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Alzheimer's Disease and Dementia

This month, the Community Health Series Partnership turns its spotlight on Alzheimer's Disease (AD). Carlos T. Carter, President and CEO of the Urban League of Greater Pittsburgh, sat down with us to discuss how AD impacts UL's clients and the communities where they live.

Carlos, what makes Alzheimer's Disease a health issue that deserves our specific attention?

Alzheimer's Disease deserves special attention because it is a significant health issue that impacts individuals, families, and communities—and there is currently no cure. The dis-

ease impacts memory and brain function. It poses a substantial societal and economic burden as it impacts the caregiver's ability to maintain a job.

Unfortunately, it disproportionately impacts Black people at a rate of 2 to 1 relative to their White peers. This is troubling as many Black families already face challenges related to health and economic equity.

AD is also of great concern because of the stigma it holds in the Black community—people don't talk about it enough. I've personally witnessed this and it's heartbreaking. When the disease is discussed in our community, there's isolation



CARLOS T. CARTER

and shame—and that must change.

In one of this month's articles, Dr. Williams comments "Dementia is a terrible disease that robs people and communities of their stories." Why is this particularly relevant to the Black community?

Our stories are important because they serve as a bridge to humanity. We use our stories to learn from each other, convey our humanity and experiences, and facilitate learning and connection within our collective communities. This is especially relevant in the Black Community as we are a verbal people and share our history through stories.

The reality is our stories have been suppressed for centuries to convey a narrative that makes others look good and Black people look bad. Given the constant assault on Black Voices, we do not need anything else suppressing our ability to tell our story. Until the lion

tells his story, the hunter is always the hero!

We can change this by our sharing our journey with the younger generation early on. When our memory is gone, those stories will live on. Stories can be preserved verbally or by taking the time to write them in a journal and publish it. Stories are powerful, as they are the way we as humans remember things best.

How can we build our communities to support those with Alzheimer's Disease—and their caregivers?

It starts by learning and talking about the disease to remove the stigma. It's

hard to build a community when there are secrets and shame. That's why talking about our experience with the disease as a patient or caregiver is so important. It's a first step in removing the stigma and isolation. It creates an opportunity to connect and receive support.

For caregivers, it's important to know about—and use—the community resources available to assist. We must encourage and praise them for using these services to help relieve burnout, exhaustion, and economic ruin. Everybody needs help sometimes! Please, don't be afraid to ask.

Dismantling dementia disparities with socially-just healthcare

According to national statistics, Black Americans are about twice as likely to develop dementia syndromes, including Alzheimer's Disease, than White Americans. However, they're 35% less likely to be diagnosed correctly.

When they are diagnosed, they and their care partners—often Black women—must work harder and travel farther to get treatment than their White counterparts.

The treatment, too, is inequitable. AD drugs are the result of research from studies of White participants who are highly educated, affluent, well supported, and in good health.

As with other chronic health problems that affect marginalized people, dementia's risk factors may have more to do with health disparities than genetics.

The disparities are bound up in systemic racism and social determinants of health like economic stability, healthcare access and quality, and neighborhood dynamics.

Dr. Lilcelia "CeCe" Williams, an OSCAR scholar in Pitt's Alzheimer's Disease Research Center (ADRC) is one of the university's future health leaders who is focusing her time and talents on enhancing our region's dementia care and research—especially for underserved communities.

OSCAR stands for Optimizing Scientific Careers in AD Research. It's a program designed to identify, attract, and foster professionals like Dr. Williams. Currently, five OSCAR scholars are taking part in AD leadership activities at Pitt, including a leadership apprenticeship with a mentor.



DR. LILCELIA "CECE" WILLIAMS

Dr. Williams brings to her apprenticeship a zeal and personal mission to end health disparities and improve health outcomes for marginalized people affected by strokes and dementia syndromes.

Her goal is to raise up minority voices and help create, promote, and sustain long-lasting AD healthcare that's inclusive, culturally responsive, and community driven. "Socially just health-

care demands that we see, hear, and value marginalized people who have dementia, as well as their care partners, family members, and friends," she explains. "Dementia is a terrible condition that robs people and communities of their stories."

Dr. Williams points to previous studies as examples for addressing underrepresentation in marginalized groups. For example, one study tracks how racism-based stress and adversity ages the brains of Black American men.

She believes research must be based on the desires and needs of minoritized people. "To build trust in what we're doing, we're getting to know people in their neighborhoods," she states. "For example, we've recently attended events on Black health and equi-

ty, as well as a Thanksgiving food distribution sponsored by the Urban League. We're humbled to be in the community listening and getting to know people in churches, barbershops, and community engagement centers."

She continues, "We want people to know we're here for them with dementia information, cognitive assessments, and help with support services. When people feel the healthcare system values them and their experiences—that's when we can chip away at racial research bias together."

One of Dr. Williams' most ardent wishes concerns AD care partners who face major challenges. "These (mostly) Black women are juggling caregiving duties and family responsibilities," she says. "Some have had to quit their jobs to take care

of a loved one. That can add an even deeper layer of financial stress and strain. Others are caregiving while holding down jobs and/or attending classes. It's a heavy burden for one person to handle."

Dr. Williams reminds care partners to take time for self-care without feeling guilty. "If you're caring for a loved one with dementia, taking even a small amount of time to get some fresh air or take a shower is a brave and vital thing you can do for them and you."

She encourages care partners to take advantage of our region's dementia resources, including Pitt's ADRC, the Jewish Healthcare Foundation, and caregiver support from Allegheny County's Health and Human services. "Please look at self-care as an act of strength."

For underserved patients, Alzheimer's care requires balance, respect, and cultural sensitivity

Dementia syndromes like Alzheimer's Disease (AD) are challenging conditions, but even more so for people who live in underserved communities with little or no health resources or support. That includes help handling ethical questions that impact decisions about AD disclosure, safety, treatment, and end-of-life care.

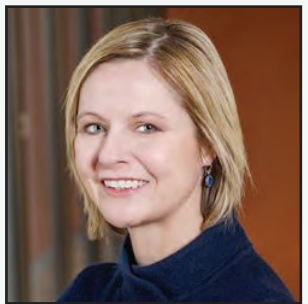
Ethical AD care

When people learn they have AD, sharing the diagnosis can be difficult. For example, a truck driver is required by law to report AD due to safety concerns for the driver and other people on the road. However, a daycare worker's risk is different even though concerns about the person's cognitive abilities and child safety are present. Dr. Jennifer Hagerty Lingler, Pitt Professor and Vice Chair for Research, Health & Community Systems, notes, "In this instance, where is the

balance between the worker's rights to privacy and children's well-being?"

As AD progresses, ethical problems intensify. "For example, if a patient refuses to take medication because she doesn't like the side effects, does the PCP and/or care partner respect her decision? Dr. Lingler asks. "What if the decision affects her safety? How does the family find ways to support the decision while managing risks to themselves or others?"

End-of-life care introduces further ethical thoughts when patients are not able to make decisions. "This is when it becomes even more important to protect the patient's dignity, comfort, and quality of life," Dr. Lingler explains. "Balancing medical interventions, respecting prior wishes, and involving caregivers and family in decision-making are the right things to do for a pa-



DR. JENNIFER HAGERTY LINGLER

tient's well-being."

Ethical AD research
Ethics in AD research has focused on recognizing that social determinants of health cannot be fully appreciated when studies favor white, affluent, healthy populations with ample support and resources. "There's an historic lack of diversity in terms who has the opportunity for informed consent to medical research," says Dr. Lingler. "This discrimination skews

research findings and disregards the unique health needs of underserved communities."

Why does this keep happening? Marginalized people are often overlooked by researchers who have representation or recruiting bias. Minority participants may be asked to participate but refuse. Maybe there's inadequate financial compensation for their time, or a long bus ride to a clinic or they don't trust healthcare providers because they've experienced disrespect. There are socioeconomic, language, and cultural barriers, too.

When marginalized people participate in AD research specifically, ethical questions arise about consent as the disease progresses and the participant loses their ability to make decisions.

Biomarkers in research complicate matters even

more. A biomarker is a sign that researchers look for in the body that indicates the presence or progression of a disease like AD. If an AD marker is found, a participant might not grasp the implications fully or might grasp them and become upset by the findings. "Responsible communication must be sensitive, clear and supportive. When you give someone difficult test results, you must do it in a way that protects their emotional well-being," says Dr. Lingler.

Ethical concerns intersect with historical injustices in medical research, especially in Black communities. Exploitation and distrust from past abuse makes people hesitate to join research groups.

"Injustices like the Tuskegee Syphilis Study and the HeLa cancer cells have created suspicion," says Dr. Lingler. "Acknowledging the

wrongs and valuing people and their communities will help rebuild trust. When that happens, we'll have information and interventions that will make everyone's quality of life better."

Dr. Lingler is happy to report there's a positive shift in the equity of medical research thanks to a new generation of culturally sensitive researchers, including Pitt OSCAR scholars.

"You'll find Pitt's next generation of researchers out in neighborhoods asking the people who live there, 'What do you need to be healthier'—and listening. The answers are helping us develop healthcare that includes everyone, not just one group. I'm confident these researchers will help Pittsburgh shine as a national example for AD research that's life changing for everyone."

Jewish Healthcare Foundation makes meaningful difference for people living with dementia

In Pennsylvania, more than 400,000 people are living with dementia. For every person who's diagnosed, there are at least 3-4 people (family members, friends, and coworkers) whose lives are greatly affected.

Pittsburgh's Jewish Healthcare Foundation (JHF) is a not-for-profit public force for good that advances healthcare services, education, innovation, and research to improve the health and well-being of the region's diverse communities, especially those who are underserved.

The Foundation accomplishes this task through activism and convening with its powerhouse of partners and by giving grants. It also receives grants for its pioneering programs,



which allows its interdisciplinary staff to support healthcare

practitioners and providers to improve quality of life and lower healthcare costs for the people they serve.

Two of JHF's many programs focus on dementia:

Dementia Friends Pennsylvania educates communities across the state about dementia. Dementia Friends Pennsylvania is part of Dementia Friends USA, a global movement that's changing the way people think, act, and talk about dementia.

The program breaks down the stigma surrounding dementia and encourages people to make practical changes that best support people living with dementia. Thanks to a train-the-trainer model, volunteer Champions offer free 60-minute in-person or virtual

Dementia Friends Information Sessions to community members, businesses, and organizations. Contact info@dementiafriendspa.org to schedule an Information Session or become a Champion!

Dementia Friendly Pennsylvania works to ensure communities across the Commonwealth are equipped to support



people living with dementia, their families, and their care partners. A dementia-friendly community is a city, county, or town where people living with



dementia are understood, respected, and supported. Every sector (faith, health systems, arts, and culture, etc.) of the community has a unique part to play. The initiative is a collaborative effort with JHF's Dementia Friends Pennsylvania, existing dementia-friendly Pennsylvania communities, including the local community Dementia Friendly Greater Pittsburgh, and the Pennsylvania Department of Aging.

Visit the Jewish Healthcare Foundation's website <https://www.jhf.org/>