

Alzheimer's meds are mostly tested in whites. That worries Black patients, caregivers

October 3 2022, by Sydney Murphy



Larry Griner resigned from his job in California and moved back to his

childhood home in Baltimore nearly five years ago so he could care for his mother, Norma.

She had been diagnosed with [Alzheimer's disease](#) almost 12 years earlier, which took away her [short-term memory](#) and completely changed the life she used to have. When the 63-year-old Griner moved back home, he watched in agony as Alzheimer's slowly stole his mother's memory. Although her memory was supposedly being helped by the medication she was taking, Griner had his doubts.

Why? When it comes to Alzheimer's medications such as [donepezil](#) (Aricept) or [aducanumab](#) (Aduhelm), the evidence on how those drugs work for Black and Hispanic patients is sorely lacking because so few were included in [clinical trials](#) of the medications. Griner is Black; his mother took Aricept.

"I could never be a reference for what the medication does, but I would be more afraid of what would happen if she didn't take it," said Griner. "I just go with what had been prescribed and make sure that she is taking what she needs to."

Aricept has been widely prescribed for years, but its effectiveness in people of different races and ethnicities is unknown because of the lack of diversity in its original clinical trials. The [racial distribution](#) of those trial participants was 95% white, 3% Black and 2% other races.

This lack of diversity has real-world consequences for patients taking medications that have only been tested in white populations. It limits the generalizability of results and hinders people's understanding of how the drug works in all racial and ethnic groups.

With Alzheimer's, that lack of evidence in minority patients is particularly pressing.

Black people are two times more likely than white people to be diagnosed with Alzheimer's disease and other dementias. Similarly, Hispanic people are about [1.5 times](#) more likely than [white people](#) to have Alzheimer's disease and other dementias.

Alzheimer's 'affects everyone differently'

But, "if they are underrepresented in trials, how do we know that the treatments are going to be effective for that segment of the population?" asked Elizabeth Smith-Bovin, executive director of the Alzheimer's Association's Northeastern NY Chapter.

In fact, previous research has found that Alzheimer's isn't the same for everyone.

When a survey asked people of racially diverse backgrounds why they were hesitant to participate in clinical trials for Alzheimer's disease, 22% of respondents said they [believed](#) that they would not be treated fairly, while 24% did not trust [medical research](#). Yet, when a survey asked a group of white respondents the same question, these figures were 3% and 10%, respectively.

Another factor impacting participation in clinical trials is that Black and Hispanic patients are typically diagnosed with more advanced Alzheimer's disease, past the point when they would be eligible for clinical trials of new drugs.

"If the disease has fully manifested itself, then how do you accurately measure the efficacy of a treatment that is designed for catching the disease in the early stages?" said Smith-Bovin.

Griner said, based on his observations of his mother's experience, "the disease affects everybody differently."

Aricept isn't the only Alzheimer's medication that hasn't been really tested in minorities: Since [racial diversity](#) was also lacking in Aduhelm's more recent clinical trials, that drug's power in ethnic and racially diverse populations remains unclear, said Dr. Lisa Barnes, a cognitive neuropsychologist at the Rush Alzheimer's Disease Center in Chicago who has [examined](#) the reasons for the persistent lack of diversity in clinical trials.

In June 2021, Aduhelm became the first new Alzheimer's drug in nearly two decades to be approved by the U.S. Food and Drug Administration, despite opposition from the agency's own independent advisory committee and some experts who said there wasn't enough proof the drug could actually help patients.

Drug trials out of reach

According to Barnes, current limitations in general study design are also a major obstacle to diverse representation in research.

"For clinical trials, there are many eligibility criteria that often exclude people," she explained.

Barnes listed ways in which researchers could diversify their research: "First, researchers need to make their research studies accessible to diverse populations. That includes where they recruit from and the requirements that they place on their research. Second, researchers can hire staff that reflect the community they aim to study, so that diverse individuals feel more comfortable engaging in the study or answering research questions."

Unfortunately, lack of diversity isn't just an issue for Alzheimer's research. In the United States, minorities make up [less than 10%](#) of participants in clinical trials, the most common method of evaluating

diagnostic tools, drug treatments, and medical devices. But [42% of the U.S. population](#) is made up of people identifying as non-white.

An estimated 50 million people worldwide have dementia, mostly due to Alzheimer's disease. This exerts a heavy toll on patients, families and society, and it inflicts an economic burden of approximately [\\$1 trillion annually](#) that is continuing to increase around the world. As the fifth leading cause of death in adults over 65, Alzheimer's disease affects people across all races and ethnicities.

To make sure studies represent the broad population affected by the disease, a push for more diversity among participants has been growing in research facilities across the United States.

"To try to remedy the shortage of clinical trials, we work constantly to try to raise awareness of new research," said Smith-Bovin.

More representative research could make a meaningful difference in the way caregivers like Griner navigate the health care system and understand the efficacy of the medications their loved ones are taking.

Griner faced these challenges and did all he could do to make sure his mother continued to do things on her own. Unfortunately, she died last June.

More information: Visit the Alzheimer's Association for more on [Alzheimer's disease](#)

Copyright © 2022 [HealthDay](#). All rights reserved.

Citation: Alzheimer's meds are mostly tested in whites. That worries Black patients, caregivers (2022, October 3) retrieved 4 May 2024 from

<https://medicalxpress.com/news/2022-10-alzheimer-meds-whites-black-patients.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.