

African Americans are more likely than whites to develop Alzheimer's. Why?

By Marita Golden June 1 at 8:00 AM

Gary Williams thought he had found a glimmer of hope. Six months earlier, his wife, Gwendolyn — 64 and a retired education professor at Bowie State University in Maryland — had been diagnosed with Alzheimer's. The disease, as Gary would come to describe it, was “a slow-moving train” in their lives.

He brought Gwendolyn to Johns Hopkins Medical Center in Baltimore, with his fingers crossed, looking for a study or clinical trial to help ease the nightmare they were living. He and his wife knew there wasn't a cure for Alzheimer's, but they wanted to contribute to finding one. There was no good news at Hopkins, though, where doctors said Gwendolyn's illness was too advanced to be eligible for a drug treatment clinical trial. To enroll her would have been risky for her health.

Gwendolyn and her husband were part of a troubling narrative about African Americans and Alzheimer's, one with onerous economic and social implications. Older African Americans develop Alzheimer's at a higher rate than any other group of older Americans. They are about twice as likely as non-Hispanic whites to develop the disease or other forms of dementia, according to the [Alzheimer's Association](#), a group that focuses on research, care and education.

Though Gwendolyn ultimately didn't qualify for a Hopkins trial, researchers fervently wish they could find more people like her who are at least willing to try. That's because, as scientists scramble to find new treatments and maybe someday a cure, African Americans are nearly invisible in clinical Alzheimer's trials: Despite representing more than 20 percent of the 5.5 million Americans who have the disease, African Americans account for only 3 to 5 percent of trial participants, according to researchers (the lower number is the one I heard quoted most often).

Hispanics also get Alzheimer's and other dementias at a disproportionate rate (about 1½ times that of non-Hispanic whites), and they, too, represent a small fraction of those in trials (1.5 percent). For both Hispanics and African Americans, their lack of presence in trials complicates efforts to broadly test potential treatments. And it makes it that much more difficult to unravel the mystery of why some groups get Alzheimer's more frequently than others.

Meanwhile, President Trump has proposed \$6 billion in cuts to funding for the National Institutes of Health — about 18 percent of its budget. A congressional spending deal struck this spring to avoid a government shutdown boosted NIH's budget by \$2 billion through September — but over the long term, if the Trump administration gets its preferred budget, NIH could still face substantial cuts. And that, in turn, could hurt the National Institute on Aging, which is part of NIH. While the pharmaceutical-biotech industry conducts a significant percentage of all Alzheimer's clinical trials and studies, the NIA is the largest public funder of Alzheimer's research.

In the months I spent working on this story, I often shared statistics with friends, white and black, and with health professionals caring for Alzheimer's patients. Rarely were people aware of the stunning prognosis for African Americans. And how could they be? No major public health campaign has rallied interest and action. The African American community's strongest institutions — churches, colleges, sororities, fraternities — have yet to respond to the silent storm of Alzheimer's with the kind of coordinated outreach efforts marshaled a decade ago to raise awareness of prostate cancer among black men. We have not, it seems, fully grappled with what Darrell Gaskin — director of the Hopkins Center for Health Disparities Solutions and the lead author of the 2013 report “The Costs of Alzheimer's and Other Dementia for African Americans” — calls “an existential threat to black America.”

Alzheimer's is the most common cause of dementia; it disrupts daily activity and cognitive skills such as memory, judgment and language. The progressive illness is marked by abnormal deposits of proteins that form amyloid plaques and tau tangles throughout the brain. The damage is so severe that it not only harms memory and speech but eventually hits parts of the brain that control bodily functions such as walking, swallowing and using the bathroom. It is not fully clear what causes the disease, but researchers cite three key risk factors: age, certain genes and the prevalence of the disease within a family. Old age is the greatest risk factor, and researchers note it to explain why women — who tend to live longer than men — make up almost two-thirds of Alzheimer's patients. (The vast majority of those with Alzheimer's develop symptoms at 65 or later. Gwendolyn Williams had younger-onset Alzheimer's, making her part of a much smaller group. According to Keith Fargo, director of scientific programs and outreach for the Alzheimer's Association, it's unknown whether there is also an Alzheimer's gap between younger African Americans and younger whites because there isn't as much data.)

Health and socioeconomic factors are also believed to contribute to a person's susceptibility to dementia. To partially explain the racial disparity in the rates of dementia, researchers point to factors such as cardiovascular diseases and diabetes that are more common among African Americans and Hispanics than among whites.

Chronic medical issues such as obesity, hypertension and high cholesterol play a role. Some studies cite higher rates of poverty, with all its associated consequences — bad housing, poor education, inadequate nutrition and health care — as contributing factors. The stress of discrimination has also been cited in some studies.

Yet while researchers have put forward these health, lifestyle and socioeconomic factors, there are also signs that genetic differences could explain some of the disparity between African Americans and whites. (Because many studies rely on people self-reporting their identities, they often don't capture nuances within groups. “Most of the work that we cite uses African Americans/blacks interchangeably,” says Fargo. “The field realizes that these terms are problematic and imperfect.”)

One of the leading researchers trying to make sense of the disparity is Goldie Byrd. Her work is multipronged: In addition to investigating a genetic component of Alzheimer's rates among African Americans, she has led the way in recruiting black participants for studies and trials. A biology professor at North Carolina A&T State University in Greensboro, she is the founder of the Center for Outreach in Alzheimer's, Aging and Community Health (COAACH), which is based at the university. COAACH opened in 2014, with the support of a \$2 million grant from Merck pharmaceutical, and it has emerged as a kind of ground zero for innovative, cross-disciplinary and community-based responses to the disease.

Byrd grew up in Magnolia, N.C., a small farming town where her family raised tobacco, corn and soybeans. Her path to this work began in 2002, when she was a visiting professor at Duke University Medical Center. There, she met Margaret Pericak-Vance, director of the school's Center for Human Genetics. At the time, Pericak-Vance was the lead investigator on a major Alzheimer's study. Among her goals was to understand the high incidence of Alzheimer's among African Americans — yet the study had 8,000 blood samples from whites with the disease and just 43 from African Americans. Pericak-Vance told Byrd about the deficit. She needed help.

Pericak-Vance is internationally recognized for the pivotal role she has played in Alzheimer's research. In 1993, she led a team that identified the APOE-e4 genetic connection to late-onset Alzheimer's. "We thought by linking APOE with late-onset Alzheimer's we were home free," she says. "But then we found out that the rest of understanding Alzheimer's was much more difficult. And as more and more technology developed and more genomic resources became available, we've slowly been chipping away at this very important disease." Her commitment to creating an inclusive study was rooted in science and personal history. She had lost a son at 14 to thrombotic storm, a rare disorder. Her daughter then introduced Pericak-Vance and her husband to a young African American man, and they eventually became his legal guardian. "He became a permanent member of our family," she says. "I realized how important it was that the type of research we did would benefit everyone."

Pericak-Vance acknowledges there was "a general feeling" in the research community that African Americans could not be enrolled in any meaningful way in medical research. For her part, Byrd, who sees inclusion as a fundamental part of her work, says she "knew immediately what the problem was": Efforts to enroll African Americans in Alzheimer's studies suffered from a lack of community engagement.

After finishing her sabbatical at Duke, Byrd secured funding from NIH to prove that she could use a community investment methodology to get more black participation in Pericak-Vance's study. Yet nothing came easy. Byrd and her staff encountered obstacles that even she, as a black woman representing an HBCU (historically black colleges and universities), had to work to dismantle.

"We knew we had to first build trust," she says, "and we needed people to tell us how to do that."

In talks with ministers, presentations at health fairs and before fraternities and sororities, at barbershops and beauty salons, they saw how the power and pain of collective memory had made African Americans wary of medical studies. Not surprisingly, the Tuskegee experiment of the 1930s came up. In addition, the legacy of segregation had left black communities walled off from white hospitals, doctors and researchers. And when whites came into black communities for research, people complained that they felt exploited — and believed their knowledge was disregarded.

Still, the main issue, Byrd says, was simply that many people had never been asked to take part in a study. “The more they learned about the research, the more they wanted to be part of it,” she says. “When they were asked in surveys if they would participate in a trial or research, 80 percent of the time they said they would.”

She found that the Greensboro African American community was less concerned about the legacy of Tuskegee than the need for culturally sensitive outreach that would ensure participants were informed about how blood samples would be used.

They also wanted a supportive relationship with the researchers so their questions could be addressed. To accommodate those without transportation, Byrd often had blood samples taken in homes. Over 18 months, 178 African Americans joined the study — more than tripling the number of black participants who had signed up in 10 years of open enrollment recruiting.

Byrd and Pericak-Vance ultimately would recruit about 1,000 African Americans, whose blood samples became part of the Alzheimer’s Disease Genetics Consortium, an NIA-funded project to identify genes associated with the onset of late-stage Alzheimer’s disease. Because of Byrd and Pericak-Vance’s efforts and the work of others who also brought African Americans into the study, the consortium was able to add the largest collection of African Americans with Alzheimer’s to its research pool.

Margaret Pericak-Vance: “We don’t know why yet the variant in African Americans conveys greater risk, but we are actively researching the question. The fact that we know there’s a difference now gives us the ability to see how it increases risk and opens the door to looking at potential targets for new therapies in the long run.”

It’s making a difference. In 2013, the consortium found that the ABCA7 gene was a higher-risk indicator for Alzheimer’s in African Americans than in non-Hispanic whites. “The variant that is found in African Americans in the ABCA7 gene contributes more to the Alzheimer’s disease risk factor in African Americans than the variant that is associated in non-Hispanic white individuals with the disease,” says Pericak-Vance, who is one of the consortium’s leaders. “We don’t know why yet the variant in African Americans conveys greater risk, but we are actively researching the question. The fact that we know there’s a difference now gives us the ability to see how it increases risk and opens the door to looking at potential targets for new therapies in the long run.”

Pericak-Vance later used Byrd’s outreach model at the University of Miami, where she launched the Research in African American Alzheimer’s Disease Initiative, along with programs that target the Hispanic population. Recently, the two researchers added a new dimension to their 15-year collaboration: As part of the national Alzheimer’s Disease Sequencing Project, several schools — North Carolina A&T, the University of Miami, Columbia University and Case Western Reserve University — are working to recruit 100 black families with two or more members affected by Alzheimer’s to research genetic elements of the disease.

The Alzheimer’s Association also has partnered with the study to raise awareness of the project, which received NIA funding last June.

Pericak-Vance calls Byrd a great collaborator. Yet in their early years of working together, Byrd declined an invitation to join Pericak-Vance at Miami. “It was so important,” says Byrd, “to do this research at an HBCU, a school in the heart of a black community, among the people most affected by the disease and least studied, at a school where we were creating the next generation of African American medical researchers and scholars to fight it.”

In October, five years after Gwendolyn and Gary Williams visited Johns Hopkins, I was with Gary at their home on a quiet cul-de-sac of colorful bungalows and neat lawns in Cheverly, Md. We sat at the kitchen table; through glass doors, we could look onto the deck and the garden that Gary tends, which offers him solace at times. A man with combustible energy and radiant calm, he was rambling through papers piled on the table and in chairs as we spoke.

Gary retired from the D.C. Office of Tax and Revenue in 2006. When Gwendolyn got sick, his son moved back home to help. He’s proud of how much closer they’ve all become — his daughter Marshae; son Maurice, a D.C. police officer; and the grandchildren, Ashley, 17, and Journie, 9.

As he talked, he was alternately reflective, philosophical, nostalgic, tearful and impatient. He recalled how, at first, Gwendolyn — a lifelong educator who once worked as a teacher and administrator in Prince George’s County schools — couldn’t remember the classes she had to teach or the assignments she had given her students. She’d do things like drive to church on Friday thinking it was Sunday. Initially they thought the memory loss was connected to her diabetes, but the memory issues grew worse.

“She tried to carry on as normal, but I could tell this wasn’t normal,” Gary says. “She was putting plastic dishes in the oven. She couldn’t follow directions, and began wandering.”

A PET scan revealed Alzheimer’s. Eventually, his wife, who had loved reading, writing, traveling and singing, lost the ability to speak.

For a while, she lived at home. Maurice returned there in 2013 “to take some of the weight off my dad.” “My mother and I were already close,” Maurice told me, “but actually we got closer, as mother and son, and we got closer as a family.” Later, a home health aide provided additional support.

But, eventually, those efforts were not enough, and doctors recommended Gwendolyn be moved to a care facility. Gary chose Arden Courts in Silver Spring, Md. “To watch the slow deterioration of my wife, the loneliness and the isolation” — those are the biggest problems, Gary told me. “Sometimes I have to sit in the car for 15 or 20 minutes to get myself together before I go in to see her. I sit there. Sometimes I pray. Sometimes I cry.”

The disease has reshaped the family’s attitudes on health. “I do fear that I have the Alzheimer’s gene, and that has made me much more health-conscious,” Marshae says. “I realize now I need to take better care of myself. Growing up I heard about people getting dementia in their 80s and 90s. Not their 60s, like my mother. I’d like to see more done to educate people and prevent the disease.”

“My mother was an educator, and even in this disease she was teaching me,” Maurice says. “Teaching me [to] take care of myself. Our whole family now has a new perspective.”

In January, Gary took me along to visit Gwendolyn. Arden Courts cares exclusively for those with Alzheimer’s and other dementias, and provides the kind of services that Gary says he could afford only because of long-term-care insurance. The facility has five locations in the area and a racially and ethnically diverse residential population. The halls in Silver Spring’s facility are bright with colorful murals. At one with a seaside theme, beach chairs and balls are set up. At another area, a corner is decorated like a “hobby shop,” and bookcases and photographs claim other walls.

Gary, a deeply religious man, proudly told me that he had arranged for a choir and a magician to perform for the residents. This was home for his wife, but it was clear that it had become home for Gary, too. We found Gwendolyn in the dining room at a table with three other residents. Unable to walk or stand, she sat in a wheelchair staring at her plate. Gary greeted his wife’s tablemates, then touched Gwendolyn’s shoulder, kissed her cheek and whispered hello.

He then suggested we wait in the den for private time with his wife. When she was wheeled in, Gary stood and gently stroked her face. Because Gwendolyn’s spine had collapsed, her neck no longer supported her head. Her chin rested on her chest. Gary and the doctors agreed that she was too fragile for corrective surgery. Her gray hair was in cornrows and she had the artificial plumpness caused sometimes by medications. I recalled reading that in Alzheimer’s, just as memories are lost, so, too, the body “forgets” how to function.

Stooping close to her, I leaned in, clutched her hand and introduced myself. She quietly moaned in acknowledgment of my presence and touch. I watched her eyes blinking in response. While Gwendolyn sat with us, hearing our words, Gary smiled as he told me how he and his children and grandchildren celebrated Christmas with Gwendolyn at Arden Courts.

Later, Marshae told me about her sense of comfort when she’s with her mother. “She can no longer get the words out, but she loves to sing, always did, and sometimes when I visit her on my own we sit and sing spirituals. Her favorite is ‘An On-Time God.’ ”

One of the most challenging issues for Alzheimer’s families is finding institutional support for their expansive needs. Byrd’s center, COAACH, is a leading innovator on this front. COAACH’s 3,000-square-foot facility has a staff of 12, which includes the center’s director, two researchers, public health educators, data analysts and administrative staff. Alzheimer’s caregivers can attend support groups there and take classes on caring for loved ones. Volunteers can donate blood samples for genetic research. A&T’s biology students intern at COAACH, where they learn how to do research and develop models to help further understand the disease. Deana McQuitty, who teaches in the speech program at A&T, is conducting research at COAACH to develop strategies to help caregivers communicate more effectively with Alzheimer’s patients as well as strategies to prolong speech for patients. COAACH also sponsors an annual caregivers’ conference that attracts hundreds from North Carolina and neighboring states.

This, Byrd says, is what the future of Alzheimer’s care must look like: all-inclusive, and supporting researchers and caregivers as much as those with the disease. “It was most important to me to leave something in the community,” she says. “The goal of

COAACH is to help people manage all aspects of the disease.”

A greater sense of urgency to include more African Americans and other people of color in trials is growing across the Alzheimer’s community. One of the most ambitious efforts is a national project conducted by the Global Alzheimer’s Platform Foundation. Set to launch this spring, the project will work with academic researchers, nonprofit groups, pharmaceutical companies and Blue Cross Blue Shield to support a network of 40 clinical trial sites, with a wide range of goals.

“The GAP sites pride themselves on having a trial or study for everybody,” says John R. Dwyer Jr., president of the foundation. The project has two major aims: decreasing the time of trials and increasing enrollment of African Americans and other underrepresented groups. Targeted cities include Kansas City, Nashville, Phoenix, Chicago and Washington. The plan is to run public service announcements and do digital outreach about Alzheimer’s in communities of color. Faith leaders, elected officials, and local cultural and social influencers will be recruited to help encourage participation in the trials.

Progress is being made on other fronts as well. One of the clinical trials generating the most hope for a meaningful Alzheimer’s treatment, as well as establishing protocols for effective recruitment of African Americans, is headed by Harvard University researcher Reisa A. Sperling. Focused on the United States, Canada and Australia, the study is seeking to prevent memory loss by clearing up deadly pockets of amyloid, the protein linked to Alzheimer’s. NIH, NIA and Eli Lilly are funders.

Phyllis Ferrell, of Eli Lilly’s Alzheimer’s disease platform, says that, because NIH and NIA are funders, “we have a requirement that every fifth person we screen for possible enrollment in the study has to be a person of color.” (Although this is not a universal requirement for all NIH/NIA funding, adequate racial inclusion is the goal for all projects.) Sperling told me they were excited to have reached 13 percent in the screening so far.

George Vradenburg — a Washington-area philanthropist who, with his late wife, Trish, founded US Against Alzheimer’s, a group that includes specific initiatives aimed at African Americans and Latinos — told me recently, “When Trish and I started US Against Alzheimer’s, we wanted to start a movement, a mobilization to find out why women, blacks and Latinos are disproportionately affected.”

Goldie Byrd: “As a people and as a community, we need to do more. We criticize the pharmaceutical industry, the medical and research community, but we can’t afford to wait. We simply cannot afford to let our people remain uninformed about this disease and its impact.”

“Currently there are 20 drugs in the last phase of testing expected to reach the market in the next five years,” Vradenburg says. “But trials are long and expensive. It can require two years to recruit volunteers and two years for the trial. We have to develop faster, less expensive, more inclusive and diverse trials so that we have medicines that work for all populations, not just segments.”

As researchers continue to look for explanations and to experiment with different drugs, what is most needed now from the public — and from the institutions that remain bedrocks of the black community — is awareness. Studies show that many African Americans see the symptoms of Alzheimer’s as signs of normal aging, even though they are not. And African

Americans (and Hispanics) experience missed diagnoses for Alzheimer's and other dementias more than non-Hispanic whites. "As a people and as a community, we need to do more," Byrd says. "We criticize the pharmaceutical industry, the medical and research community, but we can't afford to wait. We simply cannot afford to let our people remain uninformed about this disease and its impact."

For his part, Gary Williams has written letters to his elected officials, from Capitol Hill to the Prince George's County Council, asking each to support increased funding for Alzheimer's research. He never heard anything back from their offices, but that has not dampened his determination. When he can find the time, he says, he wants to be more active in speaking out about the disease.

In the days after my visit to Gwendolyn, Gary and I talked several times. What he most wanted was to know more about Alzheimer's and to feel that it's possible to make the disease less likely for his grandchildren.

He wanted to be assured that there were people doing all they could to find a cure or a treatment that would make a difference for others.

"I love Gwendolyn more deeply now than before," he said at the end of one call. "I miss her and think about her all the time."

A week later, six weeks following our visit at Arden Courts, Gwendolyn S. Williams died, shortly after midnight, a few hours after she turned 70 years old.

Marita Golden is an award-winning novelist and nonfiction writer. Her latest novel, "[The Wide Circumference of Love](#)," is about an African American family dealing with Alzheimer's.

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