a patient whose condition improves or who wants to resume curative care, can return to hospice at a later date. As Dr. Byock said, there are now unlimited benefit periods in hospice. They are not limited. And under the BBA, the hospices are required to provide data on how they use Medicare funds, and this is really for the purpose of allowing our agency to evaluate the rate structure and whether it is really adequate. We expect that this will help us learn which services are the most important to patients, as well as to be sure that we are paying appropriately.

That concludes my oral statement. I know there are a number of questions related to Medicare coverage, and I will wait.

[The prepared statement of Ms. Buto follows:]



Testimony of
KATHLEEN BUTO
DEPUTY DIRECTOR
CENTER FOR HEALTH PLANS & PROVIDERS
HEALTH CARE FINANCING ADMINISTRATION
before the
U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON GOVERNMENT REFORM
on
HOSPICE AND END-OF-LIFE CARE

October 19, 1999



**Testimony of
Kathleen A. Buto, Deputy Director
Center for Health Plans & Providers
Health Care Financing Administration
before the
House Government Reform Committee
on
Hospice Care and Other End-of-Life Issues
October 19, 1999**

Chairman Burton, Congressman Waxman, distinguished Committee members, thank you for inviting us to discuss the importance of hospice care and other end-of-life issues. The programs we administer provide care to more than 70 million people in the United States. We are committed to ensuring that, at the end of life, they receive appropriate care tailored to their own needs and that they understand their rights and options.

Medicare and most state Medicaid programs cover hospice services for terminally ill beneficiaries. Hospices provide comfort, counseling and relief from pain, rather than curative care. Hospice care brings important extra sensitivity, a focus on patient and family, and a special form of care to the dying. Medical, psychosocial, and spiritual needs are addressed by a specially qualified interdisciplinary team, with an emphasis on keeping the patient at home with family and friends as long as possible.

Medicare's hospice benefit is designed to give hospices the greatest latitude in meeting patients' end-of-life care needs. The care provided includes traditional services, such as nursing care and drugs to control pain, as well as social services and homemaker assistance. And, at the discretion of each hospice and patient, it can include complementary treatments such as acupuncture and massage therapy.

Medicare and Medicaid also require hospitals to ask all patients upon admission about advanced directives, such as living wills, which can help ensure that patient preferences regarding end-of-life care are heeded. And we are taking other steps to conduct research on end-of-life and hospice issues, help hospices improve the quality of care they provide, and assist physicians in addressing end-of-life issues.

The Balanced Budget Act of 1997 made important changes to Medicare's hospice benefit. These changes ensure that patients whose prognosis improves or who choose to resume curative care can leave hospice and return at a later date. They also will provide us with information about how hospices are using payments they receive and a better understanding of which services are most important to hospice patients, and help us ensure that payment levels are appropriate.

BACKGROUND

Hospice care was added as a benefit under the Medicare program in 1983 and under Medicaid in 1985. The number of beneficiaries electing hospice care and the number of agencies offering services have grown steadily ever since. In 1998, 420,824 Medicare beneficiaries received more than \$2 billion in hospice care services from more than two thousands hospice agencies across the country, with an average length of stay of 48 days.

Hospice care is covered under the Medicare Hospital Insurance program and is available to all beneficiaries enrolled in Medicare Part A. To be eligible, their physician and the hospice medical director must certify that they are terminally ill, with approximately six months or less to live if their illness runs its normal course. The beneficiary must sign a statement indicating that they understand that they are choosing hospice care instead of routine, curative Medicare covered benefits for their terminal illness. Their physician must reaffirm the prognosis at 90 days, 180 days, and every 60 days thereafter.

Beneficiaries can receive hospice services wherever they reside, be it at home, a nursing home, a hospital, or other facility or setting where the patient resides. Once in hospice, they also continue to have Medicare coverage for treatment of other problems not related to their terminal illness from either their own physician, the hospice physician, or their Medicare+Choice plan if they are enrolled in one.

Services that hospice agencies routinely provide include:

- Physician services (on-call 24 hours a day, 7 days a week);
- Nursing care (on-call 24 hours a day, 7 days a week);
- Physical, speech and occupational therapy;

- Medical social worker services;
- Medical supplies (such as bandages and catheters);
- Drugs for symptom control and pain relief;
- Medical equipment (such as wheelchairs or walkers);
- Short-term care in the hospital, including both respite care and procedures necessary for pain control and symptom management;
- Home health aide and homemaker services;
- Continuous home care of eight hours or more per day during a period of crisis as needed so that the patient can remain in their home;
- Dietary counseling;
- Counseling to help the hospice patient and their family with grief and loss; and
- Any other item or service for which payment may otherwise be paid under Medicare.

Additional services to ease pain and provide comfort may also be provided at the discretion of each hospice and patient. This can include, for example, alternative treatments such as massage therapy and acupuncture. We believe that the hospice is in the best position to determine what care is appropriate to meet the goal of alleviating pain and providing comfort for each individual patient. We understand that hospices do explore and try new and complementary treatment modalities in a continuing effort to improve the care of the dying, and we encourage these efforts.

EDUCATION & TRAINING

Education and training are critically important to the hospice program. Beneficiaries and their families need to know that these services exist and how to use them. Physicians need to know when and how to determine whether to recommend hospice care to an individual patient, as well as what criteria to consider when certifying a patient's eligibility. Therapists and other ancillary providers need to understand the special sensitivities required in treating hospice patients. Hospice volunteers need to know how to provide the assistance and empathy that are the hallmarks of hospice care. And agency surveyors who inspect hospices to ensure compliance with health and safety regulations

need to understand the essential differences between hospices and other kinds of health care providers.

For beneficiaries and their families, we have a brochure that describes in plain English how the hospice benefit works, what their rights and obligations are under the benefit, and how to contact national and state hospice organizations. This brochure is available on our www.medicare.gov website. Hospice information and references are also included in the *Medicare & You* handbook that is mailed to all 39 million Medicare beneficiaries each year.

For physicians, we have worked with the National Hospice Organization as it developed guidelines on how to determine hospice eligibility for patients with an illness other than cancer that can make prognosis more uncertain. We have distributed these guidelines to physicians through our contractors who process hospice claims.

These guidelines are particularly important in addressing concerns about potential misuse of the hospice benefit. These concerns resulted from identification by the HHS Inspector General of isolated but egregious cases in which unscrupulous hospice providers had billed Medicare, for sometimes several years, for services to beneficiaries who were not terminally ill.

Terminal disease prognosis is not an exact science, and many legitimate hospice patients live longer than six months. Therefore, we issued a bulletin for hospice providers in 1995 stressing that it is essential for physicians and hospices to document the clinical factors that lead them to the six-month prognosis. This bulletin also suggested more frequent review of a patient's condition in cases where the prognosis is less certain. The Inspector General also has issued compliance guidelines to help hospices design programs to avoid improper claims.

We have also provided special training to speech, physical, and occupational therapists, and other caregivers, on how to best provide care and sensitivity when working with

hospice patients. And for hospice volunteers, we have worked with experts to provide training on how to help hospice patients with everyday tasks such as shopping, bathing and dressing.

And for state surveyors who inspect hospices for compliance with health and safety regulations, we have conducted special training sessions, as well. For example, one such session in 1997 included a presentation on effective symptom control, quality care for the terminally ill, and quality of life indicators that surveyors need to take into account by Ira Byock, M.D., who is also testifying at today's hearing.

ADVANCED DIRECTIVES

In addition to the hospice benefit, it is important for beneficiaries to know how advanced directives, such as living wills, proxy appointments, and durable power of attorney, can help ensure that they get the kind of end-of-life care they prefer. Living wills specify individuals' desired medical decisions in case they are incapacitated and cannot speak for themselves. Proxy appointments and durable power of attorney attestations designate someone else to make medical decisions in case an individual becomes incapacitated.

Individuals have the right to elect or decline to complete an advance directive. However, the Patient Self Determination Act of 1990 mandates that all institutions receiving Medicare and Medicaid funding inform patients of their right to accept or refuse medical treatment through an advance directive. And, the Balanced Budget Act requires that the advance directive be placed in a prominent place within the individual's medical record.

We are taking additional steps to help improve the quality of end-of-life care. For example, we are asking Medicare's physician-led Peer Review Organizations (PROs) to address end-of-life issues. PROs hold state-level contracts with Medicare across the country to help promote quality care. Under new contracts this year, they can undertake quality improvement projects focused on pain management in end-of-life care. In such

projects, they would try to improve ways of controlling pain, providing comfort to patients, evaluating patient and family perspectives on quality of care, and measuring pain management.

Medicare's Office of Clinical Standards and Quality also is providing technical assistance to hospice organizations in developing ways to measure the quality of care provided in hospices. These measures will help identify areas where improvement can be made and then monitor that improvement over time.

BALANCED BUDGET ACT CHANGES

The Balanced Budget Act of 1997 (BBA) made important changes to Medicare's hospice benefit. One of these changes helps ensure that patients whose prognosis improves or who choose to resume curative care can leave hospice and return at a later date. Before, if someone was discharged after being in a hospice for more than seven months (210 days) they were banned from ever getting hospice coverage again. A provision included in the BBA allows such patients to be readmitted with full hospice coverage when appropriate. This should end concerns among some providers that discharging patients from hospice care could make them ineligible for the benefit if they need it later.

The BBA also included a requirement that hospices submit data on their costs to the HHS Secretary for each fiscal year beginning after October 1, 1998. This information will help us to better evaluate the adequacy of Medicare hospice reimbursement rates.

Hospice rates were originally set based on costs incurred in a demonstration project that began in 1980. The rates were adjusted several times by Congress and, since fiscal 1993, have been statutorily set at the previous years rates plus an adjustment for inflation. Hospice agencies are paid a set prospective rate based on whether they are providing routine hospice care in the patient's home, continuous care in the patient's home, respite care in the hospital, or general care in the hospital. (Medicare has a specific palliative care billing code for hospice and other patients admitted to a hospital for non-curative care.)

We look forward to the more objective assessment of payment rates that hospice cost data can provide. However, in order to allow time for providers to prepare for this new requirement, we have delayed implementation. Hospice agencies must submit cost reports starting in April 2000 for fiscal years beginning on or after April 1, 1999.

Other BBA provisions also helped to strengthen the hospice benefit, for example by:

- waiving some ancillary staff requirements for rural agencies that can demonstrate that they have been unable to recruit specific personnel;
- allowing agencies to contract with physicians rather than have them as employees;
- protecting beneficiaries from liability when hospice claims are denied because the patient was not terminally ill; and
- protecting agencies from liability when hospice claims are denied because the patient was not terminally ill, as long as the hospice did not and could not reasonably have been expected to know that the beneficiary was ineligible for coverage.

CONCLUSION

We are committed to ensuring that beneficiaries receive appropriate care at the end of life that is tailored to their own needs and that they understand their rights and options. The BBA has helped to strengthen both the hospice benefit and the advance directive requirements. We look forward to continuing to work with provider and beneficiary advocacy groups to further advance end-of-life care. I thank you for holding this hearing, and I am happy to answer your questions.

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Mr. HORN. Thank you very much. And our last witness on this panel is Dr. Patricia Grady, the Director of the National Institute of Nursing Research, which is part of the National Institutes of Health, Department of Health and Human Services. Dr. Grady.

Dr. GRADY. Thank you. Good afternoon, Mr. Chairman, and members of the committee. It is a pleasure to be here today as Director of the National Institute of Nursing Research to discuss a topic that affects all of us—how to ensure that the end of our lives is as free of pain and other symptoms as possible; that this final phase is one of comfort and dignity; and that our choices about care are respected and implemented.

The NINR is the lead Institute within the NIH responsible for coordinating research on palliative care at the end of life. Today I will summarize conventional and complementary end-of-life research supported by the NIH. The goal is to discover how best to promote quality of life leading to a peaceful death. But, first let me provide some background.

Two national reports were published in 1997 that heightened concern about end-of-life care. An Institute of Medicine report recommended a change of focus—from very aggressive conventional care to one of palliative care in the final phase of life. A Robert Wood Johnson Foundation study identified the undertreatment of pain in terminally ill patients and a lack of awareness of “do not resuscitate” preferences. NINR studies also supported these conclusions. Overall, the indications were that the public was not satisfied with care at the end of life.

This became a call to action. NINR convened an NIH workshop on symptom management and terminal illness, in which palliative care experts and scientists identified gaps in research and focused on appropriate interventions to maximize quality of life. Dr. Ira Byock of the previous panel participated in that workshop.

Next, NINR issued a trans-NIH program announcement to stimulate end-of-life research. The following year, in 1999, NINR issued a request for applications, joined by seven other NIH components and the Agency for Health Care Policy and Research. This request has resulted in 12 funded grants so far.

Let me now briefly describe some of the new and ongoing NINR supported research. We are testing interventions for cancer pain using guided imagery, cognitive restructuring, and relaxation techniques. Guided imagery is also being tested to find out which patients with cancer pain will benefit. In another end-of-life study, the use of acupuncture, massage therapy, vitamins, herbs, and nutritional supplements, in addition to conventional care is being assessed in patients with chronic illness. Other investigators are examining life support technology, especially mechanical ventilation, to learn which aspects of maintenance and withdrawal of life support are considered problematic, something the chairman spoke eloquently about just a moment ago. Decisions about how life-prolonging technologies are influenced by hospital routines are being examined. Ethnic and cultural differences in treatment preferences, approaches to decisionmaking, and family caregiver satisfaction with end-of-life care are also under study.

Two recent findings provide additional promise. A relaxation technique and music therapy, when combined with the usual pain

medication, provided better pain relief following abdominal surgery. Another study determined that patients can differentiate whether difficulty in breathing is caused by distress and anxiety, or whether it results from physical causes. This distinction will help in selection of appropriate therapies.

Let me now turn to the research of seven other NIH components. The Warren G. Magnuson Clinical Center on the NIH campus is responsible for patients enrolled in approximately 900 clinical research protocols. The Clinical Center will initiate a multidisciplinary program to provide state-of-the-art pain management, symptom control, and palliative care, and will include education and research components. The Rehabilitation Medicine Department provides support for patients with chronic pain using complementary techniques including massage, guided imagery, and acupuncture.

The Social Work Department provides counseling and information on palliative care and hospice support. Bereavement counseling and spiritual guidance are also available. The Bioethics Department is involved in end-of-life research studies.

The National Cancer Institute is examining the placebo effect in pain treatment. Other studies include clarifying the relationship between depression and chronic pain and determining the effectiveness of biobehavioral pain management in terminally ill patients.

The National Institute of Neurological Disorders and Stroke has two recent basic research findings to help unravel the mysteries of chronic pain states. Using gene therapy in an animal model, scientists were able to separate the normal protective sensation of pain from the pain caused by disease.

The National Institute on Aging's studies include how staff and family manage end-of-life care in nursing homes, and how to reduce the stress of decisionmaking during the final phase of life. A Dementia Study Group is conducting research in the care of late-stage Alzheimer's patients using a hospice approach and with progressive limitations on medical interventions.

The National Institute of Dental and Craniofacial Research shares the lead with NINDS of the trans-NIH Pain Consortium and will operate the Pain Research Clinic at NIH. A recently developed animal model of gene therapy for restoration of saliva production could help end-of-life patients chew, swallow, and speak.

The Office of Behavioral and Social Sciences Research is cosponsoring an NIH workshop next week on "Spirituality, Religion and Health."

And on a strong closing note, the National Center for Complementary and Alternative Medicine's palliative care research focuses on increasing patient comfort, diminishing pain, and easing symptoms. Of note is research on therapies that may benefit end-of-life patients, such as hatha yoga, acupuncture, St. John's Wort, and ginkgo biloba.

In conclusion, with sufficient emphasis and resources, end-of-life issues can be resolved by health care research and practice commu-

nities. NINR is pleased to have a central role in addressing how we might achieve these results. Thank you, Mr. Chairman. I will be happy to answer any questions and I will also be happy to respond to the concerns of the previous panel.

[The prepared statement of Dr. Grady follows:]

Improving Care at the End of Life with Complementary Medicine

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IMPROVING CARE AT THE END OF LIFE: RESEARCH ISSUES

Good afternoon, Mr. Chairman and members of the Committee. It is a pleasure to be here today as Director of the National Institute of Nursing Research (NINR) to discuss a topic of importance to all of us – how to ensure that the end of our lives is as free of pain and other symptoms as possible; that this final phase is one of comfort and dignity; and that our choices of the type and extent of care are respected and implemented.

I am here today before this Committee because the National Institute of Nursing Research (NINR) is the lead Institute within the National Institutes of Health (NIH) responsible for coordinating research on palliative care at the end of life. Whether palliative care research involves conventional or complementary approaches, its purpose is to add scientifically verified evidence to our base of knowledge about appropriate and compassionate health care. Research on end of life focuses on clinical management of physical and psychological symptoms, communication, ethics and clinical decisionmaking, support of caregivers, and delivery of care. These scientific investigators come from many disciplines rather than any one discipline and often work in teams. The collaborative goal of this research is to discover how best to promote quality of life leading to a peaceful death.

Today I will discuss how end of life issues are receiving increased research and public policy attention. Recent trends and NIH research responses to these trends will be summarized, including complementary therapies. And finally, I will identify future opportunities and challenges.

End-of-life concerns were highlighted in a 1997 report by the Institute of Medicine (IOM), “Approaching Death: Improving Care at the End of Life.” This report recommended a change of focus when a patient is considered to be in the final phase of

life -- from very aggressive conventional care to one of palliative care, which stresses comfort and quality of life acceptable to the patient and family members. In addition, the Robert Wood Johnson Foundation funded the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) which also identified some disquieting facts. Serious pain, common in most terminally ill patients, was undertreated; discrepancies existed between patient desires and actual treatment; and almost half of physicians studied were unaware that their patients' preferences were "do not resuscitate." Furthermore, there were many reports from experts that the public was generally not satisfied with care at the end of life. The IOM stated that while technological advances in health care "continue to increase life expectancy, attention to the quality of life and to the inevitable experience of dying has not kept pace."

National trends point to the need for research in the end-of-life area. The aging and growth of the population predict an increase in the prevalence of chronic illnesses. More than 2 million Americans died in 1998, most from chronic illness that they had endured for a long period of time. More than 70% of deaths occur in those over 65 years of age. Furthermore, a shift is taking place from patient care in the hospital to family care in the home, which presents a special challenge for family or friend caregivers. Such caregivers need help with learning health care delivery skills, problem solving, and use of community-based services.

The IOM and SUPPORT study results provide a basis for the research being undertaken by NINR and other researchers. For example, families report that clinicians underestimate pain levels and other symptoms of patient distress. Families also report distress that some clinicians view the death of their family member as a failure. Patients

report distress caused by abrupt changes in settings, such as when they are discharged from the hospital to a nursing home. Patients without health insurance are likely to use expensive hospitalization for symptoms that could be managed by hospice or home health nurses.

Soon after the IOM report was published, NINR convened a research workshop to address symptom management and other issues of terminal illness. The meeting, “Symptoms in Terminal Illness: A Research Workshop,” was cosponsored by the National Cancer Institute (NCI), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute of Drug Abuse (NIDA), and the then Office of Alternative Medicine (OAM). Palliative care experts and basic and clinical scientists involved in end of life issues were convened to assess the state of the science in this area and make recommendations for research. The workshop focus was on major symptoms of distress, including pain, dyspnea (difficulty breathing), cognitive disturbances, and cachexia (muscle wasting and weight loss). The report emphasized the importance of intervening appropriately in the dying process to maximize quality of life at the very end of life.

Because of NINR’s research experience and expertise in the key areas of end of life and its history of collaborative effort, NINR was designated as the lead to coordinate NIH research efforts. NINR issued a program announcement, in collaboration with NCI, NIAID, NIMH (National Institute of Mental Health), and OAM. The request was made to stimulate integrative, multidisciplinary research programs in basic and clinical areas to address the constellation of symptoms at the end of life across disease conditions.

Earlier this year NINR initiated a Request for Applications (RFA), which was cosponsored by seven other NIH components and the Agency for Health Care Policy and Research (AHCPR). The RFA was issued to generate scientific knowledge leading to improved care for those at the end of life. Twelve grants resulting from this RFA have just been funded -- the majority by the NINR. Let me briefly describe some of these new and ongoing studies.

In the behavioral area, NINR researchers are testing interventions for cancer pain, such as guided imagery, in which patients imagine, for example, their immune cells attacking a tumor; cognitive restructuring, where patients can put an unpleasant experience in a less stressful context; and relaxation techniques. Guided imagery is also being tested to reduce postoperative pain in children, in combination with analgesia, and to determine which patients with cancer pain will benefit from this technique. Certain patients may be more receptive than others.

Self care, increasingly important to the public in managing chronic illness, is also relevant at the end of life. In studying end of life patients with congestive heart failure and chronic obstructive pulmonary disorder (COPD), researchers are analyzing the use of acupuncture, massage therapy, vitamins, herbs, and nutritional supplements, in addition to conventional care.

Technology has both positive and negative effects on end of life. Research is underway to investigate the use of life support technology, especially mechanical ventilation, in older individuals. The research study is designed to learn which aspects of maintenance and withdrawal of life support technology are considered problematic and why. Also under investigation is how decisions about life-prolonging technologies are

influenced by hospital routines. Another study addresses the positive effects of technology through a computer intervention called Tele-Care for caregiver spouses of patients at the end of life. This intervention will be evaluated to ascertain effects on depression, social support and personal growth of Caucasian and Hispanic caregivers. Information gained from these studies can help guide us in providing culturally sensitive end of life care.

Models of ethnic and culturally sensitive variations of interventions, such as the one just mentioned, are needed for health care at the end of life as much as they are at all other times of life. For example, investigators are studying ethnic differences in African American and Caucasian approaches to decisionmaking, treatment preferences, and family caregiver satisfaction with end of life care for their ill family members. The burden and health of caregivers, as well as their bereavement, are also under study. Decision making, particularly regarding enhancing quality of life by tailoring health care to patients' wishes, and use of advance directives, is the focus of another newly funded study being carried out within a managed care environment.

In other ongoing research supported by the NINR, I would like to provide two promising examples. A study receiving national attention earlier this year was one in which a jaw relaxation technique and music therapy, separately or together, when combined with the usual pain medication, significantly reduced pain following major abdominal surgery. This study was published in the May issue of *PAIN*. The finding is encouraging because it is an example of a novel approach to acute pain management. Better management in both acute and chronic pain that effectively decreases the use of pharmacological agents has benefits at the end of life.

Distinguishing emotional triggers of dyspnea from physical ones is important in determining the best treatment for dyspnea at the end of life. NINR-supported research indicates that patients can differentiate dyspnea caused by distress and anxiety from dyspnea stemming from physical causes. This distinction will help in the selection of the most appropriate therapies.

Although NINR funds additional studies that involve either end of life or complementary therapies, the previous summary provides representative examples. Let me now turn to a discussion of research in other NIH institutes that addresses the central theme of this hearing.

The Warren Grant Magnuson Clinical Center

The Clinical Center is responsible for patients enrolled in approximately 900 active clinical research protocols and offers a wide range of support to meet critical patient needs. The Clinical Center will soon initiate a clinical program that will provide state of the art pain management, symptom control and palliative care to patients. The program is multidisciplinary and will have active patient and staff education and clinical research components. A fellowship training program will be developed as the program matures.

The Department of Rehabilitation Medicine of the Clinical Center provides support for patients with chronic pain – offering a variety of complementary pain alleviation techniques to reduce the impact of pain and increase functional independence. Examples include instruction in pain relief strategies, maintenance of a pain journal, and weekly classes and support group meetings focused on relief of pain.

Nonpharmacological interventions for pain management include massage, exercise and immobilization, transcutaneous electrical nerve stimulation, imagery and biofeedback. Services also include acupuncture and acupressure, desensitization, guided imagery, aquatics, relaxation training and distraction-refocusing.

The Clinical Center also uses a multidisciplinary approach to address the difficult issues associated with the end of life. Continued participation of patients in research protocols must be balanced with the needs and wishes of the patient and family members or significant others. The Social Work Department provides counseling and works with other disciplines to perform a thorough assessment of the need for palliative care and/or hospice support. Bereavement counseling is also provided. The Spiritual Ministry Department establishes spiritually supportive relationships with seriously ill patients and their families to help them face end of life. Prayer, spiritual discussions and soothing music are provided, and memorial services are also available.

The Bioethics Department has a portfolio of research projects that address the end of life. One of these, a study recently published in the *New England Journal of Medicine*, reported the results of interviews with 988 terminally ill patients about such issues as symptoms, physician-patient communication, caregiving needs, and views on euthanasia. Another study is comparing costs of care at the end of life as they relate to issues such as managed care versus fee for service; people with different types of terminal illnesses; and the use or nonuse of hospice care.

The National Cancer Institute

The National Cancer Institute has a dedicated interest in current and planned research related to palliative, hospice, and end of life care for patients. Studies show that two-thirds of people with advanced cancer experience significant pain. NCI's portfolio of pain research is wide-ranging and includes studies that test complementary strategies.

One example is an NCI-supported study that focuses on resiniferatoxin, an anti-pain substance isolated from a cactus-like plant, which may lead to the development of new pain relief drugs. There are also studies of behavioral interventions, such as distraction, relaxation, and imagery, that may offer care providers with non-pharmacological tools to help their patients handle pain.

In addition to participating in the program announcement and RFA on management of symptoms at the end of life, NCI participates in the trans-NIH biobehavioral pain research program announcement to conduct basic and clinical studies on pain. Some of the activities included in this announcement that have relevance to this hearing are: examining the role of the placebo effect in pain treatment; exploring the basic mechanisms of conscious perception of pain and affective responses; clarifying the relationship between depression and chronic pain; and determining the effectiveness of biobehavioral pain management in terminally ill and dying patients.

The National Institute of Neurological Disorders and Stroke

The NINDS supports a broad range of basic and clinical research on pain and is a participant in the end-of-life RFA. NINDS also shares the lead with NIDCR in the NIH Pain Research Consortium. Of interest to this committee is NINDS' basic research related to neurological symptoms that occur in many chronic and terminal disorders. These include pain, swallowing problems, memory loss, and nausea and vomiting. For example, two recent basic research findings are unraveling the mysteries of chronic pain states. They involve separating "good pain," that is, the normal protective sensation, from the "bad pain" of abnormal chronic pain states. Using animal models, one study selectively eliminated spinal cord nerve cells that respond to the chemical messenger substance P. In another study, mice were genetically engineered to omit a form of the enzyme protein kinase C that is involved in some types of pain signals. In both experiments, the "good pain" responses were intact, but "bad pain" was eliminated.

The National Institute on Aging

The National Institute on Aging research portfolio addresses the diverse array of end-of-life issues affecting the elderly population. Examples of studies include how staff, family, and residents manage end of life care in nursing homes, and how the stress of decision making can be reduced during the final phase of life. NIA is also one of the institute cosponsors of the end-of-life RFA. Through its Alzheimer's Disease Centers program, the NIA-supported researchers at the Boston center have established a Dementia Study Unit as a clinical model for late-stage Alzheimer's disease care, the first research group in the country to focus efforts on the difficult, emotionally charged, clinical issues

in late-stage and terminal care of this patient population. Activities have expanded to include an outpatient program, a respite care program, and an adult day care program. As a result of research in the Dementia Unit, staff developed a hospice approach to the care of Alzheimer's disease patients. This consists of assigning patients to one of the five levels of care, with progressive limitations on medical interventions. Treatment limitation decisions are discussed at a meeting of family members with the Interdisciplinary Treatment Team.

The National Institute of Dental and Craniofacial Research

The National Institute of Dental and Craniofacial Research supports studies that address key issues at the end of life – the prevention and relief of pain. Studies within the NIDCR portfolio are relevant to palliative, hospice and end of life care issues, particularly the research on pain. Sharing the lead with NINDS of the trans-NIH Pain Consortium, NIDCR also operates the Pain Research Clinic in the NIH Clinical Center. Programs within the clinic include developing better methods for assessing pain, understanding the mechanisms of acute and chronic pain, and developing new methods of pain control. Recent findings include an animal model of gene therapy for pain.

The oral complications of cancer therapy are also under study. Radiation treatment damage to salivary gland tissue and many drug therapies can result in lack of saliva, or xerostomia, which leads to difficulty in chewing, swallowing, and speaking, problems for many at the end of life. Research on salivary glands and saliva constitute a

significant component of the NIDCR portfolio. Of note is the development of another animal model of gene therapy – this time to restore saliva production.

The Office of Behavioral and Social Sciences Research, Office of the Director, NIH

The Office of Behavioral and Social Sciences Research (OBSSR), the National Center for Complementary and Alternative Medicine, and several NIH Institutes, are co-sponsoring a workshop on October 26-27, 1999 on "Spirituality, Religion, and Health." An expert panel will review the state of the science in the area, and assist in developing a research agenda relevant to NIH. Numerous issues will be addressed, including linkages to morbidity and mortality, biobehavioral and psychosocial mechanisms, social and cultural influences, measurement issues, gaps in the literature, and scientific opportunities. A report summarizing the work of the invited panel will be disseminated following the workshop.

National Center for Complementary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM), a new entity, is the successor organization of the OAM, with enhanced statutory authority and function, and increased staffing levels. Many of NCCAM's studies concern palliative care research, with a focus on increasing patient comfort, diminishing pain, and rendering disease symptoms less intense or severe. Although NCCAM does not have a specific focus on end of life, research results of many studies may be beneficial to patients at this final phase. Among these projects are an examination of the benefits of hatha yoga on

the cognitive and behavioral changes associated with aging and neurological disorders; evaluation of the effects of acupuncture on persistent pain and inflammation; a clinical study of St. John's Wort's effects on major depression; the effect of acupuncture and moxibustion (heat applied at the acupuncture point), and, in collaboration with NIA, the efficacy of ginkgo biloba (a botanical product) in older individuals who are at risk for dementia, which may have pertinence to those at the end of life.

As is evident, the NIH institutes are actively pursuing many avenues of research, both conventional and complementary, of relevance to patients and families at the end of life. Trans-NIH committees relevant to coordination of these efforts include the trans-NIH Pain Consortium, the trans-NIH Alzheimer's Working Group, and other formal and informal committees.

In conclusion, it is becoming increasingly clear that, as we look to the future, distressing symptoms considered inevitable at the end of life can be eased, and that more can be done to maintain a patient's quality of life, sense of control, and dignity. A number of issues remain to be resolved, however, through research. Our aging population depends on the health care system and the evolution of how it manages end-of-life care. We need to know more about the appropriate course of treatment during the dying process. Despite the availability of pain medications for terminally ill patients, pain is still inadequately treated. We need improved assessment tools to help health care professionals accurately evaluate symptoms at the end of life. Patients' comfort needs

and their wishes for end of life care must be respected. Family caregivers' needs must be addressed so that they become competent in providing pharmacological and other treatments, determining the changing nutritional needs of a dying person, and responding to changes in function and care required by those changes. Caregivers need assistance in coping with stress and maintaining their own health.

Complementary and conventional therapies have the potential to provide important information and new therapeutic approaches for improving care and quality of life at the end of life. With sufficient emphasis and resources, end of life issues and needs can be resolved by the health care research and practice communities. NINR is pleased to have a central role in addressing how we might best achieve these results. Thank you, Mr. Chairman. I will be happy to answer any questions.

Mr. HORN. Well, if you would just answer my first question. I am interested in, one, were there any reactions you had to panel one; No. 2, did you have any reactions to your colleagues on panel two? So you have opened it up, Dr. Grady, so let us start.

Dr. GRADY. OK. What I would like to say is that many of the studies that I have just described, we expect to serve as a basis for the development of future interventions to improve quality of care for terminal patients and their families. We were gratified and even a little surprised by the extent of the response to the request for applications we issued last year. We had over 100 responses with applications and we expect many of these to be resubmitted. They were favorably reviewed and looked very promising. So we feel that not only what we have begun funding is a step in the right direction, but it will serve as a basis for future studies.

Also, one of the concerns of the previous panelists was about the training and what is being taught in schools for people who are health care professionals. One of the studies I would draw your attention to that we have just funded, is a study to improve clinician and family communication in ICUs, a matter that was of some concern to the previous panel. The study is addressing those issues, but one of the long-term goals and outcomes of the study will be to use that information, incorporate it into the curriculum for training physicians, nurses, and other health team members who will be working with those who are terminally ill at the end of life.

I would also like to say that there were some concerns expressed about the National Center for Complementary and Alternative Medicine and would simply say that many of the studies I described in complementary medicine do reach across the NIH and in this brief time I can't address all of that, but what I would say is that the Center, what was previously an Office of Alternative Medicine, has become the National Center for Complementary and Alternative Medicine. It has increased statutory authority so that it will now have the ability to independently make grant awards in the area of its science. A new Director has been hired for that position. The budget has almost tripled over the last year and the first meeting of the Advisory Committee of the new Center was just recently held. In fact, Beth was an invited participant in that and spoke. I have seen her testimony although I wasn't there and I have met with the new Director. He is meeting with all the IC directors across the campus and he is extremely enthusiastic and committed to building the Center and so I think that the suggestion that was made to look forward is a good one. We are very, very optimistic.

Another issue is that the science is moving and this is an area of new science, end-of-life as an issue. One of the previous panelists said that no one wanted to talk about it before. It is something that we all must face, like it or not, but it is as yet a relatively uncharted area. So it is a new science and all of those who are working in the area are among the pioneers who are building the science base and the knowledge base for compassionate and appropriate care for the future.

Mr. HORN. On the issue of training and medical schools in particular, does NIH keep any data as to the evolution of medical school curricula and to what degree do some of the areas we are

talking about here come into the doctor's mind before they get their union card known as the M.D.?

Dr. GRADY. We have frequent meetings and keep very close interactions with the American Association of Colleges of Medicine and also the American Association of Colleges of Nursing. I left the latter meeting—I gave a speech this morning before I came here—so although we do not dictate the curriculum as such, all of these schools have accreditation bodies and we are in close communication with them and are often sought out for our expertise on what is an important part of the curriculum.

It is hoped, of course, that the results of research studies will be quickly incorporated into practice and into the curriculum and we do our best to try to ensure that that is not only a possibility but that that does happen.

Mr. HORN. Well, I think you are probably right. In some cases, it happens, but it would be sort of helpful if their accreditation standards and criteria had some of these things in it and that is not a new thought for medical schools. Nutrition was certainly one where doctors didn't seem to have the slightest idea what was going on in nutrition. So I would ask staff and without objection, we will put it at this point in the record.

Dr. GRADY. We would be happy to supply that for the record in more detail.

Mr. HORN. Thank you.

Now, before we finish with you and you get into it again, I am sure, did anything your colleagues say jar you at all?

Dr. GRADY. Well, we try to do our best to interface about how we can best get the research results into practice. The concerns that I heard this morning and that we are hearing more in the studies that we are carrying out and, in fact, influence the research that we are able to carry out are the issues related to terminally ill patients going to hospice care and having to give up the options of conventional therapy.

Also, the issue about the 6-month terminal illness, 6 months to the end of life. That presents difficulties for us in terms of trying to carry out cohesive studies that we can predict from, because it is difficult to anticipate 6 months from the end of any one person's life. So we are working with populations that are difficult to compare one person to the next and so we are concerned some of the findings may not be generalizable. So we are releasing findings that are somewhat more qualitative in some cases but we feel are informative. I think those were the two major issues.

Mr. HORN. Ms. Buto, do you have anything you would like to add either that the first panel said that you didn't like or that your colleagues said that you didn't like?

Ms. BUTO. It is hard not to like the first panel.

Mr. HORN. Or that you did like?

Ms. BUTO. Let me address three issues that have been raised both by Dr. Grady and the first panel. The first one is the 6-month requirement that is in the statute as well as the requirement that individuals who elect hospice give up conventional therapy, essentially the conventional Medicare benefits.

First of all, these requirements are written into the statute. That doesn't mean they can't be changed, but I think as we look at the

issue of changing both of them, one of the difficulties is if the time-frame becomes indefinite or less clear for the hospice benefit, in other words, you are eligible for hospice if you have an illness or condition that will ultimately lead to death, the difficulty there is that many of our beneficiaries are in a situation where they have chronic conditions—congestive heart failure, COPD, et cetera.

We are, in Medicare, looking at more creative options for the chronically ill. In fact, the Balanced Budget Act gives us some authority to do care management programs around chronic illness. If you remove the criteria at the same time, we are in a situation where, under hospice, we have a prospective payment system that allows coverage of drugs, for example, which, as you know, Mr. Chairman, are not available to most Medicare beneficiaries. Many of them need drugs, need that kind of therapy.

Mr. HORN. We hope we will solve that problem in either this session or in the early—

Ms. BUTO. We hope so. We certainly hope so and I know that the Congress is looking at that.

Mr. HORN. Early in the next session, in one or the other.

Ms. BUTO. But in any event, while that disconnect or that inequity exists, we are happy that drug treatment is available as one of the optional services under hospice. It is also available in Medicare HMOs. But until prescription drugs are covered more broadly in Medicare, if you extend the period of coverage such that any individual with chronic disease or serious chronic disease would be eligible for hospice, I think the issue is can we do that until we have a drug benefit? We would like to see enactment of a Medicare drug benefit and then, certainly, I think the issues around all of the benefit structures need to be looked at in relation to that. What I am trying to say is it is not an easy issue. I certainly understand the concerns that have been raised.

I also wanted to deal with the question of medical education, which you raised. As you know, Medicare finances medical education in this country almost exclusively and, again, I think as part of Medicare restructuring, there are a lot of efforts to look again at that pot of money to say, should it be related to Medicare, or should it be its own separate trust fund? And how shall it be financed, in what ways does it reflect the priorities of the country in terms of the curricula and so on? And of course, that is a very delicate issue. So I think this is a good time to talk about the curriculum.

Mr. HORN. You raise an interesting point because your clientele is primarily 60 to 65 years in age and up. To what degree do we know that the typical medical student, and not that there are internships anymore, but in residencies, what do we know about the type of clientele they will run into in terms of the hospitals they are assigned to? Do you know what proportion of the bills are paid nationwide by Medicare?

Ms. BUTO. Forty percent of hospital inpatient bills—they aren't really bills—40 percent of the inpatient hospital revenues come from Medicare on average. That is higher for some hospitals and lower for other hospitals. So it is a significant amount and, of course, we spend a lot on medical education as well.

What we are seeing in hospital medical education, again because of some changes in the way we pay, is a greater emphasis on primary care and associated specialties like geriatrics and pediatrics, for example. So that is occurring, but the degree to which curricula reflect the kinds of issues that have been raised here today, I think again the AAMC, the American Association of Medical Colleges, would be a good place to get that information.

Mr. HORN. And it would be the kind of thing, it seems to me, Medicare and VA and others maybe at their national conventions of the medical schools could be putting on exhibits, and all the rest of it and panels in terms of how one deals with people that are elderly as opposed to people that are a little more youthful.

Ms. BUTO. Our colleagues at the Health Resources and Services Administration have a lot to do with the training programs for health care professionals. I know they are also active in this area.

And then I wanted to address briefly the coverage question that keeps coming up about Medicare and covering alternative and complementary therapies. First, to say that on the issue of acupuncture, I think what we need to do is review the NIH Consensus Conference proceedings in light of our current coverage rules which do not allow Medicare to cover acupuncture. Having said that, and we will review those for issues around Medicare coverage, I think it is important for people to understand how Medicare covers services. We cover them in two ways. We cover them institutionally, hospital services, physician services, home health services, nursing facility services, and so on. We also cover them by certain practitioners. We cover mainly physician services in terms of individual practitioners. Increasingly, in the last few years, we have covered nurse practitioner services in some circumstances, nurse midwives and physician assistants. We have chiropractors covered for only one service in Medicare and so the issue of our looking at coverage is probably in relation to the structure in which Medicare operates.

Having said that, I think the structure in which Medicare operates is pretty flexible. We know that not only do hospices cover complementary therapies but also Medicare HMOs are able to cover alternative therapies and alternative practitioners, and they do that.

Mr. HORN. Is it just for HMOs?

Ms. BUTO. For hospice as well. Are you asking if they just cover it for HMO enrollees?

Mr. HORN. Right.

Ms. BUTO. Yes, HMO's offer a benefit package and it includes Medicare covered services and additional services.

Mr. HORN. Now did you need the authority of the Ways and Means Committee to do that?

Ms. BUTO. Yes.

Mr. HORN. Or do you have that authority?

Ms. BUTO. It is part of our authorization for the Medicare Plus Choice Program, Medicare HMO and prepaid health care program. We have that authority.

Mr. HORN. Having heard of all the options this morning, to what degree is Medicare able to implement some of those without law? Or do you have the authority to do it?

Ms. BUTO. Again, we can look at the coverage of acupuncture services. The part where—again, I don't want to mislead—is that we don't have a category of practitioner, an acupuncturist, who is eligible to receive Medicare payment. So we do not that—

Mr. HORN. Why is that? Why is it that we don't?

Ms. BUTO. The statute is a medical model. It was built in 1965.

Mr. HORN. I know. I was on the drafting team.

Ms. BUTO. It is finally evolving to the point where we are finally covering some preventive services for the first time like mammography screening and flu vaccine and so on, but that has been really in the last 2 or 3 years. But having said that, the service itself in the context of an HMO, in the context of hospice, we are now moving to pay prospectively home health agencies, skilled nursing facilities, hospitals get a prepaid amount. All of them have the flexibility under prospective payment systems to incorporate complementary therapies if they want to.

So within these broader payment structures, individual practitioners can get paid by the hospital, by the nursing home, by the hospice, and by the HMO.

Mr. HORN. Well, can Medicare provide funding for those particular practitioners in a new evolving field? I mean how do you handle that? It isn't just acupuncture. I mean there must be breakdowns of particular specialties even into more special things.

Ms. BUTO. Right. What we are going to, though, is I guess what we call in sort of the financing world bundling payments so as we move to a situation where we are paying in advance for a beneficiary who enters the hospital, the whole amount for the episode, the hospital can provide a wide variety of noncovered services from that amount and to the extent they find them cost effective they are doing that. They cover experimental drugs, for example, and they cover other things that are not within the Medicare benefit package.

We, again, for skilled nursing facilities, for hospice, for home health, we are also moving in that direction. So we will have an episode payment in home health that will cover 60 days and the services within that are flexible that can be provided. And that is really the way the program is generally going. We do still pay for individual services if physicians provide and those are the cases where a physician service is delivered. Again, there are some instances, but they are not very frequent, in Medicare where there are other practitioners who get payment from the program directly.

Mr. HORN. Well, let me ask you about the 420,000 patients that use \$2 billion in Medicare hospice services. This equates to just under \$48,000 for an average of 48 days and how much would 48 days of hospital care cost? Do we know those figures or just file them for the record?

Ms. BUTO. We can get them for the record.

Mr. HORN. Fine.

Ms. BUTO. Of course, some of those patients do use some hospital care as well, but the hospice payment is set for that. There is a separate rate for the hospital stay.

Mr. HORN. Well, the whole idea in 1965 was to get people out of the hospitals into the skilled nursing home and the only thing else we provided was home care and we only knew of one city that

had it, which was Detroit at that time, that had any extensive program there. So that was certainly the approach. And is massage therapy and acupuncture reimbursed by Medicare and Medicaid?

Ms. BUTO. I can't speak for Medicaid because the States have tremendous flexibility. In fact, I believe 10 States don't cover hospice. We know that 40 do.

Mr. HORN. So 40 do under Medicaid then.

Ms. BUTO. Under Medicaid cover hospice services. It is an optional service. Many of them do cover a number of alternative services including homemaker services. Again, Medicare's coverage would be probably through our broader payment systems, the use of services, but within the umbrella of paying a given provider who is authorized to receive a Medicare payment.

Mr. HORN. Now you have got a 6-month rule, for want of a better expression of it, what does that apply to and why is it 6 months?

Ms. BUTO. Well, as I understand it, and I wasn't around when the statute was enacted, that at the time it was enacted, all the research that was looking at end-of-life care was based on the last 6 months of life. So when the statute was enacted, as I understand it, it was designed to serve individuals who would be thought to be by their physicians in the last 6 months of life.

Now, as many people have said on the previous panel, that is not a cap, that is the physician's judgment that an individual is in the last 6 months of life. But that is my understanding of how it came about.

Mr. HORN. Now what statute specifically are you thinking of on the 6-month aspect?

Ms. BUTO. It is the Medicare hospice benefit.

Mr. HORN. I see. And when was that enacted?

Ms. BUTO. 1983 is when it went into effect. I think it was enacted in 1982.

Mr. HORN. Yes. That is before my time so that is why I am a little rusty on what that is, but you are taking that authority then, the 6-month rule?

Ms. BUTO. That established the benefit for Medicare.

Mr. HORN. OK. Well, let me move to the Veterans Administration now and ask a few questions. First, I would like to ask, was there anything on panel one that was said that you didn't particularly like, and anything any of your colleagues here said that you didn't like or did like? Just giving you a chance on the record one way or the other.

Dr. HOLOHAN. From my point of view, not particularly, Congressman. Dr. Salerno.

Dr. SALERNO. I would just like to say that Mr. Brinkley's remarks about the care for veterans and the need to do more is well appreciated. That is why we have confronted this issue with a national policy to improve care and we feel that we have the means to do a better job and we will by all veteran patients, and our goal is not to take care of some with appropriate end-of-life care but all of our veteran patients when the need arises.

Mr. HORN. How many veterans are currently in the VA hospice program?

Dr. SALERNO. It varies. Inpatient hospice, sir?

Mr. HORN. Well, I will give it to you either way. What are the other categories besides inpatient/outpatient?

Dr. SALERNO. Well, we contract for community services. We provide palliative care services through our home care which aren't traditional hospice services but at least half of the patients have a terminal diagnosis. So there is a lot of palliative care that is provided that isn't traditional hospice.

Mr. HORN. Well, I will tell you I will just—some of these questions—let me read them into the record, and if you wouldn't mind, work with staff and let us try and get the answers. I don't want to put you on the spot on some arcane figure that nobody has thought of for a few months.

How many veterans are currently in the VA hospice program, and break it down by categories in terms of community, in and out, and any other ways that you look at it that way? Basically it is finding out where all the hospice aspects are. Chairman Burton had some thoughts this morning when he listened to the complementary therapies such as acupuncture, music therapy, massage, so forth—are those available at all VA facilities?

Dr. HOLOHAN. As far as we know, not at all. We commissioned a study done by a contractor to look at complementary and alternative medicine in the VA. Their sample was probably not exhaustive to all 172, but they did survey practices in all 22 of the Veterans Integrated Services Networks, and they did several series of site visits, and it appears in their report that there is a fair amount of complementary and alternative practices at many VAMCs, probably the majority. They are not uniform and they probably represent the interests of a local champion or the interests of a particular administrator or manager.

Mr. HORN. Any comments, Dr. Salerno, on that? Anything else to say?

Dr. SALERNO. Yes, I think that we are particularly strong in VA in the arts, in all the creative arts programs, and we have attempted to disseminate the models of excellence in creative arts therapy throughout our nursing homes programs and all other VA settings, and we have a long relationship, 10 years, I believe, with the very special arts, and we are working to continue developing those into more services provided for patients in the last phases of life.

Mr. HORN. We have got music therapy, we have painting therapy, we have drama therapy, all sorts of therapies in the arts. Is there any way the VA has a way to sort of figure out which ones they are using?

Dr. HOLOHAN. All of the above.

Mr. HORN. Are they successful or aren't they? Pardon?

Dr. HOLOHAN. We are using all of them.

Mr. HORN. All of them.

Dr. HOLOHAN. All of the modalities you just mentioned.

Mr. HORN. Well, why don't you give us what you are using around, and I am sure there are five others by now, but just let us know to what extent are they in the VA hospitals and then if it is a VA clinic, are they also in that? What are the other categories of basic infrastructure that you have in the VA? The medical centers, hospitals?

Dr. SALERNO. Right. 131 nursing homes.

Mr. HORN. Clinics? Yes, OK. Nursing homes. What else?

Dr. HOLOHAN. Well, there are community-based outpatient clinics. There are vet centers which are basically rehabilitation counseling, but they have—particularly in the west—worked very closely with Native Americans to provide interventions for PTSD and readjustment counseling that are Native American in origin. Dr. Salerno mentioned the number of nursing homes. In the contractor's survey on the VA, one-fifth of all the questionnaires returned came from personnel in VA nursing homes.

Mr. HORN. Well, however you want to arrange it, if we could just get a little exhibit at this point in the record, it would be helpful I think to see the degree of penetration either in depth or on a broad scale and where the services might not be provided and where they are and what was the basis for that decision? Is it money or need or whatever?

And then, of course, we would like to know what is their average length of stay in the hospice program? Is that similar to other hospice programs? How relevant is what the VA does to what also goes on in other major medical institutions, non-VA?

Dr. SALERNO. Yes, in our formal, traditional hospice program, our length of stay is similar to that under the Medicare program. However, we have a number of models that would not fit the Medicare hospice model where active treatment and end-of-life planning can occur simultaneously and we have a number of—17 of our medical centers participated recently in a collaborative with the Institute for Health Care Improvement to look at models of end-of-life care for patients with congestive heart failure and chronic obstructive pulmonary disease. These are the ones where the prognosis, the 6-month prognosis, is some of the most difficult and very prevalent in the veteran population.

So we do not have for the VA provided care those sorts of constraints, so we feel that we have the ability to innovate, try new things, look at models of care that might be an example for what the future holds for the rest. Thirty-six percent of the veteran population is elderly, so we have ample opportunity to do it, but we need to do it now, and we don't have the luxury of waiting till the year 2015, 2030, before we start getting programs moving.

Mr. HORN. We heard from Mr. Brinkley this morning about a Compassion in Action program. Can that be expanded to more VA facilities?

Dr. SALERNO. We understand that as a VA system, we can't do it alone. We need to reach out to all of our and as many community partners as want to work with us to provide the care and the excellence that we want to give to our veteran patients. We are happy that seven of our medical centers are working with Compassion in Action or they are working with us—seven medical centers. I would like to see that in 170 of our hospitals. We are open to trying to do something on a more rather than one-by-one basis, but to really encourage the field to do more actively.

We need volunteers. The backbone of our system is volunteer, and we will work very hard with our veteran service organizations, Compassion in Action and any other groups, to really provide the

services that will extend our ability to give the care that we think veterans deserve.

Mr. HORN. In the testimony you have made, you noted the strategic goals for pain management, planning, and access to programs. Are these goals currently being met?

Dr. SALERNO. We just introduced the pain management strategy in VA in the spring. Within 2 weeks, we had a toolkit for pain management in the hands of every medical center available to all staff on the Internet, and we had a patch in our computerized patient record system where we put pain assessment, a very simple, straightforward zero to 10 scale in the computerized medical record under the vital signs package.

So our intention this year is to put in place a performance measure, looking specifically at how well we are doing. While we understand that measuring how many times people assess pain does not really tell us how well it was done or whether we have made any headway in really addressing pain issues, we intend to as part of the kickoff for our meeting in November, we intend to really put the tools to be able to manage pain effectively in the hands of all clinicians who practice in the VA.

Mr. HORN. Again, some of these questions we could put with that earlier exhibit. Do all VA facilities have inpatient hospice programs? Do each of these programs have hospice trained volunteers? And then just getting on to how many patients is a nurse assigned to care for? I assume that depends on the type of ward it is or the relation to the disease or process, whatever happened. So I think you have probably got those data and we will just put in the record without objection. So I am sure there are other questions staff on both the Democratic side and the Republican side might well be asking and everybody is under oath and if you would do us the favor of answering some of their questions, we will put those in at this point.

I am going to conclude with Dr. Grady. We started with you, Dr. Grady.

Dr. GRADY. Yes.

Mr. HORN. So we are going to conclude with you. Would you summarize what the complementary therapies can be? NIH seems to say they are appropriate to provide during end-of-life care. How do those work, I mean the complementary ones?

Dr. GRADY. The studies that we are doing now, we expect to be able to point in the direction to which of these therapies are most effective, but the full range of therapies that have been mentioned this morning are being tested, the guided imagery, the music therapy. In fact, I gave one example of a study that was very successful using music therapy, massage therapy and others as well. So that really almost for each one that has been mentioned, there is a study addressing it.

Some of these studies are further along than others. But as I said, this is a new science and so many of these studies are really—this is the first time that these have been looked at in a systematic way with a larger population. Some areas are smaller populations simply because it is just one of the first times those questions have been asked.

The therapies are being tested out in acute hospital settings, in home care settings, and in hospice settings. We have a number of studies that we are working with the VA system, in fact, across the country. Some of those are targeted to the elderly and we expect to learn information to be used at end of life so that we are really going across almost the whole gamut.

The issue that came up in the earlier panel, and I think is an important one to consider, is the issue of getting the results into practice and that is a more difficult issue. We expect to be able to provide the findings that say these things seem to, this therapy, for example, seems to be more effective in this population of patients at this time at the end of life, but getting any new therapy into practice these days is a whole lot more difficult than it used to be.

The scrutiny is much greater because of a variety of issues. Included in these are really related to the standard that is required in order for a new therapy to be implemented. We are looking at evidence-based practice issues. We are looking at outcomes research requirements. We are looking at managed care constraints and the fact that there are such a wide variety of choices that, as Mrs. Marks was mentioning this morning, it is a little confusing for patients to determine how to select from which of these that may be available.

So again we feel that it is important that we support these studies and that they are carried out in the best interest of the patient so that we get information that is reliable. Which of these therapies are reliably effective? Which are safe? And in fact, that we can provide that information. But then the next step is trying to get help, work with other agencies to get those therapies into practice and paid for.

Mr. HORN. On the therapies, does that really come out of physical therapy or does it come out of chiropracting or what?

Dr. GRADY. All of the above.

Mr. HORN. Yes. I guess I am just trying to figure out, is there a program somewhere either in medical schools or health schools where they get into massage therapy? I am just not familiar with it.

Dr. GRADY. Yes. There has not been up until recently. These, as has been addressed earlier this morning or earlier this afternoon, are relatively new on the horizon of treatment choices. The fact that they have been available even on a small scale has not been something that people have always known about. Now that there are more complementary centers across the country and alternative medicine centers, the consciousness of people is being raised so they are beginning to ask questions. We plan to be the ones who provide a great deal of information to clarify which of these work the best and in what circumstances.

Mr. HORN. Now are most of these therapies licensed by the various States? I think physical therapy certainly is.

Dr. GRADY. Yes. Physical therapy involves an educational training program and licensure. For others, the answer is in some cases there are types of licensure, but in terms of having an overall licensing board, most of these do not. So the issue of quality control is constant, for example, if someone is trained by Dannion or Ira, they will have acquired a certain set of skills and abilities and that

will be predictable. In other cases, it is not predictable. So you raise a very good and a very important question.

Mr. HORN. Well, it is interesting the comparability between States. As you know, in some areas like the uniform State laws, there is a group of commissioners that try to get the same language on the books everywhere. I don't know the degree to which a similar relationship exists between the States although they are all organized now, both Governors and everybody else, and it might well be that you could get some common standards there which would bring dignity to some of the professions.

Dr. GRADY. Yes. Our concern is similar to those of nearly everyone who has expressed their thinking today; the concern to help to provide the best care for the patients and make available for them the most effective therapies, but also keeping in mind that we have a certain role related to safety and health and welfare in a protective sense. So we are really trying to strike the balance as is everyone else, I believe.

Mr. HORN. Now, would you explain to us a little more about the music therapy project and the pain management? What else is being done in that area?

Dr. GRADY. Yes, I can describe the study that I alluded to earlier. This is a study that was completed earlier this year. It used a jaw relaxation technique and music therapy for individuals in a clinical trial where patients either had the regular therapy, or they had the relaxation therapy and the music therapy in addition to regular therapy for pain. That is routine pain medication.

Mr. HORN. You used the word "jaw" there. Give me that again.

Dr. GRADY. Yes. It is you can using the relaxation technique, you can focus on one particular part of your body and will it to relax, and this particular relaxation technique uses the jaw. So that if you are sitting in a particularly long committee meeting and you are wanting, hoping someone will finish talking—

Mr. HORN. I am thinking of the House floor actually and we have got a lot of patients out there.

Dr. GRADY. Yes. I can provide more information on this for you, but you can will your jaw to relax. There is a tendency for people to clench their jaw when they are either bored or anxious or in pain, and so this technique focused on relaxing the jaw, willing it to relax, and teaching the person to be able to do that at will. And so the combination of that and the music therapy, the combination of those two alternative therapies or complementary therapies with the routine pain medication was more effective than the pain medication alone, in terms of relieving pain and for longer periods of time. It was a very interesting finding and has a very practical approach for individuals. This was for people who were having major abdominal surgery but it is expected that the approach is likely to work in other situations such as end of life.

Mr. HORN. What about the music therapy? We mentioned here the painting, drama, all the rest? Have we got any studies NIH is doing in those areas?

Dr. GRADY. Not using drama therapy. Using music therapy and guided imagery and other situations, yes. But I don't recall any using drama therapy.

Mr. HORN. Now I have a number of cultures in my congressional district. In fact, in the Long Beach Unified School District, which is fifth largest in California, there are 70 different languages spoken in the household of the parents, and that is true also of the city of Los Angeles which is simply the bigger city and we are the second city and there are 79 others in the 10 million person county. So we have a lot of cultures that are different. A lot of them are recent immigrants, so forth. So what are the differences that we know between cultures on making end-of-life decisions?

Dr. GRADY. We can help to get started to answer that question. The 70 we can't address yet. But we are funding studies to look at the differences in preferences, cultural differences in Hispanic and African American as well as Caucasian populations related specifically to decisions about treatment, what type of treatment, whether to accept treatment. The decisions about how to make decisions, in fact, because there are differences in whether or not the individual makes the decision, whether the families gather together to make the decision, whether, in fact, the family makes the decision for the individual in certain circumstances.

So those are the areas that are being addressed. Also, caregiver preferences, whether or not the individuals wish to provide caregiving at home versus other settings, and who would be the person to give it? We have a number of studies that look at caregiver support. One of the issues we found in several areas and particularly in end-of-life is that the caregivers, it has been mentioned these are mostly women, but the caregivers tend to have difficulty meeting the demands that are required to fulfil that role, both in terms of the training needed, but also in terms of their own energy and coping skills. There are some cultural differences in that area so that is also under study.

Mr. HORN. Anything anybody would like to add to this discussion? This is your last chance. We are about to close down. Doesn't look like we have got too many volunteers, but we really appreciate each of you and your statements and your interaction.

As usual, I want to thank the staff that put all this together. The majority staff here is Beth Clay to my left and your right, and Heather Bailey and Carla Martin on the majority staff, and then the minority staff, Sarah Despres and Kristin Amerling, and the official reporter, Victoria McLaughlin, and we thank you for all you are doing. So thank you very much and we will hope to get the information in the next 2 weeks. We will work it into the hearing and you all have been excellent witnesses and we are adjourned.

Dr. GRADY. Thank you, Mr. Chairman.

[Whereupon, at 4:40 p.m., the committee was adjourned.]

