

Community Counternarratives Shattering Deep-Seated Stereotypes Related to Aging and Dementia One Person at a Time



^{1,7}Lilcelia A. Williams, PhD, ²Hector Salazar, BSN, ⁴Christine McClure, EdD, ²Yuchen Zhang, BSN, ²Julie Klinger, MA, ²Melissa Glasser, PhD, ⁴Marquita Smalls, MPH, ^{3,7}Kyaïen Conner, PhD, ⁵Dara D. Méndez, PhD, ¹Thomas Karikari, PhD, ^{1,7}Ann D. Cohen, PhD, ^{2,7}C. Elizabeth Shaaban, PhD, ⁶Jennifer H. Lingler, PhD

¹University of Pittsburgh Department of Psychiatry, School of Medicine, ²University of Pittsburgh, School of Nursing, ³University of Pittsburgh School of Social Work,

⁴University of Pittsburgh School of Public Health ⁵University of Pittsburgh, Department is Epidemiology, ⁶University of California, Davis, Betty Irene Moore School of Nursing, ⁷Alzheimer's Disease Research Center

Background

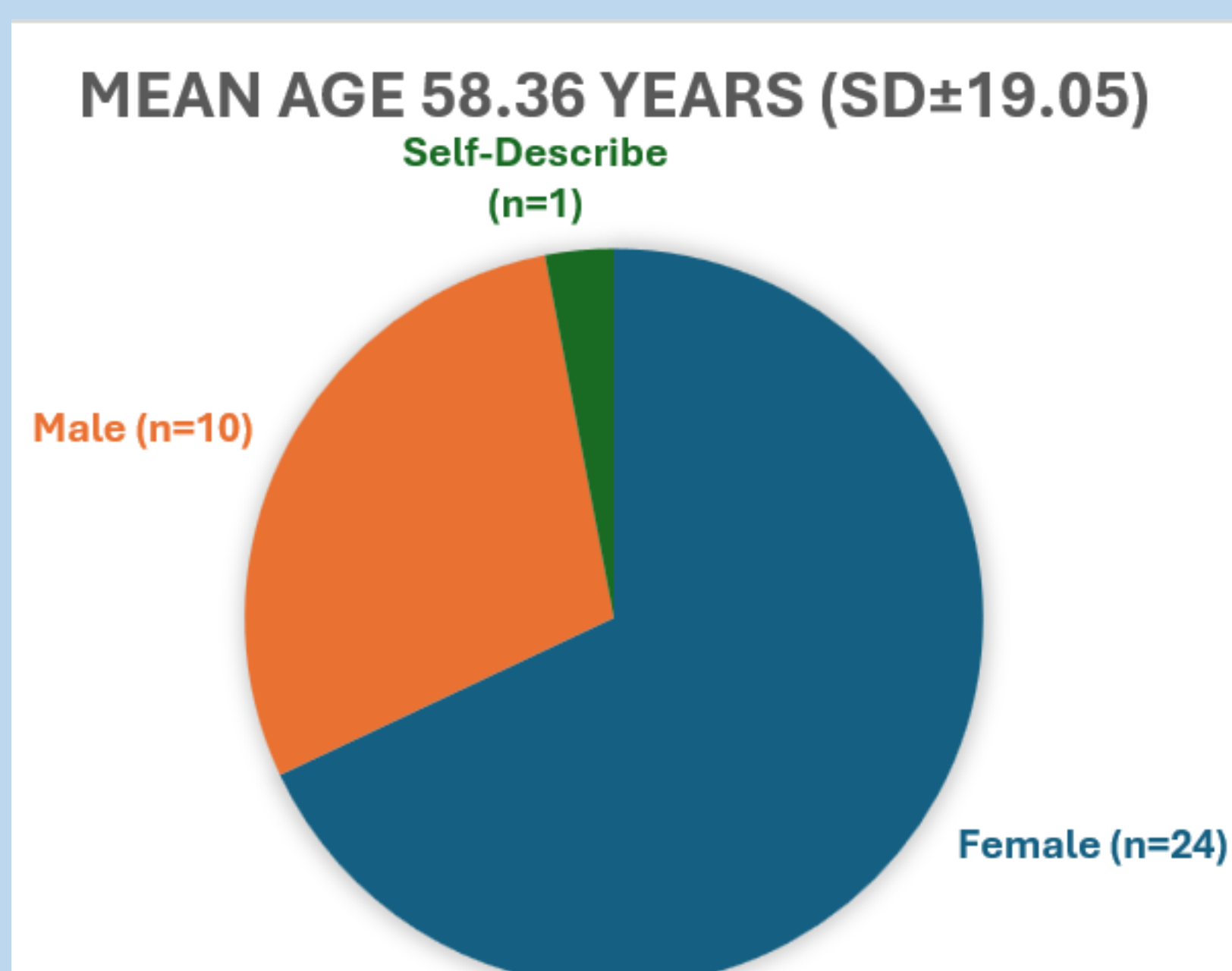
- Stereotypes and discrimination negatively impact the health outcomes Black American adults
- Structural and social forces may be compounded in the context of stigmatizing conditions like Alzheimer's disease (AD)
- Stereotypes, discrimination and stigmas indirectly contribute to delays in detection and diagnosis

Methods

- Ethnographic data collected from Black American adults (BAA) in the Southwest region of Pennsylvania via:
- Group discussions (n=14) with 140 individuals informed an interview guide and overall approach
- Semi-structured in-depth individual interviews (n=25)
- Participants were purposively sampled
- Transcripts from semi-structured in-depth interviews were analyzed using an iterative team approach to identify counternarratives

Participant Demographics

25 BAA study participants participated in semi-structured interviews



Corresponding Author: Lilcelia A. Williams, PhD
law193@pitt.edu

Parent Study Objectives

1. To develop and disseminate a community-focused narrative campaign that combats stigma around brain health disorders and aging within communities of color in Allegheny County, PA.
2. To lay the groundwork for radically disrupting the mainstream route to early ADRD detection and to do so at a time, and in a manner, that will position those who have historically been last to access advances in ADRD care to be among the first to benefit from the field's most recent therapeutic breakthroughs.

Findings & Exemplary Quotes

Our analysis revealed **six distinct counternarratives** that defy stereotypes and stigmas about AD, cognitive aging, and caregiving. The following counternarratives emerged:

- **acknowledge social support provided by “chosen family” as imperative**
- **depict the experience of a young male caregiver, debunking societal attributions and gender assignment of caregiving activities**
- **show defiance in expressing one's agency and value upon being asked about one's lived experiences relative to those in the majority social group**
- **honor the wisdom of older Black American adults**
- **counter fatalism by calling mental health a choice**
- **assert that living is not merely surviving in life, and with aging**

“If you don't have family, have some type of network where people can check on you. Make sure that you're eating. Make sure that you have whatever medical supplies you need. Make sure that you're having some kind of personal interaction.”

“... because I don't know of anything [else]... has shaped my experience as a Black man, because I don't how to be anything but a Black man...”

“I don't want to just go older. I want to grow wiser, and I just made that statement that there was such a term. Older people used to use that you can be a young fool, and you can be an old fool. But you're still a fool. So, I don't just want to grow older. I want to grow wiser.”

“It's really hard to know how to get better if you're just surviving ...living versus surviving. [When] living you have choices.”

“My sweet grandmother... She's like my best friend. I lived with her for the first 10 years of my life...But this disease took my grandmother away from me and doing something like this as hard as it is really as a testimony to what she would want me to do to tell her story, to help someone else.”

“So, in my early 20s, I got into some meditation stuff and just kind of like a lot more thoughtfulness. That was early on because I was a single parent and trying to navigate all those waters. And then later on it became really important to stay grounded in how I thought because I felt like the world was really challenging to navigate as an African American male.”

“So, it's, it's [mental health] super important to me. It's important to my partner and being a personal trainer. I have focused more on the mental component of the training and benefits more than a physical cause. The physical or just a byproduct of what I'm making myself do, mentally anyway, and then how do I push people and encourage them to see themselves in a better light and then they get the physical benefits of that as a as a byproduct.”

Semi-Structured Interview

Question Domains & Introductory Prompt

Domain One: Growing Old/Aging in the Black American Community

We would like to know what growing older is like or seems to be like in your community.

Domain Two: Personal Experiences with Growing Older/Aging

Let's shift our focus to talk about changes in memory or thinking that can sometimes happen as we age.

Domain Three: Brain Health and Decision Making

We know how important it is to have accurate and timely information about your health. In this section, we would like to discuss how you make decisions about your health as you grow older.

Domain Four: Engaging the Black American Community Around Brain Health

In this final section, we as researchers would like to better understand how to engage with the Black/African American community about brain health research.

Domain Five: Closing Thoughts

Before we close our conversation, is there anything else that you think is important for us to understand about aging, brain health, and cognitive changes in the Black American community?

Conclusion

Participants highlighted common misconceptions related to dementia is a normal part of aging, surviving is living, caregiving is a female responsibility. The stories gleaned provide a foundation for a narrative campaign which will be deployed and evaluated to combat stigma around AD and cognitive aging in Black American communities.

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