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Palliative Care and the Health Care Crisis in the United States: A Candid Conversation with Dr. Diane Meier

University

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Dr. Meier is the recipient of numerous awards, including a 2008 MacArthur Fellowship, the National Institute on Aging Academic Career Leadership Award, the Open Society Institute Faculty Scholar's Award of the Project on Death in America, the Founders Award of the National Hospice and Palliative Care Organization, and the Alexander Richman Commemorative Award for Humanism in Medicine.

The Herbert Lourie Memorial Lecture on Health Policy, sponsored by the Maxwell School of Citizenship and Public Affairs of Syracuse University and the Central New York Community Foundation, Inc., honors the memory of Herbert Lourie, MD, a distinguished Syracuse neurosurgeon, professor, and community leader for nearly 30 years. Generous contributions from his family, friends and colleagues, and former patients have endowed this series.

The Policy Brief series is a collection of essays on current public policy issues in aging; urban and regional studies; education finance and accountability; public finance; social welfare, poverty, and income security; and related research done by or on behalf of the Center for Policy Research (CPR) at the Maxwell School of Syracuse University.

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Policy Brief

Palliative Care and the Health Care Crisis in the United States: A Candid Conversation with Dr. Diane Meier

Diane E. Meier, MD and Suzanne L. Goldhirsch, MA

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Introduction

This paper is a synthesis of the 2012 Lourie Lecture, framed as a series of questions and responses, and supported by images used in the lecture. I'm going to focus on the growth of this new field called palliative care and will make the connection that the crisis afflicting healthcare in the United States cannot be addressed without widespread scaling and implementation of palliative care across the system. My subject is not end-of-life care, but rather care during serious illness. A serious illness is something a person can live with for many years, such as emphysema, or end-stage renal disease on dialysis, or dementia. Of course, serious illnesses are also progressive and eventually lead to end-of-life, but I want to address care for a much broader patient population, not those who are clearly dying and who will qualify for hospice services.

What is the core underlying principle of Palliative Care?

The core underlying principle that informs the practice of palliative medicine is its focus on the patient as a person. In a talk to the graduating medical school class at Harvard in 1921, a famous Harvard physician named Francis Peabody notoriously said, "The secret of the care of the patient is caring for the patient." Of course,

Peabody came to his observation from wisdom handed down by poets and leaders thousands of years before him – Hippocrates, writing in 400 B.C., "I will follow that system of regiment, which according to my ability and judgment, I consider for the benefit of my patients." And about 1,500 years later the prayer of Maimonides, read at my medical school graduation, saying, "May I never see in the patient anything but a fellow creature in pain." This is the underlying principle that is supposed to inform the work of everyone in healthcare. We're here to serve the patient.

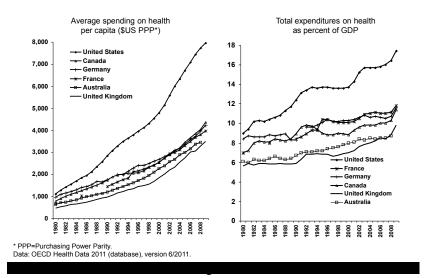
How does palliative care improve the value equation in health care?

The value equation refers to the ratio of quality over cost and the aims of healthcare reform are to improve this equation either by strengthening quality, reducing spending, or preferably, both.

Let's begin with some international comparisons of healthcare spending to illustrate why the value equation is such an important issue in the U.S. The following chart is from the Organization of Economic Cooperation on Development (OECD), a group including the United States, Canada, Norway, Switzerland, Australia, and New Zealand. (Figure 1)

On the left hand Y-axis is average spending on healthcare per capita, and on the X-axis, years 1980 through 2008. And just looking at the left side, you see all those countries clustered together—France, Germany, Canada, the U.K., and Australia—and they are spending about \$4000-\$5,000 per person per year. The U.S. on the other hand is spending about \$8,000 per person, per year. The most recent data is \$8,400 per person for healthcare. We're spending approximately twice as much as our peer nations on healthcare.





On the right hand side of the chart, the analysis shows the percent of GDP that is spent on healthcare. The X-axis here is 1980 to 2009 and the Y-axis is percent of spending on healthcare in terms of GDP. Healthcare spending in other developed countries is in the range of 10-12 percent of their economy, while in the U.S., at this point in 2009, healthcare spending accounted for about 17.9 percent, roughly one-fifth of our total economy.

And what is all this spending buying us? Unfortunately, despite our high spending, the U.S. has the lowest life expectancy at birth and the highest rate of mortality preventable by standard healthcare.

What are the consequences of this high level of spending on healthcare in the U.S.?

Every day there are stories in the national media about the consequences of this kind of health care spending. In one particularly poignant and, I think, instructive example, there was an upper middle class, two-professional family in Florida, with two insurance policies, who had a child with a congenital birth defect. The child's care reached the maximum of both insurance policies, caused this family to lose their home and declare bankruptcy, and the child eventually died at the age of four. This does not happen in any other developed nation. Our country is unique among developed nations allowing routine destruction of a family because of healthcare costs. In fact, the number one cause of personal bankruptcy in the United States is healthcare costs.

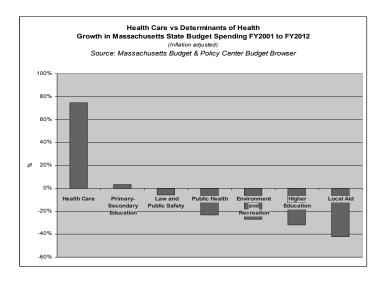


Figure 2. Health Care vs. Determinants of Health Source: Massachusetts Budget and Policy Center, 2012.

How does all this healthcare spending affect the individual States? The federal government can borrow, but that is not true at the state level. State budgets must be balanced and when more money goes to one sector, less goes to other important areas. Over the last ten years in Massachusetts, for example, there has been an 80 percent growth of spending on healthcare, leading to reductions in spending on everything else. (Figure 2) When we spend more money on Medicaid, we are cutting the funds for other public goods – education, clean air, housing, environment and recreation, public health, law and public safety, police, fire, etc. I don't think many Americans understand that these are real tradeoffs. This trend clearly raises some questions about what kind of society we want to live in. What kind of society do we want to leave for our children? Whether we realize it or not, we are making a choice here

Where does the money go?

The high spending on health care and the poor quality of that care are not equally distributed across our society. Of course, high spending is highly concentrated on those Americans who are sick. And that makes sense. We should be spending money on those who are sick. That's the whole purpose of a healthcare and an insurance system, to care for us when we get sick. The problem is that the way we spend the money and the amount that we spend are wasteful and fail to meet patients' most important needs. This concentration of spending among a very few very sick people is why palliative care is relevant to the future of the healthcare system, and the future of our country. And it is because the sickest 5 percent, and this is approximately true across all payers, account for half of all healthcare spending.

The data can be analyzed in different ways. If you just look at Medicare beneficiaries, and of course Medicare is mostly older

Lourie Lecture Policy Brief

people, a higher percentage of Medicare beneficiaries need healthcare. Roughly 10 percent of Medicare beneficiaries account for 67 percent of Medicare spending. And if you look at Medicaid, a means tested insurance plan for the poor, the numbers are closer to 5 percent, and if you look at commercial insurance, slightly under 5 percent. But this highly concentrated spending is true regardless of who the payer is, and regardless of the age group of the population. The 1 percent of the sickest patients account for 22 percent of total spending.

One of my favorite New Yorker cartoons sums up this situation in one line. It's a mouse saying to a lion, "It is thorn-like in appearance, but I need to order a battery of tests." (Figure 3)



"It is thornlike in appearance, but I need to order a battery of tests."

Figure 3. *The New Yorker*

This is how we're teaching young physicians to think...or not think actually. A lot of what we're teaching is to order every test and procedure so you don't get sued. Order everything because you'd hate to miss it. Order everything because you don't want to be embarrassed on attending rounds for having failed to order something. What we're not teaching is "let's think about what makes sense in this patient." Let's think about what's really best for him or her from a quality of life standpoint. We're thinking about other things.

How does palliative care transform the old model of treating serious illness?

Palliative care is central to improving value because the palliative care patient population is driving most of the spending. These are people with multiple chronic conditions, cognitive impairment, functional impairment, or perhaps with one really serious illness, like metastatic non-small cell lung cancer or ALS or pulmonary fibrosis. The conceptual shift for palliative care diverges from the old model where it was an either-or choice for the patient and family—pursue disease-directed curative therapies or else choose hospice. These were two completely separate and mutually exclusive goals of care. We're going to cure you, or at least prolong your life, or else we're going to give you comfort and connect you to a hospice program as you approach the grave. This either/or approach clearly had nothing to do with the needs of patients and families, and everything to do with how the payment system was organized. That's how the care was paid for, so that's the kind of care patients got. The payment system drove the options that patients and families had available to them.

What factors led to a paradigm shift for palliative care?

Healthcare professionals who recognized the need to focus on quality of life at the same time as disease treatment pioneered this conceptual shift at the core of palliative care. We were seeing people who were not eligible for hospice and who were not dying, but who were in pain, who were depressed, who were anxious, who have eight different specialists, who have no idea what their future is likely to hold, and who are in and out of the hospital, often for diagnostic and therapeutic interventions of uncertain benefit and some risk. This recognition, combined with large private sector philanthropic investments, created the transformed field of palliative care. Between the Robert Wood Johnson Foundation, George Soros, and multiple other charitable foundations, something close to 400 million dollars has been spent to develop and scale palliative care models in the United States over the past 15 years.

The push to develop palliative care didn't come from payers, and it didn't come from government. It came from the private sector. The model that is now being promulgated around the country is one where from the point of diagnosis of a serious illness to a cure, or to 10 or 15 years of living with that disease, a patient gets both evidence-based, disease-directed therapies and also care focused on quality of life at the same time. (Figure 4) When a person reaches a point usually late in the illness where disease-directed therapies are no longer helping, or when their burden outweighs their benefit, that's when it becomes appropriate to utilize hospice. The fact that patients must give up insurance coverage for disease-directed treatment in order to access hospice is a key reason why the median length of stay in hospice, which is supposed to be up to six months, is only about 3 weeks, and declining over time. People do not want to give up life-prolonging treatment that can help them

until they no longer have any choices—and that's usually quite late in life.

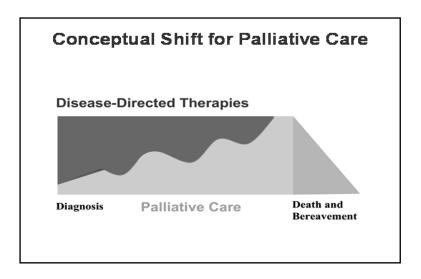


Figure 4. Source: Center to Advance Palliative Care, 2012a.

How does language shape the public's perception of palliative care?

About a year ago, we conducted public opinion research with a polling firm in Washington, Public Opinion Strategies. We polled 950 likely voters across the country. It was a representative sample of young people of voting age, who were black, white, Latino, Asian, Southern, rural, urban, and from a range of socioeconomic status and religious affiliations. Notice please that we polled the public, not doctors. Figure 5 shows the language describing palliative care that the people in our poll reacted to with strikingly high (>90 percent) approval levels, determined by asking if people would want this kind of care for themselves or for a loved one

What language appealed to the public at large?

Interestingly, the public preferred the term *serious illness*, not advanced illness...or terminal illness...or life-limiting illness... or life-threatening illness. Those phrases imply hopelessness or proximity to death. Serious illness, on the other hand, is something that can be cured or that a person can live with for a long time.

We tested the word *suffering* in the poll. In palliative care, we clinicians often talk about the relief of suffering, because that's what we see. Doctors, nurses, chaplains, and social workers see suffering every day. But that is not how patients and family define what they are experiencing. They don't say "*I'm suffering*." This is another example of mismatch of our language with what patients and families are feeling. Whatever the diagnosis or stage of illness or setting of care, the goal from the person's standpoint is for us to help *improve the quality of life*. Another highly ranked characteristic was that palliative care is '*for both the patient and the family*.' The notion that the family is also part of the circle of care was very appealing to those polled.

Palliative care is provided by a team. The word "team" implies that health care providers are communicating and the team of doctors, nurses, and other specialists work with a patient's other doctors. We work with the patient's other doctors to provide an added layer of support—what we do at the same time as other therapies are provided. This added layer of support helps patients and families have the best possible quality of life.

The last sentence is a key message... 'Palliative care is appropriate at any age and any stage of a serious illness and can be provided together with curative treatment.' We had a 24-year old patient named Kara with acute myelogenous leukemia and who was admitted to the hospital through the Emergency Department, having collapsed at home. She had a white cell count of 250,000,

all of which were blasts, and terrible pain from a marrow packed with immature white blood cells. She was profoundly short of breath and as a result was having panic attacks. Our palliative care team was called because the primary team could not manage the pain.

We were able to adjust her analgesic regimen and get the pain under control, and then remained actively involved in her and her family's care throughout her several-month stay for her bone marrow transplant. Kara's fine now, married, just finished with graduate school, sends a Christmas card and a check for \$50 every year. If she had to wait until she was dying to get palliative care, our team would never have gone to see her, because the goal of care for this young woman was a cure. Palliative care is not end-of-life care.

When our poll respondents were asked, more than 90 percent said they wanted palliative care for themselves or a loved one, and that preference was consistent across all political parties, tea partiers to progressives all reported the same high level of endorsement for wanting palliative care as defined here. (Figures 5 and 6)

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Figure 5. Source: Center to Advance Palliatve Care, 2012b.

Exceptionally High Positives

Once informed, consumers are extremely positive about palliative care and want access to this care if they need it:

- √ 95% of respondents agree that it is important that patients with serious illness and their families be educated about palliative care.
- √ 92% of respondents say they would be likely to consider palliative care for a loved one if they had a serious illness.
- 92% of respondents say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

Figure 6. Source: Center to Advance Palliative Care, 2012c.

How would you describe what you do for patients and families?

Palliative care clinicians assess and treat physical, emotional, and spiritual or existential distress. We are highly skilled at complex emotion-laden communication with patients and families about the reality of the illness, what to expect in the future, the treatment alternatives and their pros and cons, and we will defend your right to get care that will help you achieve your goals...even if we disagree with them. It is about determining your goals and supporting you in achieving those goals. It's about patients as people, and determining what matters most to the person, and then helping them achieve that. The person, our patient, is in charge.

We also work to make sure that people don't fall through the cracks when they leave the hospital. That they go home with a care plan that is actually safe and sustainable.

Is there evidence that palliative care improves quality of care?

What do we know about palliative care? We know that it improves symptoms, quality of life, length of life, family satisfaction, family bereavement outcomes, and the likelihood that the care received actually is what the patient wanted. And on the flip side, on the cost side, there's now quite a bit of data showing that palliative care in essentially every setting where it's been studied, markedly reduces healthcare spending.

How does palliative care influence quality of care? A controlled trial done at Massachusetts General Hospital randomly assigned newly diagnosed lung cancer patients to receive the best cancer care from Mass General's oncologists or to receive both best cancer care and simultaneous palliative care. From the day they entered the study, both teams, throughout the course of their illness, saw them whether it was five years or five months.

The patients who got both regular oncology care and palliative care had better quality of life, fewer symptoms, markedly reduced major depression - 75 percent reduction in the risk of major depression, were less likely to be hospitalized to get chemotherapy in the last two weeks of life, and were more likely to get hospice in the last weeks of life. What was surprising about this study, and what got this paper published in *The New England Journal of Medicine* and then broad media coverage, was that the patients who got both types of care lived longer. They lived almost three months longer. (Figure 7)

Palliative Care Improves Quality in Office Setting

Randomized trial simultaneous standard cancer care with palliative care co-management from diagnosis versus control group receiving standard cancer care only:

- Improved quality of life
- Reduced major depression
- Reduced 'aggressiveness' (less chemo <
 14d before death, more likely to get hospice, less likely to be hospitalized in last month)
- Improved survival (11.6 mos. vs 8.9 mos., p<0.02)</p>

Temel et al. Early palliative care for patients with non-small-cell lung cancer NEJM2010:363:733-42.

Figure 7. Source: Temel et al., 2010

What might be some possible explanations? Hope...being hopeful, could that prolong life? We know that depression itself is an independent predictor of mortality in every study that's looked at it in specific diseases – heart failure, dementia, emphysema, and cancer. You do worse if you have depression, and that may also be because of depression's adverse impact on immune neuroimmune function. The reduction in major depression was not because of more antidepressant prescribing in the intervention group as the oncologists prescribed just as much antidepressant therapy as the palliative care team did. It was presumably something about the human support, the relationships, the trust, and the feeling of safety.

What else might have accounted for this gain in survival? One possibility is to look at the risks of spending time in a hospital. If you are immunosuppressed from chemotherapy or radiation, or just debilitated and sick, and you come into the hospital and pick up one or more antibiotic-resistant infections, you may die. There was also a difference in the likelihood of hospitalization in these two groups. I think it's a combination of factors, reduced depression, feeling in control, feeling supported, not being in terrible pain or short of breath, and also avoiding the risk of hospitalization.

Figure 8 depicts the results of a study conducted at Kaiser, about 13 years ago. This also is a randomized control trial, in a globally budgeted healthcare system they can see where their money is going. They know how much they're spending on home care, doctor's office visits, hospital, ICU, nursing home care. In this study, they randomized patients with heart failure, emphysema, and cancer to receive either regular Medicare home care as the usual care group versus home palliative care for the intervention group. Doctors, nurse practitioners, and social workers went to the patient's home, called regularly to ask people how they were doing, and they went to the home when necessary.

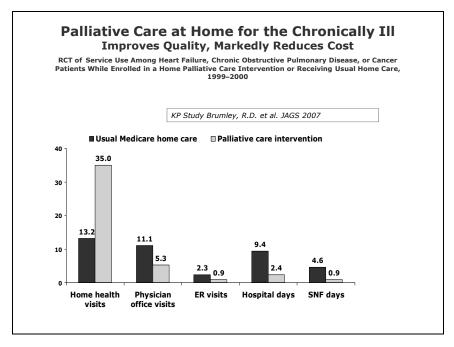


Figure 8. Palliative care at home improves quality and reduces cost. Source: Brumley, *et al.*, 2007.

The palliative care group got three times as many home visits. By offering palliative care home visits, they also reduced physician office visits by 50 percent; ER visits by over 50 percent, hospital days by 80 percent, and skilled nursing facility days by 80 percent. Net/net, their return on investment was 3 to 1. They now provide these services across the entire Kaiser system. The VA does this across their entire system too because they are also globally budgeted and can rationally put resources where they need to be to take the best quality care of the most vulnerable and most costly patient population. This model is what the future of our system will look like. We've got to start shifting resources out of all these other settings and into the home setting.

A third study done in rural areas involved a randomized control trial of telemedicine for palliative care. (Figure 9) These were cancer patients treated at Dartmouth, the regional cancer facility for much of Vermont and New Hampshire. Many of the patients live far away from the regional cancer center so the researchers created a model that actually fit the needs of their patient population, which was telemedicine. They trained a group of RNs to call patients regularly and go through a checklist with the patient and the family on every call. When was your last bowel movement? How many pain meds did you take in the last 24 hours? How would you rate your worst pain? What was it at its best? What's on your mind? What's bothering you? And then speaking to the patient's spouse. How are you doing, Mrs. Jones? How are you sleeping? Is anybody giving you a break? What are your biggest concerns? The nurses were in regular communication with the primary care doctor, so if a prescription needed to be changed, the nurse would get on the phone to the primary care doctor and say, "This is what the assessment showed, and would you please call in a prescription?"

RCT of Nurse-Led Telephonic Palliative Care Intervention

- N= 322 advanced cancer patients in rural NH+VT
- Improved quality of life and less depression (p=0.02)
- Trend towards reduced symptom intensity (p=0.06)
- No difference in utilization, (but v. low in both groups)
- Median survival: intervention group 14 months, control group 8.5 months, p = 0.14



Bakitas M et al. JAMA 2009:302(7):741-9

Figure 9. Source: Bakitas, et al., 2009.

The investigators found better quality of life and less depression, just as in the prior study, and reduced symptom intensity. But the median survival, while it did not achieve statistical significance, was also different. Maria Bakitas, the nurse researcher who did this study, is in the middle of a NCI-funded R01 to replicate this study with larger numbers. This is an inexpensive intervention. It's about relationships and being heard, and knowing whom to call when there's a problem. It's so simple, and yet we don't reimburse for it.

The final study in this group looked at the adverse effect on families of 'business as usual' in the U.S. healthcare system. This study compared family outcomes when the patient died in hospice with family outcomes where the patient died in an ICU or in a hospital. Family members of patients who died in an ICU had a five-fold increased risk of PTSD (Figure 10), and the family members of patients who died in the hospital had nearly a nine-fold increased risk of prolonged grief disorder. These data arguably reflect the highest social cost for usual medical care. People with PTSD and prolonged grief disorder don't go back to work, can't take good care of their children, do not recover on their own, have serious morbidity, and actually increased mortality as well. That's the unmeasured hidden cost that adds to the dollars we're spending on that ICU care.

Consequences of Late Referral to Palliative Care

Serious Adverse Outcomes for Bereaved Caregivers:

Compared to care at home with hospice,

- Care in ICU associated with 5X family risk of Post Traumatic Stress Disorder; and
- Care in hospital associated with 8.8X family risk of prolonged grief disorder

Wright A et al. Place of death: Correlation with quality of life of patients with cancer and predictors of bereaved caregivers mental health. JCO 2010; Sept 13 epub ahead of print

Figure 10. Source: Wright, et al., 2010

And what is the evidence on the costs side of the value equation?

Several studies demonstrate that hospital palliative care consultation leads to approximately a \$3,000 savings per patient for patients who get palliative care compared to matched control patients who don't. The savings were much higher for patients who died in the hospital compared to patients who didn't get palliative care and also died in the hospital.

A similar analysis for four hospitals in New York State with very high Medicaid/payer mix found even higher savings in the Medicaid population. If you're a health policy person, however, it is not enough to save hospitals money—they are seeking interventions that reduce total spending across the full continuum of care. Hospitals have a strong business case for doing this because they get a fixed payment per hospitalization, whether the stay is short and uncomplicated or long and complicated. The hospital therefore has an incentive to reduce your length of stay and reduce your spending. But what happens when very sick people leave the hospital? Are we just shifting costs out of the acute care setting into the community setting?

Can you explain how palliative care reduces costs?

A dedicated medical team delivers palliative care, and by that I mean doctors and nurses who actually understand the disease process, what to expect, alternative treatment options, and the pros and cons of those options. The dedicated medical team must be able to focus and take the time they need to assess and understand the patient as a whole person and what matters and is most important to that person and their family. To have impact, the team spends time and listens to the patients and the families. The direct result of having that focus and time to have those family meetings is that a decision gets made. Not only does a decision get made, but it also gets communicated to family members who may

not be actively involved—what we like to call 'the daughter in California.' Also, we inform those multiple sub-specialists that are seeing this person every day, the doctor in the community, and the hospitalist of the week. And then we make sure that the care plan is honored and carried out. What's hard for the public to believe is that taking the time necessary to do these things actually does not happen as part of usual care. We come in and try to rationalize the system and make it work in service of trying to achieve an informed patient and family's goals for their care.

How many U.S. hospitals offer palliative care to their patients?

Figure 11 tracks the growth in hospital palliative care over the last 10 years. The number of hospital-based palliative care teams has tripled. About 70 percent of all U.S. hospitals, and nearly 90 percent of hospitals with more than 300 beds, now report palliative care teams.

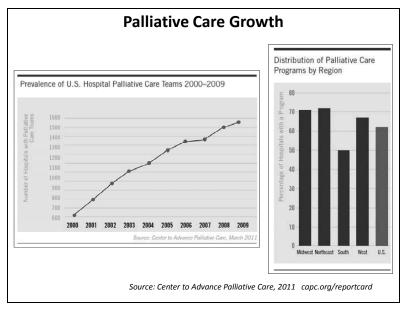


Figure 11. Center to Advance Palliative Care, 2011a.

New York State (Figure 12) gets a B, which means between 60 and 80 percent of hospitals in NY have palliative care, and we're definitely improving. On this chart, the darkest states are the ones that get an A grade—Washington, Oregon, Nebraska of all places, Minnesota, Maryland, and Vermont. Many of these are rural states and they don't have very many hospitals, and most of their hospitals are big regional centers, so it's not that hard for them to get to 80 percent. The worst part of the country for access to palliative care is in the South.

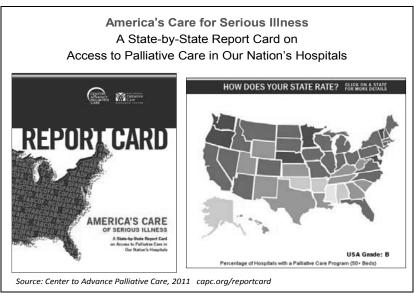


Figure 12. Center to Advance Palliative Care, 2011b.

What do U.S. doctors think of palliative care?

The younger the doctor, the higher their exposure to palliative care during training. (Figure 13) Younger physicians who went to medical school and did residency in teaching hospitals that have palliative care teams think it's just a routine and standard component of good care. And they don't want to practice in a setting that doesn't have it.

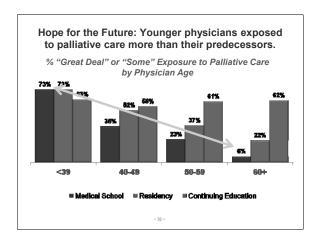


Figure 13. Source: Center to Advance Palliative Care, 2012d.

How can we build palliative care across care settings in the U.S.?

The National Quality Forum (NQF), which is the nation's leading quality endorsing agency, has placed palliative care in its top six priorities for the nation. In order to assure that palliative care is actually delivered to those who will benefit, and to encourage the highest quality of that care, a set of measures reflective of important outcomes were recently endorsed by the NQF. (Figure 14)

NQF-Endorsed Palliative Care Measures 02/14/2012

http://www.qualityforum.org/Measures_List.aspx#e=1&s=n&so=a&p=1&cs=148

- CARE: Consumer Assessments and Reports on End of Life Care
- · Pain Screening
- Pain Assessment
- Dyspnea Screening
- Dyspnea Treatment
- · Treatment Preferences

For hospice only:

- Proportion with spiritual assessment
- Family Evaluation of Hospice Care

For cancer only:

- Proportion getting chemo last 14 days of life
- Proportion in ED last week of life
- Proportion >1 hospital stay in last 30 days of life
- Proportion admitted to hospice
 days
- Proportion not admitted to hospice before death

Figure 14. Source: National Quality Forum, 2012.

It is important to integrate NQF-endorsed quality measures for palliative care as our nation is shifting away from paying for volume (fee for service medicine), and shifting towards paying for quality. The NQF is the national organization that determines and defines quality in health care. If you don't have metrics that are endorsed by the NQF, and included in so-called value-based purchasing initiatives, you can't get paid for delivering quality.

Right now, hospitals are about to be paid less if they have a high number of readmissions after 30 days, or a high number of deaths in hospital, or a high number of new pressure ulcers, or central line-associated infections. In theory, this should motivate hospitals to pay more attention to quality because their paycheck will be reduced if they don't. Hence, getting endorsed measures becomes critically important so that palliative care can be included in this value-based reimbursement environment.

What about palliative care and health care reform?

Health care reform is trying to reduce reliance on fee for service and get us closer to a Kaiser or VA type population health and globally budgeted model. Recalling that 50 percent of spending is on the palliative care patient population- those with multiple chronic conditions, serious illness, functional impairment, and/ or cognitive impairment. The Affordable Care Act is increasingly requiring organizations to begin to move away from fee for service and to learn to assume risk and to manage the health and healthcare of populations of patients. If you can't safely and efficiently care for those 5 percent of highly complex and vulnerable patients, your health system will not survive financially. For this reason, as well as concerns about improving quality of care, major healthcare systems are now investing in scaling and integrating palliative care.

Who gains the most from improving access to palliative care?

It's interesting to think about who stands to gain the most, financially, from improving access to palliative care. When we markedly reduce the reliance on hospitals, which is the most expensive part of the system, it's the payers who benefit. Payers think about managing risk and controlling costs by assessing the needs of their members and trying to match the benefits and services they provide to fit those needs. If they fail to invest in enough services to effectively manage risk and prevent health crises, they will end up paying for much more costly and unnecessary hospitalizations. (Figure 15)

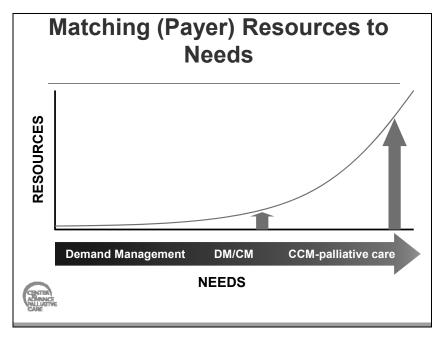


Figure 15. Matching payer resources to needs (DM= disease management; CM= care management; CCM= complex care management).

Source: Center to Advance Palliative Care, 2012e.

Healthy people don't need much, but sick people need a lot of management and it's expensive because much of it has to be face to face, in person. And so, increasingly, payers are trying to find providers who can deliver community-based palliative care. Their biggest problem is finding the workforce. Hospice nurses are overwhelmed. Hospices don't have any spare workforce to do home-based palliative care. Hospital palliative care teams are completely overwhelmed, and understaffed and don't have any extra people to provide home palliative care.

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Clinicians seeking to build palliative care capacity that can serve people in their homes and communities should work with the major payers in the community to develop a mechanism to reimburse and provide this all-important care.

In summary, the field of palliative care is growing rapidly in response to the aging of the population, the unprecedented ability of modern medicine to help the chronically ill live for a long time, and the need to restore a balance to our healthcare system so that it honors quality of life as much as quantity of life.

"Although the world is full of suffering, it is full also of the overcoming of it."

Helen Keller, Optimism

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