

**NWX-HHS-AOA-1**

**Moderator: Amy Wiatr-Rodriguez  
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Coordinator: Welcome and thank you for standing by. At this time all parties are on a listen-only mode until the question and answer session. At that time you may press star 1 to ask a question. Today's conference is being recorded, if you do have any objections you may disconnect at this time. I'd like to now turn the meeting over to our host, Miss Amy Wiatr-Rodriguez. Ma'am you may begin.

Amy Wiatr-Rodriguez: Great, thank you so much. I am Amy Wiatr-Rodriguez with the Administration on Aging within the Administration for Community Living. And I'll be moderating today's webinar, Advanced Stage Dementia and Palliative Care, which is the final webinar in a five part series.

Before I introduce our speakers we have a few housekeeping announcements. First, if you have not done so please use the link included in your e-mail confirmation to get on to WebEx so that you can not only follow along with the slides as we go through them but also ask your questions when you have them through the chat feature. If you don't have access to the link we e-mailed you, you can also go to [www.webex.com](http://www.webex.com), click on the attend a meeting button at the top of the page, and then enter the meeting number which is 664421994.

If you have any problems with getting into WebEx please call WebEx technical support at 866-569-3239, again that's 866-569-3239.

As our operator mentioned all participants are in listen-only mode. However, we welcome your questions throughout the course of this webinar. There are two ways you can ask your questions. First is through the web using the chat function in WebEx. You can enter your questions and we'll sort through them and answer them as best we can when we take breaks for questions after each presenter.

And secondly after the presenters wrap up we'll offer you a chance to ask your questions through the audio line. When that time comes the operator will give you instructions as to how to queue up to ask your questions. If there are any questions we can't answer during the course of this webinar we will follow-up to be sure we get those questions answered. If you think of any questions after the webinar you can also e-mail them to us at my e-mail address which is [amy.wiatr@acl.hhs.gov](mailto:amy.wiatr@acl.hhs.gov) or to any of the e-mail addresses that are included in the PowerPoint slides that are the basis for this webinar. As the operator mentioned we are recording the webinar. We will post the recording, the slides, and a transcript on the AOA website as soon as possible.

So now we get to go into our presentations. And first I'd like to introduce our speakers today. They include Basil Eldadah, M.D., Ph.D, with the Division of Geriatrics and Clinical Gerontology in the National Institute on Aging. Susan L. Mitchell, MD, MPH, Professor of Medicine with Harvard Medical School, and Senior Scientist, Hebrew SeniorLife Institute for Aging Research. Greg Sachs, MD, FACP, Professor of Medicine, Chief, Division of General Internal Medicine and Geriatrics at Indiana University School of Medicine, also Investigator with IU Center for Aging Research at Regenstrief Institute Inc. And finally we have Greg Link, Aging Services Program Specialist, Office of

Caregiver and Supportive Services, in the Administration on Aging/  
Administration for Community Living. At this point I'd like to turn it over to  
Dr. Basil Eldadah who is with the Division of Geriatrics and Clinical  
Gerontology at NIA to kick off today's webinar. Basil.

Basil Eldadah: Hi, thanks very much. Thanks for having me, and welcome to everyone. I'd  
just like to start out by giving a brief overview of our Institute -- the NIA --  
and how it fits in with palliative care. If I could ask you to advance to the next  
slide please.

This is our mission at the National Institute of Aging. We're a research agency  
focused specifically on the well-being of older individuals. And we have  
several goals. One is to conduct research on aging processes, you know, aging  
across the lifespan, age related diseases of which Alzheimer's and related  
dementia is certainly one, and also special problems and needs of the aging,  
geriatric syndrome, things like kinds of impairments of multi morbidity, all  
within the purview of our research mission. We're also interested in training  
research scientists, developing and providing research resources, and  
disseminating health-related research-related information which is what we're  
doing today.

Next slide please. So this is how we're organized. We have four extramural  
program divisions that deal with different areas of science related to aging and  
geriatrics. The division of Behavioral and Social Research, the Division of  
Aging Biology, which focuses on the basic biology of aging, the Division of  
Geriatrics and Clinical Gerontology, and the Division of Neuroscience. Three  
of these four divisions, Behavioral and Social Research, Geriatrics and  
Clinical Gerontology, and Neuroscience are the divisions that deal most  
directly with issues related to palliative care. And if anybody has any

questions or ideas for a research proposal on palliative care feel free to contact any one of us in these divisions, and we can help you.

I should also point out that the NIA is one of many of the institutes and centers at the NIH that deal with palliative care. But there are several others of the 27 institutes and centers, including the National Institute on Nursing Research, the National Cancer Institute, the National Center on Complementary and Alternative Medicine and the National Heart, Lung and Blood Institute, and there are many others as well.

The next slide please. These are some relevant funding opportunities. The first one titled “Advancing the Science of Geriatric Palliative Care” is a new initiative that was just released last week. And this focus is specifically on a variety of different research issues related to palliative care in older adults. And if you click on any of these three links, you’ll be taken to the text of the program announcements, and you’ll see the areas of science that are relevant to the different divisions at the NIA as well as our partnering institute, the National Center for Complementary and Alternative Medicine. And it’s possible that other NIH institutes and centers may also be deciding what to do in the very near future.

Also relevant to our program announcements on pain and aging, these of course are specifically focused on pain and are not included in the above announcements on geriatric palliative care, but as in combination both of these sets of announcements really lay out the scope of our interest in palliative care and symptom management in older adults.

And the last slide please. Now I just want to point out that the NIA in addition to supporting investigator initiated studies and other specific investigations, we also support several research centers focused on broad areas of science.

Most relevant to this webinar is the Alzheimer's Disease Research Centers which are supported through our Division of Neuroscience.

The Claude D. Pepper Older Americans Independence Centers, these are supported by our Division of Geriatrics and Clinical Gerontology. And the Resource Centers for Minority Aging Research which are centers that are focused specifically on providing the health of diversity populations and increasing diversity representation of a scientific workforce and these centers are supported by our Division of Behavioral and Social Research. So that's it for my overview of NIA and how we try to fit in to the whole palliative care world and I'll turn it over to the next speaker.

Amy Wiatr-Rodriguez: Great, thank you so much Basil, and we appreciate your opening comments. And now we're pleased to hear from Dr. Susan Mitchell with Harvard Medical School and Hebrew SeniorLife Institute for Aging Research who will give us an overview of the clinical course and care of patients with advanced dementia. Susan.

Susan Mitchell: Yes good afternoon. Can you hear me?

Amy Wiatr-Rodriguez: Yes.

Susan Mitchell: Good. Next slide please. So the goals of my talk this afternoon will be to describe what we know about the clinical course of advanced dementia. I want to talk about the most common complications that care providers and families and patients will come across and then propose an outline to decision making for these most common complications, and I'd like to try to inform all three bullets here with the most up to date research advances.

Next slide. So we know that there's over 5 million Americans who have Alzheimer's disease, even more of course that have other forms of dementia, and that's going to at least quadruple or more over the next several decades. And dementia's also a leading cause of death in the US. It was the fifth leading cause of death in patients over 65 in 2012.

And we also know that that's probably actually an underestimate of how many people are dying with dementia in this country, because for those of you who have seen or filled out death certificates, dementia as a cause of death is almost always underestimated on these death certificates. So many statistics derived from those death certificates probably actually underestimate dementia as a terminal illness in this country.

Next slide. This slide is from 2001, a little bit dated but I think the patterns persist today. And these are data where myself and colleagues looked at death certificates from everyone over 65 who died. And again if you're familiar with death certificates on one side of them you have to indicate where the patient died. And we were just interested in where patients with dementia die.

And here you can see the color coding with red being death in the hospital, yellow the nursing home, green is home, and blue is other various locations. And the message here is that the majority in 2001, close to 70%, died in nursing homes with the hospitals the next common site of death and the home following that. There might be perhaps a more recent shift towards dying at home, but I think still the majority of these patients receive their terminal care in nursing home, so it is an important site of care.

Next. And before I go any further I just want to make sure that we're all understanding what I mean when I describe a patient with advanced dementia. Because all the information and research findings all discussed in this talk all

relate to a person who has the following features as described by the Global Deterioration Scale. It's a scale that goes from 1 to 7, 7's the most advanced stage.

And at Global Deterioration Stage 7 patients with dementia typically no longer recognize family members as such their memory deficits are so profound. They've lost all verbal abilities. I think the official definition is less than five words. They're bed bound and not ambulatory, and they're incontinent of urine and stool. So this is the type of patient that you should keep in mind as I go through the rest of the talk.

Slide. So just briefly by way of background. Research really in palliative care with respect to dementia has been around now for about 25 years or so. And we've learned that palliative care is really suboptimal across care settings, and why is this? Well, there's been, I hope, changing but persistent under recognition of dementia as a terminal illness unlike other more commonly recognized terminal conditions like cancer.

I'm going to talk about the challenge of prognostication, of actually recognizing when someone with dementia is approaching the end of life. Hopefully changing, but there has been a lack of high quality research to help guide treatment decisions and palliative care for patients with dementia. And there has also been an underutilization of the hospice program which is the main program in this country that cares for people who are near the end of life.

Next slide. This illustration makes the point about the challenge of prognostication. In the upper illustration graph that's labeled cancer it's trying to show that a patient with cancer may be typically -- this is a trajectory as they approach death -- they may be going along and then they will -- again

typically, not everyone's the same -- will have a more rapid decline towards death, which is generally recognizable when that decline is happening. In contrast, patients with chronic disease such as dementia the trajectory towards death is somewhat less recognizable and may be characterized by a gradual decline towards death punctuated by more sudden illnesses. For example, pneumonia where they all get quite sick but recover maybe not to the level they were before and then approach death in that way. So again it's more challenging to actually recognize exactly when that terminal trajectory begins, it's less steep.

Next slide. So the issue of prognostication as I mentioned is challenging but it's also important, and it's important because we know it helps guide patients' family provider decision making, and there have been many studies now that show if these parties recognize that death may be near they'll perhaps make decisions towards less aggressive care. And as most of you know prognosis also is an eligibility guideline to get into the Medicare hospice benefit where patients are supposed to have an estimated life expectancy of less than 6 months.

The challenge again with prognostication with advanced dementia, there's been very little work until recently actually trying to be able to empirically predict when a person with dementia is close to the end of life. And in fact the hospice guidelines who some of you may be familiar with -- and I bet Greg is going to talk a little bit more about -- were never derived using any scientific methodology.

So we were interested -- myself and my colleagues -- to see if we could approach this a little bit more rigorously and we received funding from the NIH to conduct a study called ADEPT - The Advanced Dementia Prognostic Tool. And what we did is we used data from the entire country from the

minimum data set -- which is a set of assessment instruments using all the nursing homes in the countries with many variables -- and we tried to use very sophisticated statistical techniques to derive a risk score that we can apply and try to see if we can predict when someone with advanced dementia would die, whether or not they would die in the next 6 months.

And without getting into the details of the approach, we also compared it to hospice eligibility and we actually, once we made our score, we tested it out in 600 patients in real life. On day 1 we applied our score and whether or not they would meet hospice criteria. Then we followed them the 6 months to see if they actually did die and how well both our score and hospice predicted that death.

And that acronym there, AUROC, you don't really need to know what it means. But the value there tells you how good the score method works. In short the .68 means that 68% of the time our ADEPT score was able to identify when someone with advanced dementia died in 6 months, whereas hospice was only able to predict it correctly only 55% of the time which is slightly better than chance.

So even our 68% though however is not anywhere near perfect and in my mind what this ADEPT study told me is that it is very challenging to predict even with the most sophisticated methods when someone one with advanced dementia is near the end of life. And in my mind if you are a GDS -- Global Deterioration Stage 7 -- patient who wants care directed towards palliation you should be able to receive that care whether or not you have a month to live or even a year to live.

The next slide. So let's turn to the clinical course of dementia, and we learned a lot about this from another study funded by the NIH called the CASCADE

Study, which this acronym stands for Choices, Attitudes, Strategies for Care of Advanced Dementia at the End-of-Life. And this was a study of 323 nursing home patients living in 22 nursing homes around Boston. And it was a prospective study. We identified these patients and then we followed them for up to 18 months. And really the point of this study was to get a better understanding of exactly what happens to patients in the final stages of dementia and also what their families go through.

Next slide. And just for the sake of time I'm going to highlight the major findings from the CASCADE Study. Over 18 months 55% of the people in the study died -- that's about 40% over a year -- which is a mortality rate not unlike you'd find for a metastatic cancer, so a lot of people died. And then we identified the most common complications, for example over the 18 months 90% of patients developed an eating problem, close to half developed recurrent infections and fever.

And of note other conditions, acute conditions that may lead to death like stroke, hip fracture, myocardial infarctions were extremely rare. I think in the last 3 months of life only, there were only seven such events which told us that these patients were not in fact dying from these other conditions like stroke or fracture. They were in fact dying from dementia and the expected complications such as pneumonia.

And I think it's important for people to realize that for example if a patient with metastatic cancer got pneumonia in the last 2 weeks of life you still probably would say they died of cancer and similarly for dementia patients who got pneumonia -- which there are many in the last few weeks of life - their still underlying reason they died was from their dementia and the frailty from that.

Another point from the CASCADE study was the frequency of burdensome symptoms. Over close to a quarter had documented pain and 30% had documented shortness of breath. As they approached death these two symptoms increased not unlike again trajectories that you would see in cancer. So a lot of potentially modifiable and treatable symptoms.

Next slide. And finally from the CASCADE Study we also I mentioned followed the proxies, most often family members of these patients, and documented all the decisions they made over the course of their loved one's care. And just to highlight that the most common decision was about eating problems, roughly a third of all decisions you see in the pie chart here. And the next most common decision related to the treatment of infections, if you combine pneumonia and febrile illness you get about 25%. For the remainder of my talk then I'm going to focus on those two most common conditions and try to operationalize an approach to them.

Next. We should highlight that advanced - sorry decision making is critical in advanced dementia. And because of what we learned from the CASCADE Study and other people's work, we now know there is a great opportunity for advanced care planning because we know of the most common complications that are going to come up, and we know about the most common decisions that are going to face families.

And this really is an opportunity to elicit wishes and prepare people for those future discussions, and it may not be that in the moment they're going to be able to prospectively to make a decision, but at least when that feeding problem or pneumonia comes up it isn't a surprise, and perhaps they would've already considered their wishes. So advanced care planning I'd like to underscore many times is really critical to all this.

Next slide. In medicine and we have an ethical framework by which we try to make decisions. The four ethical principles, first, beneficence: we try to do good for our patients; non-maleficence: not to harm them; there is a respect for autonomy which is making sure decisions are informed and respected; and then the concept of justice and what makes sense from societal perspective. So that's all well and good but how do you operationalize this in practice.

Next slide. And I'm going to offer some steps to ethical decision making. And I'll go through these steps both for eating problems and pneumonia. With first involving clarifying the clinical situation, then determining the primary goal of care, presenting the treatment options, and then weighing options, and deciding on a course based on what the primary goal of care is. So let's see how this works.

Next slide. So let's first take eating problems. The first step really is to clarify the clinical situation; we've done some of that already today. We now know that eating problems are very, very common at the end stage; it is really a hallmark of the end stage of dementia, and the last activity of daily living mostly to be lost. I think if people understand that eating problems are expected at the end stage of dementia, it is helpful.

Next slide. The second is to try to get families, patients on some trajectory of what the goal of care is. And many people, rightly so, underline that these are not necessarily mutually exclusive. But generally one would want to consider if the goal of care is life prolongation using all medical technologies possible, on the other extreme mostly focusing on comfort even if that means living a few months less and not getting all the bells and whistles in medical technology, or something in the middle such as maintaining function which could mean for example getting an oral antibiotic to treat an interim infection if it could get you back to where you were before that infection happened.

Next slide. So step three is presenting the options, and I sort of say this with a little bit of quotation marks around the options. However, with regards to problems the options are continued hand feeding -- as you see the woman feeding her loved one here in the picture -- and on the other hand long term tube feeding using usually a tube, a gastrostomy tube into the stomach or sometimes a J-tube.

Next slide. So let's look at the evidence for both those two options, but I want you to keep in mind that in terms of the quality of the evidence it would be, the best level of evidence would be a randomized controlled trial of tube feeding versus non tube feeding. But we don't have a randomized control trial like that, and I don't think we ever will.

So the next best level of that evidence is a cohort study where we compare what happens to patients with and without feeding tubes where that decision to put in that feeding tube or not was based on clinical care. We have several good cohort studies; cohort studies are always a little problematic because the reasons whether the tube was put in or not, the type of patients, may also affect the outcome such as survival, but we do have statistical techniques to try to minimize those biases.

And the last level of evidence, of which we have many, are case series where you just follow patients along and see whether or not, how they do with their feeding tube. And that gives you some interesting prognostic and descriptive information but it doesn't tell you how they would've done without the tube. So I mention this just to remember that we do not have the gold standard randomized control trial.

Next slide. In terms of the first option, hand feeding, the goal here is to provide food and drink to the extent that it's enjoyable for the patient. You really have let go of the goal of providing for example 2000 calories a day, you've really opted for suboptimal nutrition most often in favor of comfort. And it's important to underline to families that this is a means of palliative care is being instituted in that treatment and all the treatments that go with palliative care, and that treatment itself has not stopped.

Next slide. In terms of tube feeding -- again somewhat dated information, but I think fairly similar -- remarkably close to a third of nursing home residents with dementia were tube fed, again those are data from 2004. We've learned subsequent to that that most of these tubes are put in during an acute care hospitalization, in other words the typical scenario is the patient from the nursing home gets sent to the emergency room perhaps with pneumonia, maybe they've been noted or concerned that their level of aspiration and a sign goes on top of the bed of NPO -- or don't give anything orally -- and maybe they get a swallowing study in the hospital that shows they are aspirating and then the feeding tube is inserted in a busy hospital setting with suboptimal decision making. There was also wide regional variation in tube feeding, we learned over the years, in various different parts of the country, most common in the southeastern region of the States.

Next slide. In terms of why anyone would put in a feeding tube, in terms of purported benefits, families or patients or providers may even hope that it prevents aspiration, malnutrition or just the quality of malnutrition, like pressure ulcers there may be the hope that it would prolong life and for some circumstances it would promote comfort. I'm sure many of you have heard the expression by families, "We don't want our love one to starve to death."

I can't show you all the evidence for all these purported benefits, suffice it to say for aspiration we know very well now the PEG tubes or J-tubes do not prevent aspiration because people aspirate their oral and gastric secretions, and for sure if someone's aspirated before the tube with dementia, they'll probably be an aspirator with the feeding tube.

In malnutrition we have learned that from some case series that people with feeding tubes who have had advanced dementia really don't have any significant weight gain or improvement in markers like albumin, maybe because of metabolic changes. And I'll talk about pressure ulcers in a minute. I'll show you some data about survival. And comfort is a difficult one because it's hard to know what people with advanced dementia are sensing, although extrapolated data from patients dying with cancer who can speak to us experience very little hunger and thirst.

Next slide. These are some of the data regarding survival, one from 1997, and one from 2012 updated both are survival curves from large datasets. The first one from the state of Washington the second one from the entire nation comparing patients with advanced dementia who are tube fed and not tube fed using again statistical methods to try to adjust for differences in those two groups. These are cohort studies that may also affect survival.

And you don't really have to be a statistician to see that the lines in both these graphs are intersecting, in other words there was no measurable difference in survival among these nursing home residents with advanced dementia who were or were not tube fed, at least there's no difference we could find, so I think together these two both studies really suggest we can't demonstrate any survival benefit.

Next slide. I also think it's important to keep in mind risks of tube feeding when you counsel families. It is a relatively safe procedure in terms of technically and in the short term, but there are special considerations in patients with advanced dementia. The first I think families need to be talked to about, one is agitation, these patients typically can get agitated, if they get agitated with a feeding tube they may try to pull it out and that might lead to the cascade of using psychotropic medications, and in worst case restraints, physical restraints.

One thing - I'll show you a slide about this in a couple of minutes, but people should know that this was the number one cause of hospital transfers in our CASCADE Study to the emergency room, even though only 7% of the patients had a feeding tube. So families should understand if they opt for a feeding tube it may also mean that the patient is going to be transferred back and forth to the emergency room, not infrequently to deal with blockages or dislodgement.

And lastly in terms of pressure ulcers there's new data from Joan M. Teno at Brown showing remarkably an increased risk and poor healing of pressure ulcers among tube fed patients with advanced dementia, compared to non-tube fed. It maybe counterintuitive but these patients may be more bed bound and may have diarrhea et cetera that might to lead to poorer skin care.

Next slide. So to bring it together for the tube feeding then, if you want to weigh the options, hand feeding advantages: that they taste food, there's a social interaction and a focus on comfort. It does take time, which is a particular disadvantage for some nursing home resources, and if families are still counting calories the intake could be inconsistent. Tube feeding advantage: nutrition is being delivered but we have not been able to demonstrate any clear benefits, and there are certainly complications.

Next slide. So if you want to align with the goal of care, which was step four in my steps, certainly with the goal of comfort you would want to go with hand feeding in the palliative approach. If it's to prolong life the jury's still out, but again we don't have any data to support that outcome.

Next slide. And taken together you should know that expert opinion compared data really over the last 15 years has come down to say that tube feeding really has no demonstrable benefits; it really should not be offered. What I do is I don't bring this up as an option but if families ask about tube feeding I'm armed with the information I just told you about to try to help guide families about it.

Next slide. I'll go a little quicker through the pneumonia which was the second or infections most common complication in advanced dementia. Next slide. In terms of clarifying the clinical complication situation we also know pneumonia infections are very common in the end stage of dementia, 50% have a diagnosed pneumonia in last 90 days, obviously associated very high mortality in there, some discomforts certainly both associated with symptoms and also with treatments such as intravenous use or potentially transferred to the hospital.

Next slide. Again you want to align the family on a trajectory of goal of care from life prolongation to comfort and having done that. Next slide. You can present the options which I try to depict as a more palliative care approach, and the gentleman lying in bed versus antibiotic treatment.

Next slide. Antimicrobial use is extensive in advanced dementia. These are data from the CASCADE study on the x-axis you see days before death, 0 to 14, 28 to 15 days, et cetera before death. In the last 2 weeks of life close to

40% or even higher patients with advanced dementia got antibiotics, keeping in mind they all died. This is an extraordinary use of antibiotics.

Next slide. Excuse me. Sorry can you go back one slide? Right, and so the next slide. Yes. We tried in the CASCADE study to see whether the different modes of treating pneumonia, whether it be antibiotics, or different types of antibiotics, or no treatment actually affected how people live. And again this was not a randomized trial. But the blue line here, the lowest line, is the survival among patients who didn't get antibiotics, and the three other lines are the people that did get antibiotics their survival, the different colored lines there represent different modes from oral antibiotics to IV antibiotics.

And you could see definitely that the people who didn't get antibiotics had a shorter survival on the average of months than the people that did get antibiotics, and this is after adjusting for potential confounders. But one thing is very important to notice: It didn't seem to matter how the antibiotics were delivered whether oral, or IV, or IM, which is important because if someone could stay in the nursing home get an oral antibiotic and do just as well as being sent to the hospital and getting IV antibiotics and that's perhaps less burdensome for them, if again the goal of care includes providing antibiotics.

Next slide. We also followed comfort in these patients. And the score here on the y-axis is a comfort scale, SM\_EOLD, and higher scores mean greater comfort, and you can see the people that get no antibiotics had the highest comfort and then as the treatment got progressively aggressive people got less comfortable. So people who got IVs or hospitalizations for pneumonia were the least comfortable. So it seems like you're prolonging life perhaps by several months but at the cost of perhaps more discomfort.

Next slide. And briefly in terms of the principle of justice, a colleague of mine at the same time we were doing CASCADE was swabbing all the residents in my nursing home for antimicrobial resistant bacteria and found that -- which you know is a big public health concern at the moment found that -- 64% of the advanced dementia patients were colonized with an antimicrobial resistant bacteria, which was a rate three times higher than the other residents.

So this is a risk for them and also for other residents, and they also bring these resistant bacteria in to the hospitals. So the overuse of antibiotics in advanced dementia has become not just an issue of individual patient burden and comfort at the end of life, a palliative care issue, it's also a public health issue.

New slide. Putting together for treatment of infections and no antibiotics, the advantages may be greater comfort, at the cost perhaps short of survival if that's important to somebody at a GDS score of 7 with dementia, whereas antibiotics may prolong life at the cost of perhaps greater discomfort, more cost, and maybe antimicrobial resistance.

Next slide. Putting it together, if the goal of care is comfort, certainly the family would want to go with palliation only, and including things like oxygen, whatever else can make a patient comfortable. If the goal is still to prolong life, I do think antibiotics make sense, but again oral may be adequate rather than transferring the patient to the hospital.

Next slide. Now the very last issue I'm going to discuss before I finish is the issue of hospital transfers. And these are data from the CASCADE study, and we have 74 hospital admissions in the first panel and 60 emergency room visits. The number one cause for an admission and very common cause of ER visits was infections. And these ones highlighted in red here are reasons for admissions or transfers I felt were potentially avoidable, because people

would do just as well at the nursing home or didn't need transfer, didn't need to be evaluated in acute care setting. So there's a lot, I think it came close to 75% of transfers I thought were potentially avoidable.

Next slide. And again I really want to underscore in decisions to hospitalize, it's really important what is the goal of care versus survival comfort. And when we ask patients' families in CASCADE what the most important goal of care is, 95% of the proxies said comfort, even though their loved ones didn't necessarily get that. And I think it's really important to ask if a hospitalization would meet that goal, and I think for most issues except perhaps a hip fracture it probably doesn't.

Next slide. I mentioned that most -- I think about 75% of these transfers -- were avoidable, again either because they need treatment in the same efficacy in a nursing home, or it may not be consistent with the goals of care. Next slide. So in summary dementia is a terminal illness, feeding problems and infections are the most complications in decisions, aggressive interventions are less likely when families have a better understanding prognosis and complications and have better advanced care planning.

New slide. Ethical decision making in its form is guided by the goals of care. In terms of specific treatments, tube feeding has no demonstrable benefits and in my view should not be offered. Antimicrobial treatment for pneumonia may prolong life but also cause more discomfort. And I would say that most hospitalizations of patients with advanced dementia are avoidable.

Next slide. Again take home points I want to underscore again for all the providers out there that the opportunity for advanced care planning to try and focus your decisions and guidance on goals of care. Don't feel compelled to offer everything but do be knowledgeable about the best evidence when

asked. And try to use, where you can, some decision support tools, which also include geriatric or palliative care consultations where you are.

And finally the last slide. We did develop a booklet which we found very useful for our consult services and also for our long term care facilities, called "Advanced Dementia, A Guide for Families," which goes through a lot of the information I mentioned today but in a very structured way, and I think very useable way for families. And I believe there's a link to this in your resources on how to look at the booklet, and also how to order it, too, if it's of interest. But the Alzheimer's Association and other resources also have good documents to help families. Next slide. That's it, thank you very much.

Amy Wiatr-Rodriguez: Wonderful, thank you so much Dr. Mitchell. I want to remind everybody that if they do want to ask questions right now they can use the chat feature, we'll try to get to what we can now. And then at the end we will be opening up the audio line for questions.

Also I have had several people inquire about getting copies of slides, and we'll be posting these to our AOA Web site afterwards, and everyone who registered for today's webinar will get an e-mail notifying them when the slides and other materials are posted. It usually takes us about a week to get it up there, but you all will get an e-mail when that is done.

And so right now we did get one comment that maybe Dr. Mitchell or any of the other speakers that we have are welcome to respond to this as well. But we did get a comment from Michelle saying that she was recently told by a hospice employee that they are being asked to identify other health problems to qualify dementia patients for hospice because Medicare doesn't want patients with dementia diagnosis on hospice, perhaps due to that

prognostication issue you outlined. I'm wondering if you have any comments or response to that?

Susan Mitchell: This is Dr. Mitchell. So to my knowledge dementia is still a viable primary diagnosis for hospice referral and eligibility. There are concerns by hospice providers that patients may live beyond the 180 days and have to be recertified and for some hospice providers that may not be a good fiscally beneficial, however, so hospice certainly still does accept dementia as a primary diagnosis for referral. I don't know if Dr. Sachs you have any other comments about that.

Greg Sachs: Yes, I think that hospices are getting increased pressure around the diagnosis and there are concerns that if they're audited -- and that happens not so infrequently -- that they need to have other diagnoses in addition to dementia. So the ease of getting somebody enrolled in hospice simply with that diagnosis is really getting harder, so it's not an isolated event, we've been hearing that elsewhere around the country as well.

Amy Wiatr-Rodriguez: Great. And another question just came through from Robert, kind of on the same issue asking about any evidence of that. I know you mentioned just now Dr. Sachs the anecdotal and other information you're getting, but is there any, I guess other evidence out there?

Greg Sachs: No, not that I can point to in terms of numbers of audits or cases where payments have been denied or anything like that. But there's - as I'll mention towards the end of my talk, this is an area that's getting increased scrutiny and there are sort of proposals to revise the Medicare hospice benefit or the payment mechanism, and there are a lot of people who are concerned that it may disadvantage patients with dementia especially those residing in a

nursing home. So I think it's an area that people need to stay on top of and where public advocacy may be an important piece of what needs to happen.

Amy Wiatr-Rodriguez: All right, wonderful. Well I know that there are some other questions been coming though chat, we'll try to answer those maybe in an upcoming break. But at this point it sounds like because many of those questions are coming in on this similar topic I think maybe now it's time to move on Dr. Sachs to your portion of the presentation. We're pleased to have Dr. Sachs with us. He is with the Indiana University School of Medicine, and he is going to be discussing the clinical course and care of patients with advanced dementia in community based settings among other information. So, Dr. Sachs.

Greg Sachs: Thank you. Next slide please. So this is my disclosure of my potential conflicts of interest. I don't think that any of these actually represent a conflict with the material that I'll cover today, but in case you hear from Indiana University, you can attest the fact that I did have a slide present. Thank you.

Next slide please. So the goals from my presentation are to talk about dementia and palliative care in the community setting, and to do so in a sense upstream from the nursing home for the most part. I think Dr. Mitchell has done an excellent job of discussing the course of dementia for those with the most advanced disease, and in fact her ethical framework I would argue could be applied much earlier in the course of the illness as well.

I'll try to expand on one topic that she mentioned about advanced care planning and a specific type of planning called the Physicians Order for Life Sustaining Treatment. I'll talk about the challenges of evaluating and managing pain and dementia. And then briefly talk about the role of hospice

and dementia care. I'd also like to acknowledge slides that I've borrowed from Dr. Mitchell, Chris Callahan, Susan Hickman, and Dr. Lexy Twerkey.

So next slide please. So this is one of Dr. Hickman's slide, I'm sorry Dr. Mitchell's slides and one of the points that I'd like to make here is that many, there aren't - I would say there are some patients who are in this stage of advanced dementia defined by a GDS 7 who reside in the community and not nursing homes, but more importantly I think that when people think about moderate to severe dementia they don't necessarily think all the way to what I would consider to be this very advanced stage 7.

If somebody is in stage 6 they still may recognize their family, and they still may be able to communicate some. But they're ambulatory and still may be dependent on others for most of their activities of daily living. So you can be in stage 6 and still be pretty severely affected by dementia.

Next slide please. This is another of Dr. Mitchell's slides. She already mentioned the data is from 2001. And of course because I do a lot of my work in the community setting I always like to argue with her, but how it's still important, even if most of these deaths occurred in the nursing facility, not only is this data starting to get a little bit aged in terms of the affects of the growth of palliative care and hospice, facilitating more deaths in the home setting instead of nursing home, but if you think back to the last slide about the stage that many patients when they have such advanced dementia are more likely to end up with that kind of diagnosis listed on their death certificate.

Patients who have more moderate to severe dementia may die from other conditions and not have it listed on their death certificate. So especially if you start talking about the community setting you're even more likely to end up with it not being captured on the death certificate.

Next slide please. So another point to make about this is informed by some studies that colleagues of mine have done looking at cohorts of people with the diagnosis of dementia in the community setting. And that is that we often assume that the progression of the illness and the kinds of services that are provided all this is sort of a linear pathway from home, additional services, in and out of the hospital, and eventually to the nursing home and death.

Next slide please. So my colleagues who looked at a cohort of patients with dementia that was assembled in the community found a pattern that looked much more like this with many, many transitions that were not at all linear. In fact in this particular cohort, 46% of the participants with dementia actually died at home and only 19% died in a nursing facility.

Next slide. This is also from the same study, and it's a very complicated slide, and I'm not going to spend a lot of time sort of digging into it, but it actually puts numbers on the probabilities of transitioning between one setting with and without services to another. I think one of the other points I wanted to make by showing this slide is that there actually has been some research done on this topic, research done on transitions, especially from the hospital setting but many of those haven't actually included patients with dementia.

Some of the more famous ones such as Mary Naylor's study of transitions for heart failure patients, or even Eric Coleman's study about transitional coaching from the hospital didn't include people with dementia.

I think what's more likely for people to see nowadays rather than a formal research studies and randomized trials is that all hospitals have a very strong incentive now to be developing programs to deal with the interface between the hospital and the community and the nursing home in order to avoid

penalties for readmissions within 30 days. So I think you're more likely to hear about these sorts of things from local hospitals, from CMS demonstration projects, and other initiatives than from things we would find in the research literature.

Next slide please. So this is where a lot of my slides tend to look a lot like Dr. Mitchell's. I have this up here mostly to focus on the points that I'll be covering that have to do with the specific type of advanced directive and working with families on those.

Next slide. And I'll be talking about the first bullet point with the symptom of pain as being a particular challenge. Next slide please. So this again is one of Dr. Mitchell's slides, and I have a similar one in my slide deck that I use. I think one of the things that are really important to point out with the bottom panel about chronic disease and dementia is that it's also stretched out over a much longer period of time and because of that it's much harder for clinicians and families to know where they are on that trajectory.

If you can imagine if you're thinking about a participant event such as pneumonia or urinary tract infection being one of those crises, which is the one that could end up leading to death. So it's a lot harder to know where one's at in the trajectory.

Another point I'd like to make with this sort of slide is that in the cancer scenario if you imagine a patient with metastatic lung cancer, having that patient go to the intensive care unit and go on the ventilator is much more obviously burdensome and unlikely to be effective, but in the case for someone with advanced dementia we're usually talking about things like IV fluids, IV antibiotics and other kinds of treatments that a family may not perceive or a clinician may not perceive as being especially burdensome.

So I think even though ethically the decisions are very similar, I think emotionally and psychologically, they're much more difficult for families to make in the dementia case. I think they're much more likely to feel as if withholding therapy, they are at risk of becoming responsible for being connected to the proximal cause of death.

The other point I make using this slide here is that while we've talked about treatments that are given close to the end of life, if we extend this farther upstream to the outpatient setting there really are a host of decisions that families and clinicians are making with patients with moderate to severe dementia, even things like whether or not to continue cancer screening, what kind of intensity of treatment to provide for chronic conditions like diabetes, high blood pressure, or even how to respond to acute problems such as finding blood in somebody's stool. So I think harkening back again to Dr. Mitchell's slide about ethical decision making, I think I would extend that to many of these other kinds of decisions as to how they should be approached as well.

Next slide please. Okay at this point I'll transition to talking about a specific form of advanced care planning. One of the sorts of knocks on the usual kind of advanced care planning in the literature is that things like living wills are too vague, they're not often clear enough in terms of when they should be applied or to what treatments they apply, they may not be available at the time the treatment decision making needs to be made.

So in many states there is now something that's called the Physicians Orders for Scope of Treatment - POLST, in some states it's called MOST or MOLST, in Indiana we just passed it it's called POST. And what it does is it turns sort of those conditional advanced care planning documents into immediately actionable medical orders.

In many states there may be certain patients' characteristics that must apply before you can fill these out, unlike other kinds of advanced directives. But certainly patients with advanced dementia would be a group that would fit in to this. Preferences to have or decline treatments in most POLST forms there's actually different check boxes for determining what kinds of treatment as well as goals of treatment, so it's a way of really bundling together goals of care, preferences and actual treatment decisions that should transfer with the patients across settings. And in each state that has passed a law relating to this, there's a specific recognizable and standardized form that's used. It also requires the signature of a physician because it is a medical order.

Next slide. So most POLST forms have four sections, and importantly they actually line up quite well with the kinds of treatment decisions that we have to make for patients with advanced dementia as outlined by Dr. Mitchell. Section A is more like a do not resuscitate order. Section B is about various kinds of medical interventions that include things like intensive care, unit care, dialysis, chemotherapy, surgery. Section C is about antibiotics. And Section D is about feeding tubes.

So the people who have helped draft laws for POLST in many states have had our patients in mind when drawing up these forms. The second half of this slide here, the right hand panel is drawn from data from colleagues who've looked at whether or not implementation of POLST order forms led to treatment that was consistent with those orders. And you can see with the exception of tube feeding -- which had relatively small numbers anyways -- that if a nursing home resident had a POLST form in their chart they were highly likely to get the treatment that they requested or that the family requested on their behalf. Importantly these numbers are all much higher than

numbers when you look at a comparison group of usual care without POLST forms.

Next slide please. This is just a map to give you a sense of the way in which this paradigm is spreading throughout the country, it's already out of date because Indiana went live with its program in July of this year and there are others that are approaching having a program's launch.

Next slide please. Now going to the transition to one of the other symptoms that's particularly challenging, and it's challenging both for clinical care and for research. I think it's important to first recognize that the people who have dementia are elderly, and they are likely to have multiple other chronic medical conditions. They're really not healthier than other people, and many of the conditions that they are going to have are going to be painful.

We have no reliable evidence that pain sensation is significantly diminished in dementia, and there is strong evidence from multiple studies that pain is under-recognized and under-treated in older adults, nursing home residents, and patients with dementia both in the community and in the nursing home setting.

Next slide please. When we turn to trying to assess pain, if you are thinking of the nursing home residents that were in the CASCADE Study described by Dr. Mitchell, you can imagine that there's very little help from our usual way of being able to directly inquire from the patients whether or not they're having pain and have them rate it on some sort of scale from 1 to 10 or something like that.

The website that's at the bottom of this slide is from City of Hope, they have a really wonderful website that's kept up to date on a whole number of different

tools for assessing pain in older adults who are nonverbal. I think even especially once you start moving upstream from the residents described by Dr. Mitchell it's still worthwhile to try and get a verbal report from the patients about their current pain even if they aren't able to report their memory of pain and how it's been doing over the last couple of weeks.

We tend to use a proxy report from a family caregiver or in the nursing home from a staff member who knows the resident well. It's important to think about actually looking at the individual when they're moving and looking for nonverbal indicators of pain such as grimacing, holding themselves stiffly in a particular way.

We try when the patient is still residing at home to have a family caregiver work with us to do these kinds of assessments and help inform us about pain. And sometimes the family caregiver can even tell us what the patient tends to do when they're in pain. They may have their own specific pain signature or type of behavior that is a clue that pain is at the underlying cause of what's going on.

Next slide please. I show this item, the Iowa Pain Thermometer, it's one of the tools that's on the City of Hope Web site, I think it's useful because it's been used with patients without cognitive impairment, patients with cognitive impairment, and it's one of a few tools that's actually been used in a diverse population including Whites and African Americans, and found it had reasonable performance characteristics. Another one that you'll see if you go to the City of Hope website is called Pain AD, that's one that many experts seem to think has reasonable performance characteristics for the nonverbal patients.

Next slide please. In some of the work that our group and others have done I think it's worth pointing out that asking family members or caregivers to rate how well a patient is feeling with respect to pain has some special challenges. When we asked patients who were still verbal and caregivers to rate the patient's current pain there was fair amount of discord between their ratings, and there tended to be a systematic shift with the caregivers rating of the patient's pain being higher than the patient's self report.

Importantly we also found that the caregivers were more likely to say the patient had significant pain if the patient was either agitated or if the caregiver was suffering from significant symptoms of depression. So rather than assuming that you're getting an accurate read from a family caregiver on how much pain the patient is having, it's important to recognize that that's being filtered through the lived experience of the caregiver, and if they're having significant burden or depression that may be feeding into their rating. So I think it makes it much more complicated than in cognitively intact patients.

Next slide please. That said I still would urge people to have clinicians and family members try to get a report from the patient, supplement that with the caregiver report, certainly apply state of the art treatment which would include doing around the clock treatments of analgesics for any kind of serious pain and not prescribing it as needed.

Prescribing as needed pain medication for someone with cognitive problems is even less effective and it's not effective that well in patients who are cognitively intact. And many experts recognize that because of the difficulty of sorting out whether or not pain can be a precipitant of some challenging behaviors, many groups encourage an empirical trial of analgesics for challenging behaviors.

I think when you get to the question of what medications to use for treatment of pain, I think that's also very challenging. There are very few studies that have actually looked at different types of treatment, whether that's non-pharmacologic or pharmacologic, and there are many problems now with using either non-steroidal agents in our older adults, and certainly we're concerned about the use opioids as well. So not a lot of choices, that make this even more complicated.

Next slide please. I'm going to talk a little bit about a couple of projects that our group did about trying to integrate palliative care into the ongoing care of people with dementia in the community setting, and that will segway into talking about hospice as well. The Palliative Excellence in Alzheimer's disease Care Efforts, the PEACE Study was funded by the Robert Wood Johnson foundation, and tried to implement advanced care planning, symptom management, avoiding burdensome treatments in a collaborative care model in the outpatient primary care setting.

Next side please. Collaborative care basically means that we did not take the patients out of their usual primary care setting but had a special team and providers who would interact with both the primary care doctors as well as with the patient and family in the home care setting. In a lot of these studies that have been done around other kinds of issues the key features include that special team proactive assessment and management, standardized protocols, and web based tracking of the population being followed.

Next slide please. So in our study we followed 150 people with dementia at various stages, 34 of them died over a 2 year period. We collected another 100 cases of people in our outpatient practice who are not enrolled in the study and started looking at some of the important outcomes. You can see here that in fact, especially with our small numbers we didn't achieve very significant

differences, but what's important to note is in the particular practice that we were studying most of the patients were already dying at home whether they were getting care from the PEACE program or not.

Next slide please. Importantly in both groups we were already discussing hospice, and enrolling many of the patients in hospice, and having many of the family caregivers understand the complications that Dr. Mitchell was talking about so they were expecting the patients to die from their dementia.

Next slide please. Another way of looking at the groups that we studied, however, was to look at the role of hospice since it appeared that one of the things that our practitioners were doing fairly well whether it was within the PEACE program or outside of it was referring patients to hospice. So we looked at the outcomes for patients who were enrolled in hospice compared to those who did not get hospice care. And this is much more revealing, you can see from this slide that people were much more likely to die at home with hospice care, much more likely for that to be their location of choice, much more likely for the caregivers to say that they got excellent or very good care compared to those who did not get hospice care.

Next slide please. And when we looked at this in more detail adjusting for various other variables you can see that getting hospice care made it really far less likely that the patient would die in the hospital, and again 10 times more likely that they would die in their location of choice, and though it didn't reach statistical significance the trend was towards having pain better treated with the involvement of hospice.

Next slide please. So hospice is something that our group, based on this and many other studies, really sees it as something that is highly beneficial to patients with dementia and their families. So we in fact when we do our

advanced care planning with families really do talk about hospice as an eventual way of caring for people, that there is going to be a hospice in their future for the most part.

We do know from this study by Susan Miller Brown, and there are others like this that have looked at the trends for hospice use, and we've already started hearing some of the questions about it, that hospice use has dramatically increased over the last 15 years or so, the enrollment of residents in nursing homes in hospice has essentially doubled over a 7 or 8 year period, and the numbers of diagnoses that are no longer a cancer has greatly increased with a great percentage of these being either dementia or another term of frailty and debility that can be an admitting diagnosis for hospice.

And this is true also not only within the nursing home but outside of the nursing home as well where dementia is, has become a more common primary diagnosis accounting for something like 13% of all admissions to hospice in the United States. And as we've already mentioned it because of this tremendous growth and the increase in the expense to the Medicare program, various policy groups and CMS itself is starting to look at whether or not they need to change either the program or how it's paid for especially since many of the patients with dementia end up having long stays on the hospice benefit.

I think it's also worth pointing out that even though that's a concern for most policymakers there still are a tremendous number of referrals to hospice that are still made very late in the course of the illness and late in the game, so that of most hospices around the country we're talking about a median length of stay that's gone down sort of year by year so where it's now below 20 days, and many patients with dementia also have short stays if they get enrolled once they develop a complication like pneumonia.

Next slide please. Okay so to summarize, while I certainly haven't covered all of the topics or the research that's out there, I think it's fair to say that we actually know less about improving palliative care with people with dementia in the communities, having been in the nursing home that it's a very challenging issue for many reasons, whether they're conceptual, clinical or health system issues, including the fact that when patients are living in the community setting we're still relying on the family caregiver to be the one helping us to provide palliative care at home.

Excellent palliative care however is quite attainable as we saw from some of the slides both Dr. Mitchell's and the CASCADE study and others, as well as our PEACE Study that with advanced care planning, attentive symptom management and integration of palliative care principles into ongoing care this is quite feasible, and that hospice can and should play an important role in providing palliative care to patients with advanced dementia. Next slide. And that's it for me.

Amy Wiatr-Rodriguez: Great, thank you so much Dr. Sachs. We have had several questions coming in through the chat feature. We'll try to take two related ones just right now and they're both on the topic of POLST. One question from Yvette is that, "Is POLST to go along with Five Wishes or replace it?" Five wishes or other types of advanced directive kind of forms?

Greg Sachs: That's an excellent question. I think that in most states most kinds of documents like Five Wishes aren't really treated necessarily as something that's enforceable as a medical order across settings of care, whereas if you live in a jurisdiction that has something like POLST, it's something that would be recognized not only by the nursing home staff, by paramedics and then people in the emergency room in the hospital. So I would think of it in many settings as something that could be supplement to other forms of

advanced care planning. You do however have to look at the specific laws within a given state as to whether or not they say that it would essentially trump another form of advanced care planning, because in some states that is the case.

Amy Wiatr-Rodriguez: Great. And we'll do just one more from Jennifer, she was saying that she had inquired about a POLST form in Michigan and was told by a physician that Michigan only honors POLSTs in nursing homes, and she's wondering if there's a move to have POLST forms to be accepted in community based settings?

Greg Sachs: That's another good question. I think in most states where these laws exist they're not confined to one setting or another, and in fact one of the drives to have them adopted was to be able to handle transitions in care of cross settings and to overcome the problem of having advance directives that somebody has in their safety deposit box or in a chart at the nursing home that doesn't travel to the hospital, the POLST form would travel and would be recognized. So I think most states, in fact legislation doesn't restrict it to one setting or another. I think much of the research that's been done so far has actually focused on the nursing home setting, however, where the use of the POLST form is prevalent in those states.

Amy Wiatr-Rodriguez: Okay thank you. And I know we're getting others, other comments and questions coming in through the chat lines but in the interest of time we are going to move on to our final presenter for today's session, and that is Greg Link with the Administration on Aging within the Administration for Community Living, and he's going to talk about the opportunities for and resources provided by the Aging Network for individuals and their family caregivers related to advanced stage dementia and palliative care. So Greg.

Greg Link: Great, thank you Amy. You can flip it to the next slide please. And I want to thank you all for the opportunity to talk with you for just a few minutes about what I see as some of the opportunities for the Aging Network and the programs and services that are so readily attached to the network and address some of the opportunities for better advancing care in advanced stage dementia.

We've heard from both of our presenters that there are some distinct considerations for care of individuals with advanced dementia, especially when it comes to providing that palliative care and supporting these individuals and their families during advanced stages of illness.

And so what I'd like to do is spend just a few minutes highlighting several of the broader program areas that are under the aging network's purview and discuss some of the logical touch points, if you will, between the services that are most readily associated with our network and to that of advanced dementia and other types of palliative and perhaps even hospice care.

I think one thing that was kind of stark to me was -- I think it was Dr. Sachs who pointed out -- that there's really not a linear path between home and nursing home, and so I think the Aging Network has a really clear role to play in that, and I consistently heard a number of terms and phrases used in the remarks of both of the previous presenters that talked about setting goals for care, planning for care, supporting decisions, family support, and I think given the Aging Network's growth and expansion and increasing sophistication over the past several years, I think we have a real opportunity here and I wanted to talk about that for a minute.

Next slide please. Now I know that we have a lot of folks who work in the Aging Network listening in, but also for those who aren't familiar or so

familiar with the Aging Network, I wanted to spend just two seconds talking about what the Aging Network is. It's anchored by the Administration on Aging which is housed here within the Administration for Community Living.

Our main authorizing legislation is the Older Americans Act of 1965 and its subsequent reauthorizations. AOA funds through formula grants 56 state and territorial offices on aging, who in turn in most states fund through a formula, area agencies on aging at the more local or community level.

And then from there we have a network of thousands of local service providers that do everything from providing senior center services, to transportation, to meals, caregiver support services, and so on. And in addition to that -- and I'll talk about that in a moment -- the vast network of partnerships at the Aging Network is so adept at developing and nurturing and really building off of. And then of course I cannot forget the volunteers that make up a significant part of the Aging Network.

So next slide please. So some of you might be asking, well, why does the Aging Network need to consider this issue, when someone reaches the advanced stages of illness like dementia we just refer out for palliative or hospice services. Others might be thinking to yourselves well we've already ventured into this arena, but maybe we're missing something and I'm hoping that we can, you know, come up with some ideas for increasing the partnerships and the level of collaboration that we have.

When we consider really what's necessary to support individuals and families in caring for someone in the later stages of dementia, I think many of you will agree that the Aging Network's very central mission of supporting person-centered approaches and choice means that we can and should support the entire continuum of aging of an individual's life as well as offer supports to

their family members as they look to keep their loved ones at home for as long as possible.

So in thinking about a potential programmatic touch points for the Aging Network, I believe we can think of them in terms of our work around planning and program development, that is when we conduct community needs assessments or we develop state and area plans to what degree are we thinking about the Aging Network's role in supporting advanced care for persons with dementia and other types of long term illnesses, and how are we going to address it directly and, you know, what level of partnership and collaboration are we going to need to do to make that a reality?

So in the next few slides I just want to lay out some of the major program areas that currently are under, currently administered by the various components of the Aging Network, whether it's the state unit, or the AAA or the provider organization. And I've tried to arrange them in such a way that we begin with the access points to our network and end with how our network supports individuals, supports and advocates for individuals who are in long term care facilities.

So next slide please. So information provision and access assistance as those of you who work have worked within the Aging Network know that that's one of the mainstays of our work, it's been around for decades. And whether we're talking about basic information and referral or the more complex and comprehensive structures that have been recently supported by the development of ADRCs, to the provision of very specialized options counseling, I think we need to begin to think about how that can be supporting effective care transitions and how single entry points or no wrong door programs can play an integral role in supporting individuals with advanced stage dementia as well as their family members. Both with understanding

what it means to need advanced care, palliative care, hospice care, and how to then gain access to those programs and services.

So for I&R in its most basic might provide information and make referrals on the programs and services that are in the community, similarly ADRCs can offer a more structured approach for helping consumers and their family members access programs perhaps through more formalized assessment and care planning activities, to actually assisting with applications or arranging for referral to programs. Likewise where options counseling programs are developing, to what extent is this issue in the list of possible discussion topics for options counselors to explore with the people that they're interfacing with.

And finally in talking about that no clear linear path from home to let's say nursing home. I think because we're seeing such a great deal of growth in care transitions programs between different healthcare settings and home to what extent can these care transitions programs consider this issue and envelop this issue in the work that they're doing to provide the necessary supports to persons with these long-term illnesses and their family members.

Next slide please. Another potential and perhaps quite important touch point when considering supporting advanced stage dementia or the palliative care needs of older persons is the role of the supportive services that are authorized under Title III of the Older Americans Act. Those programs and services that are the most often visible and recognizable aspect of what we do I think also holds some potential for addressing some of the more specific needs of individuals and their families supporting advanced dementia.

For example in 2012 the Aging Network reported spending around \$50 million of Older Americans Act funds for services like personal care, homemaking, and chore, and another \$25 million for case management

services. So to what extent can these services be enhanced or used in a way that most effectively supports the needs of these individuals and their family members and be used as an extra layer of support and maintenance of an individual in the community?

You know if the case manager is doing an assessment of either the consumer, the older consumer, the family caregiver, or both to what extent is the assessment looking at the current needs for information, for referral in this area, to what extent are personal care and chore and other supportive services able to work with or augment other services, palliative care services, hospice services, to what extent can they work together on behalf of the family unit?

Also in our nutrition programs, you know, the highest expenditure under the Old Americans Act we'd heard earlier on many of the eating difficulties persons with advanced stage dementia have. So what role do the nutrition programs and services play in supporting the types of diets that are necessary to allow someone to stay at home versus go to a facility, you know preventing that aspiration that we heard about, to what extent can non-OAA funded nutrition programs provide the supplements necessary to keep someone with advanced illness, you know, their weight constant or meet some of those other more critical nutrition needs.

Next slide please. We've heard and read, you know, everywhere that family caregivers are the backbone, or the foundation, or the bedrock of our nation's long-term care system, and I think nowhere is this more true than in dementia care. And often times as we near the end of our life, family members are there, they're providing support, and they need support as well. We know that they play an important role in providing and supplementing the care that's provided to individuals, and as the National Family Caregiver Support Program has grown and evolved over the past 13 years or so, each of the core

services of that program, the information, the assistance, the education, the respite and the supplemental services have evolved in an attempt to meet the growing complexity of caregiver needs.

So I would offer that to the extent possible one of the opportunities for the Aging Network is to explore how can the service package that has developed under the National Family Caregiver Support Program be grown and expanded to include other service areas. You know, as our understanding of the needs and preferences of family caregivers have grown over the years we know that the needs, that those needs of the family caregivers have grown more sophisticated.

For example our most recent, AOA's most recent survey of family caregivers served by the Caregiver Support Program shows that caregivers served by that program most often need information on complex issues like medication interactions, program navigation and the benefits for which their loved ones might be eligible and including legal information. So to what extent are we ensuring that the information that we have on hand for family caregivers includes information about advanced stage illness and palliative care.

And similarly how well is the Caregiver Support Program connected to providing connections and supports to advanced and palliative care. You know, if caregiver assessments are a standard feature of access for caregivers to access Caregiver Support Services, are caregivers assessed on the extent to which they may need this type of information or support or additional support during their work in the later stages of caregiving?

And what are the opportunities to perhaps tailor and adapt some of the support groups in caregiver education programs around topics of advanced care and palliation. You know, we talked about helping teach caregivers to assess pain

of the care recipient and I think, you know, we may have some opportunities there.

Next slide please. Another potential and likely touch point for the Aging Network programs and services to that of advanced dementia palliative care is to the legal services programs that have grown out of Title VII of the Older Americans Act. No doubt that many of the legal services providers spend a great deal of time assisting with advanced directives, powers of attorneys, living wills, et cetera, so to what extent are legal services and programs and providers tailoring information and assistance to older individuals facing the types of decisions that need to be faced during the advanced dementia care or to the families that are struggling with the many decisions and choices that have to be made, often times very quickly or, and in response to, you know, a rapid deterioration in the disease and now need to act now as opposed to planning for the longer term? So to what extent can the legal services interventions that we have in place be grown to include this and perhaps many of them are and that would be great. Next slide please.

Amy Wiatr-Rodriguez: Greg this is Amy. I just wanted to say that we're right at the end of our allotted time but we, so we'll still get through the rest of your slides, and we'll do some Q&A for those of you who are able to stay on the line. Again, apologies that we're running over.

Greg Link: Okay all right I'm almost done. I just wanted to talk briefly about the role of the Long Term Care Ombudsman. You know we talk a lot about home and community based services but certainly the Aging Network has a presence in long-term care facilities. So in the Ombudsman in their triple role as resident advocate, consultant to facilities, as well as state level policy advisors, I think Ombudsmen also are a logical and important player in advanced stage and palliative care.

In support of residents, to what extent are Ombudsman, you know, focusing on complaint resolution to ensure that the care needs are appropriately met throughout the resident's stay in the facility, you know, and Ombudsman can support and help in the care planning process and can help link residents to legal services for the development of advanced directives. And their consultative role Ombudsman can be a resource to the facility as it works to better address and understand these issues. And then finally at the state level as the role is, you know, policy development they can help states explore some of the very complex and myriad issues associated with this.

My next and final side and I'm not going to go into any detail but I talked about the Aging Network and its incredible capacity for partnering. And how the Aging Network although our funding is limited we through partnerships and collaboration have managed over the years to accomplish some tremendous things.

And I think that around this issue of advanced dementia care, palliative care, I think there are some real partnering opportunities and opportunities for the various components of the Aging Network to really look at where the partnerships are strong, where they may need to be strengthened, to what extent for example are the AAA advisory boards looking at this issue in their communities?

How are caregiver and respite coalitions that may be in existence working on this issue and are working in support of it? To what extent are the aging network organizations at the state and community level connected to hospice and palliative care organizations or to Alzheimer's Association chapters and other dementia advocacy organizations in their states and communities to

really think through in a holistic way how the community will support individuals and their family members who are facing advanced illness.

So the last few slides are some resources that we have put together. I just draw your attention to those. I think most are self-explanatory and we've got some websites, some fact sheets, some research studies, so I encourage you to check those out. I will turn it back over to Amy

Amy Wiatr-Rodriguez: Great, thank you so much Greg. And as always there's just so much information and so many good questions and comments to get to. So my apologies for going over but we do want to for as many of you who are able to stay, and we'll take some questions over the phone line. So if the operator could come on and tell people how to get in line to ask a question over the phone.

Coordinator: Certainly. At this time to ask your question please press star 1 on your touch tone phone. You will be asked to record your name. You will be announced prior to asking your question. To withdraw your request press star 2. Once again to ask a question please press star 1 on your touchtone phone. One moment please.

Amy Wiatr-Rodriguez: Thank you, and while we wait for any questions to line up we'll take some from the web chat. A couple of questions have come in kind of along the same lines of if dementia is what is ultimately ending lives, what is actually being recorded on death certificates? If dementia is not being, you know, represented on death certificates, what is? If either Dr. Mitchell or Dr. Sachs are available.

Susan Mitchell: It's Dr. Mitchell, can you hear me?

Amy Wiatr-Rodriguez: Yes, go ahead.

Susan Mitchell: So that's an interesting question. In the CASCADE study which was prospective and we knew everybody had advanced dementia by GDS 7 we did collect these death certificates and, you know, most commonly there were things like cardiac arrest or even pneumonia listed as the cause of death. And in that series of death certificates we had 155 death certificates of dementia.

If anyone has seen the death certificate it has multiple lines that you can put either the immediate cause of death, contributing cause of death, or other conditions. 40% of those death certificates did not have dementia, Alzheimer's disease mentioned any way shape or form even though these people clearly were in the end stage of this disease.

Amy Wiatr-Rodriguez: Great, thank you. Another question that came in, and I believe that this was related to the chart that both of you -- Dr. Mitchell and Dr. Sachs -- had included where it was talking about location of death, and it was comparing to dementia, cancer and other conditions. A question came in regarding if there are similar stages involved in -- as with dementia -- in those other conditions or if there are comparable stages?

Susan Mitchell: Greg, do you want to take that?

Greg Sachs: Sure. I think most chronic diseases do have some form of staging, whether that's cancers, congestive heart failure, chronic obstructive pulmonary disease. They probably are not as widely used among clinicians, you know, in terms of how they talk about it with patients and family members. But I think you can, you know, there is some comparability and certainly for doing research, like when Dr. Mitchell mentioned that patients with advanced heart failure or cancer have a similar prognosis as patients with advanced dementia

that's based on, you know, literature from these different disciplines that do have a staging for the different diseases.

Amy Wiatr-Rodriguez: Great, thank you. Let me check in with our operator now and see if we have anybody on the phone lines

Coordinator: There are no telephone questions, but as a reminder to ask a telephone question press star 1 on your touchtone phone.

Amy Wiatr-Rodriguez: All right. And this is Amy, we still have another couple of questions here on the chat feature. And let me just find the one that I had in mind in particular. I know that we -- especially for Greg Link's slides -- included a lot of resources and we didn't spend a lot of time on those, but they will be available in the materials that are available or that will be posted after the session.

But there is a question just in terms of any ways perhaps Drs. Mitchell and Sachs that you have in talking with families about advanced care planning when families are resistant to doing that, or do you find that if families initially resist, it just ends up being that they're, you know, as proxies they're left to make the decisions down the road? Any tips or suggestions you have on having those types of conversations with resistant families?

Susan Mitchell: This is Dr. Mitchell. I think the majority of families by the way are not resistant, not to say that the conversations aren't difficult, but most families are welcoming of information but there are always difficult families. And I would say two important things: It is not to come in with an agenda in terms of what you're hoping the outcome would be, whether it is a do not hospitalize order or whatever it is. And also to understand that you're not necessarily trying to get everything done at one shot and sometimes it takes, it

almost always takes revisiting the issues over a course of time or as the patient's illness evolves. So it's not a static process, it's a dynamic process that has to respond to different changes.

And one last point is very important with what might be called some difficult families is actually cultural barriers, literacy barriers, not even barriers but different cultural, you know, it's been shown many times that cultural viewpoints play very heavily in how people view end of life and end of life decision making.

We could have a whole talk on that to be cognizant of where the patients and families are coming from and to respect those choices and to bring in when necessary, you know, whether it's a priest or a rabbi or someone else from the community that maybe help deal with some of the problems they're wrestling with from their cultural perspective.

Greg Sachs: I could add to that, this is Greg Sachs. I think one of the key words that Dr. Mitchell used was process, so it's really important to have providers not view advanced care planning as an event like it's something that's supposed to be over and done with. Maybe executing certain documents happens at a given point in time but I think it's really important to see it as a process and for some people it takes many conversations over months and years, other people it doesn't take as much.

And I don't have a preconceived notion that I'm going to get to the same place with everybody. You know, especially when you take into account, you know, when families are struggling with serious illness like advanced dementia it's not like that makes it easier for people to get together and make decisions. So, you know, when people have conflict or issues within the

family they generally get more difficult, not easier, as they're confronting some of these things around the care of a loved one.

So I don't come in with a notion that I have to get, you know, an advanced directive or I have to get a DNR order. I like to make sure that I've given them all the information that I think is relevant for making decisions and then revisit as things evolve over time.

Coordinator: Excuse me, we do have a telephone question when you're ready.

Amy Wiatr-Rodriguez: Great, go ahead.

Coordinator: Thank you. Aruna Bhuta, your line is open.

Aruna Bhuta: Hello. My question is regarding the advanced dementia patient not being on a linear path from home to nursing home. And now the care transition models are being used but those are, it is the Coleman model, mainly on patient activation and patient being involved in making decisions and such. How can the care transitions be responsive to the dementia patients? In addition to the family what else can be done so that they would not be going back and forth from the settings? Hello?

Greg Link: I'm not sure who the question is for?

Aruna Bhuta: The question is, I think there was some discussion about the care transition models that are being used to, you know, kind of decrease the readmission rates in the hospital and that the pathway for dementia patients is not straight from the home to the nursing home or whatever the setting may be. And my question is for, I think Dr. Sachs mentioned about the care transition model and I would like to know as to for advanced dementia patient what, you know,

kind of transition model would be good so that you know they wouldn't be going back and forth.

Greg Sachs: I think that's an excellent question. On the one hand I do think that Coleman's model if you substitute the family for the patient I think that is helpful because then you can think about you are coaching the family about the transitions in care across settings, equipping them with information, and teaching them about the kinds of questions to ask that have to do with the care plan as it crosses settings.

I think the piece that it's missing is that it sort of assumes that patients are going to get better, and the piece that's missing from that model is that some of the patients need these conversations about advanced care planning and injecting more palliative care into their care plan to prevent them from being, you know, readmitted frequently.

So I think that many of these issues if you sort of combine the Coleman model with advanced care planning and discussion about goals of care for somebody with advanced dementia with a predictable course could get, help families get to the point where they would be talking about the kinds of decisions about treating pneumonia, treating other infections, dealing with feeding problems, and so I think that's the piece that needs to be combined with any transitional coaching model.

Aruna Bhuta: Thank you.

Amy Wiatr-Rodriguez: Well with that - this is Amy again and I think we're about 15 minutes past our stated end time, so I think we will wrap it up now. Thank you so much to our wonderful speakers, just wonderful information that you all

shared, thank you so much for being willing to do so and spending time with us today.

Thank you as well to all attendees who joined us and everyone who asked questions and shared comments. If you think of any additional ones or have suggestions for future discussions that we should be having on these topics, please share your feedback with us including on whether you thought this webinar was helpful or not. We do want to hear from you, you can e-mail us at my e-mail address which is [amy.wiatr@acl.hhs.gov](mailto:amy.wiatr@acl.hhs.gov). We will send an e-mail out to everyone who registered when the recorded materials from this webinar are available and that should be in about a week or so. So again thank you everyone for joining us today. This concludes today's webinar.

Coordinator: Thank you. Once again that does conclude your conference call. Please disconnect all remaining lines

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