

**Kick-Starting Brain Health Conversations with Diverse Older Adults:
A Discussion with Dr. Carl Hill**

Applications from the [GSA KAER Toolkit for Primary Care Teams](#)

GSA Momentum Discussions Podcast from the Gerontological Society of America

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Guest:

Carl Hill, Ph.D., MPH

Chief Diversity, Equity, and Inclusion Officer
Alzheimer's Association



Host:

Jennifer Pettis, MS, RN, CNE

Director of Strategic Alliances
Gerontological Society of America

Announcer:

The Gerontological Society of America, meaningful lives as we age.

Jen Pettis:

Welcome to this GSA Momentum Discussion podcast addressing Kick-Starting Brain Health Conversations with Diverse Older Adults: A Discussion with Dr. Carl Hill. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of the GSA KAER Toolkit for Brain Health and today's program. My name is Jen Pettis and I'm the Director of Strategic Alliances at the Gerontological Society of America. I'm delighted to serve as the host for today's Momentum Discussion. Joining me for this podcast episode is Dr. Carl V. Hill, Chief Diversity and Equity and Inclusion Officer at the Alzheimer's Association. We are recording this podcast episode of our Momentum Discussion in the podcast booth at GSA 2023 in Tampa, Florida. Dr. Hill, thank you for taking time out of your busy schedule to join us here in Tampa and to join me for this podcast.

Carl Hill:

Thank you so much, Jen, for having me. I'm excited about today's discussion and conversation.

Jen Pettis:

Dr. Hill, with its [2021 Alzheimer's Disease Facts and Figures](#) resource, the Association issued a special report examining race, ethnicity, and Alzheimer's in America. Before we delve into that report, can you share information about how the teams collected the data to inform the report?

Carl Hill:

When we think about 2021, there was so much discussion and civil unrest around inequity and discrimination in this country. Big kudos to the Alzheimer's Association leadership Harry Johns, former president and CEO, Dr. Joanne Pike, current president and CEO, and our Chief Science Officer, Dr. Maria Carrillo, who really championed an opportunity for us to understand a bit more about the influence of race and ethnicity on Alzheimer's in the United States. This data is a product of people wanting to take an inclusive and equitable approach to what we know about Alzheimer's and other dementia. There were two separate surveys, one of US adults and one of caregivers. The first one was a survey of almost 2,500 US adults, 18 and older. We worked with NORC at the University of Chicago to make this a nationally representative sample.

The second survey was of caregivers, of almost 1400 US adults, who were at the time or recently unpaid caregivers for an adult relative or friend aged 50 or older experiencing cognition concerns. It's important to note that for both surveys, differences that were noted in the report between racial and ethnic groups were tested and found to be statistically significant at the 0.05 level. That's important for researchers because we're always asking whether these differences are real. The survey results were rigorously reviewed, and we really took the time to ensure that the results that we found were generalizable and nationally representative.

Jen Pettis:

What did the Association find with the gender, racial, and ethnic disparities in Alzheimer's and its prevalence? Did the Alzheimer's Association discover what factors may be driving those?

Carl Hill:

The Alzheimer's Association Facts and Figures Annual Report was one of the first publications to note a disparity in Alzheimer's with Black African Americans being two times more likely than older White adults to be diagnosed. Hispanic Latino Americans are one and a half times more likely to be diagnosed. During my time at the National Institute on Aging we utilized this resource to review the pathways and the determinants and factors that create and sustain this disparity. This landmark special report was the first report to outline data on race and ethnicity in Alzheimer's in America. We found some interesting results.

First, people of diverse backgrounds and people of color want healthcare professionals who understand their unique experiences and backgrounds. However, many doubt that they would have access to culturally competent providers, which is important in this era of treatment. An overwhelmingly majority of non-White Americans in this report say that it's important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences. This included Native Americans, Black African Americans, Hispanic Latinos, and Asian Americans. Fewer than half of Black African Americans and Native Americans felt confident that there would be access to providers who were culturally competent. This is really intriguing.

Carl Hill:

Another finding that I thought is a call to action is that Black African Americans lack trust and in research clinical trials, and half of the respondents in this special report doubt that advances in Alzheimer's treatments would be shared equally.

This data is certainly an opportunity for researchers who are listening to look at that special report and craft additional studies to delve a bit deeper into some of these differences, disparities, and opportunities to understand what we might call minority health. There's a real opportunity for those of us that are working in equity in communities to take this information and to address stigma, to give people resources, to give them confidence in accessing treatments, and to give them confidence in knowing that they do belong in the healthcare setting. Fourth, is providing education and awareness to providers, which I think is a real opportunity for all of us working in this field.

Jen Pettis:

Let's talk about that a bit more. Carl, when you consider the critical first step of a provider having a brain health conversation with an individual what steps can they take right now to help increase their cultural competence to kickstart those conversations? What resources does the Association have that can support them?

Carl Hill:

There are many resources that the Alzheimer's Association has on its website, www.alz.org, for clinicians for effective communication. There are resources for caregivers and clinicians. There's work that we're doing in that space from a national perspective, but I tend to think that much of this work is local. We need to be sure that providers, researchers, and anyone working in this space remains connected to the community. What gives me excitement every day about continuing to lead the Alzheimer's Association's diversity, equity, and inclusion efforts is our infrastructure across the country and communities within 75 chapters who are looking to partner with national organizations that have a footprint in many of these communities that advocate for many populations in these communities.

Being connected in these communities is so important. If I had a chance to talk to many clinicians it would certainly be to engage in the latest, culturally competent conversation to ensure they're approaching their patient population with humility and taking the time to listen. One of the top reasons that we found in the 2021 special report for this lack of belonging is this belief that clinicians were not providing culturally competent care. These patients felt like they weren't being heard. Listening is having the humility to take the time to make sure that people feel like they're being heard. Knowing how to do that is what links the community to being involved with our chapters across the country because our chapters are looking to partner with local organizations that represent their community. That may not always be a health-related organization. It could be the YMCA or a fraternity or sorority or a civic organization that is popular in communities. Taking the time to engage and listen at a community level could have some real benefits to how these clinicians, dementia care specialists, neurologists, and geriatricians engage with their patient population in a broader sense.

Jen Pettis:

My local chapter's a great example of that. I'm in upstate New York, and we have the Capital City of Albany all the way to the Canadian border. We have very rural places as well. We focus on rural populations, including native Americans and some Amish population who both live in close communities. The person who works in our chapter has become embedded in those communities to really support them and bring culturally appropriate treats and really learn from them what their needs are and how to meet those needs. I can't say enough about that, the power of that local connection.

Carl Hill:

One community is that community. We have been informed by the community-based participatory research model, which was developed by Dr. Barbara Israel and her colleagues at the University of Michigan. They are thinking of ways to build a consortium of stakeholders that represent various organizations, various families, and people who are really interested in a topic. Their focus is the resources that various communities need to understand Alzheimer's and dementia. The FDA has approved treatments for Alzheimer's disease, and we must be sure that everyone understands what they are, what they do, and when is the right time to access the treatments.

That's particularly important in the context of this 2021 special report because of the populations such as the Black African Americans and Hispanic Latinos who we know are disproportionately affected and more likely to have Alzheimer's. If they feel that they would be mistreated in the dementia care system, then they're less likely to access the treatments at the right time. The right time in this space is at the noncognitive impairment phase of an unfortunate dementia journey. If a person misses that window, then these treatments will not be for them. That's part of health education, health awareness, community-based participatory research, or an engagement activity. With our chapters around the country, I'm really excited about an opportunity to get that information out to communities in ways that they could best utilize it. From my perspective, that's health equity. It's not an equal, everyone gets the same pamphlet or the same mailing, but thinking of strategic and creative ways to get that resource, that information out to people so that they can fully understand what these treatments are and how they can best utilize them.

Jen Pettis:

I would say even the promotion of brain health among these communities needs to be at the forefront of action. Let's try to get ahead of where that disparity is in Alzheimer's prevalence. Let's start early and talk about brain health and try to move that from a prevention standpoint as well. Let's turn now and discuss risk reduction and how health disparities impact that risk. What is behind those disparities?

Carl Hill:

We know that there is a genetic risk for Alzheimer's. One of the well-known gene that influenced Alzheimer's risk is the APOE gene, but research has not shown that Black African Americans and Hispanic Latinos are overly represented in having that genetic risk. This points to some other factors that could be at play. I've committed much of my research career and public health career to understanding what those risk categories can be. You're thinking about the NIA Health Disparities Research Framework, which outlines factors in the environmental or socio-cultural levels of analysis, or the social determinants of health, all of this is trying to understand how context and environment play a role in many of these risk factors. Research around Alzheimer's and other dementia tells us that what's good for the heart is good for the brain.

Carl Hill:

In understanding that we must first recognize that Alzheimer's is the most common cause of dementia, but there are other forms of dementia, including vascular dementia, and mixed dementia is quite prevalent, meaning that people can have more than one type of dementia. We know that lifestyle is critical in maintaining cardiovascular health, including a healthy diet such as a Mediterranean diet, which I always say something green on your plate most times you eat. Staying away from saturated fat and sugar and being mindful of diet and adequate amounts of physical activity is important.

Staying cognitively engaged is keeping the mind active. The Alzheimer's Association is leading the US Pointer study, which has just concluded its data collection and should be hearing results from the US Pointer trial. This study is seeking to understand the relationship between staying cognitively engaged with healthy diet and physical activity. They are trying to find that recipe for protecting brain health. While we know that lifestyle is important, there's a context around whether people have adequate resources to engage in these healthy lifestyles for long periods of time. People need support, people need money, they need income, they need all kinds of resources to maintain this healthy way of living.

The Arline Geronimus's "weathering hypothesis," suggests that when people face chronic discrimination and structural racism over their life course, they have unequal access to resources or unequal experiences with stress. As a result, people are accelerated in their aging. That hypothesis will be brand new to Alzheimer's and other dementia research spaces. We're utilizing that hypothesis to fully understand what these lifestyle factors are and then adding a context to those factors. The "weathering hypothesis" will be a great lens to understand how people can use these resources, and how people can engage in a lifestyle that can protect their brain health over their life course.

Jen Pettis:

You've talked a lot about what individuals can do, and how they can engage in their communities. I know the Association is working with a lot of community organizations across the country to drive brain health through diverse and underserved communities. Share some success stories with us.

Carl Hill:

Over the past two years, I've had a wonderful time working with our team across the country that are doing great work in diversity, equity, and inclusion in our chapters. We have a home office team based in Chicago who are identifying national partners that will strive to bring the research results that we learned from the US Pointer trial and determine how to translate that into information that people can use in communities. Our best way of thinking of getting those resources to communities is through partnership working with organizations.

One strategic partnership has been with Garrett Davis Productions, where we all sat around a table and thought of a stage play that would help us get information into communities in an equitable way. We focused on Black African American communities, sharing information about the Alzheimer's Association, about acknowledging the disparity that exists in Alzheimer's the resources that we provide, and relating the importance of participating in a clinical trial or the experience of being a caregiver. The stage play brought information and awareness together in an "edutainment" format which is both educational and entertaining, and people shed a tear. We certainly think that the way that we presented that information stays with people and they would be more likely to seek us out when there's a need for information about Alzheimer's and dementia. That's been one great strategic partnership.

Carl Hill:

Another one has been with the African Methodist Episcopal Church (AME Church), which is probably the largest Black church in the country and maybe in the world with churches all over communities in this country. Our North Star has been having our chapters work with churches in key places like Atlanta or Baltimore or Detroit, so that we can tailor the information that the Association has into an effective format. We've created a clergy guide in collaboration with the AME Church and we've held three annual purple Sundays, which in theory, all AME Churches across the country are supposed to have information and content about Alzheimer's and dementia during their Sunday service. We also have a national webinar where we go over Alzheimer's and dementia, one-on-one, including the importance of participating in clinical trials, and the importance of engaging with the Alzheimer's Association. Purple Sunday has grown in attendance over the last three years. We had Maxine Waters, a representative from California, join us to talk about some of the work that she's done with the Association there in Los Angeles. We're always looking for more ways to get our resources into communities. This is really based on this participatory model, knowing that we're all in this together. If we're all in this together, we've got to understand that people come to this devastating disease in different ways and acknowledging that is our pursuit of health equity.

Jen Pettis:

Thank you for all the work that you do for the Association. Collectively, I'll say all your colleagues there do such wonderful work. You mentioned the www.alz.org website, and I know there's also a 24-hour helpline. Do you want to mention that a little?

Carl Hill:

Our helpline is 1-800-272-3900, where we have the greatest call center experts in Alzheimer's and dementia, ready to field questions available every day, all day, 365 days a year, in multiple languages to answer your questions. This is one of the best resources that we have because we're able to answer people's inquiries, determine their needs, and then locate them to a chapter or answer the question right there during that phone call. Please don't hesitate to be in touch with the Alzheimer's Association.

Jen Pettis:

We've talked a bit about clinical trials. Where can folks find out more about clinical trials that they might be able to participate in?

Carl Hill:

Our website www.alz.org is where you can look up Trial Match. It's a great resource to understand some of the clinical trials that are in your area or that link to an unfortunate diagnosis that a person may have received or a loved one may have received. It's a matching service where you get a chance to see the clinical trials in your area. Participation is so important. This field has moved in such great directions with treatments, but we need to know that the treatments are safe and effective with a broad, public health scope.

There are many complex factors that relate to the underrepresentation of key populations in these trials. We must do the work in communities to make sure that people are aware of the trials that researchers are held accountable for equitable recruitment. Funding sources are holding this entire enterprise accountable for more representative research that includes people, particularly the people who are most likely to have Alzheimer's and dementia in clinical trials. We've got work to do there and we have the infrastructure and the will to get it done.

Jen Pettis:

Any last words for our listeners?

Carl Hill:

Thanks so much for all the interest that you have in Alzheimer's and dementia. Thank you for this podcast and to GSA and to James Appleby and the leadership for really providing an opportunity for all of us to hear about the latest advances in gerontological research and aging research, Alzheimer's research. This really is a critical resource. Information is power, and this podcast is certainly powerful.

Jen Pettis:

Thank you so much for all you're doing. To those listening to the podcast episode, we're coming to you from Tampa at GSA 2023, and we're glad that you took the time to listen.

Announcer:

The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit <https://www.geron.org/>.