Quality Care and Comfort at the End of Life: Changes Needed?

Alliance for Health Reform and the
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ED HOWARD: I'm Ed Howard with the Alliance for Health Reform. On behalf of our Board of Directors - most of them anyway, some can speak for themselves - I would like to welcome you to this briefing on the issues surrounding care at the end of life. It's a topic that makes a lot of people uncomfortable but, frankly, from many points of view, whether you're talking fiscal or programmatic or humanitarian grounds, it's among the most important issues we face in the health care community.

Our partner today is the Robert Wood Johnson Foundation, which has a longstanding interest in these topics. Their senior program officer, Rosemary Gibson, who is also the Foundation's resident expert on this topic, is with us today. I want to thank her and Lovisa Morea [misspelled?], the president of the Foundation, for co-sponsoring and supporting this briefing, but also for their many years of bringing attention to end-of-life issues.

We're extremely pleased to have with us today the Alliance co-chairman, Senator Susan Collins of Maine. Frankly, long before she joined our board, Senator Collins spoke at an Alliance briefing on this very topic. She's one of the founders of the Congressional Task Force on Alzheimer's disease. She was recently recognized in her home state for her work on long-term care and end-of-life issues when she received the 2006 Friend of the Maine Hospice Counsel Award. And we're very pleased to have Senator Collins with us today.

SENATOR SUSAN COLLINS: Thank you, Ed. Thank you very much, Ed. Let me start by thanking the Alliance staff and the Robert Wood Johnson Foundation for putting together this luncheon briefing to examine the ways that we can improve care for people at the end of their lives.

As Ed was talking about this being a difficult issue - and I was having a chat with a friend of mine right before coming up here about that point - it brought to mind my very first year in the Senate and I had already been very interested in end-of-life care issues, and I introduced a bill with Jay Rockefeller and I started talking about it back home. And my staff finally came up to me and said, "You have got to stop talking about end-of-life issues," and "They're downers and nobody wants to hear it." And I finally realized that they were right, that people did not want to hear it back then when I talked to the Eastern Maine Medical Center's ladies auxiliary group and when I started talking about that, the whole atmosphere changed in the room.

And that's part of the problem. Until we start being more comfortable with talking with our family, our friends, our health care providers about end-of-life care, it's going to become difficult for us to make progress on these issues.

Noted health care economist Uve Rinehart [misspelled?] once said that “Americans are the only people on Earth who believe that death is negotiable.” [Laughter] And that does sum up our attitude towards end-of-life care as well.

Advancements in medicine, public health and technology have enabled more and more of us to live longer and healthier lives. When medical treatment can no longer promise a continuation of life, however, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is simply inconsistent with their values and wishes. Clearly, there is much more that we could do to relieve suffering, respect personal choice and dignity, and provide opportunities for people to find meaning and comfort at life’s conclusion.

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

I have been, therefore, pleased to join with the Alliance chairman, my partner on these issues for more than 10 years, Senator Jay Rockefeller, in introducing the Advanced Planning and Compassionate Care Act. I believe this legislation would help to improve the way that our health care systems serves patients at the end of their lives. Among these provisions, the bill would help to facilitate appropriate discussions and individual autonomy in making the difficult decisions about end of life treatment. For example, the legislation requires that every Medicare beneficiary receiving care in a hospital nursing home or other healthcare facility be given the opportunity to discuss end of life care, and the preparation of an advanced directive with an appropriately trained professional within the institution. The bill also authorizes funding to support innovative demonstration projects that examine best practice models for end of life care for Medicare, Medicaid and the S-CHIP program, the State Child Health Insurance Program.

The Institute of Medicine has released a report that concluded that we need to improve palliative and end-of-life care for children with terminal illnesses. I think in our country, we’re doing a little bit better in talking about end-of-life care with the elderly, but we forget perhaps the most difficult population dealing with the end-of-life care, and that is children with terminal illnesses and their families. According to this report, far too often, children with fatal or potentially fatal conditions and their families, fail to receive competent, compassionate and consistent care that meets their physical, emotional and spiritual needs. Our legislation requires that at least one of the demonstration projects that we would provide funding for focuses particularly on pediatric end of life care.

As the Senate co-chair of the Congressional Task Force on Alzheimer's - Senator Clinton is the other chair - I'm particularly pleased that Steve McConnell of the Alzheimer's Association is one of the panelists this afternoon. While Alzheimer's disease is the fifth leading cause of death for people over the age 65, and the seventh leading cause of death for people of all ages, scant attention has been paid to the special end-of-life needs of the Alzheimer's patients and their families. Early communication about end-of-life issues is particularly important for individuals diagnosed with dementia because obviously they're eventually going to lose their ability to make independent decisions about their care. I'm also concerned that medical eligibility requirements for hospice care can prevent those dying from Alzheimer's from accessing quality end-of-life care.

Moreover, even when hospice care is available, hospice staff, wonderful though they are, aren't always sufficiently trained to meet the special needs of Alzheimer’s patients and their families. There are so many issues and I’m really pleased to see that so many of you who are involve in influencing public policy and the direction we take on these issues, are present today. My health care policy aid, Priscilla Handley [misspelled?], is here, she’s going to be staying for the rest of the presentations of this panel. I apologize that I cannot, but you what Friday afternoons are like for members of the Senate, we’re never here. {Laughter] And it’s only because I care so deeply about this issue that I’m here as long as I am today.

So I wish you well and I hope you’ll help us come up with some practical solutions that we who are in charge of writing laws can lead the way on. But even more than that, I hope that this conference is a catalyst for each of you to think deeply about these issues and to have conversations with your family members, with your friends, and with your health care providers. It’s so much easier to have those discussions when we’re still healthy than to wait for a crisis to strike.

So, again, thank you for being here and my thanks to Ed, the Alliance, and the Robert Wood Johnson Foundation. Thank you. Thanks.

[Applause]

ED HOWARD: Thank you so much, Senator Collins. I should do a little bit of logistical detail before we get into the substance of the program. I know there are some people who are not regular attendees at our briefings. In the packets you're going to find a lot of background information, including biographical information on our speakers, much more extensive than I'll have a chance to give them. You'll be able to view a webcast of this briefing by tomorrow morning, maybe even tonight, depending on how fast it gets loaded. And you'll be able to do that on kaisernetwork.org. You'll find the materials in your packets also reproduced on that Web site and on the Web site of the Alliance, that is allhealth.org. And within a few days there will be a transcript that you can take a look at to refresh your memory about what has been said. I want you to take advantage of the opportunity to offer comments and questions. We're draconian and our time limits on our speakers so that you can get a chance to be part of this conversation, and I want to make sure that we tap into the expertise and insights that are represented in our audience.

So do that and also, dig into that left side of your materials and pick out the blue evaluation form and make sure you fill that out before you leave so that we can make these briefings better and serve your needs better. So that at the appropriate time.

Now, we do, in fact, have a terrific panel for you today. This is an issue that I personally have been involved in for a long time. Steve McConnell and I were colleagues in the House Aging Committee many years ago, and he educated me on some of these issues. The Robert Wood Johnson Foundation had a project called Last Acts that did a lot of good work on this topic and I was pleased to be part of an advisory committee to that project. So it’s something that I care about personally and I know, by reputation anyway, everybody who’s on this panel and they are all terrific.

And we’re going to start off by hearing from Dr. Joan Teno, who’s a professor of community health and the associate director of the Center for Gerontology and Healthcare Research at Brown University, at their medical school. And both as a researcher and as a clinician herself, Dr. Teno focuses on how to measure and improve the quality of end-of-life care for vulnerable populations. And she knows as much about the connection between end-of-life care, nursing home care, the transition from one setting to another among hospitals and home care and nursing homes as anybody around, and we’re just so pleased to have you with us, Joan.

JOAN TENO, M.D.: Thank you very much. I have four key points and 10 minutes, okay? [Laughter] So that’s a point every two and a half minutes and, actually, if there’s one slide that you remember, it’s this slide.

First of all, increasingly, nursing home is the key sight of end-of-life care. They are the final home for many Americans in the last year of life as pictured in this photograph, is one of my patients, Mr. Norman. And indeed, he is parathematic [misspelled?] of the travesty of our health care system right now because we have two predominate funders of nursing home care and they provide conflicting incentives. We have Medicare that covers hospital-level care, and Medicaid that covers for custodial care in the nursing home once you become impoverished. And indeed, sort of a story illustrates how these two systems don’t work. The best thing to do with a patient with dementia, as Mr. Norman, is to keep them in the nursing home, but the incentives clearly are to take that patient away from the nursing home and put them in the hospital because simply on a Medicaid payment system, you can’t afford the IV antibiotics. And what happened with this patient was his family paid out of pocket for the IV antibiotics for him to remain in the nursing home. So that’s point number one.

Point number two, hospice provides important services that enhances the quality of life, both state and federal policy impact hospice access. And even when you’re of a patient as Mr. Norman as he was dying, and I was his physician, the hospice team provided so much more to the quality of care and his quality of life even when you have essentially the hospital medical director acting as the primary care physician.

The third point I want to make is because of these conflicting types of insurance, of Medicare and Medicaid, too many patients are lost in transition and these transitions results in an inefficiency in our health care system that is associated with potentially burdensome care for the dying. And finally, you need to innovate our health care system but when we innovate, we must remember this is a vulnerable population that deserves protection.

So, some demographics, 1989, less than one in five people were dying in a nursing home. Rhode Island is that special bellwether state that by 1997 we had one-third of the non-traumatic deaths being in a nursing home, and nationwide 24-percent of the deaths are in a nursing home. Here we are in 2001 and we have just for people who die of cancer in Rhode Island, we have 41.2-percent of cancer deaths occurring in a nursing home and 20.7-percent of cancer deaths occurring in nursing home. I think an important thing to note is nationwide when we did a survey of a representative sample of deaths in the United States, 41-percent of people who died in the United States were in a nursing home in the last month of care. And again, that reflects is often the transition going from that nursing home to hospital setting.

So, what’s the research on the benefits of hospice care? Well, first of all, greater satisfaction, less invasive treatment, fewer hospitalizations, better care practices, and I think it’s really important for a take home message that you take away from today is that hospice empowered with medicine is a scientific body of knowledge, skills, and expertise that enhance the quality of life. It’s not as simple as saying everybody can have this set of expertise, but rather we need to retain the hospice benefit in the nursing homes to ensure quality of care for a growing number of people with dementia so that they have important access to the hospice benefit.

My research, which is included in your packet today, has provided very stock confirmation of the inadequacies and the important room to improve the quality of end of life care in nursing homes. Simply stated, when you take a look at overall satisfaction with end-of-life care, the highest satisfaction, with nearly 80-percent of the people saying that the quality of care is excellent, is when you die at home with hospice services. When you die in a nursing home, that’s down to just under below 50-percent, which is quite low when you think that the majority of people on satisfaction surveys always respond excellent.

I think one of the other messages I want you to remember today is both federal and state policy impact on how access to hospice service. As many states are trying to control the Medicaid spending, they're changing how their dealing with this through case mets. And that those changes that are occurring, are resulting in decreasing the access to hospice services.

So, this is one of those slides that only a health services researcher would put up there and expect you within three minutes to get a very difficult concept. But it's an important concept and it goes to the fact that we have two predominant insurers for people in long-term care, Medicare and Medicaid. So what this is resulted in is this very picture, and this is brand-new data, it's less than 36 hours old [laughter] because we want to make sure you had nothing but the freshest data here. On the average, a nursing home resident experiences 3.3 transitions per person in the last six months of life. In some locations, for those of you who live in the deep South, it's 5.5 transitions in those last six months of life. Now, the top graph is documenting the variation in those transitions across end of life for people who had to stay in a nursing home while dying.

The bottom graph is the rate of insertion of feeding tubes among people with severe dementia. There's very good evidence that a feeding tube does not improve the quality of life, does not prevent aspiration pneumonia, does not improve functioning, does not heal decubitus ulcers. This is based on

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six authoritative reviews of literature. Yet, if you're a person with severe dementia and you're residing in the top quintile and in a region where it has the highest quintile of transitions, you're 2.5 times more likely to have a feeding tube inserted even after we adjust for evidence of patient preferences. So, the bottom line is geography is destiny and this all goes back to how we're funding our health care system and how we're dealing with nursing home reimbursement for Medicaid.

And my final point, leaving almost two minutes, which I'll give to Diane [laughter]. My point to you is as we innovate, and as we change policies and incentives for this population, we should not forget who these people are. This is one of my patients with severe dementia, who's almost becoming hospice-eligible, who spends majority of her day playing with an object that you would expect a baby to play with. This is a vulnerable population. As we innovate, we must protect this vulnerable population. We can make changes in the health care system, but it's equally important that we remember that this is a vulnerable population that deserves adequate protection while we're innovating. Thank you very much for your attention this afternoon.

[Applause]

ED HOWARD: Thank you, Joan. And I should say that those data were recent enough that they didn't get onto the version that we produces and put into your packets but it will be on the website probably later in the day and you can get that last slide.

Next we're going to hear from Dr. Diane Meier, who is the director of the Center to Advanced Cognitive Care, which is a national organization devoted to increasing the number and quality of palliative care programs in the United States. Dr. Meier is also the director of the Lillian and Benjamin Hertzberg Palliative Care Institute, and she's on the faculty of Mount Sinai, and she has a particularly insightful view of policy issues related to deliver of palliative care in hospitals. Diane, thanks for being with us.

DIANE MEIER, M.D.: Thank you and thanks very much to the Alliance and to the Robert Wood Johnson Foundation for convening us for this really critical discussion.

My charge today was to talk about palliative care in hospitals, and in 10 minutes I'm going to try to define what palliative care is; how it is similar and different from hospice; third, what we know about the impact of palliative care services on both quality and costs of care; and fourth, what I think the policy priorities are for us as a nation.

So to begin with, what is the definition of palliative care? And this is the currently accepted definition by consensus of all the major national palliative care and hospice organizations in the country. Palliative care is the medical specialty focused on preventing and relieving suffering and improving the quality of life for people facing serious illness. And you will note in that definition that it does not say anything about prognosis, it does not say anything about having to be labeled as dying, or dying in six months. It does not say anything about having to give up regular Medicare or other insurance coverage in order to access palliative care.

How does palliative care differ from hospice care then? Hospice care is a delivery model for palliative care for patients who are felt to be within the last six months of life, and for those who are willing to give up regular insurance coverage for other types of medical care. Non-hospice palliative care is appropriate at any point in a serious illness, from a point of diagnosis through treatment, treatment focused on cure, treatment focused on life prolongation, treatment focused on living with a chronic illness for 10 or more years, as well as treatment at the end of life. So it’s a much broader framework for palliative care than that provided under the Medicare hospice benefit.

So this is the conceptual shift from how medical care used to be delivered in this country where we give only life-prolonging care until someday, a light bulb goes off and we say, “Okay, today life-prolonging care, tomorrow hospice.”

As if somehow the patient changed in some dramatic way between Monday and Tuesday.

And what's missing on this slide, I apologize, is the bereavement support that hospice provides after death. But the current model that is rapidly developing in the United States for palliative care is the simultaneous care model where, from the point of diagnosis for a serious illness, patients receive both palliative care and life prolonging care. With the nature and the extent of those two therapies vary depending on the needs of the patient. But it's better in PowerPoint. This would be a sideway, not a straight line, because people go in and out of the hospital, they're stable for a period of time, they're getting mostly chronic care management, palliative care, then they get acutely ill, rushed to the hospital for rescue medicine, which works a lot of the time and returns people back to their prior setting. But as the disease progresses and people get sicker, life-prolonging treatment becomes a) more burdensome and b) less effective. And as that occurs, it's time to transition to a more predominant palliative care model and to hospice care when people are no longer benefitting from life-prolonging care.

So the three domains of focus of palliative care are physical and emotional and spiritual distress, a, b, the improvement in patient professional and inter-professional

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communication about the goals of care and a plan of care that actually supports those goals, and third, as Joan pointed out, the transition. The disaster of the transition and trying to make those transitions safe and effective and essentially invisible to the patient and family.

What data do we have on outcomes of palliative care? There are now number studies, both outside of this country and in the United States demonstrating the same thing that pain and other symptoms are reduced both with hospice and non-hospice palliative care, that satisfaction is improved and Joan has done a lot of the research doing that, demonstrating improved patient and family satisfaction, and also demonstrating in single sites studies, substantial, dramatic reduction in hospital costs in patients and families receiving palliative care. The data I'm showing you now is also very recent data, it has been presented at a national meeting, it is still under peer review. This is the sixth hospital study. I'm not going to go through every line of it but you can see, particularly if you look over on the right at hospital deaths, these are populations of patients who all died in the hospital and we're comparing those who died in the hospital with palliative care to those who died in the hospital without palliative care, and there are incredibly dramatic reductions in costs of people who were all in the hospital, all had the same outcome. The only difference is, did they or did they not receive palliative care? And the reduction of costs is not trivial, it’s substantial. And I think that has major policy implications.

And this is another picture looking at the same data. The top red line is patients who died in the hospital without palliative care, and you can see that as they get closer to their death their costs go up before death. We move people who are actively dying to the ICU, and we do lots of aggressive things that turn out not to be beneficial. That’s standard care. The other curves are patients who receive palliative care at varying points in their hospital stay. And at virtually every point at which a patient receives palliative care, within 48 hours costs drop dramatically. So it’s clearly related temporally to the introduction of palliative care consult. The later you get it, the later costs go down. The earlier you get it, the earlier costs go down. The data are actually strikingly consistent about the impact. This is eight hospitals in the United States, all of which have matured high volumes palliative care programs.

So, what’s the good news? Well, and *The Wall Street Journal* put this on their front page, that palliative care was a way to save money while improving quality a couple of years ago. What’s the good news in all of this? The number of hospital palliative care programs has more than doubled in the last five years, now 30-percent of U.S. hospitals report a program on the AHA national survey. If you look at hospitals with more than 100 beds, 75-percent of hospitals report a program. And that's where most patients receive their care, in larger hospitals. You can find a palliative care program near you if you go to get palliativecare.org. Every hospital in the country that reported a program can be found on our Web site.

What's the bad news? Appallingly little research on this area of medical care. Four IOM reports, two NIH State of the Science Conferences, all called for a major national investment in research in palliative care. The main barrier is lack of funding, less than 0.1-percent, not 1-percent, 0.1-percent of the entire NIH budget goes towards research that is focused on the relief of suffering and better care models for the seriously ill. As a result, because you can't get funded, we don't have investigators, we don't have data, we don't have the evidence base that would enable us to provide the highest quality of care to this most vulnerable populations.

Why does research matter? A) it provides the critical evidence base to guide quality of care, that's why Joan's and others work has been so crucial for those of us who are actually trying to take care of this patient population. And also, importantly, without research there is no place at the table in the nation's medical schools. If you are not conducting NIH-funded research, you do not have a place at the table at an American Medical School. What’s the consequence of that? Medical students or nursing students, social work students get zero training in palliative care. You wonder why your doctor doesn’t know how to manage pain? I’ll tell you, there was no faculty member in his or her medical school that could teach it, it was not taught. So, research is inextricably bound to academic medicine to teaching hospitals to the curriculum. Failure to invest in research is failure to invest in medical education, is failure to invest in quality of care for those patients in greatest need.

What can we do from a policy standpoint to improve this situation? I think there are two kinds of supportive policies that we need, the first improve access to palliative care, the second, improve quality of that care. So access involves work force. Do we have doctors, do we have nurses, do we have social workers who want to do this, who can make a living doing this, who can repay their loans doing this, and do we have incentives that drive hospitals, nursing homes, and community settings to deliver this kind of care? No, we do not. We need incentives. Policy can help with that. Secondly, to assure quality of care, we need to populate every medical school and every teaching hospital, and every nursing school, and every social work school with faculty who

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can teach this stuff. That also is a policy issue. We need to create legislation that supports fellowship training in palliative care. If we don't have people sub-specializing in palliative care we will not have faculty teaching it, we will not have researchers.

So, the policies for access, I think, are financial incentives. That is, payment incentives, loan repayment incentives for doctors and nurses, financial incentives to hospitals. Norway has a really interesting model. They pay hospitals on a DRG basis, but they pay hospitals, they pay a higher DRG if the patient gets palliative care. Not lower, higher, because they know they save a lot of money by incenting the delivery of palliative care. So they have DRGs just like us, but they know how to drive hospital behavior using financial incentives.

And lastly, and we're working with the Joint Commission on this, working towards an accreditation requirement, not only for hospitals, but also for nursing homes where these vulnerable people are that you can't get accredited if you don't have a program that meets certain quality standards.

What policies would improve quality of care? I would say number one, two and three is funding research. In Canada, every institute, research institute in Canada, cancer, heart and lung, neurology, are mandated to put a certain fraction of their budget, their annual budget, into palliative care research within their disease sphere. Canada, a tiny county with a very small budget, is heads and shoulders ahead of us in the quality and quantity of their research and their researchers in this field. Because their legislator said this is a priority, and we’re going to assure that it happens.

The Palliative Care Training Act was introduced in 2005 by Senator Wyden, and we are seeking its reintroduction. What this does is provide career development support for young faculty and medical schools. So again, so every medical school and teaching hospital is populated by experts in this field so that the next generation gets trained and the research gets done. And last but not least, a post-graduate medical education is under a cap. So each hospital has a fixed limit on the number of residence and fellows it can train. Right now, palliative medicine is an ACGME and ABMS approved sub-specialty, but I can’t get money from my hospital for training because to do so they would have to take it away from cardiology. Cardiology is the remunerative specialty in my hospital. Palliative care is not the remunerative specialty. So it’s great to have ACGME and AMBS approval, but it is meaningless unless we have some power to influence access to slots under the cap. Thank you.

[Applause]

ED HOWARD: Thank you, Diane. Dr. Brad Stuart is a general internist. He’s the senior medical director of Sutter VNA, Visiting Nurse Association, and Hospice, an organization that provides homecare and hospice services through most of northern California. He was just, by the way, voted Physician of the Year by the California State Homecare Organization. And we’re looking to him to talk a little bit about home based care involving both the Medicare Hospice benefit and the home care benefit, and the coordination of care across those settings in the context of end of life and palliative care. Brad, thank you for getting on a plane and coming a long way to share your expertise with us.

BRAD STUART, M.D.: Well, I really appreciate being here. It’s a privilege. We’re a far distance away from Senator Collins, in northern California, but I think we’re on the very same page about care.

I want to start with a story that I just heard yesterday from my friend, Nancy, who’s an attorney. Her father was 97, had cancer, lived in a nursing home very comfortably, was still being treated for cancer despite the fact that it was very advanced. He could not get onto hospice because you can’t get onto hospice when you’re still getting treatment. We’ll get into that a bit in a second. He fell and broke his hip, and went to the hospital despite the fact that he had an advanced directive stating that he didn't want hospitalization. His hip was repaired, but as happens to many 97-year-olds with cancer, he survived the surgery but he spent two weeks in the hospital with a long ICU stay before dying prior to discharge. When Nancy, who's a very vocal attorney, went to her doctor and said, "Why did you operate on my dad?" The doctor said, "He had a broken hip." Now, if her dad had been on hospice, at least at our place, that never would have happened. We could have kept him where he was, kept him comfortable, it's relatively simple to do, his disease was already very advanced, but there was no way that he could get on hospice. And I want to get into why that is.

Hospice, we've talked about it quite a bit, it's gold standard comfort care for patients and families, 76-percent nationwide of deaths in hospice occur where the patient lives, the patient doesn't go back to the hospital. Consequently, it's pretty sure that hospice saves money. We need better research on that. When you're speaking about hospice, you're talking about Medicare, 82-percent of patients who die in hospice are covered by the Medicare benefit, there's a little bit of private insurance in there but we're talking about people who are old and ill, and we're talking Medicare, and we need changes in Medicare regulations for hospice, and as I'll mention in a second, home care as well.

Hospice is not utilized to anywhere near the extent that it ought to be. Over two-thirds of patients never get to hospice, most of the ones that don't may never even hear about it. We're doing very well in cancer because hospice was designed for cancer, almost 60-percent now of cancer deaths happen in hospice. Heart failure, which is the commonest cause of hospital admission and readmission in this country, 12-percent of those deaths occur in hospice, and it's much tougher territory in heart failure for reasons that we'll discuss in a second.

The worst problem though, is that patients come into hospice very late. Medium survival, in other words, the point at which 50-percent of patients die, is according to an HPCO figures, 26 days. I believe that's high. Other sources talk about more like three weeks. Half the patients who come into hospice die in less than three weeks. A quarter of them die in less than seven days, and now about 10-percent of our hospice patients are dying in less than 24 hours. Not adequate for hospice.

The barriers to hospice are pretty simple to explain, although the concepts underlying them are complex. I believe the chief barrier is what you might refer to as the terrible choice. Patients are required by law to sign away their

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right to Medicare reimbursement for curative treatment, although most of the diseases we’re talking about don’t have a cure, you can’t get medical treatment and also get hospice. Not possible to do. We need to look at changing that, and I’ll have a specific proposal at the end for how we might approach it. Because patients have to sign away their right to treatment, many patients say no to hospice, and if they do come into hospice and are treated, hospice has to pay for it. And so most hospices will say no as well. The six-month rule is also an impediment but I don’t believe it’s as serious. Honestly, we’re using so little of the six months already. But you have to have a doctor sign a statement that you’re going to die in six months or less, and a lot of doctors don’t want to do that because prognostic uncertainty is a terrible problem. In some cancers, it’s relatively easier to prognose, but in heart failure, lung disease, and all the rest of the non-cancer disease it’s much more difficult to tell. Patients look in research two days before their dying, the same exact way they do six months prior to death, it’s very tough to say. And of course, nobody wants to talk about dying. And you’ve got to talk about dying if you’re going to talk about hospice.

I want to mention home care because I feel, and I think our research may begin to show that we have another tool here that can get patients ready for hospice, and get more patients into hospice, and that's home care. Home care is a separate Medicare benefit, regulated completely separately, reimbursed separately, terrible fragmentation here. Of the goals of home care are recovery and patient safety, doesn't sound much like getting people ready for hospice. You need to be homebound, meaning you can't get out of your home except to go to the doctor and maybe church, otherwise you can't get home care. And you need to have skilled needs and when they run out, you have to be discharged. We might consider changing some of those for a specific variable population as well.

Perspective payment system, instituted in the year 2000, just like DRGs did in hospitals forced patients to be discharged quicker and sicker from home care. And PPS really reimburses real well for people with broken hips who need physical therapy and terribly for heart failure, lung disease, chronic illness, terribly payments for the people, we need to follow in home care in order to continue them into hospice.

I just want to show a little bit of data from MedPack. From 1997 to 2002, in the middle of which time PPS was instituted, average home care visits per two-month episode were cut about in half. Length of stay went way down, again by about in half, therapy visits multiplied, because now all home care agencies want to get patients who

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they can give therapy and get better. And so doing what I'm about to describe has become much more difficult the last few years. The Medicare reimbursement system is kind of like - I wasn't going to say this but I think I will anyway - it's like the brontosaurus with the one brain in the head and the other brain in the tail and nobody talks to anybody else. All of the silos in Medicare are reimbursed and regulated entirely differently, and literally nobody talks to anybody else. The dollar signs I put up there just because they reflect relatively what proportion of Medicare reimbursement goes to each of these silos. Hospice there gets about 2-percent of the Medicare budget, home care about 3-percent, hospitals, there are $40 dollar signs there, in case you don't feel like counting them. For heart failure, there should be 75-, 75-percent of Medicare reimbursement for the biggest diagnosis in terms of hospitalization. Re-hospitalization, 75-percent goes to hospital care. Why? Because patients cycle in and out of the hospital, especially in the last year of their lives.

What we've tried to do at our place is, you'll see a little arrow there with in-program in the middle, we started a program with in homecare that I'll describe a little bit more in a second, that really helps transition patients into hospice through education and some other ways of opening up the hospice idea to try to get higher rates of hospice enrollment. You notice I also put Dr. Meier’s topic, inpatient palliative care within the hospital, and I should have put Joan’s nursing home area either in or all around hospice because hospice works a lot in nursing homes. All the things we’re talking about here ought to be configured into a continuum of care, and regulations ought to be changed so that we can manage these people in a more continuous way. Because right now, the cracks that you see between those boxes, patient are falling into by the hundreds of thousands. We can do much better.

I just want to describe the program that we are doing at a loss financially, I’ve had to fight for eight years with the CFO to keep doing this. Program based in home care uses both home care and hospice staff really to plant the seeds in patients and families minds about hospice. We pick patients who are very ill, and have disease that’s advancing, chronic illness. We encourage hospice, we give patients completely free choice of where they want to go, they can go back to the hospital if they want to, they can stay home, all we do is give them education about all their options and we do it again and again and again because repetition is the key to adult learning. [Laughter] We need grants to do this because we don’t have enough money for Medicare to do it. We don’t have the three dollar signs by hospice, and the four dollar signs by home care that would allow us to do this.

But here’s what we’ve been able to accomplish, and I need to call to your attention that in your handout, the data is unpublished data that I should not have stuck in there. This is the data that’s in the paper that’s referenced at the bottom of the slide, so you really should replace what’s in your handout with what’s on the screen. The controls in the right-hand column are home care patients who didn’t get any of the AIM educational intervention in their homes. The AIM column to the left of that are the patients, the proportion of patients who we were able to get from homecare into hospice. So you can look at it as the level of acceptance of hospice. And you notice I stratified it into overall rates of hospice acceptance, and rates of African-Americans because African-Americans are notoriously reluctant to accept hospice. It feels like denial of care, and you know what? It is. You can’t go back to the hospital or get treatment once you get hospice. People don’t like that. Particularly certain racial and ethnic groups don’t like that.

We were able to go from about 20-percent acceptance of hospice in the control column overall, up to 47-percent once we did AIM. And the lower 14-percent of African-American families who accepted hospice went up to rates that were virtually identical with Caucasians once they got education. It turns out that if you talk with people and

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make treatment available along with comfort, care and education, the racial and ethnic disparities tend to go away.

So, this is a simple recommendation because I’m basing it on HR1078, which is now on the floor of the House, it’s sponsored by CAPS, it’s got 40 or so, a few more co-sponsors. This is a bill that we helped write with the National Coalition for Cancer Survivorship. I’m on their board and it’s really a cancer bill, but we, I want to call your attention to section two, and if you can get a hold of the bill, take a look at it because it runs out in some detail how [inaudible] demonstration that would take away the hospice restriction on getting treatment and getting hospice. And also, you should know that AETNA and United Healthcare have already taken this restriction away from their commercial patients, Medicare should consider doing the same, not for everybody but for a defined population for whom this kind of intervention would help. I would include in this also changing the home care regulations to allow us to follow patients, even after their skilled needs go away, as long as their nearly ready for hospice. And you can put together a system that would work far better than the one we now have. Thanks very much.

[Applause]

ED HOWARD: Thanks very much, Brad Stuart. Our final panelist is Steve McConnell, who is the vice president for

Advocacy and Public Policy at the Alzheimer's Association. In addition to his public policy role, he's directed the association's program services division, he was the interim president and CEO for a while. He's also been the staff director, as I may have mentioned, at the Senate Agent Committee. Steve's going to focus on the patients with Alzheimer's and other dementias and the policy issues affecting the quality care at the end of life for this very substantial population. Steve, thanks for being with us. Senator Collins was very happy to have you with us today.

STEVE MCCONNELL: Thank you, Ed. Well, I appreciate Senator Collins' leadership, along with Senator Lincoln. I'll talk about a bill that they sponsored. But I want to acknowledge Ed and the Alliance. Ed really is the leading expert, as far as I'm concerned, on health care policy and the Alliance has done such great work. So we appreciate that. He's been a mentor and a friend for many years. I was going to say he's forgotten more than most of us have learned, but in my organization, we're careful about talking about that. [Laughter] But I also want to thank the Robert Wood Johnson Foundation, acknowledge my colleague, Jane Tilli [misspelled?], who is an expert, much more than I, on end-of-life care.

I wanted to - this is really talking about a specific case, people with dementia and Alzheimer's disease, and end-of-life palliative care needs. Just to point out that there are now five million people with Alzheimer’s disease, and a large proportion, a larger proportion than we ever thought before, are under age 65. Every 72 seconds, somebody develops Alzheimer’s disease. And if you look at them in the future, right now there about 425,000 new cases of Alzheimer’s each year, you can see by the middle of the century that will be a million new cases of Alzheimer’s annually.

As Senator Collins mentioned, Alzheimer’s disease is the seventh leading cause of death among the entire population, fifth leading cause among people over 65. And this chart, I think, is particularly interesting because the latest statistics from the CDC on death attributed to various diseases is 2004. We looked at the trends from 2000 to 2004 among several conditions, and you can see that deaths attributed to Alzheimer’s disease are up 33-percent, that’s the yellow bar, but look what’s happening, deaths attributed to heart disease, down 8-percent, breast cancer down 2.6-percent, prostate cancer down 6-percent, and stroke down 10.4-percent. So those are successes in the sense that we’re managing those diseases only to allow people to live longer, so they can face Alzheimer’s disease, that increasingly is the future.

People with Alzheimer’s disease don’t just have Alzheimer’s or dementia. About a third of them have coronary heart disease, almost a third have congestive heart failure, diabetes, COPD. So it's a population with very complex medical needs and it's an underlying issue in all of their care that is frequently overlooked in the health care system. By way of example, if you take diabetes, people with diabetes, the total cost for people with diabetes and without dementia is about $8,000 dollars, but if you add dementia, that's the tall bar there, it increases dramatically. So it's the presence of dementia that complicates the care for other underlying conditions. Imagine somebody going in and getting diagnosed. If they don't have dementia, they follow the regimen. If they do, they go home and end up back in the emergency room because that regimen is forgotten. The same with congestive heart failure, you can see the dramatically higher costs when you add dementia.

So I wanted to talk briefly about what are the conditions that are unique to people with dementia and Alzheimer's that make palliative care, hospice care, good end-of-life care, so important. One, dementia leads to complete dependence. That's something I think many people overlook in this country, that somehow it's a memory problem. But in fact, incontinence, inability to swallow, all those things result as dementia progresses into the later stages, and eventually dementia will kill you. Second, the individual's ability to make decisions and have control, communicate those decisions, have control over the end of life, is complicated. If you have cancer, other physical ailments, you frequently can maintain that. With dementia, you lose that. And if you don't have an advanced directive, then somebody has to make those decisions for you. Third, many families, providers and professionals do not understand the progression and severity of dementia. So our - we don't have well-trained professionals, many families don't understand how this disease progresses, how severe and serious it is, and as a result, people frequently get poor health care. And finally, dementia, when you look at caregiving, the experience of caregiving, people who are caregivers for a person with dementia have more serious health problems, are much more likely to die prematurely than caregivers of people with other conditions. So this is a problem for caregiving in general.

So to talk about, I skipped over slightly, so in the end-of-life setting, this is a statistic that I still have a hard time processing, but 67-percent of dementia-related deaths occur in nursing homes. The statistics that Joan talked about where those numbers are increasing, you can see that if you have dementia, you're even more likely to end up dying in a nursing home. The notion that's been talked abou, about frequent transfers between nursing homes and hospitals, is a huge issue. And hospice has been historically underutilized for a variety of reasons I'll talk about, but you can see the trends over the last five years that 6.3-percent of hospice, with an average length of 44.9 days in 2000 rising to 9.5-percent average length of stay of 72.4 days. Now, you can imagine what's happening as a result of those statistics. CMS is getting real nervous, so we'll come back to that issue in a minute.

So let's talk about four barriers and some solutions. First of all, the barrier of ineffective management of dementia care, the fact that there are inappropriate transfers. Some of this is because of the incentives that are built into the system. The person transfers to the hospital and stays there three days, they then qualify for a skilled nursing facility benefit, and that perverts the system. There are other bed hold issues that contribute to inappropriate transfers. Again, imagine a person with dementia being transferred from any setting to another is hugely complicated. It frequently leads to additional healthcare problems because of their disorientation.

Inadequate physician payment for time required. You've got to deal with somebody that's very difficult to communicate with, you've got to frequently deal with the family and the caregivers, and because of their multiple conditions, complex care, it just takes more time and physicians are not paid for that.

Third, aggressive interventions are frequently the case, you figure, when in doubt throw the book at the person. That’s what often happens in the health care setting when the individual can’t communicate their desire not to have more aggressive treatment. The health care system frequently errs on the side of give them full treatment.

And finally, diagnosis and orders do not follow the person’s problem. That is true for most people, but it’s especially problematic for people with dementia.

So the solution is we need appropriate physician office payment for assessment of chronic care, management, I think, is also been mentioned, appropriate hospital payments to cover the costs and the time and the complexity for caring for somebody with Alzheimer’s dementia.

Second barrier is inadequate access to palliative care. The hospice medical eligibility criteria of six months to death is very complicated to determine. And it’s interesting - the hospice benefit really was designed for people with cancer. And if you look at it, there’s a study recently published, I’m sorry I don’t have the slide, that shows people with cancer and other organ failure problems function at a sort of mid-level of dependency until the last three to six months when they fall off a cliff. So it makes sense to define the hospice benefit in terms of people that sort of hit that cliff. But you compare them to people with dementia, for the entire year before death, they're functioning at an extremely low level, and a very high level of dependency. So that argues that the six-months notion does not make sense for this population in particular. So the eligibility criteria and the duration of the benefit are problematic, need alternative hospice medical eligibility and palliative care benefit.

CMS concern, as I said, because of the increased use, we see that as a victory, that more people are accessing, with dementia, are accessing the hospice benefit. CMS is now investigating this as a problem. Fortunately, they are meeting with us and talking with us, we're asking for all the data that they're looking at. If there is a problem, we'll work with them to solve it, but it is not necessarily a problem that more people are accessing this benefit and accessing it longer. As Brad talked about, that's one of the problems with the hospice benefit now. People get it too little, too late.

And finally, consumers and providers have inadequate knowledge about the progression and terminal nature of dementia. And the solution is more medical training, consumer education, nursing, and nurse aid training. To respond to that, we have actually worked with Senators Collins and Lincoln to develop the Geriatric Assessment Chronic Care Coordination Act, which is not designed just for people needing palliative or end-of-life care, but the idea that we should assess a persons multiple chronic conditions, develop a plan, and pay for that, makes sense. That alone would help in general with people at all stages that have multiple chronic conditions, but also at the end of life. This whole idea of reviewing the use of hospice benefit is something that we should all keep an eye on, and make sure that comes out right. To make sure that we're not just going to cut back on something because of utilization is going up, and it may be very appropriate, in fact we think it is.

State and federal training requirements for people delivering care and services to people with dementia. And dementia care practice care recommendations, which we were actually issuing on end-of-life care in August, and those are designed to provide guidance to people with dementia that are in residential settings. There are a number of other things that have been talked about today that make a lot of sense in terms of supporting research, the Palliative Care Training Act, etcetera, that are important.

And finally, these are in your packet and these are resources, there is in the second bullet, barriers to quality end of life care for people with dementia and residential settings, I think you'll find that many of the issues that have been talked about today are summarized there. And then the end-of-life care for people with dementia and residential

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settings will be - is that on our Web site now, Jane? Or it will be? The first item. Okay. So, go to our Web site and you can find end-of-life care practice issues and there will be more forthcoming. Thank you.

ED HOWARD: Okay, thank you, Steve. [Applause] Let me remind you that there are microphones at various places, you can stand up and ask a question, I encourage you to do that. There are green cards in your packets that you can write a question on and hold up and someone from the staff will bring it forward. And if you have to leave before we finish the Q&A session, don't forget that blue evaluation form.

Now, we have somebody at the microphone, if you would identify yourself and try to ask all your questioners to keep their questions as brief as they can so that we can get-

MALE SPEAKER: Oh, we can talk on and on and on.

ED HOWARD: -get good [inaudible] from our panelists. Yes.

BARBARA MARONE [misspelled?]: I'm Barbara Marone, and I'm with the College of Emergency Physicians, so I was glad to hear you talk about that sort of revolving door into the emergency department. I think, while I agree with you, Dr. Meier, that physicians do need a lot of education on this issue, a lot of our members see this as a huge problem, particularly with this revolving door with the nursing home.

And a lot of it comes back to the family not understanding and the families saying you must save them, you must do something. And I think with the support of Senator Collins and some of the other folks in Congress, it's great, but we need to get this up, this whole expenditure on end-of-life care issue closer to the money people. The Stark Health Committee, the Finance Committee and I was wondering if any of you had any ideas on how to sort of raise this issue up because this is tremendous in terms of overall spending.

BRAD STUART, M.D.: We were talking before we came up here - we were both over at Ways and Means before we came over here. And I don't, you can talk about your experience, I actually had a very, very good talk with the health subcommittee person from Ways and Means. We talked for over an hour and we're probably what was once the children's health insurance an physician cutback issues are handled, which needs to happen now, we'll probably get back together and do some real exploration of some of the things that I was talking about anyway, Diane can talk about her. But, what we want to look at is defining, what I want to look at, is defining a population of very, very ill people. The ones who in the last year of life have seven times the Medicare expenditures of the ones further up the curve, really tackle that population and get some interventions that tie together tools that we already have. We don't have to create new benefits. And tie together what we're doing in hospitals and nursing homes, and create a system. And we may be starting to go down that road.

STEVE MCCONNELL: If I could just - Ed and I worked for Claude Pepper back before there was actually a hospice benefit. And I remember when the debates around that, there was great fear that creating this as a Medicare benefit would run up costs. And when they became convinced, when the government became convinced that it would be possible to do this, at at least cost neutrality, it developed support. There's a bit of a trap in making everything we do be a savings, because I think frequently it costs a little more to deliver good care, and we get better care and more expenditures on one side and we save over here, but the government has a hard time sorting that out. But I think the cost issues are going to be critical to this debate.

ED HOWARD: Let me just follow up if I can, Steve and Brad, in some of the statistics that you displayed showing the increase, or showing the decrease rather in the number of visits in the home care benefit on average, and the number of days, that was, if I'm, if my memory serves, in response to a very large earlier growth in homecare expenditures and visits over the previous four or five years. And now that Congress has pledged fealty to pay as you go, and in light of the fact that we just heard about, from you, about how hard it is to

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identify people who are going to die within six months, how do you identify the kind of sub-population of very sick people to whom you would allow access to a liberalized home care benefit?

BRAD STUART, M.D.: Okay. I don't want to take up a huge amount of time with this, but we found in our program that first we ask the old palliative care eligibility question, of physicians and of home care nurses, because we studied it and 10- to 15-percent of all homecare nurses are carrying in their caseloads 10- to 15-percent of their patients should already be in hospice. So we asked them and doctors, would you be surprised if you patient died in six to 12 months? If the answer is, "Nah, we wouldn't be surprised." Then do they have a burden of disease - this is tough on Alzheimer's, by the way - but do they have a burden of medical disease that shows they are progressing? What is their functional status? Is it low and decreasing? What is their intake? And there actually are algorithms out that, at least in heart failure now, that use those multiple factors plugged into web based algorithms that put out numbers showing prognosis. I think the science of this is, we're not there yet except in heart failure, which is relatively easier. But I think there are ways to pick patients whose disease is advanced enough to benefit from this.

And to add to that, I am willing to go on record to say that I don’t agree with the trade association approach to opening hospice to everybody. I think we have to focus on a benefit that’s defined better than it now is. I think going back to MedPack’s 2006 recommendations for reconfiguring hospice reimbursement would be a great idea. Look at reimbursing hospice more in the first day or two, which is very expensive, and the last day or two, which is very expensive, and go ahead and reduce it in the middle, when it’s not so expensive. I feel that it’s very fair to define the population and to make the reimbursement reasonable, and then study it scientifically and see if we’re preventing hospitalization. One day of hospitalization, that cost would pay for many, many days of the right kind of care at home. And that’s what we need to be focusing on.

ED HOWARD: Very good. Yes, ma’am.

NAOMI NIRELAND [misspelled?]: My name is Naomi Nireland, and I’m with the American Hospice Foundation. I just want to make two comments. While we’re waiting for the laws to be changed and the policies to be improved, I’d like to encourage us to do two things that we can do in the meanwhile. One of them is look at the way the policy is being implemented on the ground in a way that discourages for example Alzheimer’s patients from being admitted to hospice because of the way that the rules are written so that, and the average length of stay is implemented so that hospices have the incentive to admit short-term patients to over, to counteract the long-term patients. And I think what we have now doesn't work as well as it could if it were interpreted better.

And secondly, we know what, we're beginning to see, to measure, what quality end-of-life care looks like, thanks to Joan Teno's work and others'. And I would like to encourage the reporting out, the sharing of that information to the public, to payers, to policy makers so that improvement happens as we measure it. We know that happens in other industries, hospitals, home health agencies, and the rest, can we now move the field forward with respect to quality of care by measuring and reporting out so that we can have an integrated process of quality improvement. Thank you. Joan, you might want to add to that, I don't know.

ED HOWARD: Anybody else? We have an unusually large number of questions that have been submitted on cards, let me just start with the one that came in on top. Can you speak to the adequacy of the work force, both in numbers and in competencies? Diane, why don't you start? To deliver hospice or palliative care.

DIANE MEIER, M.D.: Yeah, the work force is inadequate. Highly inadequate. And there, you can't lump this, you have to split it by discipline. Within medicine, most people graduating from medical school have an average of between $150 and $200,000 dollars in debt. So, even if they wanted to enter a primary care specialty, like geriatrics, like general internal medicine, like family medicine, like palliative medicine, they would have to be independently wealthy to do so. Or they would have to get a job salaried within say a hospice, or teaching hospital. But you can't go into practice and make a living in those specialties and even hope to get married, have a family, buy a house, send your kids to college. So that is a policy fix, clearly. The best and the brightest go into cardiology, surgery, GI, ophthalmology, plastic surgery: follow the money. It's not because they don't care about patients. They want to make a living wage after nine years of post-college education. That's okay, that's reasonable. But you can't expect everyone to be self-sacrificing.

As one of our graduates said to us the other day, "Well, I admire Mother Teresa, but I don't want to be her." And that's what or current environment is asking doctors to do if we enter these fields. And that's obviously a non-starter.

For nursing, the issue is, I mean, lots of people want to become nurses, they can't get into nursing school. Why? Because nursing schools are not adequately staffed, they don't have enough faculty, faculty aren't paid enough.

Nurse practitioners' schools, it's even more competitive than medical school at this point. I mean, we have a desperate need for nurses. The bottleneck is so narrow, that's fixable at a policy level, and has to be done. It's not that there aren't people who want to do this work. There are, they can't get into school. They can't get trained.

So, the work force analyses have been done by Ed Salsberg for palliative care and we actually have a report on that, and just as in geriatrics, we're absurdly underprepared for the societal pressures to meet the needs of seriously ill, chronically ill older people from a work force standpoint.

ED HOWARD: Steve, you want to add?

STEVE MCCONNELL: Yeah, I think it's important too, that, I agree with all that, that there is the consumer side of this. If there is consumer demand, that will help drive reimbursement, training, and a variety of other things. And there was an interesting study done looking at people that had come to a couple of medical clinics asking them what kind of care they would like. And about half of them said they would want comfort care - this is care at the late stages of dementia - about half said they wanted comfort care and a quarter said they wanted extensive care, and some of them didn't know. They were then shown a very brief video, which I tried to get for you all but I couldn't get rights to it, that showed a person in advanced stages of dementia, about a two-minute video. And after watching that video, 80-percent said they wanted comfort care because they saw that it made no sense to aggressively treat somebody in the advanced stages of dementia.

So part of this is educating the consumer so that they demand a palliative care of good end of life care, and some things will follow from that. And the interesting thing to is there was no difference by ethnicity, as we frequently worry about people, minority groups and so forth being concerned about losing access to care, that somehow palliative care, hospice, is about cutting them off from certain care. But after seeing a video, a simple educational program, there was not differences by ethnicity.

ED HOWARD: Brad?

BRAD STUART, M.D.: I just want to add very quickly, I saw that same study and the striking thing that I want to accent while you say, is this is another intervention that resolved the racial and ethnic disparities for comfort care that we often see because we think of it as the doctor has to talk to the patient, the family, and convince them of something in one office visit. A video intervention like this, or seeing people in the home and educating them, seems to allow for better education and acceptance of things that

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look difficult when we do them the old way. So we need to do more of that kind of thing.

ED HOWARD: Let me just go back to the original question about work force, because there's another question that takes up the same notion. If the pipeline is clogged, if you will, and there are some disincentives to getting a lot of new people into the professions with this kind of expertise, this questioner wonders whether we shouldn't turn in the interim to continuing education for existing providers. He happens to be a pharmacist, it looks like, and says that he hasn't seen many offerings to take advantage of that kind of education in his profession. I wonder if that's something that has been explored or deserves a little more juice. Joan?

JOAN TENO, M.D.: I think it's had the opportunity to work in Rhode Island and tried to improve pain management in all nursing homes in Rhode Island, and one of the key lessons we learned is education is an important part of the solution, but not sufficient. You must do multifaceted interventions to improve end-of-life care. So, while we did a lot of education, it was as important to change the regulations that were acting as barriers to getting opiates into nursing homes. So a very simple thing that we were able to work with our state legislature to do is to make it permissible for a physician to fax an opiate prescription from the nursing home, rather than having to have someone hand-deliver an opiate prescription, and that removed an important barrier to providing opiates in the nursing home. So I think really the important lesson is the health care system needs multifaceted interventions that remove barriers from regulatory, that enhance education and knowledge and skills and create almost sort of pathways for people to do the right thing at the right time.

DIANE MEIER, M.D.: That said, as Joan said, education is part of the solution, as for people who are already out in practice, of all disciplines. And actually there are a lot of great educational resources thanks to a many-year investment by the Robert Wood Johnson Foundation, by the National Hospice and Palliative Care Organization, there are online courses, there are two-and-a-half-day intensive immersion courses. These things can all be found on CAPCs Web site and on the NAPCO Web site. There are a lot of resources out there to teach yourself or to go and be taught by others.

ED HOWARD: Question for Joan Teno, at least initially. How can we reconcile human end-of-life care in nursing homes with regulations that make deaths in nursing homes suspect?

JOAN TENO, M.D.: That’s really a tough question. In one Southern state, if you die in a nursing home, it’s treated as a homicide investigation, so it's not surprising that all the deaths in that state virtually are in hospitals. So, I think one of the things we have to look at is with the implementation of perspective payment in hospitals, we now are discharging people quicker and sicker to the nursing home setting, and that setting is often become the place of care and the site of death for these people.

We now need to have regulations to now deal with the fact that people are now dying in nursing homes. For example, often many people who are dying of advanced stages of dementia have weight loss. That's not a bad thing because that's part of the terminal disease trajectory where people have difficulty with the ability to swallow.

I think one thing that I also want to echo that Steve said so eloquently, but want you to remember, is the fact that we have an increasing number of dementia people on hospice is a good thing. Okay. You may see rising health care costs in this one part of the hospice benefit, but also hospice reduces this whole churning of this going back and forth between acute care hospital and that is controlling healthcare costs in terms of terminal hospitalization for people with dementia.

STEVE MCCONNELL: I just wanted to mention one of the things, I wasn't aware of the statistic that when people are transferred, that statistic that Joan showed, transferred more frequently, they are two and a half times more likely to get a feeding tube. There's a lot of evidence that the use of a feeding tube in late stage dementia is actually abusive. It does not contribute to better health care, and think about the additional costs, prolongation of life and other kinds of things. So that's just another specific example of how if you can prevent that transfer in the first place through hospice palliative care, you can save on other medical problems and expenses.

ED HOWARD: Okay. Questioner asks, since Medicare Advantage plans have the financing and care flexibility that they do, are there any particularly good ideas that surfaced that should be used in traditional Medicare? And I presume, Brad, that some of the flexibility is what allows you to do what you do in the AIM program.

BRAD STUART, M.D.: Well, yes and no. Medicare, those of you who have been around for a few years remember Medicare Plus Choice, which was real capitation for Medicare. And that's, in fact, when we got our first Robert Wood Johnson Grant in 1998, as part of their Excellence End of Life Care Initiative, that started the whole ball rolling for us. We did our intervention something like AIM in Medicare Plus Choice. But that's not the real world, that's - at least it's not Medicare fee-for-service. In that world, you can do whatever you want. There aren't the same kinds of regulations because you get your capitation payment per member per month for all the people that you see and you can kind of make up what you want to do. The regulations that need to be changed are in Medicare fee-for-service because Medicare Advantage is gone on fairly well, but where the money is and where the patients are is in Medicare fee for service. And that's where I believe the home care regulations and the hospice regulations and some of the other Medicare fee-for-service regulations need to be tinkered with for patients with far advanced illness, so that we can get better outcomes.

STEVE MCCONELL: I would just add that I totally agree with that, but there are examples of pace and other kinds of things where you're really integrating Medicare and Medicaid payments that you reduce the incentives for some of this inappropriate healthcare. The VA may be another example, but the reality is that most people are on fee for service, we've got to make that work.

ED HOWARD: Several panelists noted, the questioner writes, that the payment criterion for Medicare reimbursement for hospice was six months, and largely based on evidence from patients with cancer. In reforming this payment criterion, would any of you recommend a hospice payment time period based on a patient's primary diagnosis, or some other criterion? And is the notion of a time period rational and coherent at all? That last part is not the question.

STEVE MCCONNELL: The most challenging, or one of the most challenging, is people with Alzheimer's and dementia, and what we're seeing is people diagnosed earlier and earlier who are functioning quite well. So I think the diagnosis would be very tricky to use that and we've tried to find ways to improve the eligibility criteria, it's just very difficult. So I'm not sure diagnosis makes a lot of sense.

BRAD STUART, M.D.: I was the - I had the notoriety of being the primary author of the non-cancer guidelines for hospice that were adopted by what was then HICFA, now CMS. And I was crucified by my friends in hospice because it made it more difficult to get certain patients into hospice. But I would do it again, not for hospice. I don't believe that the six-month rule is the primary problem. I have to say though that I think in Alzheimer's, it makes it very difficult because Alzheimer's goes, has such a long inexorable, gruesomely difficult course. We've got, I think, to almost treat Alzheimer's a little separately. But for hospice as it's not constituted, I don't know if it's a bad thing to have hospice come in towards the end of a patient's life. Now, 24 hours or one week, come on, that's ridiculous. The financial data I'm most familiar with, I think were from the late '80s, early '90s, show that Medicare, CMS breaks even at something over two months of hospice. If you're on much longer than that, then per diem hospice payments total more than a couple one or two terminal hospitalizations. But under two months, it's found money for patients to be in hospice because they stay out of the hospital and you're trading expensive hospital days for a month or two of hospice. I kind of think that's a good thing.

What I think needs to be tinkered with is this terrible choice that people are confronted with that makes them refuse hospice, which means they have to give up their chemo, give up all their treatment in order to get into hospice. We've got to be like Aetna and United Health just did, and allow people to have both. And I want to see Aetna's numbers because I know they're not just doing it out of the goodness of their heart, they're saving money too, and so would we.

DIANE MEIER, M.D.: I guess I want to say that one of the problems with all these policies predicated on prognosis is that it's a false platform for developing policy. We cannot predict when people are going to die and if we force doctors and patients to identify patients as dying, it's not going to happen. So we need to get over that and talk about complexity and need. We need to identify who are high users, who have high-risk diagnoses, who's been in the ED or hospital more than once in the last six months, and focus our care on them whether they're going to live 10 years or 10 days because those are the very high costs, high burden of illness patients. It should not be based on prognosis, because that's, we've learned the difficulties of that, let's not repeat that error.

ED HOWARD: If you'll permit a non-expert to get into this, Joan Lynn, who has appeared on a number of these programs and is one of the recognized experts on hospice and end of life care, showed a slide at a meeting I attended a couple of years ago, to the effect that the day before people died, 50-percent of them had a prognosis of six months or more to live. It does make it difficult to make that kind of a judgment, doesn't it? Perhaps even-

BRAD STUART, M.D.: I actually referred to that in my 10 minutes, it really, what it said was that even for patients in the hospital who clearly were ready to die and were very ill, and in fact did die in two days, flipping a coin would have been as accurate in predicting their death as looking at their doctors prognosis or the computer algorithm that tried to predict prognosis. And Joan was part of the study, she can probably comment even better.

ED HOWARD: Let me though, you talked about the Aetna and other private-sector initiatives, and presumably that's going to yield some results that you can use in trying to make the judgments about public policy changes. Questioner

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has asked about the availability of data for other studies of palliative and end-of-life care, where are the data that you can go to for everything from the quality of care to the knowledge by patients and their caregivers about their benefits? And the questioner lists a whole bunch of interesting questions that could be the subject of what looks more like health services research than it does clinical research.

DIANE MEIER, M.D.: Well, you know, you search the medical literature by topic, or by author, the CAPC website has every study we can find on the impact of hospital palliative care on clinical outcomes and utilization outcomes, and-

ED HOWARD: What? What-

DIANE MEIER, M.D.: CAPC, www.capc.org, the Center to Advance Palliative Care. So, on the resources tab are publications, so that's a place to start and then do further research under those authors. NHPCO has a list of relevant citations as well on their Web site. The *Journal of Palliative Medicine* increasingly carries important articles in the fields, you can search under the *Journal of Palliative Medicine*. But it's not all in one place. You have to do your diligence and do your homework and go to the relevant Web sites and look for their citations.

JOAN TENO, M.D.: Now, death is common part of our life, but we know little about the quality of care and the quality of life that persons face in dying. To my knowledge, there's only been one national study, which we did in 2000, that tried to comprehensively describe the problems and the conditions that patients and families face while dying. I think it's important that this is the one segment of our health care system in terms of an illness trajectory that accounts for about a third of Medicare's budget. We need information to describe what are the problems, what the concerns, are with the quality of care to help inform public policy. We have not done a mortality fallback survey since 1993. A mortality fallback survey is where we go and ask a next of kin about the decedents last year of life, we even when we did it in 1993, we asked about alcohol, we asked about drugs, as asked nothing about pain, nothing about whether the person died in the preferred setting of care. So I think it's time that we bring the mortality fallback survey so as we innovate and make change in our healthcare system, that we have some notion of what's happening.

For example, we have some notion of what happened with perspective payment in terms of the impact on utilization, one of the important questions is, how often, when you make those changes in perspective payment of home care services did you result in people now dying in a nursing

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home, as opposed to dying at home? That information you could collect from a mortality fallback survey.

ED HOWARD: Okay. Let me circle back to, this is a card based question that actually gets back to something Senator Collins referred to. Conversation, it says, has primarily focused on adults and elderly, what's known about children? Are there important differences in considerations? Do family caregivers have to make that terrible choice that has been referred to? And how well are nurses and physicians able to care for this population, either at home or in the hospital?

DIANE MEIER, M.D.: Actually, children's palliative care is fundamentally different from adults because most children in palliative care actually have congenital and chronic diseases. It is not cancer that is the majority of disease in pediatric hospice. And most pediatric hospice programs actually don't require parents to make a terrible choice because a, they can't. The parent can't make that choice. And b, palliative care and life-prolonging care are usually one and the same thing for these are very disabled kids on ventilators, on feeding tubes since birth, that family members are struggling to take care of at home. A tine fraction of them are pediatric cancers that follow a trajectory more similar to adults. So, the needs are very different, also the numbers of patients in need, thank God, are tiny compared to the number of older adults in need of this kind of care.

ED HOWARD: Thank you. We have about five minutes and we have two people standing at a microphone, three people standing at a microphone who are going to ask really quick questions while you fill out your evaluation forms. Yes, we'll start there.

NORRIS STEGER [misspelled?]: I'm Norris Steger with AARP. I just want to follow up on something Diane said about prognosis not being the right way to define a benefit. And while I totally agree with that, I think what policy makers really struggle with, and especially in this environment, is the cost, and when we look at it from the beneficiary point of view, I think any of the legislation we've been looking at, this year is dealing with chronic care management or medical home, whatever, who's going to be eligible for these benefits? We can't, even if we want to open it up to every Medicare beneficiary, given the cost constraints, we can't. So we really need some help in defining who's going to benefit the most from these different types of services. And I think, having learned what we have from hospice's experience, if we can, I mean, I thought the heart failure data, for example, was fascinating. If that kind of information about sort of the high-cost treatments of Medicare, who's not getting palliative care treatments and if you all have some more thoughts about that, that you can share in two seconds, like I said, it's going to get me. But, how to define who's appropriate.

BRAD STUART, M.D.: Well, we've kind of touched on this a lot, but as someone who's delved into heart failure a lot, the Toronto model, what Doug Lee [misspelled?] and his group up in Toronto have devised, it was published in *JAMA* a year or so ago. A multi-factorial calculator where you can plug in variables, he purposely chose variables that were easy to obtained on hospital admission, so you can pull up your web based calculator, plug in the age, the respiratory rate, the serum, sodium, the creatinine, those are just all measure that you get on patients when they're in the hospital, do they have dementia, do they have cancer, do they have liver disease, and once you fill all those in, out pops what core tile of mortality risk that patient is in and what their three-month and one-year life expectancy is. And as we said, that's easy to do relatively for heart failure. It's harder for other illnesses, but at least it's a precedent. And I wonder if we really couldn't start doing something like that for a more diagnosis non-specific very ill population. I think it's probably possible to do, but I'm not aware it's been done anywhere and that quantitative of a fashion.

DIANE MEIER, M.D.: The organizations that have done very well by targeting like paradigm health, the old Franklin

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Health, it’s proprietary and none of these private insurance companies are going to publish their data, so give that up, because they’re competing with each other. They use an equation that incorporates primary diagnosis, so if you have pancreatic cancer, you come up, and utilization. And it’s all administrative data. You don’t have to go to the medical record, you don’t have to go to the hospital IT, its charge data. And because it’s easy to access for large populations, and they’re, not everyone they target is appropriate, they probably miss a lot, their sensitivity and specificity is not perfect, but they save a lot of money and they’re doing very well, thank you, because of their data. And it’s really utilization and primary diagnosis, and maybe secondary and tertiary diagnosis.

BRAD STUART, M.D.: To feed it back very quickly, we have Medicare claims data and we could be doing that.

ED HOWARD: Okay. We have time in one, get in a quick one.

FEMALE SPEAKER: I am a journalist for a grant from the Kaiser Family Foundation to spend this year writing about palliative care and end of life, and two of you I’ve gotten to know fairly well. I’ve been really struck how much is happening in the field in hospices and in hospitals and somewhat nursing homes that people in Washington are completely unaware of that’s not on policymakers’ screens at all.

Quickly, given the, can you each just say one thing that you think is going to look different in two, three, fours years just because, what, hospice is changing already, what is something that we can look to that’s going to be different in a few years, even if Congress, to all of our surprise, doesn’t do anything.

STEVE MCCONNELL: Well, what’s going to look different is that the panic about Medicare costs is going to get much worse. Sometimes that leads to looking at things that there’s a reluctance to look at, and that may help in this cause, although sometimes it causes really bad policy decisions, but I think that’s going to be a huge issue.

JOAN TENO, M.D.: And I’m going to be the optimist and I think with the implementation of the electronic medical record in nursing homes, which is starting to happen, we have two nursing homes in Rhode Island that are doing that. We are finally going to see appropriate flags put in place to prevent medical errors and to help make the right drug choices for persons. So, I’m optimistic for the future because we’re going to be implementing electronic medical records in the nursing home setting and we’re going to be able to do studies that will improve and enhance the quality of care.

DIANE MEIER, M.D.: I'm optimistic too that it will only be the late adopters, marginal hospitals that don't have a palliative care program in three to four years that it will be standard of practice. Within five years that there will be accreditation requirements, that there will be quality measures, that there will be novel approaches to payment, that helps sustain and strengthen these programs. Because that's the track we're on, so I think that's what's going to happen.

BRAD STUART, M.D.: All right. I'm going to be a pessimist. [Laughter] Just because, I mean, I wouldn't keep doing this until my hair turned this gray if I weren't an optimist, but I'm going to say just to kind of balance things, that there will be another OIG inquisition into homecare and hospice, because home care and hospice are so needed and increasingly utilized that CMS, in its wisdom, will not see fit to study how increasing home care and hospice use in a particular way would decrease hospitalization, they will not look that broadly, they will say, "Hey, there's nine billion going on 10 billion going to hospice, we've got to make that less." And I predict that's going to happen. So I hope it doesn't, but I-

ED HOWARD: So you researchers out there figure out a way to make that connection that Dr. Stuart was talking about.

BRAD STUART, M.D.: If those of you have the ability to stop that could do that, we would really appreciate it. [Laughter]

ED HOWARD: They can do it. Yes, you've got the last word.

DANA RICHARDSON [misspelled?]: Hi, my name's Dana Richardson. I'm from GAO. Quick question, if each of you could kind of waive a magic policy wand, and make something happen, would you rather see the development - or which, I guess, do you think would make a bigger impact in end-of-life care, developing a formal palliative care program under Medicare that wouldn't have any restrictions regarding six-month prognoses, or giving up palliative care, or changing hospice care, getting rid of that six-month prognosis and getting rid of that requirement that people have to give up quality care to elect hospice?

STEVE MCCONNELL: I get to go first again. Well, I wouldn't support either of those. I think the fact of the matter is we've got to do probably some demonstrations to show the value and the cost potential savings of a palliative care benefit while we're continuing to make sure that the hospice benefit works as well as it could. I think it's probably not realistic to just open up either of those immediately.

JOAN TENO, M.D.: I'm going to agree with Steve, and I'm going to give you my closing comment in response to Brad's sort of OIG comment. And it strikes me as odd that living longer is fraudulent care.

DIANE MEIER, M.D.: Lot's of people have talked about a palliative care benefit and I'm like a broken record saying it would be a disaster if there was a palliative care benefit. Every hospital in the country would close down their palliative care program because they would get reimbursed so much less money than for that patient's underlying cause of illness. So palliative care DRG would shut down the field overnight because somebody comes in with lung cancer and pneumonia, and all sorts of problems, the DRG for lung cancer and pneumonia is going to be 10 times higher than the palliative care DRG. And what it will do is dis-incent palliative care for patients who most need it, so we have to be very careful what we wish for because of the law of unintended consequences. So I wouldn't be in favor of that.

BRAD STUART, M.D.: Well, again, repetition being the key to adult learning, I'm just going to say again very specifically what I said in my 10 minutes. I don't believe that palliative care benefit is necessary, I would advocate very strongly for, if we can pull it off, defining a very ill population in some of the ways we were talking about, not for everybody who's ill but for the people that are the most ill I would allow those people to access hospice along with treatment. I would take away the terrible choice, and I would absolutely alter the home care benefit - and we need to talk more about this because it's indirect - but alter the home care benefits so that you do not have to be homebound and have specific skilled nursing needs in order to continue on homecare. Because we have the Grand Canyon right now between home care and hospice, and people are falling into it and going back to the hospital. I know we can save money and reduce pain and suffering by doing those three things.

ED HOWARD: Okay. There's your agenda. We've come to the end of our time and I will bore you one more time asking you to fill out the evaluation form. But I do want to take this opportunity to thank the Robert Wood Johnson Foundation for its support, both for this program and for this issue over the years. Thanks, Senator Collins, for stopping by and getting us off to a rousing start and before I thank the panelists, I want to thank the panelist's niece - Joan Teno's niece allowed her aunt to bring her here as opposed to some other part of the celebration of her birthday that would otherwise taken place. So Frances [misspelled?], thank you very much.

[Applause] And happy birthday.

[END RECORDING]
