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**The Clinical and Cultural Challenges of Dementia in African American and Hispanic Communities**

**Moderator:** Hello and welcome to Public Health Live! I'm Rachel Breidster and I will be your moderator today. Before we get started, I would like to ask that you please fill out your online evaluation at the end of the webcast. Continuing education credits are available after you take our short post-test and your feedback is helpful in planning future programs. I want to let you know the planners and presenters of Public Health Live! do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in this activity. No commercial funding has been accepted for this activity. As for today's program, we will be taking your questions throughout the hour by phone at 1-518-402-0330 or via e-mail at [phlive.ny@gmail.com](mailto:phlive.ny@gmail.com). Our guests are Dr. Jennifer Manly, an Associate Professor in the Department of Neurology at Columbia University and Ms. Teresa Santos, the Care Coordinator at the Montefiore Center for The Aging Brain and Memory Disorder Clinic. Thank you for joining us.

**Moderator:** Good morning. Thank you both so much for being here with us today.

**Speakers:** Good morning.

**Moderator:** Let's get started. Dr. Manly, would you start us off, with just reviewing what the objectives are for today?

**Dr. Manly:** Sure. Well, at the end of the session, the participants will be able to list at least three barriers in the diagnosis of Alzheimer's disease among Hispanics and Latinos and African-Americans. They will be able to explain the principles of a dignified Alzheimer's disease diagnosis relative to Hispanic and Latino and African-American communities. And they will be able to identify some educational resources that are available for care givers and families for understanding Alzheimer's disease in the Latino and African-American communities.

**Moderator:** Excellent. Thank you. Now to sort of set the groundwork or lay the framework for us, can you start off by explaining, what is essentially the difference between dementia, senility, and Alzheimer's?

**Dr. Manly:** Dementia is a term that refers to a decline in memory and other cognitive abilities that is severe enough to interfere with activities of daily life and social interactions. We really think of dementia as an umbrella term. There are different subtypes of dementia

under that umbrella. The term that you referred to as senility is a term we don't use anymore because it suggests that severe cognitive decline is a normal part of aging, which it is not.

**Moderator:** So looking at dementia, what are the different types of dementia? Do we know anything about what causes them?

**Dr. Manly:** We know a lot about what causes these subtypes of dementia. And the slide that the viewers will see in a little while shows the subtypes of dementia that I was referring to before that are under that umbrella of dementia and their approximate frequency. Alzheimer's disease is the most common form of dementia, and it's caused by abnormal deposits of a protein called beta amyloid. It causes plaques in the brain and tangles of another protein called tau. Vascular dementia is another common type of dementia caused by blockages of blood vessels or strokes or bleeding in the brain. Dementia with Lewy Bodies is another subtype of dementia caused by abnormal clumps of a protein called alpha-synuclein. This protein is the same and these clumps are the same as seen in Parkinson's disease but in dementia with Lewy Bodies it has a different distribution in the brain. Mixed dementia is much more common than we thought. Previously, it's when more than one cause of dementia is present in the brain. Most commonly Alzheimer's and vascular changes, but it can involve Lewy Bodies dementia. Frontal temporal dementia is where cells die or are dysfunctional in the brain, mainly in the front or the anterior or side temporal regions of the brains.

**Moderator:** So Teresa, looking at this slide it's obvious that Alzheimer's is the largest cause. I would understand that to mean it has the largest impact. Is that correct?

**Ms. Santos:** That's what we find in our clinic, that it does have the largest impact. But on the same notion, we find that families are often relieved, patients are often relieved to know there is something other than Alzheimer's because they associate Alzheimer's with this rapid decline. And I think it's a relief when they find out that there are varied forms of Alzheimer's. And that gives them hope.

**Moderator:** Which is, I'm sure, very important.

**Ms. Santos:** Yes.

**Moderator:** Now, Dr. Manly, what are the problems that usually bring a person to the doctor for a dementia evaluation? How might that look different across different cultural or ethnic groups?

**Dr. Manly:** I think that the most common problem that brings people to the doctor's office is severe memory loss. People are complaining of problems, forgetting names or faces or appointments, repeating questions over and over, forgetting conversations. People also have complaints about decline in planning or problem solving, tasks that they are counted on to do somehow don't get done or don't get done quite in the way they should. Some people have confusion with time and place, not knowing what day it is or what year

it is. And a common complaint is also getting lost while driving or other visual problems like difficulty reading. Compared to non-Hispanic whites, we know from the research literature that African-Americans and Latinos are more likely to present at the doctor's office with behavioral disturbances like aggression or paranoia or wandering. And so that's one way in which the doctor -- doctor's presentation can differ across ethnic and racial groups.

**Moderator:** Interesting. Now, Teresa, what are some of the other symptoms that people with dementia notice? How do those differ across racial or ethnic groups?

**Ms. Santos:** We find in our Bronx community in particular is that they -- they are forgetting the family recipe. It's been handed down from generation to generation. This is very common in African-American and Hispanic and Latino community. That's always been a large red flag for the family members. But there's increased problems with word finding, word searching. For example, they will say give me that thing so I can write down that stuff. The family member says, a pen? Yes, yes, a pen. There's a lot of word searching that occurs, the decreased judgment and decision making which is very pertinent in this community, because they tend to live multi-generational homes. So often times the matriarch or patriarch of the family is helping with childcare. We have had incidents where a grandfather would be the person to walk the 5-year-old to school. We encourage them to rethink that. Now that we have a diagnosis of dementia or we're having an evaluation of dementia, you know, there could be some judgment decisions that are not the best for the person to be walking them to school. And again, withdrawal from work and social activities. Changes in mood and personality. That's a big one as well. You have the person that was normally very docile, suddenly becomes aggressive or you have someone that was aggressive, suddenly becoming docile. That's another red flag for the family. We see it often.

**Moderator:** A number of different symptoms to be aware of. Now, looking at the big picture, Dr. Manly, can you tell us about the impact that Alzheimer's disease has?

**Dr. Manly:** It's a big impact and it's growing. Because the baby boomer generation is now getting older and reaching the age above -- ages above 65. And the reason why that's important is that age is the biggest risk factor for dementia. And the number of people who are age 65 and older with Alzheimer's disease in the country right now is about 5 million people. In 2025, we estimate that it will be as many as 7 million people. By 2050, almost 14 million people with Alzheimer's disease in the United States. So that means that about 11% of the people age 65 and older and 32% of people age 85 and older have Alzheimer's disease right now. It disproportionately affects women. That's because women live longer than men and age is the biggest risk factor. Also because about 65% of the caregivers for people with Alzheimer's disease are women. But the true impact of the disease really has to take into account the long disability, long period of disability that's associated with dementia. It really increases the cost and the burden of care. We think that without a way to delay the onset of Alzheimer's disease or without expansion of services to help families cope with Alzheimer's disease, dementia will overwhelm the current health care system.

**Moderator:** Absolutely. You would agree with that statement?

**Ms. Santos:** Absolutely.

**Moderator:** Certainly, the numbers you provided across the board are pretty staggering. But I understand there are differential risks for dementia across racial and ethnic groups. Can you talk a little bit about that? Keeping in mind the large numbers we're talking about, how it impacts certain populations even more.

**Ms. Santos:** Sure. So the entire population is aging, including ethnic minority groups. Research has shown that African-Americans, Latinos and American Indians are at higher risk for developing Alzheimer's disease. And dementia and cognitive decline as compared to non-Hispanic whites. The figure that is being shown right now is from a study in California that followed people enrolled in -- that were enrolled in the Kaiser Health Care System. It shows the incidence rate of Alzheimer's disease by age group starting from about age 65 on the slide and ending at 90 and older. In this study, Asian Americans were the lowest risk of developing Alzheimer's. The upper line is for African-Americans who were at the highest risk of developing Alzheimer's disease and Latinos and American Indians were at much higher risk as compared to the Asian Americans and whites in the study.

**Moderator:** Looking at those numbers, we clearly see there's higher rates among African-Americans, Hispanic and Latinos, American Indians. What could be causing those higher rates among those groups?

**Dr. Manly:** We don't know exactly what causes these disparities. We do know that they are not explained simply or by any known genetic risk factor or medical conditions like stroke or chronic cardiovascular diseases like hypertension and diabetes, even though those are more frequent in African-Americans and Latinos. So we're investigating these disparities coming from different perspectives, trying to look at the contribution of behavioral, biological and social mechanisms. Social factors like stress associated with discrimination are currently under investigation. Right now, the research points to social factors as being the most strong -- the strongest influences throughout the life course, especially educational experiences, early life education and socioeconomic status that seem to be driving these disparities.

**Moderator:** Interesting. Now, we recently visited with Dr. Joyce Simons, an African-American woman from Rockland County, New York, who was diagnosed with early onset dementia. She spoke with us about her experiences with being diagnose and interacting with family and friends.

**Dr. Simons:** My name is Joyce Simons. I got the diagnosis about -- in 2007. I started to notice that there were some things that were not quite right -- well, I had a stroke, actually. I was sitting at my desk one day, and I realized I couldn't spell of and the. My driving was not good at all. My perception -- my spatial perception was off. So anyway, I did see a

neurologist. She did confirm that I had a stroke. And she said that I had a combination of the stroke and Pick's disease. I began to go to the Alzheimer's Association. They have a support group. The leader, god bless her, the leader said, well, after seeing me a couple of times in the group, she said, I'm not sure that you have Pick's. Maybe you should see - - get a second opinion. I went down to Columbia Presbyterian and saw a neurologist there. She said, you definitely don't have Pick's. She said, you have a mixture of Alzheimer's disease -- early onset Alzheimer's, but vascular dementia, which usually people get from a stroke. That's how I found out. I never knew really that there was a beginning and a middle and an end. I just always saw the end. So when I -- I was really upset, because I just could see myself just not doing anything, just sitting in a rocking chair. When you mention Alzheimer's to people in the African-American community, it really isn't accepted. You know? It's like an old person's disease. And when you tell somebody, instead of hearing what you are saying, they start to focus on themselves. They often say, that happens to me. That happens to me. And I didn't know what to say. So I stopped telling people. It was hard for my family. My daughter and my husband know that there were some issues. But my son didn't take it too well. And he would say, don't let those doctors put that in your head. You are fine. You are fine. You know, you just forget sometimes. Someone in my family said to me -- that's family. You remember what you want to remember. She's like my favorite person -- one of my favorite people. I said, she didn't mean it. But I'm thinking if my family doesn't see it -- you know, I have some friends who work with elderly people. And because they work with end stages people, they don't really see the beginning. And so they would tell me, you know, that you don't have that. You are just stressed or what have you. Like I said, you almost have to spend time convincing them. It got to a point where I said, it's not worth it. It makes them feel uncomfortable. They think that, if she could get it and she's so young, maybe I could get it, too. You know, I try to live one day at a time. You know, today and the next day. I notice that I'm having a difficult time with keeping the days straight. Really difficult time. But, you know, I'll just look at calendars. You know? I try to do as much as I can on my own. And my family is very -- very good -- when I say, I don't know what day it is, they will say, you just keep going, whatever day it is. They're supportive. My friends are very supportive.

**Moderator:** So let's talk a bit more about the aspect of disparities that we just touched on, which is stigma. Can you explain to us or talk to us about how stigma might be contributing to some of the disparities in Alzheimer's disease and dementia among African-American or Hispanic and Latino communities?

**Dr. Manly:** Sure. Well, some people feel stigma -- they feel that a diagnosis of dementia discredited or discounts the person with dementia. They feel the dementia dying diagnosis is their fault. Stigma can be subtle. It cannot just affect patients and their families but also medical professionals who also have assumptions and stereotypes, may have assumptions and stereotypes about people with dementia. This stigma causes fear and discomfort and embarrassment, which can lead to a delay in getting a diagnosis or getting care for some of the symptoms of dementia. If there is fear or if there are assumptions around what people with dementia are like, the interactions with medical professionals and care providers can be superficial. And unproductive and not what they should be. Research shows that caregivers who feel more stigma associated with

dementia also are more burdened by caregiving or feel a greater burden associated with caregiving. Social isolation can occur when people feel stigmatized by the disease. And because participation in research often involves interactions with research staff and also careful tracking of the disease, people who feel stigmatized by dementia are less likely to participate in research, which is an important part of tackling and battling this disease.

**Ms. Santos:** Absolutely.

**Moderator:** Teresa, how does that stigma, in your experience, impact their interaction with their medical provider?

**Ms. Santos:** First and foremost, they're afraid to go out and meet medical providers because of the stigma and fear. You know, right now we're looking at approximately 390,000 New York state residents that have Alzheimer's disease. The number is probably greater, because the stigma and fear keeps them at home. They're not in a rush to go out there and learn that they have Alzheimer's disease or dementia on top of the cardiovascular, on top of the Type II Diabetes, and the other health issues. A majority of Americans with Alzheimer's disease are women and they are also caregivers. It's a double whammy. They are hesitant to go out. Older African-Americans are about twice as likely and Hispanics and Latinos one and a halftimes as likely as older whites to have Alzheimer's, again according to the literature we have read and are sharing today and the research. What I have found in our practice also is that the adult children of these cohorts, the adult children of the patients that we're seeing are often times fearing the stigma as well. We're looking at adult children that have become leaders in their community. They have taken on positions of power. And they don't want -- they don't want this label placed on their parents. So often times, they are just -- I find that they have the stigma and they have a sense of denial as well. I think this is important for the medical providers to know because we have to tailor our approaches with this knowledge and not assume that they're just -- because they're educated or because they are familiar with the medical establishment that they are going to accept the diagnosis easily. It's just such a complicated web.

**Moderator:** Absolutely. Now, Dr. Manly, what do we know about participation of ethnic minorities in research? And ways to improve that.

**Dr. Manly:** We know that African-Americans and Latinos are much less likely to participate in clinical research studies or clinical trials for Alzheimer's disease and dementia. We know that this is associated with lack of trust to the research community. And part of it is that when -- for example, when people call up who are interested in participating in a trial, if they are Spanish speakers, if the staff at the study don't have bilingual or Spanish speaking staff, it's hard for them to navigate that. So the cultural competency of the office where potential participants are being recruited from and the research staff is critically important. There is a legacy of abuses in research, including Tuskegee, but others also that is really in the forefront of people's minds. There's also -- because the diagnosis of Alzheimer's disease and many of the clinical trials use cognitive function as an important end point, there's memory testing and there's testing of other

cognitive functions. The legacy again of misuse of I.Q. tests is off putting to many ethnic minorities. The other big barrier is that there's very little evidence of benefits of medical research for minorities. There are disparities that are -- persist or even widening in health. And I think the community is very aware of those disparities and doesn't trust that research will be able to solve that. And then I think people have -- people have their own and their family has -- have experiences of discrimination in the medical setting that makes it so that people want to minimize their contact with people who are doing research. And then I think that in addition to the cultural competency that research staff and researchers, principal investigators need to have, there's also a lack of access to information about is there a trial, what happens when you are in a trial and what are some of the potential benefits to people who are participating in clinical trials.

**Moderator:** Teresa, everything that Dr. Manly has gone over, are these things that you hear and see with your clients as well?

**Ms. Santos:** Absolutely. I mean, I wouldn't dare put a percentage on the amount of times that someone in the African-American community in particular has brought up Tuskegee, the Tuskegee study to me. When we speak of research or trials. Even when we speak of medication. When they speak of taking -- being prescribed a medication, their mistrust is still there. And it just -- we have to overcome it. It's a barrier. It's present and it shouldn't be ignored. And in the Hispanic and Latino community, what I have found is that often times, you know, we do have a great cohort of English speakers in the Community. However, when you look at the cohort that is affected by Alzheimer's and the dementia, they tend to be 65 and 70 and 75 and over and a lot of them, Spanish is the primary language. Just by that barrier, it removes them from a lot of testing, because a lot of the testing that's out there that's been showing promise, you have to be English dominant. So, yes, there are studies that exist that will not exclude someone due to lack of the language proficiency in English. But that still serves as another barrier. It's been cited to me.

**Moderator:** Certainly, quite a few barriers that we have to overcome in order to increase participation. Dr. Simons shared thoughts about the challenges and mistrust that exist in some communities. Let's hear from her again.

**Dr. Simons:** African-Americans are very leery to participate in research because of the Tuskegee study. And that was so -- I mean, the first thing people think about is that study. And they won't. That's one of the reasons why they don't have a lot of information specifically about us is because, you know, we don't go into research. Quite honestly, I hate to admit it, but I'm not thrilled to go into research either. We have a lot of diabetes. We have a lot of high blood pressure. Heart disease more so than anybody else. Like when America gets a cold, we get the flu. That's another reason why I think African-Americans don't particularly get diagnosed is because a lot of times they have so many things wrong, they don't need -- they feel, I don't need to own Alzheimer's. I don't need another thing that I'm going to the doctor for. People haven't said anything to us about Alzheimer's. And I think if they say that, I think -- I never thought of that before. But I think if they say that, that there is a higher incidents of Alzheimer's among African-Americans

and Hispanics, people will begin to look at it. You know? They will begin to see, well, this is another thing that we have. They will begin to seek treatment and seek treatment early on. In general, doctors and nurses need to know that they should look at the culture of the people they're serving. And I know that they know this. But a lot of times there's so much that goes on -- I mean, they have to see people. They don't have the time. Everything is developing so fast, particularly in how you treat patients, how many patients you have to see. Start educating the medical students. Start early and don't just -- I don't know if they do. I heard stories where they spend a minimal amount of time talking about Alzheimer's. I think the education of the -- of medical students and nursing students would be -- is really key.

**Moderator:** Dr. Simons really shared a valuable perspective, I think, with us in the audience. Can you talk to us, Dr. Manly, about do all of the factors really impact the rates that African-Americans and Hispanics or Latinos are diagnosed with Alzheimer's disease?

**Dr. Manly:** Absolutely. So thinking back to the discussion we had before about the higher incidence and higher rates of Alzheimer's disease among African-Americans and Latinos, those are from epidemiological studies, studies that are not clinic-based studies. They define a community cohort without asking people necessarily to present to the doctor. What we know about Alzheimer's disease is that it's really a severely underdiagnosed disease. Only about 50% of the people who meet the criteria for Alzheimer's disease have a formal diagnosis that they got by visiting a doctor or a neurologist or a geriatrician. And although those numbers that were reported in the 2015 facts and figures that the Alzheimer's Association puts out were not broken down by race and ethnicity. There is evidence that this rate of under diagnosis is even higher among African-Americans and Hispanics. And I think that the reasons for that are mixed. We talked about the cultural competency of physicians, primary care physicians and other medical professionals that are interacting with people, that this may be one factor in why African-Americans and Latinos are even more underdiagnosed. The stigma, fear and shame that we talked about before is another possibility. There's cultural differences in the recognition of symptoms and whether people distinguish these symptoms between normal aging and something that is abnormal or not expected with aging. And then obviously, there are socioeconomic differences that relate to access to medical care. Some people may not have the access to a proper diagnosis.

**Moderator:** So now let me ask you, Teresa, to talk with us a bit more about what is obviously an important part of this -- important component of the puzzle, culturally and linguistically appropriate for this discussion.

**Ms. Santos:** Absolutely. For example, in our facility and a lot of larger facilities, it's easy to assume or see that materials will be provided in multiple languages, that a community that they are serving is reflected in the staff. But that's not often the case. So we really emphasize that we look at the broader picture and not just look at these major organizations and major medical centers like ours. But people need to learn how can they use translator services at a health care facility, provide documents in the client's language



and look out for the red flags of literacy, which is an often overlooked linguistic barrier. I can't tell you the amount of times I handed someone a piece of paper and they go, you know, Teresa, I forgot my glasses. Can you read it for me? That's always the red flag for me. I will say, are you having a difficult time reading this document? As sensitive as I can. Normally they say, I can't read this. Again, it's going back to this cohort. We're looking at a lot of patients that are 70, 75 and over in New York City in particular, we have a lot of immigrants that come from the islands. They were working on the farm or forced to work early. While later generations are achieving doctorates and masters and great strides, the patients we are seeing -- they tell me, I had to work. I didn't have the luxury you guys had of going to college. So that said, it's important for the staff to reflect the community it serves. I can't tell you the amount of times that people love to hear a Bronx accent in me. You are from the Bronx. You remember when this store was on grand concourse? That helps a lot. They have told me that it's nice to have a staff that reflects the community and it's bilingual. We have a large bilingual staff. Most major medical institutions have bilingual staff. If you don't have access to a translator, these are things that -- there's a policy that is attempting to address these disparities across the board. It's called -- I want to read it to make sure I get it right. Its culture is The Culturally and Linguistically Appropriate Services Standard -- it was issued in 2000. Among the mandates of this policy are making sure that there are interpreters available, services and materials in their languages and amongst the suggestions are the ones about having a culturally diverse staff.

**Moderator:** Excellent. I think the importance of that probably can't be overstated.

**Ms. Santos:** Absolutely.

**Moderator:** Dr. Manly, we have talked about the barriers that diverse communities face in getting diagnoses. Are there really concrete benefits to getting an early diagnosis, whether I find out now or later, does it make a difference?

**Dr. Manly:** So I think it's important to talk to patients and families that even though there's no cure right now for dementia or Alzheimer's disease, even though there's no treatment that can modify the course of the disease. Early diagnosis does have concrete advantages. One of them is that some of the symptoms that travel along with dementia may be reversible. I'm thinking of depression as an example. It really complicates everything among people with dementia that if treated, it can increase quality of life for the patient and for the family. Diagnosis, especially telling the difference between those different subtypes of dementia under the umbrella is much more accurate early on in the disease. Advanced care planning is one big reason why we advocate for early diagnosis. Once the patient loses the capacity to make decisions, it's really difficult for them to participate in making plans. It's important when we are making plans to respect the wishes of the person with dementia. And that's not possible once they lose decision making ability. Early diagnosis helps families learn about dementia and make plans for the future early on with their loved one who has dementia. And also allows for making better use of the available resources like support groups where having that early diagnosis status is so important.

**Moderator:** While an early diagnosis might not necessarily be able to cure you of Alzheimer's, it can minimize some of the harmful things and increase the capacity for the care being appropriate to what that person wanted when they're in a sound state of mind.

**Dr. Manly:** Exactly.

**Moderator:** Now, given that information, what is the typical path to diagnosis for ethnic minorities?

**Dr. Manly:** I would say there's no typical path for diagnosis in ethnic minorities. We talk about a diagnosis with dignity. Unfortunately, for ethnic minorities, that diagnosis -- that diagnostic path is not the one with the most dignity. It can be very stressful and confusing, especially because of the intersection of that lack of cultural confidence of a number of institutions, not just the medical community, lack of resources and discrimination. I have heard several stories where the diagnosis of dementia comes as a result of an arrest and someone going to jail because their behavior was unusual. Someone who was wandering or out in the yard or got the wrong house. These kind of stories will then escalate into a path to diagnosis that's not -- not the one that I think we should all be advocating for, which is first that with the physician will take a thorough medical history. Then the physician or a neuropsychologist will do testing of memory, thinking and problem solving. Then a physical and neurologic exam to look at some of the symptoms that may help with that differential diagnosis and rule out other causes of cognitive decline and blood tests and brain imaging can rule out -- again, rule out our causes of cognitive decline.

**Moderator:** Thank you for sharing all of that information. Now, Teresa, can you give us an example of a screening test for dementia that would be considered both culturally and linguistically appropriate?

**Ms. Santos:** Definitely. Where I'm based at the Montefiore Center for the Aging Brain, we're in the process of exploring new forms of testing, screening tools, just to kind of aid in the process in the hopes of removing cultural and linguistic barriers. So right now what we're using, we have the picture-based memory impairment screen for dementia. Its four pictures screening tool. It has been validated for use in low education population. As you can imagine, it's also reflective of culture because one of the things with this tool is that, for example, this is the one we use in the US there's a different one that is being used in India that would have four pictures reflective of common things in India. There's one that's being used in Japan that has four pictures reflective of things in Japan. Right now, the goal is to develop and validate a picture-based memory screening tool. This tool was validated in India. We're working on securing validation here in the Bronx. We're administering the tool. So far, it has been showing promise. Right now, we don't have anything that removes all the cultural biases. But we're hoping with the implementation of tools such as this it helps removing some of the barriers that exist.

**Moderator:** Dr. Manly, when people are not diagnosed early, does that impact the care that they are able to receive?

**Dr. Manly:** Yes, it does. I think that there's an interaction between the impairments in memory that people with dementia have and other chronic conditions. So people with dementia have a harder time managing those chronic conditions. Even common ones like hypertension and diabetes, people have to regularly remember to take their medication or manage a treatment schedule that becomes much more difficult once you are dealing with Alzheimer's disease or another dementia. Research shows people with dementia have more acute care events than people without dementia. As a result, the costs associated with health care are much greater for people with dementia compared to people without dementia.

**Moderator:** Now, what else, Teresa, have you found useful in working with the people in your practices?

**Ms. Santos:** Well, in our practices, we found that it's extremely important to work with the diet. We're looking at the patient and the caregiver. We have few patients that come in without a caregiver, especially in the African-American and Latino community. We're following the national New York State standards basically that we're looking to focus on the model of prevention and wellness and not just sickness. One of the things we're going to introduce is diet, nutrition workshops. Everybody is excited about that. The use of music is not just bringing out the best and bringing out conversation with the patients that are diagnosed with dementia but also for the caregivers to ease their stress. We had someone come in and play the piano. It was just amazing the transformation that you just felt in the room. It was beautiful. That's again focusing on the wellness. We provide assessments that are -- that have a language amongst the providers so that we can quickly have an engagement pass off to each other, this is how this patient presented, so when the caregiver comes into the room and joins us, it's a comprehensive communication pattern. Again, this is from the national New York State measures. It's been working really well.

**Moderator:** Excellent. Now, can you tell us briefly how people from African-American and Hispanic or Latino communities who have Alzheimer's disease or other form of dementias, how they tend to receive their care?

**Ms. Santos:** Actually, they tend to receive their care predominantly by family members. You know? When I meet with the families, I go through the whole menu of options, home health care, adult day programs, and other opportunities. But what I have found is that they don't -- they really just want to focus on ways they can continue to be the caregiver at home. I don't know the numbers off the top of my head, but they have to be staggering as far as a family member being the primary caregiver. What I have seen is that in the African-American community, they see it more as a privilege. They love it. Their stress level is -- it's just lower because they see this as their duty. While what I have seen in the Latino community, while they see it as a duty, I found they express more stress. This is completely based on my own research in that I have been running a care -- a caregiver support group for three years now. It's made up of 90% Latinos and Hispanics and 5% African-Americans. That shows me right there in this -- I would like to expand that and see how true those numbers are. But more -- the other point that's relevant is the daughters. I had one patient that had eight children. And one daughter. The daughter is

the only one that accompanied her to the appointments. It was interesting.

**Moderator:** What kind of services or what else do you offer to those folks who are caring for someone who is living with Alzheimer's or dementia?

**Ms. Santos:** In addition to the support group, which I facilitate monthly, I also let them know about other support groups. Sometimes my support group is not convenient for them. I encourage everyone from the first meeting to connect with the Alzheimer's association or similar organizations because I always say why reinvent the wheel? They're doing an excellent job. Their website is phenomenal. They have one caregiver center that you link on to that I cannot tell you how many people have called or e-mails and said thank you for that resource. The professional caregiver services, transportation, meal delivery, home health care services. That is met with resistance. This is their job. This is their job. Who am I to tell them that -- they aren't going to cook food? Do they know how to make food from Jamaica, from the islands? That's a tough sell, the meals on wheels. I introduce it. Give yourself a little break. I understand that it doesn't have to be every meal. Give yourself a break so you are not always the caregiver. You can be daughter. You can be son and just play that role and let these people come in and do some of this work. Go to the movies, go to the park.

**Moderator:** Remember to take care of yourself. So you can take care of the person you love.

**Ms. Santos:** Remember to take care of yourself. Absolutely. I encourage them to eat right, exercise and avail yourself to the services that are there, supportive counseling. You would be amazed how many people don't think that these things are important. Once they start engaging in them, I get a lot of thank you cards.

**Moderator:** A lot of relief, probably. Dr. Manly, can you talk to us briefly about the resources that are available to help people that are facing the disease? I understand the Alzheimer's Association has a document called Principles for a Dignified Diagnosis?

**Dr. Manly:** Yes. To make it brief, this is something everyone should read. It's a document that was authored by people with dementia. The intention is to help patients and families work together in partnership with their doctors. If you read through this, you are going to learn many different ways to address that stigma problem that we were talking about before that really prevents quality interactions between medical professionals and patients and families with dementia.

**Moderator:** Excellent. Thank you. Teresa, are there other resources that you might access routinely that perhaps are available in Spanish?

**Ms. Santos:** Absolutely. The Alzheimer's Association again, they have multiple languages. But they have been an excellent resource for Spanish materials. The national institute of health has a phenomenal publication list available. I try to order a lot of them and have them in the office and have them ready. But these that are -- that were stated

here are phenomenal.

**Moderator:** Excellent. Thank you both very much for all of the information you have shared today. I think we have covered quite a bit of information that probably many people aren't as familiar with. I'd like to take a few moments to take questions from the audience. The first one that we have is, is there a difference in the prevalence of AD, which I'm guessing Alzheimer's disease, based on socioeconomic and educational?

**Dr. Manly:** Yes. What we found is that within African-Americans and within Latinos, early life education is a really strong predictor of who will go on to develop dementia. In fact, it's a stronger predictor than race, ethnicity itself. We're also -- because many of the African-Americans and -- African-Americans in our community were born and raised in the south, we know that -- it's not just studies here in New York but across the country are finding that rural -- growing up in a rural environment with low education puts people at higher risk for developing the disease. So this isn't saying that just because you grew up in a rural community you will get Alzheimer's disease. It means that we're trying to find risk factors or factors that are associated with more likelihood of developing the disease. But there are also resilience factors that we're beginning to investigate as well.

**Moderator:** Sounds like there's a lot of factors to consider and there's still a lot more research to be done.

**Dr. Manly:** Absolutely.

**Ms. Santos:** Right.

**Moderator:** The next question that we have are, what are effective outreach strategies that dementia programs can use to reach out to, engage and support Hispanic and Latino communities and African-American when we are talking about caregivers?

**Ms. Santos:** When we are talking about the caregiver in particular, often times, and the caregivers are the ones there. They are accompanying the patients. The patients do not come alone. They come with a daughter, a sister, a family member. There's the first step in reaching out to them. If they're not coming to the -- the problem is we're trying to get them to the medical center. So I always say, bring information to where they're at. Bring information to people -- think outside the box. Go to the barber shop, the salon, and the churches. The churches is a big component in the African-American and Hispanic and Latino community. Go and give a presentation. Because the information will be disseminated in that manner rather than websites or -- websites are great. After we get them through the door. If you want to get them in the door, go to where they are at.

**Dr. Manly:** I want to add that establishing a partnership with a community you are trying to reach to is incredibly important. It's important that partnership be an equal one. Once you make these contacts, once you have these people who you might consider to be gatekeepers, keep them as an advisory group to you. Keep them in contact with them. Let them guide your outreach. They may have some of these ideas.

**Ms. Santos:** Absolutely.

**Moderator:** I think that's especially important given all that you have shared today in terms of some of the discrimination, a lot of the mistrust, cultural barriers, the idea of not only being representative of the community and going out there and not expecting that patients will come to you. There are so many different experiences that you have described.

**Ms. Santos:** Yeah. We have a deacon, speaking of approaching a gatekeeper. We kept him on the board. It has become where this deacon is the person that brings three or four patients to all of their appointments.

**Moderator:** That's great. Another question we have, can you talk more about any proven strategies for lessening the stigma about the disease in African-American and/or Hispanic or Latino communities?

**Dr. Manly:** I think proven is the key word here. It's difficult. And the other key word here is whether it's been proven in ethnic minority communities. I know that general strategies for reducing stigma include getting more information to people. Once you learn more about the disease and once you learn more about what people face with the disease, stigmas begin to reduce. There's another factor to keep in mind that people may -- their attitudes may change in terms of their attitudes about people with dementia, but their behavior may not. So those are two outcomes that we want to keep in mind. The other thing that's been proven to reduce stigma in stigmatized diseases is having contact with people with the disease. So the more contact people have with people with dementia makes them realize that they are, you know, people who are just like you and me. They have a disease on board. They are battling it and living with it. So then the fear and the discomfort can reduce.

**Moderator:** Absolutely. We have another question. I'm a director of adult-based services. It wasn't mentioned by the care coordinator from Montefiore. I feel as an advocate, it's important the social and medical model adult day care services are an integral part of the care giving services for the Latino and African-American communities. Can the care coordinator from Montefiore speak to the importance of this form of care giving?

**Ms. Santos:** Absolutely. That's day one. Day one we do mention the benefits of adult day care, Social model, medical model. I often times write it on a prescription pad, because I know that they will follow it if it's a prescription pad. If I tell them to go out there and socialize, they look at me and say, I'm not going to senior center, all they do is gossip. This gossip is good. This gossip is healthy. This is stimulation going on in your brain.

**Moderator:** Keeps you engaged.

**Ms. Santos:** Rather than a passive activity of watching television. Thank you for the question. I do -- I introduce that at the initial session. My initial meeting with the family is

to encourage them to engage in social models and day centers. Unfortunately, some of them funded by the Department for Aging are not the best fit for the patients if they're progressed with memory impairment, because they will wander. They will leave the program. The supervision isn't there. We look at medical models that require they have long-term care insurance or some form of payee because it can be costly. I will introduce them into the avenues of securing outlets for payment for that. That's a huge part. We really advocate that.

**Moderator:** That's all the time we have for questions. I would like to thank you so much for everything you have shared. If you have any brief closing comments you would like to share with the audience before we wrap up?

**Dr. Manly:** Thank you for having us.

**Ms. Santos:** Same. Thank you for having us. Great to get this information out there.

**Moderator:** Absolutely. Great to get the information out. Thank you both.

**Speakers:** Thank you.

**Moderator:** Thank you for joining us today. Please remember to fill out your evaluations online. Your feedback is always helpful to the development of our programs and continuing education credits are available for today's program. To obtain nurse continuing education, CME, CHES, and social work credits, learners can visit [www.phlive.org](http://www.phlive.org) and complete an evaluation and the post-test for today's offering. This webcast will be available on demand on our website within two weeks of today's show. Additional information on upcoming webcasts and relevant public health topics can be found on our Facebook page. Don't forget to like us on Facebook to stay up to date. Now, you can also let us know how you use Public Health Live! by taking a brief survey at [www.phlive.org](http://www.phlive.org). Please join us for our next webcast on December 5<sup>th</sup> focusing on transition care partnerships: building bridges for improved communication and care coordination across the health care continuum. I'm Rachel Breidster, thanks for joining us on Public Health Live!