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### Palliative Care: A Novel Solution to the Healthcare Crisis

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# Policy Brief

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Palliative Care:  
A Novel Solution to the Healthcare Crisis

*R. Sean Morrison*

**No. 43/2010**



**Center for Policy Research**

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Dr. Morrison's research focuses on decision making at the end of life, pain and symptom management in high-risk and medically underserved populations, and quality measures in palliative care. He has received numerous awards for his research in geriatrics and palliative care and has been named a Brookdale National Fellow, an Open Society Institute Project on Death in America Faculty Scholar, and an American Federation for Aging Research Paul Beeson Faculty Scholar. He is an active clinician who cares for healthy older adults and those with serious illness.

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# Policy Brief

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## Palliative Care:

A Novel Solution to the Healthcare Crisis

*R. Sean Morrison*



# Palliative Care:

## A Novel Solution to the Healthcare Crisis

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### Introduction

Palliative care is specialized healthcare for anyone who is diagnosed with a serious and life-threatening illness, starting when they get the diagnosis, regardless of the prognosis. Although hospice is a form of palliative care, most palliative care is not end-of-life care or hospice, a common misperception that deters many people from using palliative care when they would benefit from it. Palliative care improves quality of care, reduces hospital costs, and helps clinicians address the needs and wants of patients and their families, which is why I refer to it as a “novel” solution to the longstanding healthcare crisis.

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information, and choice.

73 FR 32204, June 5, 2008, Medicare Conditions of Participation for Hospice Care, 42 CFR418

## We Need to Make Palliative Care More Available

### *More Older People with Serious Illnesses*

When you look at median life expectancy in 2010, there's been a dramatic change. For roughly the past 30,000 years of human history, life expectancy stayed the same, between 35 and 40 years. Today, the median age of death in the United States is about 78 years (NCHS 2010), but that statistic masks some interesting facts. If you get to 65 your life expectancy is no longer 78; it jumps to 82. Of those who reach age 82, life expectancy goes up to 88. And half of those who get to age 88 can expect to live until their mid-90s. As a result, the number of people over age 85 is projected to double to about 9 million by 2030 (Census Bureau 2010).

The number of folks with multiple chronic diseases is increasing almost as dramatically. Robert Friedland (2004) estimates that the population with activities of daily living (ADL) limitations, most of whom are elderly, will rise from about 5.2 million people in 2000 to 12.7 million by 2050. So we are facing an increasing population of seriously ill older adults with multiple needs.

### *Inadequate Treatment of Pain and Distress*

Much of the research described below comes from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) conducted in the early and mid-1990s at five US teaching hospitals of more than 9,000 patients suffering from at least one of nine serious illnesses—acute respiratory failure; chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), chronic liver failure, nontraumatic coma, metastatic colon cancer, advanced non-small cell lung cancer, multiple organ system failure with malignancy, and sepsis (Murphy et al. 2000).

The first part of the study was observational and documented patients' experience of pain during their hospital stay (Desbiens

and colleagues 1996). Nearly half of patients reported moderate to severe pain—not on admission to the hospital, not within 48 hours after being admitted, but a week into their hospital stay. In other words, somewhere between 43% of patients with advanced heart disease up to 60% of those with colon cancer were still experiencing moderate to severe pain after a full week of care in some of our best hospitals. And unfortunately these data have not changed since this study was published.

Judith Nelson and her colleagues (2001) looked at several measures of distress among cancer patients who were admitted to a critical care unit at Mount Sinai Medical Center. These patients reported a high incidence of such disturbing symptoms as moderate to severe shortness of breath (34%), depression (39%), unsatisfied hunger (55%), pain (56%), anxiety (63%), difficulty sleeping (68%), unsatisfied thirst (71%), and overall physical discomfort (75%).

### *Family Burden of Serious Illness*

And it's not just those who are ill who suffer. At least 34 million households with caregivers deliver care at home to a seriously ill older relative (Houser and Gibson 2008). On average they're spending about 21 hours per week in caregiving, which is half a fulltime job. Nearly one-half of all caregivers consider their caregiving responsibilities to be highly stressful, which puts them at a significantly increased risk for death, major depression, and other serious illness (Schulz and Beach 1999). A very conservative estimate suggests that family caregivers' unpaid contributions are approximately \$375 billion per year (Houser and Gibson 2008).

So what happens to families who have to pay for a seriously ill relative? Kenneth Covinsky and colleagues (1994) interviewed seriously ill patients (or their surrogates) in the SUPPORT study who survived their initial hospitalization and were discharged. The



families of those patients look just like us. They had Medicare, third party traditional insurance, Medicaid, or managed care. They were not an underserved population. Nevertheless, 34% of those patients required “considerable” caregiving assistance from their families, and in 20% of cases someone in the family had to quit work or the family made another major life change—moving to a smaller home, postponing another family member’s medical care, changing or deferring a student’s college education—to provide that care. Family illness from stress happened in just over one in 10 families and, all told, one of these things happened in 55% of support families.

Presidential candidate Barack Obama put it this way (2007):

We have reached a point in this country where the rising cost of health care has put too many families and businesses on a collision course with financial ruin and left too many without coverage at all; a course that Democrats and Republicans, small business owners and CEOs have all come to agree is not sustainable or acceptable any longer.

### *Caregiver Dissatisfaction with the Current Health Care System*

Patients’ families are not very happy with us as a health care industry either. Joan Teno and colleagues (2004) studied caregivers of people who died in various institutions in the United States. They found that almost 80% reported that patients and families didn’t have enough contact with their physician and didn’t get enough support. Half the patients didn’t have enough support or enough information about what to expect in a setting of serious illness. Thirty-eight percent of families said they didn’t get enough support and one in five said they didn’t get enough help with their own emotional needs.

### *Insufficient Medical Training in Palliative Care*

I spent four years in medical school at the University of Chicago, three years as a resident in internal medicine at New York Hospital Cornell Medical Center in New York City, and three more years as a geriatric fellow at the Mount Sinai School of Medicine. Until the second year of my geriatric fellowship I did not step outside of the hospital to take care of a patient, so everything that I saw was an acute exacerbation or an acute illness. I received absolutely no training in how to manage chronic disease, and this was typical of medical education in the 1980s. During my first year pharmacology course I had a 30 minute lecture on pain management that dealt with how opioids were metabolized in the liver and then excreted by the kidneys. But when you're sitting at the bedside with a patient who's in excruciating pain, that knowledge base does not help you very much.

### *The Quality Chasm*

As the Institute of Medicine wrote in their report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001, 1):

The American health care delivery system is in need of fundamental change. Many patients, doctors, nurses, and health care leaders are concerned that the care delivered is not, essentially, the care we should receive.... The frustration levels of both patients and clinicians have probably never been higher. Yet the problems remain. Health care today harms too frequently and routinely fails to deliver its potential benefits. Americans should be able to count on receiving care that meets their needs and is based on the best scientific knowledge. Yet there is strong evidence that this frequently is not the

case. Crucial reports from disciplined review bodies document the scale and gravity of the problems.... Quality problems are everywhere, affecting many patients. Between the health care we have and the care we could have lies not just a gap, but a chasm.

## **Palliative Care: The Novel Solution**

That's the bad news. Now let's shift to the good news. Let's talk a little bit about the modern specialty of palliative care.

### *Distinguishing Palliative Care from Hospice*

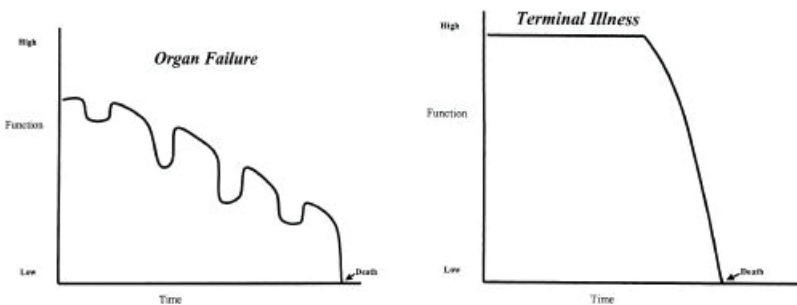
I want to start by dispelling a couple of myths, because when you begin to talk about palliative care, even in 2010, people automatically link it with hospice. While we're going to talk a little bit about how hospice fits into the continuum of palliative care and how palliative care is an integral, important, and essential part of hospice, palliative care encompasses much more than just hospice.

The Medicare hospice benefit, which was enacted in 1982, provides palliative care coverage at the moment the Medicare beneficiary is willing to do two things: (1) give up their coverage for hospitalizations and acute care, that is, give up curative care, and (2) be certified by two physicians that they've got less than six months to live. Hospice is covered by most third party insurances and most state Medicaid plans, although unfortunately because of the rising costs associated with the increasing number of people enrolling in Medicaid, we've actually seen state Medicaid plans cut their hospice benefit.

Unfortunately, hospice in the United States is significantly underutilized. Despite the fact that it is targeted at people who have a prognosis of six months or less if the disease follows its usual course, the average length of stay in hospice is under three weeks. Think about that for just a minute: this is a government benefit that

everybody pays for, and yet fewer than 40% of Americans actually access it before they die. Why? Because hospice was developed in the United States along a model that says, when you are diagnosed with a really bad disease we provide lifelong or curative care up until the point where things aren't working anymore. Then we tell you it's time to switch goals and focus just on comfort. As one of my hospice colleagues says, we throw you over the hospital wall into a system of end-of-life care and hospice. (See Casarett's 2007 proposal to redefine hospice in the United States.)

One of the fundamental problems with the Medicare hospice benefit is that people don't die that way in this country Lunney, Lynn and Hogan (2002) classified a random sample of Medicare decedents by what they called "trajectories of dying," that is,



**Figure 1.** Trajectories of Dying: Terminal Disease (Cancer) and Organ Failure (CHF/COPD) (Lunney, Lynn and Hogan 2002, reproduced with permission)

patterns of functional decline over the last twelve months of life. They were able to distinguish the trajectories of patients with a terminal illness, typically cancer, from patients with organ failure, typically congestive heart failure or chronic obstructive pulmonary disease. Cancer patients tended to do really well with their illness for a long time, until, as one of my oncology colleagues says, they start to fall off the functional status curve. This is just a short time

before the point when doctors get quite good at predicting life expectancy, at about three weeks. What's the average length of stay in hospice? Three weeks (NHPCO 2009).

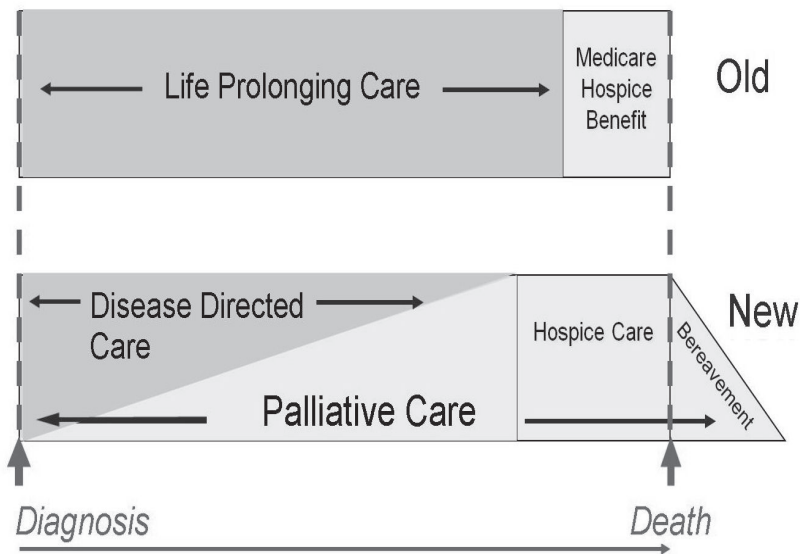
Now let's look at a typical patient with congestive heart failure a year before death. She starts out not doing quite as well as the cancer patient, but not that badly overall. Then maybe she goes out for Chinese food, takes in a big salt load, and heads for the Emergency Department to get all the fluid taken off her lungs. She comes back but not quite to the level of functionality where she was before. A while later she goes to her grandson's bar mitzvah and winds up in the Cardiac Care Unit on a mechanical ventilator. A few days later she comes out of the hospital with another small loss of functionality. Eventually she experiences another acute crisis and dies of a lethal arrhythmia after doing nearly as well as she had been all year long. I challenge anybody in this room to pick a point on that graph and tell me when she had six months or less to live.

## Changing the System to Fit the Patient

About ten to 15 years ago we asked ourselves: What model of palliative care can we provide that actually meets the needs of patients and families?

And so the modern definition of palliative care, quoted at the beginning of this brief, came about: patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. It occurs throughout the continuum of illness, really from the time of diagnosis of a serious or life-threatening event. And it addresses physical, intellectual, social, and spiritual needs to facilitate patient autonomy, access to information, and choice. What's missing in this definition? Death, the D word. Because it's not about prognosis, it's about need.

This is the old model, compared to the new model. I suggest that when we're diagnosed with a serious or life-threatening illness, all of us want our pain and other symptoms addressed and we would like to be comfortable. Some of us may want to talk about and designate a health care proxy or advance directive, but some of us may not want to go there. Some of us may even want to talk to our providers about what will happen if things don't go the way we hope and want them to go. We may want to talk about



**Figure 2.** Comparing the Old Palliative Care Model, Embodied in the Medicare Hospice Benefit, with the New Model of Palliative Care That Starts with a Diagnosis of a Serious or Life-Threatening Illness.

what's it going to be like at the end of our life. As the disease progresses, there is a balance between treatments directed at patients' conflicting goals. For many people who are at the end of the disease, all efforts will be focused on comfort, and this is when they enroll in hospice. But for others, who may die anywhere along the continuum in Figure 1, it's not about giving something up, and

it's not about saying that I'm going to relinquish curative or life prolonging treatments.

*The Human Faces of Modern Palliative Care*

What does modern palliative care look like? Let me show you two of my patients.

Kate

Kate was 21 when I first met her. She had just finished college and decided to travel. She got on an airplane to Australia, got off the plane in Australia with the worst headache of her life. She was transported from the airplane to the emergency room at Melbourne Hospital and diagnosed with acute leukemia. She spent the next two and a half years in and out of hospitals, and the last eight months of her life in an isolation room in my hospital. She went through two bone marrow transplants, neither of which was successful. And the goal for Kate, literally until the day before she died, was to cure her disease.

She received palliative care from our program for that entire time, and she and her parents said over and over that they couldn't imagine she would have lived that long without the support of our team. She had the worst pain you can imagine, terrible spiritual distress, and a number of very complicated treatment issues. But we all agreed—the goal for Kate was to cure her disease. A Do Not Resuscitate (DNR) order was written the hour before she died. That's when her family finally recognized that the end was near.

Clay

Here's another one of my patients, Clay Felker, a giant in journalism who founded *New York* magazine. His wife, by the way, is Gail Sheehy, who wrote *Passages* and a number of other books (see also her essay on palliative care in the last week of her husband's life in CPAC 2008). Clay had two cancers, both

of which were cured. He died of complications of treatment; the radiation therapy for his first cancer made it so he couldn't swallow properly and he had recurrent aspiration pneumonias. When I first met Clay and started talking to him, he didn't want to die. He was still teaching his students, they were still coming to his apartment, and he was still enjoying life. He wanted treatments that were going to allow him to continue to live in the same way, but he didn't want treatments that were going to prolong his life unnecessarily. There was no discussion about focusing on comfort with Clay until about two weeks before he died. That wasn't because we didn't have those conversations—we had several of them. Rather, it was about matching treatments to his goals. As I finally said to Clay, we don't have any high tech hospital treatments that are going to make you live longer, so it's OK if you want to spend your time at home. And then he accepted hospice.

## Palliative Care in 2010

When I started in this field about 1995, I thought I had a career's worth of work ahead of me. In 2000, about 600 of our nation's hospitals reported a palliative care program. In 2008 that number was just under 1,500 and in 2010 we're up above 1,500 now. That's 55% of all hospitals in the United States but more importantly it's 75% of our major hospitals, those with more than 300 beds (Goldsmith et al. 2008; AHA 2009)

As more patients are being taken care of in nonhospice palliative care, we're seeing those patients enter into hospice as well because it is a natural transition for them. In 2008, 40% of people accessed their hospice benefit before they died (NHPCO 2009). That's the good news and the bad news, because it means that 60% still are not. But we've gone from one million to nearly one and a half million Americans who access their hospice benefit.

We have palliative care programs throughout most of the United States. In 2008, with the exception of Oklahoma, Mississippi, and



Alabama, every state had a palliative care program (CAPC 2008), and Oklahoma proudly tells me they now have some. By the way, there are lots of reasons to live in Vermont or New Hampshire, but the large number of palliative care programs in those states is one of them.

We've seen a dramatic increase in the number of clinical palliative care programs. We have seen increasing public and professional awareness of palliative care; it was recognized as a medical subspecialty two years ago not only by internal medicine and family medicine but eight other specialty boards. No other subspecialty is supported by that many boards of medicine. We've seen greatly enhanced professional educational training. Not every medical student is graduating with a background in pain management and palliative care, but the majority are getting some experience, and that's a major step forward.

## Documenting the Benefits of Palliative Care

In a relatively short period of time we went from a novel concept in recognition of a problem, to where we are actually facing a workforce shortage—we don't have enough people to provide the palliative care service that people need. This is due in part to a growing body of research that documents the benefits of palliative care.

*Palliative care improves quality of care, addressing the quality chasm documented by the IOM in 2001.*

David Casarett and colleagues (2008) surveyed family survivors of veterans who received inpatient or outpatient care from a Department of Veterans Affairs (VA) medical facility in Philadelphia in the last month of life. They compared those who received palliative care with those who did not to determine if palliative care consultations improved the outcomes of care. They found that, compared to standard care, palliative care was superior

for providing emotional and spiritual support, information and communication, care at the time of death, access to services in the community, well-being and dignity of the patient, care concordant with patient preferences, pain management, and treatment of PTSD symptoms.

However, Casarett's study wasn't a randomized controlled trial. There have been a number of similar studies like this one, but whenever I try to present them somebody says, "Well it's really not a randomized controlled trial and the groups are different. Somehow people who access palliative care are different from people who get regular care."

In response to that criticism, Jennifer Temel and colleagues at Massachusetts General Hospital (2010) took lung cancer patients with advanced lung cancer who normally receive aggressive treatment at the end of life and randomly assigned them to receive usual cancer care or usual care plus palliative care. They found that, compared to usual care, palliative care was associated with significantly improved quality of life, fewer depressive symptoms, and fewer burdensome treatments. Furthermore, despite the fact that fewer patients receiving early palliative care also received aggressive end-of-life care, they survived on average 2.7 months longer than patients without palliative care.

Getting palliative care with your chemotherapy increases your survival time over chemotherapy alone. We don't know why this is the case, because those studies haven't been done yet, but I've got some ideas. First, if your pain's better controlled you function a little bit better. If you're sleeping at night you can actually get up in the morning. You're at less risk for infection. If your family is supported and you're not depressed—we know those two indicators are associated with decreased survival—you may live longer. And, speaking as a clinician, a really provocative thought is that a lot of what we do to people has deleterious side effects, but

giving you chemotherapy near the end of your life may actually benefit you a little. However, those are only hypotheses.

*Palliative care addresses patients' and families' needs.*

One of my students (Gelfman et al. 2008) contacted families of people who died just six weeks earlier, which is a hard thing to do. She did a series of both qualitative and quantitative interviews with them and found that families were significantly more likely to report their emotional and spiritual needs were met, and significantly more likely to feel that they could take care of their seriously ill older relative after consultation with the hospital palliative care team.

*Palliative care supports doctors.*

When doctors refer a patient to palliative care a number of good things happen. Palliative care helps doctors who may prefer to say, "There's no easy way I can tell you this, so I'm sending you to someone who can." We physicians should all know how to do talk to patients about really hard things, but most of us don't. We get very little education about it. How do you tell somebody they have cancer? How do you tell somebody that the treatment that you're providing is no longer working and you need to shift gears? These are hard conversations to have and nobody likes to have them. I do this for a living and I am still anxious, nervous, and worried when I have to tell a patient that things are not going the way we had hoped. It is a lot easier to say, "Let's just keep doing what we're doing." We spend a lot of time teaching our palliative medicine fellows, our trainees, and our nurses how to have these conversations.

Palliative care saves time for the physician: my average family meeting with a patient and family in the setting of a complex illness, where we're wrestling with hard questions, is about 90 minutes. By comparison, an oncologist sees patients in his office

every 10 to 15 minutes. If that oncologist has a 90 minute family meeting, that is 9 patients he did not see, and 9 patients he did not bill for. You can understand why somebody might be reluctant to devote that amount of time. But palliative care teams do that for a living. They're paid to provide that type of service, at least within hospice. And they're available to help with other things that the doctors aren't trained to do, like bedside management of symptoms, talking about goals, deciding about treatment choices, and helping patients and families decide when to withhold or withdraw treatments that are no longer meeting their goals.

*Palliative care does all this while at the same time saving money, or at least keeping things cost neutral.*

According to the Centers for Medicare and Medicaid Services, national health expenditures were \$2.3 trillion in 2008, or \$7,681 per person, and they are projected to reach the \$4.5 trillion mark by 2019 (CMS Fact Sheet 2010). But when we actually look at where health care costs are coming from, the top 10% of sickest Medicare beneficiaries account for nearly two-thirds of the costs, and the top 5%, the sickest of the sick, account for close to half (KFF 2009).

We've been focusing on the 90% of Medicare beneficiaries who account for only one-third of health care costs. If we really want to make a really big dent in the Medicare budget we've got to figure out how to take care of that 10% who are driving two-thirds of the costs, and who are not well served by the current system.

The primary setting for health care expenditures are hospitals; that's where Medicare dollars are going. And yet hospitals themselves are facing the most hostile operating environment they have ever experienced. They have less discretionary funding, they're closing beds and laying off staff, and they're reducing capital expenditures. Very few hospitals in this country are actually building; they are reluctant to embark on projects where the

immediate cost benefit is not apparent. So how are hospitals able to survive in the current marketplace?

- By increasing revenues, by transforming from acute care hospitals into surgical hospitals. My hospital has completely reconfigured itself into a leading cardiovascular surgery center.
- By encouraging surgical admissions with short stays to reduce expenditures. The average length of a hospital stay for acute care is 5.6 days in the U.S., a full day below the median of western developed countries (Anderson and Squires 2010).

We have tried very hard—with standardized care and uncomplicated admissions—so ensure that someone who comes into the hospital with congestive heart failure and nothing else will get put on the CHF pathway and will be well taken care of. Someone who comes in to have a total knee replacement and nothing else will do just great. But for chronic care patients with five other illnesses on top of that, which is the average for my patients—a little cognitive impairment, a little osteoarthritis, some COPD—those patients don't fit a defined the pathway very well and they stay a long time.

Palliative care, however, is a feasible solution for hospitals, for a couple of reasons. One is that it improves throughput as hospitals shrink bed capacity. Think of a hospital as a plumbing system, where people flow through a pipeline. There are a couple of bottlenecks in the hospital pipeline.

- One is the emergency department (ED)—once the ED is full the hospital admissions flow literally shuts down, because if they can't put somebody from the ED into a bed, the ambulances go someplace else—it's called diversion.
- The other bottleneck is the intensive care unit (ICU), which typically has a fixed maximal bed capacity. If there is somebody in the ICU whose goals are not being met by their treatments or who

should be in another place, and the ICU is filled to capacity, the ED must hold any excess ICU patients because it's the only other place in the hospital where they can get that critical care. Then the ED fills up and the hospital admissions flow shuts down.

If you walk through the ICUs of a modern American hospital, you'll find a lot of patients there who could probably have their needs met in other places but nobody has actually sat down with their families to talk about the goals of care and what they're hoping to accomplish. Palliative care does that, and thus enables some people in the ICUs to move to more appropriate treatment settings. It also facilitates people moving from the hospital back to the community or to other places, either by referral to hospice or to community palliative care programs, or by marshalling resources in the community for this very small but very complicated group of people.

How much does palliative care reduce hospital costs? My colleagues and I analyzed administrative data from eight very diverse hospitals serving both low-, medium-, and high-income markets in a mixture of community hospitals, academic medical centers, and cancer centers (Morrison et al. 2008). On average, people who received palliative care and were subsequently discharged saved about \$174 per day, or \$1,700 per admission. For people who died in the hospital those numbers were about \$374 per day, but \$5,000 per admission. Patients who received palliative care were significantly less likely to die in an intensive care unit than a regular bed, yet their survival time was exactly the same.

If we assume that 50% of hospitals now have palliative care programs, which are seeing about 1.5% of all hospitalized patients (a conservative estimate; the right number is probably about 10%), that's \$1.2 billion in savings per year in 2010. When we increase that number to about 5% of hospitalized patients, then we save about \$4 billion per year in hospital cost, and at 7.5%

of hospitalized patients it's \$6 billion per year, which is some significant savings.

## Policy Initiatives to Promote Change

What do I want to do before I retire in 10 years? I want to make sure of three things.

- That every American knows what palliative care is, and knows that the appropriate time to request it is when they are diagnosed with a serious or life-threatening illness.
- That all health care professionals have the knowledge and skills to provide some palliative care. That doesn't mean that every single physician in this country needs to be a palliative care physician. But every single physician in this country should know how to treat pain, how to communicate bad news, how to refer to hospice or palliative care, and how to access appropriate services.
- And finally, that wherever you are—in a long-term care setting, in the hospital, or in your home—you have access to palliative care.

To get there, I propose four practical changes. We need to address the workforce issue. We need to improve access and quality. We need a better evidence base. And we need to address public and professional misconceptions.

### *1. Build a Larger, More Effective Palliative Care Workforce*

#### Increase Funding for Palliative Care Training in Medical Education

Right now we have about 4,500 board certified palliative medicine physicians in this country, which is only one for every 31,000 people with a serious or life-threatening illness. Yet 26 states in the U.S. still do not have palliative medicine fellowship training programs and aren't training palliative medicine specialists, although that is changing rapidly.

For those of you who are not familiar with how graduate medical education is funded in the U.S., students finish their four years of medical school about \$250,000 in debt. After that, Medicare pays for their further training. It's a balance; hospitals get cheap labor, and doctors don't have to pay for another seven years of training. But there is a cap on graduate medical education. The number of slots for residents and fellows in the U.S. is fixed, and hospitals cannot increase that number. Normally, the only way to start a training program is to steal a slot from another specialist. My hospital is actually over the cap because we were grandfathered in. When I started a palliative medicine fellowship training program in my hospital I could not get Medicare dollars to support those five fellows; they are all supported by philanthropic donations. That is how it works at almost every academic institution in the U.S. Fortunately, there are some initiatives in Congress to change that.

Loan forgiveness programs have greatly increased the number of clinicians who are going into NIH-funded research, because when you come out of medical school with a staggering debt you think very carefully about your career choices. There's a reason that people become surgeons and dermatologists and radiologists instead of going into internal medicine when they're making career choices. Loan forgiveness programs would really help draw more doctors to internal medicine.

#### Midcareer Training

Medicine is of the few professions in which it's really hard to change career paths midstream. If, at age 45, I want to become a surgeon, that means going back to do a five-year surgical residency. If my colleague wants to be an internist and go into palliative medicine it means doing another year of fellowship training before she can sit for the boards. There are very few doctors who are willing to make that sacrifice in midcareer, in terms of time, lost salary, and drudgery. But some people in the



health care workforce really want to do palliative care, so we need to develop midcareer training that answers their needs.

### *2. Develop Palliative Care Program Standards*

Palliative care program standards are still voluntary. Any hospital can open up a palliative care program; there is no certification program. And the business model we've developed is difficult to demonstrate and sustain, primarily because it requires palliative care programs to compare their patients to patients not receiving palliative care. When the percentage of patients getting palliative care increases, the comparative group shrinks, which is what we experienced in our hospital, and then it's hard to continue to make our case. So one of the things that we keep pushing is the idea of having palliative care as a component of accreditation for hospitals.

### *3. Increase Funding for Palliative Care Research*

The recently passed national health care reform included recommendations that the National Institutes of Health devote more funding to palliative care research. It's now law, but we've still got to figure out how to make it happen. A simple 2% increase in NIH funding would be extremely beneficial.

We have developed funding mechanisms to support junior investigators in aging quite well; now we need to do this within palliative medicine, using the model of AIDS in the 1980s. The NIH realigned AIDS research by establishing an office of AIDS research which coordinated AIDS research throughout the entire institute and transformed AIDS from a fatal disease into a lifelong chronic illness.

### *4. Changing Public and Professional Misperceptions*

During the recent national health care reform debate, simple language to enable doctors to be reimbursed for talking to patients

about their wishes was characterized by opponents as a mandate for “death panels” and was subsequently stricken from the final bill. So if you, as a healthy adult, come to my office and spend 20 minutes talking to me about your wishes in the event that you have a serious and life-threatening illness, or are hit by a car, do you know how much money I’m allowed to bill Medicare for that conversation? Zero. It’s an unreimbursable expense of my time.

## Conclusion

Some people say that fear of talking about dying is a distinctly American phenomenon or a manifestation of 20th century technology. The reality is, it’s not. This quote from Leo Tolstoy’s short story, *The Death of Iván Ilých*, written nearly 130 years ago, gives us a brilliant description of what it is like to die in the setting of a death-denying society.

What tormented Iván Ilých most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he need only keep quiet and undergo a treatment and then something very good would result. (Tolstoy 1886, as translated by Louise Shanks Maude and Aylmer Maude, 285)

When you think about it, it is probably ingrained within us; there is an evolutionary advantage to not wanting to die.

We’ve spent a lot of money to transform the culture of death and dying in the United States. George Soros put a huge amount of money in a project on death in America (Open Society Institute 2003). The Public Broadcasting System, with funding from Robert Wood Johnson Foundation, broadcast “On Our Own Terms: Moyers on Dying.” (Moyers, Moyers, and O’Neill 2000). The RWJF promoted excellence in end-of-life care, including a

consumer advocacy group to improve to access palliative care called “Last Acts.”(RWJF 2004).

The problem with doing all this is, as Woody Allen put it:

*I don't want to achieve immortality through my work....I want to achieve it through not dying.*

Nobody aspires to better end-of-life care; they want better quality of life. Furthermore, if our goal is to improve the care of the seriously ill, then we need to consider that most of the people who need us aren't dying, and even among the subset who are, many are not going to want to acknowledge that. So we really need to de-couple palliative care from end-of-life care. What we do is not improve care at the end of life, but improve care for people with serious and life-threatening illnesses throughout their life.

Life is pleasant. Death is peaceful.  
*It's the transition that's troublesome.*

Isaac Asimov, US science fiction novelist  
and scholar (1920-1992)

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