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○ Dementia- related stigma
perceived as:

- * social rejection
- * internalized shame
- * social isolation
- * financial insecurity

Associated with:

- low self-esteem
- isolation
- poor mental health
- decreased quality of life
- Relationship changes
- avoidance of help-seeking behaviors
 - delaying the diagnosis and utilization of health and social services



The Experience of Stigma

(Alzheimer's Association)

- *A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation.*
- *Relationships with family may change. Family members may not want to talk about the disease, perceive you as having little or no quality of life, or may avoid interacting with you.*
- *Others may approach your care partner to ask about you rather than asking you directly how you are doing.*
- *The reaction of some friends and family to your diagnosis may prevent you from seeking help from others.*

Factors associated with Stigma

- Ageism
- Ignorance
- Fear
- “War” metaphors for confronting this “epidemic”
- The “Alzheimerization” of the dialogue to support Euthanasia
- Negative terminology (e.g., “wandering” vs. “walking about” and “challenging behaviors vs. “change in behaviors”
- Defining “self” in relation to cognitive function (“I think therefore I am”)

You Are More Than Your Diagnosis

Alzheimer's disease is now part of your life, but it doesn't have to define who you are.

Our identities are often defined by what we do rather than who we are. The qualities that make each person unique represent a range of domains from physical traits to our relationships with others.

The diagnosis of Alzheimer's or another dementia may impact how you see yourself. Only you can decide how much you will allow the disease to be part of who you are.

At the end of this activity, you will see how you are more than your diagnosis.



I AM MORE

Let's Get Started!

You Are More Than Your Diagnosis

Profession

SELECT OR ENTER THE WORDS THAT BEST DESCRIBE YOUR CURRENT OR PREVIOUS PROFESSIONS.

You may select or enter up to 5 responses.

Teacher

Construction Worker

Homemaker

Executive

Enter your own response

Enter your own response

Enter your own response

Enter your own response



You Are More Than Your Diagnosis

Talents & Hobbies

SELECT THE WORDS THAT BEST DESCRIBE YOU, OR ADD YOUR OWN CUSTOM RESPONSES.

For best results, select or enter up to 5 responses.

Runner

Photographer

Woodworker

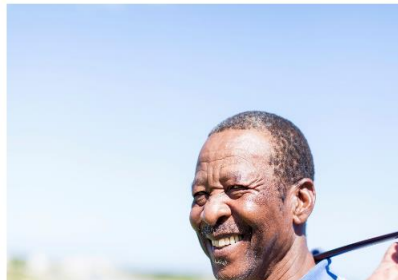
Gardener

Enter your own response

Enter your own response

Enter your own response

Enter your own response



You Are More Than Your Diagnosis

Relationships with Others

SELECT THE WORDS THAT BEST DESCRIBE HOW YOU IDENTIFY YOUR RELATIONSHIPS WITH OTHERS, OR ADD YOUR OWN CUSTOM RESPONSES.

For best results, select or enter up to 5 responses.

Partner

Grandmother

Friend

Neighbor

Enter your own response

Enter your own response

Enter your own response

Enter your own response



You Are More Than Your Diagnosis

Personality Traits

SELECT THE WORDS THAT BEST DESCRIBE YOU, OR ADD YOUR OWN CUSTOM RESPONSES.

For best results, select or enter up to 5 responses.

Funny

Shy

Adventurous

Easy Going

Enter your own response

Enter your own response

Enter your own response

Enter your own response



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AfricanAmericansAgainstAlzheimer's

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane."

— Dr. Martin Luther King, Jr.

Addressing the Disparate Impact of Alzheimer's on Communities of Color and Women

UsAgainstAlzheimer's Center for Brain Health Equity

[Learn More](#)

Dementia –related Disparities

[Please Click Here for Coronavirus-Related Resources](#)

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5.7 million

Americans currently have Alzheimer's disease.

20%

of Americans with the disease are African Americans, and they bear 33% of its national cost.

4th

Alzheimer's is the 4th leading cause of death among older African Americans.

The Costs of Alzheimer's and Other Dementia for African Americans

The economic burden of Alzheimer's and other dementias for African Americans was \$71.6 billion in 2012. Caregiving for African Americans with AD represents the bulk of these costs—more than 60%. More than 60% of the costs are borne by the families of African American women with AD, and close to half of the costs are concentrated in the



African American individuals with dementia have:



- higher rates of hospitalization
- more frequent hospitalizations
- greater severity of illness,
- longer lengths of stay
- higher readmission rates

Controlling for age, gender, ethnicity, education, cognitive status, and comorbidities, African American participants with dementia had worse admission physical function scores, more delirium, and more depressive symptoms as compared to White individuals.

Article

Disparities in Physical and Psychological Symptoms in Hospitalized African American and White Persons with Dementia

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Abstract

Objectives: This study examined differences in physical function, delirium, depressive symptoms, and behavioral and psychological symptoms of dementia (BPSD) in hospitalized African American and white older adults with dementia. **Methods:** This secondary data analysis using baseline data from an ongoing trial testing family-centered function-focused care included African American ($n = 159$) and white persons ($n = 135$) with dementia. **Results:** A multivariate analysis of covariance showed that controlling for relevant demographic and health characteristics, African Americans with dementia had lower physical function, more delirium, and more depressive symptoms upon admission than white participants. There were no significant differences in BPSD between African American and white persons. **Discussion:** To our knowledge, this is the first study to examine racial differences in admission symptoms of hospitalized persons with dementia. While the findings are preliminary, they can be used to inform the design of future research, including identifying the causes of disparities.

Theoretical /Conceptual Considerations: Cumulative disadvantage and life course theories/structural racial discrimination

Interventional considerations: informed and adaptive

References and Resources

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