

NWX-HHS-AOA-1

Moderator: Amy Wiatr-Rodriguez
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Coordinator: Welcome and thank you for standing by. At this time all participants will be in the listen-only mode. After the presentation we will conduct a question-answer session. At that time, to ask a question dial star 1 on your touchtone phone. Today's conference is being recorded. If you have any objections you may disconnect at this time. I would now like to introduce your host, Ms. Amy Wiatr-Rodriguez. 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, Diverse Populations, Health Disparities and Dementia, which is the third in a five-part series.

We are waiting for a couple of our presenters to still join the line using the special presenter pass code, so hopefully they'll be looking at their Chat feature and dialing in with the information provided there. For everybody else, I'll go through just a few housekeeping announcements to get us started.

So first, if you have not already done so, please use the link included in your email 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 emailed you, you can also go to www.webex.com, click on the Attend a Meeting button at the top of the page, and then enter the meeting number, which is 668009432. If you have any problems with getting into WebEx, please call WebEx Technical Support, at 866-569-3239. Again, that's 866-569-3239.

Occasionally people have problems with their Webinar - or Web browser settings. I can't fix that, but hopefully the folks at WebEx Technical Support can. As the operator mentioned, all participants are in a 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 as we can when we take breaks for questions after each presenter. In addition, 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 how to queue up to ask your questions. If there are any questions we can't answer during the course of the Webinar, we will follow up with you. If you think of any other questions after the Webinar, you can also email them to us at amy.wiatr@acl.hhs.gov, or to any of the email addresses that are included in the PowerPoint slides that are the basis for this Webinar.

As the operator mentioned, we are recording this Webinar, and we will post the recording, the slides and the transcript on our Web site as soon as possible,

and everyone who registered for today's Webinar will get an email letting them know when the slides are posted, and other materials are posted.

Our speakers today include Jim Varpness, Regional Administrator with the Administration for Community Living, Neelum Aggarwal, MD, Associate Professor, Rush Alzheimer's Disease Center, Lisa Barnes, PhD, Associate Professor, Rush Alzheimer's Disease Center, Jose Luchsinger, MD, Assistant Professor, Columbia University, Gwen Yeo, PhD, Director Emerita, Stanford Geriatric Education Center, Lori Jervis, PhD, Associate Professor, University of Oklahoma, and Jed A. Levine, Executive Vice President, Alzheimer's Association, New York City Chapter.

At this point, I'd like to turn it over to Jim Varpness to kick off today's Webinar. Jim?

Jim Varpness: Thank you, Amy, and welcome everyone. We're pleased to be partnering today with NIA, National Institute on Aging, and others in this third Webinar series of ours. On behalf of the Administration for Community Living, I want to thank all of you for taking time to attend this Webinar today. Next slide.

The purpose of these Webinars is really twofold. It's to improve coordination of the federal resources available, to assist people with Alzheimer's disease and other dementias, and their family caregivers, and to encourage awareness of research participation opportunities, all of this really in support of the National Alzheimer's Projects Act's aim to prevent and effectively treat Alzheimer's disease by 2025. Next.

Here we have the five goals of the national plan to address Alzheimer's, one, to prevent and effectively treat Alzheimer's disease by 2025, to optimize care,

quality and efficiency, to expand supports, to enhance public awareness and engagement, and to track progress and drive improvement.

I'm happy to report that we've already made some, or had some accomplishments towards some of these goals regarding populations disproportionately affected by Alzheimer's disease and related dementias. Next slide.

The national plan to address Alzheimer's disease required a task force to create a plan of action to address the needs of specific populations. The task force considered the special needs of three subgroups of people. These included the individuals with younger onset dementia, racial and ethnic minorities, and individuals with intellectual disabilities such as Down syndrome.

The task force provided a number of recommendations from key stakeholder groups, that included better screening and detection of Alzheimer's disease among specific populations, increased awareness for primary care practitioners who interact with these specific populations about the increase of risk of dementia, and a better understanding how to help people with dementia most effectively, including how to maintain home and community living.

However, in order to improve conditions for ethnic and racial minorities and other specific groups, we have to overcome a lack of research that has been conducted to date. The simple fact is this, we need more people, and to attract more people from these special populations to participate in clinical trials. Next.

Today's Webinar addresses the experience of dementia in certain diverse populations. We will focus on American Indian, Alaskan natives, African

Americans, Hispanic and Latinos, Asian and Pacific islanders, and lesbian, gay, bisexual and transgender people with dementia and their families.

Future Webinars will focus on younger onset dementia as well as advanced stage dementia and palliative care. Last month's Webinar, as you know, addressed dementia in people with intellectual or developmental disabilities, including Down syndrome. All materials will be archived at the Web site on this slide, and everyone who registers for each Webinar will get an email notifying when these materials are up and posted on our Web site. Next.

Finally, one recent development I'd like to share is that just a few weeks ago, the Health and Human Services department selected a team comprised of ACL, NIA and CDC to participate in a special project to support innovation. Recruiting Older Adults into Research, or ROAR, will address the issue that clinical trials and studies that test therapies to prevent or cure disease like Alzheimer's urgently need volunteers.

Their research often struggles to find participants to fill these trials, resulting in delays or cancellation and substantial waste of resources. And as you will hear from the following speakers, more research on Alzheimer's and other dementia is critically needed. And more research, including participants representing diverse populations, is key to address the threat of Alzheimer's and other dementias.

Today's Webinar will address current and future research directions and opportunities, as well as resources, when working with certain populations. We look forward to hearing the thought provoking presentation ahead, and I want to thank you for your interest in today's session.

Amy Wiatr-Rodriguez: Great. Thank you so much, Jim. And we're going to keep things going, and next we're going to hear from Neelum Aggarwal with Rush Alzheimer's Disease Center, who's going to give us an overview of the scale and scope of issues, as well as research directions and opportunities and specialized resources. So Neelum, I'll turn it over to you.

Neelum Aggarwal: Oh, thanks Amy, and welcome, everyone to the Webinar series. I am so pleased to frame this discussion on issues of health disparities and dementia in diverse populations, and Jim mentioned subsequent presentations after we are going to delve a little bit deeper into the discussions for each of the groups that he outlined. Next.

Typical housekeeping, the disclosure information is listed there for you. Next. And objectives, I'm going to really go through four objectives in today's presentation, the first being an overview of the aging population, then move over to latest research trends. Opportunities and challenges are important to discuss, and then also the thinking about what we can do with potential solutions. Next.

Now, if you take a look at this slide, it is typically the slide one sees quite a bit when dealing with aging populations. The main thing is just to realize, visually, that the 85 and older age group is really the population that is increasing in size and number. And that has implications for the country. That has implications for many people who do work in this area. Next.

If you take a deeper look in, though, with regards to race and ethnicity, you can see that - a couple of things on this pie chart, and one of them is that the older population is becoming obviously more racially and ethnically diverse over the next 50 years.

And when you look at the non-Hispanic white population, which was 84% of the population in 2000, over the age of 65, it's expected to decline, but we're also now having gains in other ethnic groups on, basically, the African American, the Asians and a little bit of a gain in our Native Americans. So you can already see how the pie is shifting, if you will. Next.

Taking a look at Alzheimer's disease specifically, again, the trending is very large, and showing to large numbers of developing Alzheimer's disease. And one way to think about this is that Alzheimer's is really projected to quadruple to about 16 million by 2050, a staggering number for the U.S. By the way, this is also occurring globally, so these numbers are quite high. Next.

One area that is emerging and for many people, we're watching this trending, the lifetime risk for Alzheimer's disease. And it appears that the incidence of the disease is higher in women than in men, and in the past the thought had been that, well, women are living longer, so the higher longevity could be the reason.

We're taking a better look at this, though, and just to keep in mind that there may be some specific pathogenic mechanisms to explain the higher incidence of these cases. So that's something to keep an eye out for in the future. Next. Now, moving into the next part of the presentation, it's really highlighting the latest research trends that have an impact, studying the course of dementia in diverse populations. Next.

And in this way to think about this area or at least this section of the presentation is, what are we trying to accomplish with diagnosing, or how are we approaching diagnosing Alzheimer's disease? Jim mentioned that there are some criteria that we've been looking at, and we've had a revamp, if you will, of the diagnostic criteria for Dementia and AD.

And there were really four main goals with that revamping of these diagnostic criteria. One was to define the natural history, relate the clinical symptoms to underlying pathophysiology, use present knowledge to gain a better diagnosis of the disease, and diagnose the disease, and then to - really to define a research agenda.

The other thing that's important to realize is that this redefinition was really trying to make the criteria more accessible to primary care and to maybe non-specialists who are seeing people with dementia. Next. So visually, one can think of what we're trying to do in this slide, that really kind of goes right from an intervention stage to treatment, primary prevention.

And if you can take a look at this progression, we tend to speak about the disease in progression, and therefore the research opportunities are coming at all of these touch points in this slide. Next.

One other thing that's important to know is the clinical definitions of dementia past and present. So right now, for past, you know, we had a typical definition of a decline from some previous higher level of functioning, interfering with work or usual social activities was the definition. But frankly, there were a lot of issues that physicians, practicing physicians and healthcare providers had with really trying to understand where do comorbid medical conditions play in here and what is the impact of them on the two principles above? And also relationships now, with multigenerational relationships, marital and child-parent relationships, what is the view of a cognitive issue in these relationships? Next.

So the new definition, if you will, of dementia is pretty well the same. And below you can see the reference sent for the article, and I would suggest if you

haven't read it, I would suggest reading it. But it's really, again, keeping the two main features, cognitive decline, but we're now putting in behavioral symptoms more into this definition. And also the work or usual activity impairment is also a mainstay.

We have issues with memory, executive functioning and other, you know, neuropsychological domains, if you will, but we're really still focusing on the two key areas above. Next.

Now, the Alzheimer's diagnostic criteria past, we really wanted to focus again, and we used to focus quite a bit on this memory. And memory would be the first thing that was impaired, and then other cognitive functions would follow in declining. Next slide.

One thing to take from this new present criteria is that memory, yes, it's important, but we are realizing that many people are not presenting, typically, with memory in the beginning. And this is something that we're seeing, that there are different presentations that can be occurring, and now you can see, if you take a look at Point B, clear cut history of worsening cognition by report or observation, and the memory issue, although there, is not the number one presenting symptom, which I think is important.

The other area I highlighted is that we are now using biomarkers, and introducing the concept of a biomarker or a longitudinal type of a, maybe an imaging marker to help us in diagnosing. And this is going to be very important in the future. Next.

So, moving into Alzheimer's, dementia and diagnosing, I have to talk a little bit about the issue of possible Alzheimer's. Because again, many of our cases, and specifically from minority populations and diverse populations, many

people fall into this area where we're not sure if it's Alzheimer's because we have cerebrovascular disease or we have some other neurologic or non-neurologic medical comorbidity that may be occurring.

And this is something that, you know, to take heed of, and to make sure that even though this may be occurring, it can be Alzheimer's disease, and to really kind of push forward into really going to clinical eval to make sure that we are really trying to pick up that decline, and not getting lost into the possible AD category. Next.

Now, mild cognitive impairment is an important area and focus for research, especially in our minorities, because it - in the past it's been talked about as an intermediate or a gray zone. And impairment in one cognitive domain, usually it's in recent memory, but there are definitely other domains that can be affected. But independent functioning is the key, and neuropsychological cutoff scores have been used in the past. Next.

The new definition for MCI really is taking a look at a change in cognition from prior level. Again, we have one impaired domain, but many other things are important - next, that could be helpful in an MCI state, is that the functional ability of a person should really still be able to be performed without any problem, non-demented. And this is the diagnosis that, from a research perspective, we're really trying to look at in our minority diverse populations, because we feel many people may be falling in this category. Next.

The clinical - Alzheimer's disease, as mentioned before, it's really looking at a research criteria, operational research criterias, and this is something that we're spending a lot of time on in the research world, how are we best able to diagnose pre-clinical AD. Next.

Having said all that, you can imagine we do have challenges to the physician, the practicing physician, in addition to the researcher, because there is still confusion. Next.

One of the areas of confusion has to do with this concept of what is the normal aging process and the myth of forgetfulness, well, it's an inevitable consequence. I'm happy to say that this is changing. Working with many of my colleagues, and colleagues on the call that are really out there trying to get the message, this is not an inevitable consequence. But it still persists. The other issue is that everyday forgetfulness occurs in a lot of people. And when that happens, the result is, well, I don't think it's that big of a deal.

So the term MCI is going to be very important to start using more and more to get people in tune that there is an issue here, and that this is something to take note of. Next.

Now, word from the field - I use the word field, and in Chicago, me and my co-presenter, Dr. Barnes, we're in the field quite a bit. We do a lot of community work in our research. And here are some of the quotes that I've heard over the years.

"Dr. A., no one dies from having AD." Well, we know that's not true, but that's what's happening in the field, at least people are talking about it that way. "Dr. A, there's no way to stop the disease when it starts, so why go through the trouble of getting treated with a memory medicine?" Again, some of these beliefs are changing, and these views are changing, but they're there.

And then the last thing that I'll be talking about is - later in my presentation, is the trouble of thinking it's really because of strokes and stress. And that's an

important concept, and I think that's an important take-home for our minority populations about the strokes and stress, and (unintelligible). Next.

So when you think about obtaining care for Alzheimer's disease and dementia, one of the things is, as you know I - a geriatrician and neurologist may be the place right in the middle of this triangle, if you will, of the hierarchy of where we can get treatments. Hospitals, private practice, group practices, this is where people may come in, and frankly, here is where the criteria, the new criteria may be applied or not applied. Next.

But if you really think about what's happening, it's that it's the academic centers that are really utilizing the new criteria, and they're at the top of the peak, if you see that. Minorities are really being seen and met in large numbers in our urban clinics, in the rural areas where they live, and they're going to the primary care and the physician clinics, which may not be using these criteria as easily as we would hope they would. Next.

The other issue that is occurring is diagnosing issues. This slide is a good slide because it really shows you in a way how many neurologists may think - and other clinicians may think about diagnosing someone with cognitive issues. The goal is still in - is to rule in or rule out a dementia, not really to diagnose AD, and all of these other types of dementias are what we're thinking about when we see someone. So we have to start to change a little bit of how we're thinking about diagnosing, and where are we going, especially with MCI. Next.

Both of these issues with the care - access to care and the diagnosing really results in people coming in later to be seen, and we've seen that, and I'm sure many people on the call know this, that many of our minorities are coming in at a later stage of the disease. Next.

Now, the other thing that's important is when you think about research trending again - next, is to think about what are the risk factors for dementia. And I've just listed a few of them. They're multiple, but if you notice, I've put the cluster of cardiovascular conditions that are really seen in large numbers and high numbers in our minority populations.

And one thing to think about is when you have such a high load of these types of risk factors, the physicians themselves are really dealing with managing those conditions on a regular basis, and that takes up a lot of time. And the patients themselves often will say, no doctor is really managing the medical condition, and they're really not talking about signs and symptoms of MCI or early AD. Next.

Other risk factors that are known to many people on the call, I'm sure, is, you know, the obesity, the overweight issue we have in our population, sleep issues, physical fitness, dietary. Again, a lot of these conditions have really serious potential health related issues and, you know, comorbid and mortality issues - next, and that is really what's keeping a lot of our physicians busy, if you will, with diagnosing or managing their patients.

I'm throwing in two slides, in the following two slides, to just highlight what's going on with stroke, because a lot of the conditions I've just went over are implicated in stroke. And you can already see here the stroke adjusted death rates are very high. African American are quite high, and the Asians are also surprisingly high. Next.

And so the stroke mortality seems to be something that's playing into a lot of the work we're doing in the field, and when we work in minority populations and you - this is a very common slide about the, basically the stroke belt here

in the U.S., where you can see the stroke mortality rates, and the Southeastern region of the U.S. is remaining quite high. Next.

Now, if you think about research and what we can do and where we should be thinking about focusing our efforts, there are really three cornerstones, if you will, to think about how risk factors and areas could be looked into. And of course at the top, we have our age, sex, race, our typical demographics, genetic profile, medical conditions, immune status of our people.

But if you start now to go into the environment, neighborhood, social contact, psychosocial factors, pollution, housing, that's all becoming increasingly important as psychosocial determinants of the health. And then if you go into biologic, which is bacteria, alcohol, smoke, trauma, it's increasingly becoming an area that we're looking into, and nutritional aspects can all affect persons and whether or not they develop dementia or AD, and may be very important in our minority populations. Next.

Moving on to three, the...

Amy Wiatr-Rodriguez: Neelum, let me just interrupt, if you're - if there's any way you could speak up a little bit...

Neelum Aggarwal: Sure.

Amy Wiatr-Rodriguez: That would help, thanks. Okay, go ahead.

Neelum Aggarwal: The other thing is with - moving - next. Yes. Discussing some of the opportunities and challenges, now you notice I put opportunities and challenges together. They go hand in hand. And working in the field that you have to recognize and realize that this is always going to be a challenge in

many cases, but when you overcome these challenges, the opportunities are tremendous. Next.

Here is what we're dealing with, and we are dealing with multiple areas and issues that really people are being faced with when they're out in the field working in this area, or in their institutions, the demographics, unequal access language, healthcare quality, culture. Next.

And one of the things that is really important to think about is this health disparities, and how it really can affect participation in studies, participation in clinical trials, observational studies, participation in general. There are many socioeconomic differences that can be noted.

One of them - and education and behavior, from our populations, but one that I'm going to focus a little bit on is this lack of trust issue. Next.

When you think about barriers that lead to lack of trust or mistrust, this is a nice way to conceptualize this. We have barriers to awareness, opportunity and acceptance. And all of these areas may not be occurring in one person, but they are - can be a - they can be occurring with the person on multiple levels, or with the community that one is actually working in. Next.

The one thing that I would like to point out, distrust exists in all of our ethnic groups, and that's something to keep in mind. For African Americans, we have the history of the racial discrimination and exploitation, with the Tuskegee study and also with Henrietta Lacks' story, which is - I'll mention at the end of the presentation. Also, a lot of good info from Dr. Corbie-Smith has really talked about African American beliefs with the medical and healthcare system, especially with doctors, and what doctors would, you know, ask people to participate in and not explain research.

I think these are two areas of really potential improvement for us, continuing improvement. Next.

Now the other thing is, okay, how do we manage this? How do you manage mistrust in the community? And a couple of things on the slide are, you know, fairly obvious, but this isn't - you know, sometimes we lose this. You have to be in the community setting performing the talks and the outreach. You have to know the neighborhood, and you have to know the issues that are facing the neighborhood, very important. Also, talking about topics that are relevant to the community and the health concerns, and be very careful of the world trial or study. This is an important concept. Sometimes there are negative connotations for these words, and you have to be careful in understanding where the community is with these two words. Next.

Other things to consider about is health literacy. This is becoming a very, very important area in medicine. It is the strongest predictor of health status. It is stronger than age, income, employment status and education level. And it's just a lot more than being able to read. You have to understand the information presented. So therefore, clinical care, study consent, all of that is very important, dependent on literacy. It impacts everything. Next.

Now how to manage that, the physicians, the whole healthcare team really needs to understand the importance of literacy and what we can do to basically improve our ability to communicate so we can avoid the outcomes.

Here is the thing, if we can improve our health literacy and our ability to be competent - next, we will have people coming in studies, participating and staying in studies. Communication is very important. You need to learn the language of the community. You have to understand the words. And the

teach-back and show-me techniques have been used in medicine for a while now, to try to gather a sense of understanding. Next.

The other thing that's important is clinical trials. Some of the things on the slide that I have pointed out are really important. What is a trial? How are they run? This has to be explained, and in our experience, it's not explained well enough a lot of times, so people aren't understanding what's being involved with the trial. Next.

Cultural competency plays into this, and again, there are different definitions of cultural competency, but really it's a set of behavior and attitudes that people - are embedded in systems and used by professionals. And it requires a reality-based examination of the stereotypes that we may have, as a group and individually. Next.

How do you become culturally competent? Well, basically, understanding the environment that we're dealing with, where people are living, and also the diversity and how the whole team is important in becoming competent. Next.

Consenting is a big issue, and consenting for trials is one of the things that we do a lot of here. And one question and one thing I always try to frame the discussion is, what have you heard about research as it relates to this issue? And I think that's a nice way to frame it, and then deal with the consenting issue after that. But what have you heard, to the patient family, can be very helpful. Next.

Now, some solutions to highlight, with some of these challenges - again, these are challenges, great opportunities, but we need some solutions. Next. And one of them at Rush has been utilizing Lunch and Learns, which I'm sure many centers are using, and many organizations are using. Effectively what

you're doing when you're talking about healthy aging in Lunch and Learns, is you are really teaching health literacy.

And the format we've used is really a roundtable discussion, maybe a few PowerPoint slides, but it's mostly a discussion, and there's a lot of Q&A involved. Principal MD or MD - principal investigator or MD is the presenter for these Lunch and Learns, along with the staff. That seems to be very important, and it continues to be important in our cohorts. Next.

The other thing to think about is home visits. Now, we do a lot of them at Rush. All of our studies, basically, have home visits. And what home visits really do is that you become knowledgeable of the cultural values, family dynamics and social issues, and also the team becomes aware of these issues.

Initially, we performed all these home visits for our observational studies. Now we've extended them to clinical trials. And we have the team that goes out in the field and collects the information, but also interacts with the participant. What it has resulted in is recruitment rates and retention rates that are successful. And once we have our cohort or our group of people that we are engaged with, we're able, then, to follow up based on Zip code or neighborhoods to increase efficiency. Next.

Now, the other thing that's important is, when you talk about recruitment - next, is how does that help with study recruitment and retention? Well, they address the barriers right in the beginning, of the knowledge of what the study is, and then transformation process, they help with that. They help with trying to get the information to people in the community and the home that may be participating in the study. They also guide our study staff and researchers, and they also accelerate the transfer of this knowledge. So home visits have been very helpful from the clinical trial perspective on our end.

Now final comments, one thing to think about is that, you know, the home visit model, obviously, is very intensive but you know what, they work. That's something that if a center can figure out how to do, I would suggest that. The changing demographics of the country, the minorities or - in our communities are really becoming the majority, and many are aging in place. The disparities in healthcare are increasing, unfortunately, and we are seeing much more comorbid medical conditions taking the prominent role.

What this means is, is that the quality of life issues for the patients and caregivers and family is becoming increasingly important. There are multiple issues that need to be looked at and addressed when we're dealing with our communities, and effective strategies have to be multi-dimensional to address the concerns and expectations. Next.

For homework, I have a suggested reading list for everyone on the call. If you haven't read some of these articles, especially the book by Rebecca Skloot, I would suggest that you read this. This is very helpful reading when you're dealing with trying to recruit and retain participant or patients in your communities. Next.

The final two slides are going to be really discussing where are the NIA funded Alzheimer's disease centers, and you can see, from the U.S., we have a variety of locations for our funded centers, that can provide care, guidance and management with dementia and Alzheimer's Disease. Next.

And also, this next slide really tells you where the areas of focus are for our centers, so we would have - under-represented groups are listed, and specific populations. I think I'm going to wind up my presentation on this last slide, and hand it back to Amy.

Amy Wiatr-Rodriguez: Great. Thank you so much, Neelum. This is - there's so much wonderful information here, and we're ready to get even more. I'm going to turn it over to Lisa Barnes with Rush Alzheimer's Disease Center, talking about some African American perspectives in terms of research participation. So Lisa?

Lisa Barnes: Thank you, Amy. Good afternoon. I'd like to thank the organizers for inviting me to be a part of this Webinar, and I'd like to thank Neelum for setting up a really nice framework for my discussion. Next slide.

A growing body of evidence suggests that African Americans are about two times as likely to have Alzheimer's disease and other dementias. This slide shows data from a community-based epidemiologic study called YCAP out of Columbia, and it shows the estimated prevalence of Alzheimer's disease and other dementias in three ethnic groups by age. And what you can see is that older African Americans are proportionately more likely to have Alzheimer's disease and other dementias, compared with older whites.

What I plan to do during my presentation is to present some of the work that has been done across the field to address this issue in African Americans, and then I'll present some of the work we've done at Rush as an example of where I think the opportunities are for advancing our understanding when it comes to African Americans and Alzheimer's disease. Next slide.

Now, as you heard in the first presentation very nicely, there are many challenges to diagnosing Alzheimer's disease in diverse populations. In fact, there are significant barriers to both detecting dementia, and providing an accurate diagnosis. In the interest of time, I'm only going to focus on a few of these, including structural, cultural and medical factors. Next slide.

But the crux of the problem, I think, is how we have been diagnosing Alzheimer's, is that we've been relying heavily on performance on cognitive function tests. And it's pretty well established that older African Americans perform more poorly on average than non-Hispanic white elders.

And these differences often exist even after we control for differences in years of education, occupation and income. And the problem is that the cut point for impairment on these tests are usually based on white samples, which results in high false positive rates for African Americans.

And because we know that performance on these tests is influenced by many factors, more than just pure ability, it raises important questions, and it makes performance and impairment difficult to interpret. Next slide.

So the question becomes, why are there these higher rates of Alzheimer's disease among African Americans? And I'll focus a little bit on the four factors listed on your slide, genetics, medical comorbidities, SES and cultural factors, as areas where people have started to examine to see if we can figure out why the rates are higher. Next slide.

I start with genetics because whenever you have a racial difference, people want to see if it could possibly be explained by genetics. There have been several genetic variants associated with late onset Alzheimer's disease, but most of the research in this area has been with whites.

ApoE-ε4 is the most well established risk factor gene, and also the ε4 allele is much more common in African Americans, is linked to Alzheimer's disease, has been inconsistent. However, a recent report by Reitz et al, that was just published this year in JAMA, they did a genome-wide association study, and amongst - using several African American cohorts, which included about

6000 people, and their purpose was to identify genetic loci associated with late onset AD.

And they found the same $\epsilon 4$ allele at the ApoE locus that is well established in whites, but they also found an association with another variant at the ABCA7 gene, that's also been found in whites. But interestingly, in the African Americans, it was associated with an increased risk of about 1.8 fold.

And interestingly, both of these genes are involved in lipid metabolism, so this sort of suggests a potential target for future studies to look at, to see if these particular gene variants can help us understand the increased rates. Next slide.

Dr. Aggarwal nicely talked about the different medical comorbidities, and this is another potential explanation of the increased rates in African Americans. We know that there's an overall poorer health profile for older African Americans, in particular vascular health.

There are a number of vascular health conditions and risk factors that are more prevalent in African Americans than whites, including diabetes, hypertension and stroke, and there's a vast literature that demonstrates that these and other vascular conditions play an important role in Alzheimer's disease.

So the fact that minorities are presenting with these kinds of factors, as you heard in the first talk, could really help us understand why we're seeing more Alzheimer's disease. Next slide.

I've already touched on socioeconomic status, and it was also talked about in the first presentation, but briefly, African Americans tend to be more socioeconomically disadvantaged, including having lower levels of education,

lower incomes, and they tend to work in jobs with higher rates of occupational hazards, compared with members of the majority population.

And we know that all three of these indicators have been associated with the risk of AD, particularly in white samples. So the area - the research is really ripe to start looking at some of these factors to see if it can help us explain the higher rates in African Americans. Next slide.

Cultural factors have not been as well researched, but they are gaining attention as possible explanations for the increased rates in African Americans. And these include things like educational quality, and different proxies have been used to conceptualize quality, but I think literacy - and here, I'm really talking more about reading level, rather than health literacy, but literacy is probably the most well-known factor that has been examined when it comes to African Americans.

But others have been looked at as well, including early life residence and perceived discrimination, and these factors are definitely playing a role when it comes to performance on cognitive function testing. And more research needs to be done to see if it may help us understand the increased rates of Alzheimer's disease diagnosis.

We know that African Americans, on average, also have less knowledge about symptoms, and they're more likely to think of the symptoms of AD as normal aging, as you heard earlier. And this may affect their threshold for seeking care.

We also know from the literature, it's been well documented that they come to the attention of the healthcare system at later stages of the disease. And when

they do present, they are less likely to receive Alzheimer's medications. So all of these factors need to be taken into account. Next slide.

So, we're faced with a real problem here, where we have a picture of increased risk, and a host of factors that have been shown to play a role in the disease, many of which are more prevalent among African Americans. And so, what's the impact if we don't consider these factors? You know, when someone comes to our clinic, and we just give them cognitive function tests, and we make the diagnosis, if we don't look at these other factors, what's the impact?

Well, potentially we could increase the rate of misdiagnosis of Alzheimer's. Clinical trials of treatment might be less informative, and currently available treatments or interventions might be less effective. Next slide. So what do we need to do in order to move the field forward when it comes to African Americans and Alzheimer's disease?

Because of all of the complexities with interpreting cognitive test performance in this population, I would argue that we need to have more longitudinal studies that look at change over time, so that we can identify risk factors for Alzheimer's disease, some that might be uniquely relevant to African Americans.

We need to determine biologic pathways linking risk factors to disease, by including studies of autopsy as well as biomarkers for both blood and neuroimaging, and we need to develop strategies to prevent Alzheimer's disease, because ultimately, that is going to be how we really put a dent in this problem for our aging community. Next slide.

In order to do this, we need studies that include large numbers of African Americans without dementia. We need studies that include annual testing with

detailed assessment of risk factors, and we also need studies that include donation of blood for genetic testing, and biomarkers that will allow us to measure changes in the brain. Next slide.

And so that's what we have been doing at Rush, where you heard in the first presentation, where we're out in the community, we're really connecting with people, life to life, and our philosophy is, in the heart of the community, ever seeking to win the community's heart. Next slide.

And at Rush, we have several cohort studies, but two of them, in particular, focus on older African Americans. One is the Minority Aging Research Study, also known as MARS, and the Rush Clinical Core, which is part of our federally funded Alzheimer's center. And together they include more than 800 African Americans who are 65 years or older, who enroll into our studies without dementia.

And as you heard, we do annual, in-home cognitive testing, where we assess various risk factors, we do blood draws, and we give them a complete neurological exam. Both studies offer organ donation as an optional component. And to date we have over 200 African Americans who have expressed interest in donating their brain, and over 50 autopsies in demented and non-demented to date. Next slide.

So as we look at people over time, what we can see here, I'm showing you two graphs. The graph on the top with the red and black spaghetti lines, showing you individual trajectories of performance over time in a random sample of blacks - blacks are in the black line, and whites with - in the red line.

And what we see - I'm plotting performance of people who started our study at different ages. So age is plotted on the bottom axis, and performance on our

cognitive function tests is plotted on the other axis. And what you can see is that there are wide individual differences in where people start and how fast they decline, with some declining precipitously and others remaining stable or even improving in both populations.

However, if you look at the other slide, on the right hand side, when we average out these individual trajectories of change, which I'm showing in this graph here, I have whites plotted on the top now, and blacks plotted on the bottom, and here I'm showing you study year, time on study.

And what you can see is that although whites, on the top, start out at a different level, a higher level, the lines are exactly parallel over time, suggesting that blacks and whites are declining at the same rate. Next slide. And you might think that maybe this is just unique to our volunteer cohorts at Rush.

Well we have another study here at Rush called the Chicago Health and Aging Project, which is a population-based study of about 10,000 blacks and whites over the age of 65, who've been followed since 1993. And you see the exact same pattern, where whites are the red line on top, and blacks are the black line on the bottom, and although they start out at different levels, they are declining at exactly the same rate. The lines are exactly parallel all the way out for 12 years. Next slide.

So what we've tried to do in our studies is, you know, we follow people over time, and we want to identify risk factors that influence change over time. And over time we have found that some risk factors appear to operate the same in African Americans and whites, with some decreasing risk and some increasing risk - next slide, but others appear to operate differently in blacks and whites. Next slide.

But we can't stop there. We have to also be able to relate these risk factors to changes in the brain. And so here I'm showing you some very preliminary data from 33 African Americans who came to autopsy, who are matched to 66 whites, and they're matched on age, gender, education and (MMSE) at death. Next slide.

And what you can see is that African Americans are much more likely to have mixed pathology at death, compared to whites. And so this is really kind of consistent with the clinical picture we see, and all the different factors that seem to play a role. Next slide.

So in summary, African Americans are more likely to have cognitive impairment and AD according to what we see in the literature, but because of challenges associated with interpreting test performance in these populations, future research needs to consider longitudinal studies of persons without dementia, and identify risk factors, to help us understand the complex ways in which risk factors interact with biological pathways to influence clinical disease in this population. Thank you.

Amy Wiatr-Rodriguez: Wonderful. Thank you so much, Lisa. It's fascinating information that you're sharing. And now we're going to hear some additional information from Jose Luchsinger from Columbia University, who's going to share some insights on Hispanic and Latino people with dementia and their family caregivers. Jose?

Jose Luchsinger: Yes, thank you. Thanks for the opportunity to present our perspective on, you know, dementia in Latinos, and some of the work that we're doing here in Northern New York City. Next.

So the first thing that I want to state is that minorities are growing as a share of population more than non-Hispanic whites, and this is particularly true of Latinos, who are the ethnic group with the fastest growth in the United States. Next.

You know, although Hispanics are younger in comparison to non-Hispanic whites, as can be seen by this age distribution pyramid, actually the fastest growing age group in the population is people over the age of 75, and in this group, Hispanics have the fastest rate of growth. So they are the ethnic group with the fastest growth in the percentage or in the - of a age group that's at highest risk for dementia. Next.

The other thing that's important about Hispanics, and which Hispanics actually share with African Americans as well, is a higher prevalence of obesity and other chronic risk factors. And this is true for Mexican Americans, for example. This slide is from NHANES, the national study of nutrition and health. And here you can see that obesity prevalence is higher in Mexican Americans compared to whites, particularly among women. Next.

And this is also true of our community of Washington Heights, that is comprised largely by Hispanics of Dominican origin, and as you can see here, one in three adults in Washington Heights and Inwood report low physical activity, and one in six is obese. And the natural consequence of this is a higher rate of diabetes, which as most of you have heard, is growing in epidemic proportions in the United States, but particularly among minorities. Next.

So here you can see, for example, that if you consider, you know, national prevalence of diabetes, and also pre-diabetes, here defined as glucose intolerance, you can see here that compared to non-Hispanic whites, which are

in the yellow column, African Americans were the blue column and Hispanics were the red column, have, you know, visibly higher prevalence of both diabetes and diabetes plus glucose intolerance, also called pre-diabetes, compared to non-Hispanic whites.

So the people in the age group of 60 years or older, who are at the highest risk of cognitive impairment including dementia, have around 50% prevalence of both pre-diabetes and diabetes, and this is much higher among minorities compared to non-Hispanic whites. Next.

So the important thing about this is that we, in research here in Washington Heights, we have seen, for example, this graphic shows the hazard ratio or the relative risk of the dementia plotted against quartiles of waist circumference, which is a measure of central obesity.

And what you can see is that particularly among the youngest old, people who are in the highest quartile of waist circumference, again, a measure of obesity, are at a higher risk of dementia. And this is driven particularly by the high rates of obesity in minorities, which are over 2/3 of the population in our studies. Next.

And this translates into also an association of insulin resistance and diabetes, which are caused by obesity, with a doubling in the risk of Alzheimer's disease and all cause dementia, meaning Alzheimer's disease and vascular dementia as well. Next.

And as I said before, you know, the rate, the prevalence of diabetes for example, in our population is quite high compared to non-Hispanic whites. It's actually twice as high in African Americans compared to non-Hispanic whites. Thus, 39% of cases of Alzheimer's disease in Northern Manhattan

could be explained by hyperinsulinemia and diabetes, I mean, that's almost half of the causation, of you will, of Alzheimer's disease.

And actually, we published a paper last year in which we showed that if we eliminated ethnic disparities in diabetes, we could eliminate 18% of disparities in cognitive impairment, meaning dementia, and also a definition of MCI that we used for that study.

So as Dr. Barnes said, you know, targeting things like diabetes, for example, or prevention of diabetes, are particularly important in minorities, in preventing and perhaps treating cognitive impairment and we're actually conducting clinical trials.

We recently completed a pilot clinical trial of Metformin in people with mild cognitive impairment, in which more than 50% of the sample was African American and Hispanic. And we seem to have a - evidence of benefit, and we're hoping to do a Phase 3 trial with a very high Hispanic and African American participation. Next.

So the status of the field right now is summarized by this statement from a consensus conference that was hosted by the National Institute on Aging in 2010. I won't read you the whole statement, but what it basically says is that currently, we cannot recommend a treatment for the cure or prevention of Alzheimer's disease. Next.

And, you know, the consequence of that is the burden of dementia is increasing, you know, particularly in minorities. But I'm going to focus on Hispanics for the sake of this presentation. And I would state that Hispanics have a higher burden of dementia caregiving for two reasons.

One, because there's a higher dementia prevalence - and Dr. Barnes showed some data, a graphic showing that the incidence and prevalence of dementia is higher in African Americans and Hispanics in New York City, and the other issue is that there's particular attitudes about caregiving that are related to culture.

And in the case of Hispanics, there is what's called a high prevalence of familism, meaning a high involvement of the family in the care of the people with dementia. And also, in my own experience as a clinician but also described in different studies, Hispanics are less likely to delegate care, you know, even when the dementia is very advanced, because of issues of guilt and because of, you know, issues of feeling responsibility for the care of their elders. So this results in a higher burden from dementia caregiving. Next.

So, you know, more evidence is needed on caregiver interventions and minorities in general, and Hispanics in particular. There is a paucity of data in Hispanics from the most common caregivers intervention, for example, the REACH and the NYU Caregiver Intervention, or counseling interventions for caregivers of people with Alzheimer's disease, but there is really very little data on whether they work on minorities or not.

And the other important thing is that psychosocial stressors and lack of resources are particularly high in Hispanics. This is also true of African Americans here in Northern Manhattan. What I mean by this is that they have less economic resources. A lot of them are poor, and thus they don't have the resources to cope appropriately with the burden of caring for their loved one with dementia. Next.

So in this regard, we are carrying, in addition to our studies of dementia prevention and dementia risk factors, we're doing a project in caregivers,

Hispanic caregivers in particular. And we just finished this week, this project called the Northern Manhattan Caregiver Intervention Project, which is a randomized trial testing the NYU Caregiver Intervention versus Case Management, in 139 family or relative caregivers of people with dementia.

And we should be able to report those results, I think, in September. And we were recently funded by the National Institute of Nursing Research to begin the New York City Hispanic Dementia Caregiver Research Program, in which we will give long term follow-up of the randomized trial that I mentioned previously.

We're also creating a new registry of Hispanic caregivers, just to understand who they are, what their sociodemographic characteristics are, what their social stressors and what their environmental exposures are, as well as their mental and physical health. And the other thing that we want to do, as part of this program, is to work with the caregivers, develop new interventions that are culturally sensitive. Next.

We also have some pending projects. The one, the first one in the slide, the Northern Manhattan Hispanic Caregiver Intervention Effectiveness Study, which we called NHiCE, was submitted to (PCORI), and is a randomized control trial of the NYU Caregiver Intervention versus the REACH in Hispanics, trying to answer the question of, you know, which is better in Hispanics, and among Hispanics, who benefits the most? Is it the spouses? Is it the children? Is it women? Is it men, et cetera? And we're waiting for a funding decision next month.

And we're now working on submitting the Northern Manhattan Dementia Daycare Assessment Project, which is basically a study looking at the

effectiveness of a daycare program versus home care for particularly minorities in Northern Manhattan. Next.

So in conclusion, you know, Hispanics have a higher prevalence of dementia, compared to Non-Hispanic Whites and, you know, this, it parallels, you know, what Dr. Barnes presented for African Americans. The burden of dementia caregiving on Hispanics seems - is proportionately high.

And I think a big part of that is that there's cultural characteristics that are particular to Hispanics, and that make caregiving difficult. And more research is needed on the risk factors prevention and treatment dementia in Hispanics, including supporting caregivers. Thank you.

Amy Wiatr-Rodriguez: Wonderful. Thank you so much for your presentation. And right now we actually have a question that's come in over the Web Chat feature. I'm wondering, maybe Dr. Luchsinger, you or any of the others who are presenting today could respond to this.

The question comes from Marissa, and she asks, "Does the research mean to suggest that Alzheimer's disease is a 'third type of diabetes' as has been suggested? And does research mean to suggest that preventing diabetes lowers the risk of Alzheimer's disease?"

Jose Luchsinger: Okay, I can answer that. So, there's a term that has been coined called Type 3 Diabetes, as was mentioned by the person who's asking the question, which reflects the fact that insulin signaling is lower in the brain of people without diabetes. Now, Suzanne de la Monte, who's the main investigator who - and the one who coined this term, she refers to a disorder that's independent of diabetes in the periphery, if you will.

And now it's a diabetes that was mentioned in this presentation, mostly type 2 diabetes. So, you know, that, the development of that concept is a work in progress, is controversial, but again, it's whether that diabetes of the brain, which is characterized by lower insulin signaling, whether it's related to peripheral diabetes or not, is not clear.

In terms of, you know, whether prevention of diabetes helps prevent Alzheimer's disease, we don't know. I recently finished a clinical trial of a medication called Metformin, but it's a pilot trial. It showed that people, at the end of a 12 month period, people without diabetes but who were at risk for diabetes who used this medication were, seemed to have better cognitive function at 12 months.

And where - we have applied for a Phase 3, that is a larger trial, to prove this. The reason why I used Metformin is because Metformin has been shown to be effective in the prevention of diabetes. There's - I'm also participating in a study called the Diabetes Prevention Program, and we are taking measurements of memory there. We are hoping to also get, you know, brain imaging so that we can answer the question of whether the prevention of diabetes amongst people with pre-diabetes can prevent the memory decline that leads to Alzheimer's disease. But I'm not in the liberty of sharing the data from that study, and we also need more time to answer this question.

So in summary, we don't know if preventing diabetes can prevent Alzheimer's disease, and that's research that needs to be carried out.

Amy Wiatr-Rodriguez: Great. Thank you so much for your response. And just a reminder to others, too, that if you would like to ask questions through the Web Chat feature, that is available to you. And we also will be opening up the phone lines as we finish up with our other presenters, for questions there.

But now, we're going to turn to Gwen Yeo, from the Stanford Geriatric Education Center, to talk about perspectives of Asian and Pacific Islanders affected by dementia. So Gwen, I'll turn it over to you.

Gwen Yeo: Thank you very much. I'm very happy to be here today. Next slide please. The topics that we're going to be dealing with very briefly today are the older populations among Asian and Pacific Islander categories, some limitations of the data about dementia, and what we do know about the prevalence and perceptions and assessment, management and caregiving for dementia. Next slide.

So the first thing we need to understand if we're going to understand dementia in these populations is we need to deconstruct Asian and Pacific Islander, and then not to lump them together because of their small numbers, as done in much of the research and policy making. We need to recognize the uniqueness of each of the populations, and the historical experiences they've had as populations of elders, and the variability within the populations. Next slide, please.

And this is just an example of the importance of deconstructing Asians. This was a study done by Mui and her colleagues in New York City, looking at the prevalence of depression, and you can see the vast differences she found between the different populations in the Asian category. And these would have all been hidden, had they been averaged or taken as a group, so we would never know these kinds of variations. Next slide, please.

So who are the Asian American elders, first? In 2010, 1.4 almost, elders in the United States identified themselves with one of the Asian categories, and the largest of which was Chinese, followed by Filipino, and then Japanese and

Asian Indians, and then Korean and Vietnamese. And then there were some very small populations from Southeast Asia, the Cambodian, Laotian and Hmong. But then there were lots of other, very tiny populations of Asians as well. Next slide, please.

The - one of the unique cohorts is those folks from many of the Asian countries who have immigrated as older adults after they've been retired, or in some cases widowed, and they're at increased risk of isolation, and they're completely dependent on their children, in many cases. Next slide, please.

So in terms of the Native Hawaiian and other Pacific Islander American elders, they were combined with Asians in the census until 2000, although they're very culturally and physically distinct. They're still frequently lumped with Asian in analyses because of their very small numbers, which in 2010, the 65 and older population numbered 31,000.

The largest of those are the Native Hawaiian population, the 14,000, and followed by the U.S. Protectorates of Samoa and Guam, and then other populations that have emigrated from the Pacific islands. So, next slide.

What do we know about the prevalence of dementia among the American elders from these populations? Next slide.

So this is just to show you the holes in the data in the literature. There's - a lot of the populations have very little or no information. Next slide, please.

But we are fortunate, in terms of the prevalence, to have two very well defined studies for Japanese Americans on dementia. The - in Hawaii, the Hawaii Heart Study population that's been followed since the 1960s, of men, of Japanese American men, was analyzed in the 1990s, and for those who were

71 and older, found that 5.4% had Alzheimer's and 4.2% had vascular dementia. In Seattle, the study of Japanese American men and women, 65 and older, found that 4.5% had Alzheimer's, and 1.9% had vascular dementia, which was considerably less than what was found in Hawaii. Next slide, please.

So, there is - other than the Japanese Americans, there are no known studies of prevalence of dementia in the other Asian American elders. So this is a huge need and opportunity for research in - so that we would know something about those populations. Next slide, please. I think I'm going to skip this slide. Would you go to the next one, please?

So in California, the - elders who were found to have dementia, were found from Asian and Pacific islander populations, were found to have 78% with Alzheimer's, 13% was vascular, and then the smaller numbers with the other types of dementia. Next.

The only Pacific Islander population that's been studied in terms of dementia, are those from Guam's indigenous population, the Chamorros. And in the last 50 years a very unique dementia has emerged. It's similar to Alzheimer's, but it does not have the amyloid plaques. It does have the tangles. It's labeled Guam Dementia, and there are approximately 9% of older adults in Guam that have been diagnosed with Guam Dementia.

They looked at environmental factors that might explain this, and it's been focusing on the Cycad seeds, which is a type - is flour made from the Cycad seeds, and it's a type of palm. Next slide.

And there are some other unique risk factors for dementia in other specific Asian Pacific Islander populations, including the very high rates of obesity and diabetes among Native Hawaiian and other Pacific Islanders.

And we should just mention that since we've been talking about diabetes, diabetes is also higher in several of the other Asian populations as well, and especially among Asian Indian. There's PTSD among the Southeast Asian population of Cambodian, Hmong, and Vietnamese elders.

There's very low educational levels, which has been found to have a high correlation with higher rates of dementia among the Hmong, and specifically, 42% had no formal education, and they'd never been to school. There were - in terms of protective factors, the Japanese American elders who lived in Japan for a period of time, and have maintained traditional Japanese lifestyles were found by one study to have a lower risk of dementia.

There is some evidence that curcumin, which is a widely used spice among Asian Indian cooking, may also be protective. Next slide, please. So let's look at the perceptions of dementia in different populations. Next slide, please.

Among the Chinese Americans, there were 18 studies of caregivers that were reviewed by Sun and colleagues. They found that the attributions for dementia included fate, wrongdoing, the result of worrying too much or just craziness.

In the early stages, the caregivers frequently attributed the dementia to normal aging, just a return to a childlike state. But as it progressed, their concern came to be a stigma. It was defined as a mental illness, and labeled craziness, or sometimes a contagion. It caused a lot of feelings of shame or loss of face for the family. And Liu has used the term tribal stigma to describe the extension of the humiliating feelings to the entire family. Next slide, please.

In terms of the Koreans, the stigma is also very strong. The major attributes have been not keeping the mind active enough, inactivity due to living alone or isolation, problems with brain chemistries, stress, introverted passive personality, unresolved personal or family conflicts or hardships, or a particularly unique Korean illness conception of han, which relates to issues that can't be shared with others, changes, based on the immigration to the U.S., and head injury. Next slide.

So the - in terms of Vietnamese findings, they also saw dementia as a normal part of aging. And the physical factors of brain shrinking or going flat, overeating, stroke, blood pressure or clogged arteries, heredity, medication issues.

Psychosocial factors included worrying or thinking too much, loneliness and isolation, difficult life events, out of balance, difficulty adjusting to the U.S., loss of respect from younger generation. In some cases, spiritual factors played a part, or fate. And some - and occasionally possession by spirit or karma. Next slide.

Hmong have no particular word for dementia. The closest translation is chronic confusion. They also saw it as a normal part of aging, like an old tree that's hollow. So they're - they say there are too many things on their mind. There is not enough blood that gets to the brain. It's a kind of emotional stress, or a person's soul or spirit is captured or taken away. And in that case, it needs to be treated by a traditional healing ceremony performed by a shaman. Next.

And there were some focus groups done in Hawaii with different Hawaiian populations, and the Filipino and Native Hawaiian populations also saw dementia as a normal part of aging. Next.

So in terms of assessment - next, there are specific barriers that relate to the fact that all of the populations that have been studied see dementia as a normal part of aging. So the conception is that it's normal, so nothing can be done, is a decreased incentive for families to bring an elder for assessment, as is the stigma that's also in all the populations. And because it affects the entire family, there is this great disincentive for assessment.

So as a consequence, the populations have been reported, presentations of dementia to healthcare providers tend to be in later stages. For example, the Japanese American men with dementia whose family recognized memory problems did not receive a medical evaluation in 53%. Next.

There are challenges once they do get - come for assessment, and many of those revolve around language. And just to make the point that with the exception of the Japanese and Filipino elders who are more likely to speak English, 29% to 86% of the 65 and older various Asian American populations speak little or no English.

So there are huge numbers that have no English at their - are able to respond to assessments in English. And so that means it has to be translated. And once that's done, there are all kinds of problems, including linguistic differences or lack of terms in some languages, idioms that are difficult to translate and make no sense in other languages such as "no ifs, ands or buts." That makes no sense in other languages.

The lack of and differences in education that lead to low literacy in the Chinese elders. They may have been educated, learned to write with a brush, so they may not be able to use a pencil very adequately to copy figures. And there are just very few culturally fair evaluation tools. Next, please.

There are two that I would like to mention, however. The CASI is a screening instrument, and developed by Evelyn Teng and her colleagues, and has been used with many, many different Asian languages. And the Cross-Cultural Neuropsychological Test Battery, the more comprehensive battery developed by Malcolm Dick and his colleagues, and it also includes the CASI. Next slide, please.

So in terms of caregiving, I - next, the most important thing to understand is the issue of family-based care. So, almost all the members of the Asian American populations that have been studied expect that elders will be cared for by their family members. So as a result there is - especially those who are more recently immigrated, the use of formal long term care programs is very minimal.

So when families are very distressed, as they frequently are with the care of elders, and their only option is a nursing home placement, there is frequently an extreme sense of guilt. Next slide, please. We don't have time to go into the caregiving literature from all the populations that is available, but I wanted to mention Chinese Americans.

The review of literature of 18 different studies found that they were heavily influenced by the cultural values of family harmony and filial piety that conferred a strong obligation. And the stigma reduced their social support, even including within their family. It increases their stress and reduces their help-seeking.

There is mixed evidence on whether or not the filial piety actually produces better wellbeing or is - or more depression among the caregivers. The frustration, there was clear frustration with the low level of culturally and

linguistically competent information and services, and a reticence to participate in research. Next slide.

We do have a few resources that would be important for people to know about. Next. And one is a workbook and DVD that was developed by my colleague, Dolores Gallagher-Thompson, based on her extensive research on the effects of cognitive behavioral therapy-based psycho-educational approaches. And in this set, the skills were taught to - with a narrator in Mandarin or English, and then referred to the workbook to learn more about the techniques. It's available from the Stanford GEC. Next slide.

We also have, in Stanford GEC, a set of our book that came out in the second edition in 2006, which includes chapters on working with families from these populations, as well as a chapter on assessment of Asians. Next slide. And we also...

Amy Wiatr-Rodriguez: Okay, and Dr. Yeo, we just need to wrap up here to move on to the rest, so.

Gwen Yeo: Right. I wanted just to mention the - let's see, the Webinars that are also available from Stanford GEC. So thank you very much. I'll just end there.

Amy Wiatr-Rodriguez: Okay, great. Thank you so much, and my apologies. There's so much great information for us to try to get to and fit into the short time that we have. So thank you very much for providing that. And as a reminder, we will be posting all of those slides and materials on our Web site afterwards, so people can get the full information.

At this point I'm going to turn things over to Lori Jervis from the University of Oklahoma, to share some information on American Indian and Alaska Native perspectives. Lori?

Lori Jervis: Thank you very much. Could you go to - there we go. Next slide, please. Next slide, please. Back one. So today I'm going to be talking to you a little bit about what we know about American Indians and Alaska Natives and dementia, and specifically talking to you about prevalence, cognitive assessment, caregiving and talking to you about what we can think about in terms of future directions. Next slide.

And so what do we know about dementia in American Indians and Alaska Natives? Well, honestly, not as much as we should, and this is particularly true when thinking about Alaska Natives. There is very little empirical research that's been done on this population. So unfortunately, most of what I'll be talking about today is going to be about American Indians versus Alaska Natives. We have a long way to go. Next slide.

To start with, let's talk about prevalence. So we know not a whole lot about prevalence among American Indians and Alaska Natives in the United States. Probably our best study at this point, in terms of large numbers, comes from Canada, ironically.

There was a study conducted - just came out in 2013, this year, from Canada, using health databases from their national healthcare system there, and it shows that First Nations populations have a higher prevalence of dementia than non-First Nations populations. And it also, interestingly, shows that dementia disproportionately affected younger age groups in males. And so that's a little different than what we would, I think, in some level, expect to find. Next slide, please.

Another study coming from Canada - and one reason, I think, we're talking about Canada here is this is one of the earlier studies to be produced, empirical studies, looked at Cree Indians, and found a prevalence rate - comparing Cree to Non-Indians, and found that both groups had similar prevalences of probable dementia, about 4.2%.

There were a couple of methodological limitations to that study. One, the Cree had much lower educational levels than the Non-Cree. And also, the Non-Cree sample had included institutionalized populations. So that probably skewed things just a little bit, but still this was a very important study.

One very important finding from this study is that the Cree had more vascular or what was called alcohol-related dementia, and the Non-Natives had much more Alzheimer's disease.

Next slide. And then that basic finding about the Alzheimer's disease versus the non-Alzheimer's disease dementia really comes through in a series of studies after that.

So this study in a Navajo Nation nursing home found kind of a similar finding about very little Alzheimer's disease, but a lot of non-Alzheimer's disease dementia. Another nursing home in a Northern Plains tribal nursing home found, again, quite a bit of dementia, all in all, but a lot of this was non-Alzheimer's disease dementia. Next slide, please.

A couple of genetic studies have come out on dementia in American Indians, and these are from the Southeast Culture area. And the first of these was one with the Cherokees, and this basically found that the degree of genetic Cherokee ancestry was associated with a lower frequency of Alzheimer's

disease. So this is kind of supportive in some level of previous studies mentioned. Next slide, please.

A couple more of these kinds of studies, these with the Choctaws, the first that E4 allele frequencies and tau H2 haplotypes were lower than whites. And then second one really looked at AD disease course, and interestingly found that the course of the disease was not associated with blood quantum.

Blood quantum basically refers to degree of Indian blood, and it is a problematic term. But it's one that gets bounced about quite a bit in Indian country. And so basically the conclusion here is, well, where you find less Apo E4 frequency, of course you're going to expect to find probably less AD. Next slide, please.

So what's the summary of these studies so far? Basically we don't know the prevalence, but there is a, you know, pretty strong possibility that we're going to, you know, find higher prevalence - frequencies of dementia among natives, but that most of this is probably not Alzheimer's disease. And why is that? Next slide.

Well, shorter life expectancies probably have a lot to do with this, given the fact that Alzheimer's disease is really strongly associated with advancing age. So, of course, if people don't live as long, they're probably not likely to live long enough to acquire Alzheimer's disease. So that's a piece of this puzzle.

Genetic factors could well be part of this. But then one thing to think about here is that acculturation and so called lifestyle is something that really has to be carefully teased out from genetic variables. And the issue of how blood quantum gets sort of mixed in with how people live, with the different risk

factors and protective factors that are associated with that, we need to kind of think about all of that when we think about genetic factors. Next slide.

When we think about risk factors - and I think this has been really dramatized in every presentation so far, the different risk factors that really are highlighted in all of these groups, and I see the same ones repeated again and again. I think the traumatic brain injury stands out here as well, and is important to keep in mind.

Diabetes, of course, is really epidemic in this population, and that would go a long way in terms of, I think, preventing some of this. The poverty, we really can't overstate that, and all the risk factors that come with that, given the fact that this population is more than twice as poor as the general population. Next slide.

Cognitive assessment, we find a lot of the same issues mentioned in previous presentations here, the need for culturally relevant tests. The challenges are just enormous in developing culturally relevant tests when it comes to American Indians and Alaska Natives, given the fact that we have 566 federally recognized tribes and Alaska native villages. Plus we have a bunch of state recognized tribes as well. With those tribes, we have culture areas. We have tribes that have different degrees of acculturation. Then there are tribal members who have different degrees of acculturation as well. We have geographic variation across the country. We have, you know, regional differences. There's rural and urban differences.

At this point, the American Indian, Alaska Native population is primarily urban, which I think a lot of people don't realize, but then the urban and reservation population is still very, very important. So as you can imagine, with the vast numbers of tribes, with all of these differences, trying to think of

how you go about coming up with assessments that are going to work with all of them, it's a pretty daunting task. Next slide.

That said, there have been some studies that have found some existing assessments and norms to be applicable for American Indians, and that's important to know. However, some of these tribes have had relatively high levels of acculturation. So you've got to keep that in mind if you're thinking about using that with other groups. They may or may not work as well.

One study funded, by NIA, of 140 Northern Plains American Indian elders, did find quite a range of rates of cognitive impairment, using different kinds of assessments and different sets of norms. And so I think the lesson learned from that is that the tests and set of norms really do matter a lot. And so, kind of, you know, that's something that really needs to be thought about as well. And that's with one tribe. Next slide.

And, you know, with that same study, kind of thinking about well, what predicts better performance with these different tests, some of these things that you might expect, you know, did crop up. On both of the tests we see more education predicting better performance on the tests.

We see not receiving SSI, which is usually an indicator of being, you know, extremely impoverished, you know, predicting better performance, for instance. So, you know, there are things that really do kind of matter with respect to what's going to predict better performance on these tests. Next slide.

Let's turn to talk about dementia caregiving and services for a minute. So this work has primarily been conducted in the Southwestern United States, and it focuses on burden. And here we find that guilt really predominates, I think, as

far as what kind of affects people the most, from that literature, in a nutshell, just boiling it down.

One focus group with Pueblo caregivers did highlight respect, that they perceive themselves as - according to tribal elders, contrasting with their perception that white caregivers tended to resent and infantilize elders. So their perception was that they respected their demented elders more. Next slide.

And I think, like other presentations, we see here that the family really is where you find the caregiving done. Now, is this exclusive to American Indians and Alaska Natives, or even ethnic minorities? No. I mean, you do find the family being where a lot of the caregiving is done.

But here, I think what's important to note is, you know, how much of this is choice or not. I think it's a little bit of both. And some of this is about the cultural emphasis on familiar interdependence, and also some sense of taking care of one's own. But dire necessity comes into it. Next slide, please.

And this is particularly true when you come to rural reservation settings where there's really not much choice for people who really don't have the economic resources. Those who are dependent on the Indian Health Service will find that there's not much long term care, if any, provided. And that is a real problem.

There may not be adequate dementia assessment available to people. For those who need nursing home care or its equivalent, they're not probably going to find culturally appropriate residential care facilities within proximity, which is a serious issue. And so those are the kinds of things that people are facing that

I think really intensify that feeling of needing to care for one's own, even though it can be not ideal in a lot of cases. Next slide.

So that sense of, you know, wanting a continuum of care for different situations that people might find themselves when someone has dementia, it's, you know, that's the ideal, but the reality is that it's not there, in most cases. And if it's there, there's going to be probably no mechanism for coordinating it. Next slide.

As far as access to clinical trials, here's a situation where I think we're really lacking. I mentioned that most American Indian - not most, but the majority of American Indians, Alaska Natives these days, do live in urban areas. And so it would be great if there was a possibility of people being able to, if they wanted to, participate in research or clinical trials.

But as you can see here, of the 13 cities with the largest numbers of natives, you find that seven do not have Alzheimer's disease centers, for example. And so you can see there's opportunity also, for involvement, if you do live near one of those centers, you know, places that have one. But many don't have one.

And of course, this is also a situation where we do have a significant population of natives that's rural, reservation, lives nowhere near any of these places, and has no opportunity to participate. Next slide.

So, where are we? Where are we going with this? Prevalence, we don't know yet. We have some ideas, but we really don't have prevalence down at all. And we still need to know. Culturally relevant cognitive assessment, we really do need to kind of get a little further with this, because we can't really conduct

studies that are going to make sense or provide adequate healthcare without getting further with this.

Dementia caregiving and services, we still don't really know what this looks fully, in terms of informal or formal care. And, you know, we do have a sense that some American Indians, Alaska natives may not seek help, due to a whole variety of things, such as normalizing dementia symptoms.

I didn't really get too far into that. There haven't been a whole lot of studies done on how people perceive these things, but we could go further with this as well. And then finally, research and clinical trials, I think there tends to be a sense, American Indians and Alaska natives are not going to want to participate in this.

That is surely true of some people, particularly people who are more traditional, but I think it's a stereotype to sort of assume that those vast numbers of tribes are - and all the people within them are all going to think identically.

I think the issue can be accessed for a lot of people, or even knowing that these things exist. So I think we also have a ways to go on this as well. Thank you very much.

Amy Wiatr-Rodriguez: Great. Thank you so much, Lori. And now in the interest of time we're going to move right into Jed Levine, who's with the Alzheimer's Association, New York City Chapter. Jed's going to help us understand some perspectives of lesbian, gay, bisexual and transgender individuals with dementia and their caregivers. So Jed?

Jed Levine: Thank you. Yes, go to the next slide, please. So what I hope to do today is give you a little bit of background, and to help you understand what the issues are for older gay men and lesbians and bisexual and transgender persons. There's actually very little information in the research literature.

Very little research has been done, so much of this is going to be taken from my kind of clinical experience and working in developing support groups and programs for people who are LGBT and who are caregivers. But I want to give you a little bit of background and understand some of the terminology.

LGBT is an acronym, which stands for lesbian, gay, bisexual and transgender. And it's a catchall term, but it's important just as with the Asian and Pacific Islanders, that we don't lump everybody together, but that recognize that this refers to a diverse group of people with regard to their sexual orientation, sexual identity, gender and gender identity as well.

We estimate that in 2010 there were one to three million older LGBTs, and that number is projected to double or triple in the next 20 years. So it's a significant cohort. And also according to a report from the LGBT Aging Project, one out of four same sex couples has a partner over 55, and one out of ten has a partner over 65.

Most older people today - and I think this is really important to recognize, even the young old, were raised when being homosexual was not something that was spoken about or admitted openly, and was highly stigmatized. It was a time when you couldn't get hired if you were gay. You could indeed get fired. You could be arrested. You could be sent to jail.

It was a criminal offense, very, you know, highly marginalized, leading to a separate community where gay men and lesbians could meet comfortably,

often in bars or in clubs that were in specific areas of often large cities or towns. And this led to a huge distrust of mainstream institutions, including those that provided medical care, and also, you know, provided the safety net when one became ill or disabled or older.

And one of the most important components of that was their own immediate family. So many gays and lesbians were rejected by their family of origin, indeed disowned, told never to come home again. And they couldn't turn to the police, because the police were often hostile.

And they couldn't turn to their church because churches often excommunicated them, and told them that their lifestyle was an abomination. And even social services were often denied. So the sense of community and the sense of family, redefining family, becomes very important when we talk about older gay men and lesbians and their caregiving roles.

Things started to change in the United States in the late 1960s. Actually a little bit earlier there was some activity, but it culminated in the Stonewall Uprising, which I know many of you have heard of, which led to the formation of several gay rights organizations. And so - and now we have both nationally and internationally, you know, annual gay pride marches, which commemorate that event.

Another major event in the lives of older gay men and lesbians was the depathologizing of homosexuality by the American Psychiatric Association in 1973, when they removed it from the DSM manual. And that was a huge landmark and milestone, because no longer was being gay an illness. It was a sexual orientation.

Another major influence on the LGBT community was the advent of HIV and AIDS, which was originally called gay-related immune deficiency. So there were these, you know, hundreds and thousands of healthy young men who were becoming seriously ill.

And again, remember, many of them didn't have the usual safety net of a family, so they turned to their partners, their friends and the larger LGBT community to provide support and comfort. And it also created a cohesive and powerful advocacy movement to find a treatment or a cure, and that movement still resonates today. Next slide.

And there have been some other important major milestones in the LGBT community, so it's been a busy couple of decades, actually, including the issues of older adults, which typically or historically had been marginalized in the larger LGBT movement, and also the fact that the issues of LGBT elders were not addressed within the larger aging services, advocacy research and service networks.

So there's been this dichotomy, which we've been trying to close and bring the two, LGBT and the aging closer together. However, there have been steps, both forwards and backwards, but mostly forward, in recent years, which result in significant benefits for older LGBTs and caregivers.

So in 1992, Don't Ask, Don't Tell was signed into law, which allowed gay men and lesbians to serve in the armed forces as long as they didn't do that openly. And then in 2011, that was abolished and people could serve openly. And in 2004, Massachusetts became the first state to legalize same sex marriage, and we now have 13 states and the District of Columbia which have legalized same sex marriage.

And actually, just last - about a month ago, in June, the Supreme Court repealed DOMA, giving equal access to federal benefits for those same sex couples who were married, meaning that for many older adults who were dependent on two incomes, they now have access to social security survivor benefits, which is really a huge milestone, and also the caregiver programs and other resources that exist.

The other thing I want to mention is that although things have certainly improved in the United States and much of Europe, in other parts of the world it is still very dangerous to be a homosexual or to be gay. And indeed, Uganda is one of those countries. And Russia, if you saw Harvey Fierstein's op ed in the paper on Monday, talking about how President Putin has just passed a law allowing police officers to arrest any foreign nationals who appears gay or gay friendly and put them in jail for 14 days. So there are still very strong pockets of homophobia, and where it really is very dangerous to be gay or lesbian in the world. Next slide.

Our - the bulk of my presentation, as I said, is taken from our experience at the Alzheimer's Association New York City Chapter, in developing support groups for LGBT caregivers. And this came from - next slide, from the demand from the community.

People were asking for a place where they could openly share their experience, learn from each other, and heal, you know, from the emotional wounds of caregiving, in a place where being gay or lesbian was going to be accepted, and was not going to be an issue, and indeed, where there, you know, that nontraditional relationship, that family of choice, rather than the family of origin, is often the makeup of that caregiving dyad, or sometimes not dyad, but group.

And the other thing I want to just remind everybody that is if you haven't done it, don't really understand how demanding it is to care for a relative or person or a friend with Alzheimer's or a related disorder, how draining, how constantly demanding it is. And the need for the support groups, so, you know, there's been a lot of literature that supports the benefit and the value of support groups.

And we were hearing, as I said, from the LGBT community that they wanted groups where their nontraditional relationships would be honored. The other thing is that it's not unusual for LGBT elders to be caring for two or more individuals. Indeed, one woman was caring both for her mother and her partner who had different levels of dementia, and they were in the same nursing home and it was enormously burdensome to her.

There also was more - in - we find in the groups, that there's more discussion and disclosure of issues of alcoholism, overeating, depression, than there are in some of the other groups. And - next slide, that people reported that in some groups they were feeling misunderstood in the groups for spouses.

Many - the New York City Chapter as well as many of the other chapters of the association have specialty groups, and they often are for spouses alone. And one fellow said, you know, was told that his relationship with his partner is different from the other members' relationship caring for his wife.

There are also the issues of coming out, which is the process of admitting, or stating that you are gay or lesbian, and that's a real process for individuals, that takes time and people manage it in different ways. So it's - for some individuals, it was - they did not want to - they felt uncomfortable coming out in the straight group. Next slide.

The other theme that came out of these groups, and with my discussion with LGBT caregivers, is that many of them had been caregivers during the AIDS epidemic, and so that was their first experience of caring for somebody who was seriously ill, and that stimulated and reawakened their own fear of getting seriously ill or dying.

And the fact, also, that AIDS often has an element of dementia that closely mirrors Alzheimer's disease, and there are many similarities to AIDS in that medical treatments, especially in the 80s and 90s, it was a medically incurable. Medical treatments were modest at best. It created strong feelings of helplessness and hopelessness, and the ill person became totally dependent on someone else for all of their activities of daily living. It sounds very much like Alzheimer's and other dementias. Next slide. So the - as I - you know what, I think we can move on to the next slide.

The - both the issue of AIDS and caring for somebody, you know, brings up issues about who is going to care for them when they grow older or more dependent, if they don't have a partner or a child. And there are certain assumptions that are made, that the gay relative, the gay son or the lesbian daughter is the one who is going to be doing the caregiving, because they don't have a traditional family to care for.

And this last bullet, which is the homophobia or fear of homophobia in care settings is very profound. So many people are forced to go back into the closet because fear of disclosing their sexual orientation or their relationship with the caregiver is a really strong element, and it's something that we need to do more work in training direct care workers and in the nursing home staff about cultural sensitivity and cultural competency around LGBT issues. Next slide.

There actually was just an interesting article in ASA Aging Today in the July and August, 2013 edition, about this communal caregiving piece, that it is still quite common that it's groups of friends who care for one another, and they take - they have rotations, and they have work charts, and they provide services for one another. And again, this seems more common in the LGBT community. Next slide.

Amy Wiatr-Rodriguez: Okay, and Jed, if you could wrap up in just the next few minutes, so we can get to the Q&A part.

Jed Levine: Okay, good. I will be glad to do that. So we did partner with SAGE, here in New York, since 1995 in developing the first support groups for gay men and lesbian caregivers, and we can go to the next slide. And go to the next slide.

And I just want to mention that the group member concerns are actually in many ways very similar to other support groups, about acceptance, and difficulty accessing services, and dealing with the whole range of feelings that everybody has. Next slide.

But there is this very strong need for research on LGB - there is a growing body of research on LGBT aging. There is almost nothing about dementia specific concerns. And - I was just, came back from the Alzheimer's Association International Conference, and there were no research papers or posters presented on LGBT and Alzheimer's issues. So there is, you know, this is an area that's ripe for development.

There is - when we get to resources, I'll - let's go to the next slide. It's important that health and human services providers and agencies and medical providers make the environment LGBT friendly. And we don't have time to

go into how we're going to do that, but you can find that by going to the - next slide, to the National Resource Center on LGBT Aging.

This is in partnership with SAGE, and it is a wonderful resource for information. The brochure that you see there is an Alzheimer's Association brochure that our national association has created, and that's available online at alz.org. It's also available through the local chapters.

The other - there are other research papers and resources that are available. The National Gay and Lesbian Task Force is the only place - next slide, that did a - oh, I'm sorry. That Advancing Care is a newsletter that we have prepared for staff who are working in nursing homes, and we did one issue on Gay and Gray, Welcoming LGBT Elders in Long Term Care.

And this is available free of charge. You can subscribe online at alz.nyc.org/ltc. Next slide. And - okay, so the other resource for information and help, actually for all of the diverse populations, is the Alzheimer's Association, our nationwide 24 hour helpline at 1-800-272-3900. Operators answer in English and Spanish, and we have language capacity to 170 languages.

And the Alzheimer's Web site is also a great resource of content and help and support. So I think that's it. I think I will end there.

Amy Wiatr-Rodriguez: All right, great. Thank you so much, Jed. And my apologies to you and the other speakers, but we just simply - we need more time to talk about all the great information and the interesting research directions that we really all need to explore coming up.

So at this point, I know that we may be running over a little bit, but I think it's still important that we open up the phone lines to see if there are any questions from people on the line. So if we could have Holly, our operator come on, and tell people how they can do that.

Coordinator: Yes, thank you. At this time if you'd like to ask a question over the phone, dial star then 1. Please unmute your phone and record your first and last name clearly when prompted. Once again, to ask a question over the phone, dial star then 1. One moment.

Amy Wiatr-Rodriguez: Great. And while we're waiting for people to queue up, I just want to mention a couple of things. Right now you can see the registration for our next two Webinars is open. Again, the information will be posted on our Web site and we'll send out an email to everyone who registered for today's Webinar when that information is available.

Also, one of our NIA colleagues, Dr. Nina Silverberg, also reminded me that there was a health disparity session of the Alzheimer's Disease and Related Dementias meeting, held at the NIH campus in May, in the service of the National Alzheimer's Project Act. And we'll include the link for that session and materials when we do post the slides on line.

Let me check and see with our operator, do we have anybody queued up for questions?

Coordinator: We do have a couple of questions in queue. One moment. And our first question comes from Angela Poston. Your line's open.

Angela Poston: Hi. Several people pointed out that AD caregiving is a risk factor for developing Alzheimer's or dementia-related illnesses, especially in minority

populations. My question is, outside of look at the psychosocial factors, is there research, or is anybody researching sleep deprivation as a contributing physiological factor?

Amy Wiatr-Rodriguez: This is Amy. I don't know if any of our presenters would like to respond to that?

Nina Silverberg: This is Nina Silverberg from NIA. I can answer that. We do have some ongoing research on the topic of sleep and Alzheimer's disease. Lack of sleep is a risk factor for cognitive impairment. And there's been quite a bit of work done on both animals and humans.

Right now there are some clinical trials in preparation on CPAP, which is Continuous Positive Air Pressure, which is a way that helps people with sleep apnea, because sleep apnea is - seems to be one of the biggest contributors. So yes, this is an active area of research right now.

Amy Wiatr-Rodriguez: All right, great. While we're waiting for the next question, you know, Nina, is there anything else that you'd like to add, since you're - you joined us?

Nina Silverberg: I just wanted to thank, yet again, all our speakers. I want the audience to be aware that these are some of the very top researchers in their respective areas. And I want to thank Jed in particular, because even though there are no top researchers in his area, I think he did a wonderful job of presenting what's available out there for LGBT populations.

So thank you to the speakers. And for the audience members who are in the service-providing field, I would ask that you consider talking to the

grandchildren of your relevant people, and see if they want to get interested in doing some of this research that's clearly needed. So that's all I wanted to add.

Amy Wiatr-Rodriguez: All right, great. Let me take out one question that we got over the Web Chat, and then we'll do another couple over the phone. So a question came from Diane and she said that she's an adult protection case worker. She often sees undiagnosed, untreated clients who have dementia, and she wonders how to get more appropriate information to primary caregivers who often discount the symptoms that are seen in the field.

Neelum Aggarwal: Hi, this is Neelum. I think I'll take that question for Diane. One way that you can get a little bit more attraction in getting more information is trying to frame the discussion around medical illnesses. And this is something that I do quite a bit in the field when I do our research studies, but when we start to raise awareness, again, focusing on what are the medical concerns, what are the issues, and then relating that to cognitive health, and how does that relate to thinking.

How does that relate to performance? And many people can get their head around that and, you know, as I try to point out in my slides, the primary care for the most part is really being focusing all their attention on managing the medical issue that many of our people are facing. So that seems to take precedent.

And that's just how it is. And the medical conditions are vast. They're serious. They're chronic. And if somehow thinking, performance and thinking declines can be brought in that discussion, framed that way, you may have better success rates in getting information to the primary from the family and caregivers, regarding the patient and the other way.

Amy Wiatr-Rodriguez: All right, thank you. Holly, our operator, do we have any other questions on the phone line?

Coordinator: We have no questions at this time, but once again, to ask your question, please press star 1. One moment.

Amy Wiatr-Rodriguez: Okay. And while we're waiting for that, there is a question that came in via the Web Chat, and that - this may be for Dr. Yeo, but any other presenters, also, please jump in. We have a question from Serena, asking about if there are any kinds of task forces or groups trying to gain more insight on assessment skills in working with some of the different populations and different ethnic and racial groups.

Gwen Yeo: Yes. Well, there are, at several different levels, task forces that are attaching some research and also getting information from the field from working with caregivers and so forth. I can - if you want to email me, I have - the email is on the last slide, it's gwenyeo@stanford.edu, I can give you more specific information about some of the groups that are working.

NIA certainly has done some of the work with different populations. But it's pretty scattered, so it's certainly not comprehensive.

Amy Wiatr-Rodriguez: Okay. So it sounds like if people want to learn more about that they can email you or, you know, feel free to send an email to me and I can send it on to, you know, whatever appropriate person to follow up.

Gwen Yeo: Right.

Amy Wiatr-Rodriguez: Okay, wonderful. Another question came in, and this is for Dr. Jervis to maybe explain. Somebody was asking if you could just define First Nations.

Lori Jervis: First Nations is basically a term that's used in Canada, and it's kind of an over-arching term that includes the various different kinds of native groups in Canada. So in Canada there's kind of a different categorization scheme of native groups than what we have here, and so that's their sort of over-arching term.

Amy Wiatr-Rodriguez: All right. Any other questions, Holly, coming in on the phone line?

Coordinator: Yes. We have two more questions.

Amy Wiatr-Rodriguez: Okay, go ahead.

Coordinator: The first question is from Diane Donaldson. You may ask your question.

Diane Donaldson: Good afternoon. I'm the one who asked the other question from - regarding working in the field, because I work in adult protection. And just listening to all this wonderful data, I'm wondering if we can somehow get information to the families and people in the field through - some of the high risk factors were diabetes and hypertension.

Has there been any effort to collaborate this information with the National Stroke Association or the National Diabetic Association?

Jed Levine: I can - you know, I - from the Alzheimer's Association, nationally, and the New York City Chapter, that we are working with the Heart Association and the Diabetes Association as well in getting out information. And indeed, last

year, we did a co-sponsored program specifically for Latinos, actually. And we're doing the same thing with - for African Americans because of the higher rates of those illnesses.

So we certainly are trying to collaborate and get our messages lined up, because if we can control one, hopefully we can control the other.

Diane Donaldson: Thank you very much. Appreciate everybody's efforts.

Amy Wiatr-Rodriguez: Great, thank you. And I think we have time for one more question from the phone, and then we'll do one more question that came in on the chat, and then we'll wrap up.

Coordinator: Carol Crecy, your line is open.

Carol Crecy: Good afternoon. I just wanted to thank all the presenters for a wonderful presentation, very informative. But I also wanted to share with the audience that the Department of Health and Human Services here at the federal level is right now developing online training for workers in long term care facilities about dealing with LGBT issues.

Jed Levine: Great.

Carol Creasey: And Jed, I will be contacting you a little bit later, off line.

Jed Levine: Wonderful. That's great.

Amy Wiatr-Rodriguez: Great. Thanks so much for sharing that, Carol. All right, well let me go - and I - we'll take one more question that came in on Chat. A question came from Michael, saying that Arizona has a State Native American

Dementia conference annually. They're hoping to have one in Washington State. Are there any other areas that are doing similar types of conferences? So I don't know, Dr. Jervis, if you're aware of anything, or anybody else is? I can say from the AOA/ACL perspective, I know that we do have an annual national Title VI conference, which is those tribes that receive funding under the Older Americans Act to provide services to their elders.

And I believe that they do have sessions there. It's not a conference dedicated to dementia issues, but they do have sessions there, focusing on dementia as relates to that population or subpopulation. But I don't know, Dr. Jervis, or others, are you aware of anything else?

Lori Jervis: I'm not aware of a lot of conferences that focus specifically on dementia, although there are quite a few different conferences that are out there. But that's great and I'm - I would like to hear more about it.

Jed Levine: In...

Nina Silverberg: This is Nina. Oh, sorry.

Jed Levine: Go ahead.

Jed Levine: In New York City, we are - we work with the local medical associations, the Hispanic Medical Association, the National Medical Association, which is the African American Medical Association, and an organization of Asian physicians, and we do an annual dinner for doctors around - bring in researchers and talk about the incidence prevalence and the issues of dementia care within those communities.

And I've also done that for the Gay and Lesbian Medical Association, GLMA as well as my national association. But that's fairly local, so.

Gwen Yeo: In Northern California, we have - in Stanford Geriatric Education Center, and the Alzheimer's Association and other organizations co-sponsor a conference every year on updates of dementia. And we always have a session on some - related to minority or ethnic cultural issues in that conference.

Nina Silverberg: And I was just - this is Nina. I was just going to add that all - I don't know if the question was specifically about Native American or not, but all of the Alzheimer's centers funded by NIA, which are listed on the map that Dr. Aggarwal presented, each one of them has an Education and Outreach Core, and those Cores all conduct regular outreach programs to their local community.

Amy Wiatr-Rodriguez: Great. Well with that, I think we'll try to wrap up today's session. Again, thank you to all of our presenters. We very much appreciate you taking the time to share your expertise and experience with us. Thank you to everybody who's joined today's session, and especially to those of you who raised such stimulating questions.

If we didn't get to your question, I will follow up with them and make sure that we get them answered. Next time we'll have to look at adding even more time for Q&A, because there's just so much discussion, dialogue and interest in these issues.

If anyone does have any additional questions, if you have a suggestion for future Webinar topics or if you'd like to share any other feedback with us on whether this Webinar was helpful to you, we do want to hear from you. You

can email us at amy.wiatr@acl.hhs.gov. We do want these Webinars to be as useful to you as possible, so we very much welcome your suggestions.

As I mentioned before, we'll send an email out to everyone who registered when the recorded materials from this Webinar are available. And again, thank you for joining us. We look forward to having you with us at future events. This concludes today's Webinar. Thank you.

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