

From the Voices of Black Dementia Caregivers: The Need for Culturally Responsive Education on Navigating Care

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Program of Research

Promoting	Promoting quality of life for African American families affected by dementia and exploring how religious activities and spiritual connectedness can promote meaningful engagement among persons with dementia.
Creating	Creating innovative research programs and testing new models of care to address the needs of diverse caregiving families.
Placing	Placing culturally responsive, evidence-based programs and interventions in the hands of those who need them.

Disclosures & Funding



RRF | Foundation
for Aging

UCDAVIS
HEALTH

Betty Irene Moore Fellowship
for Nurse Leaders and Innovators



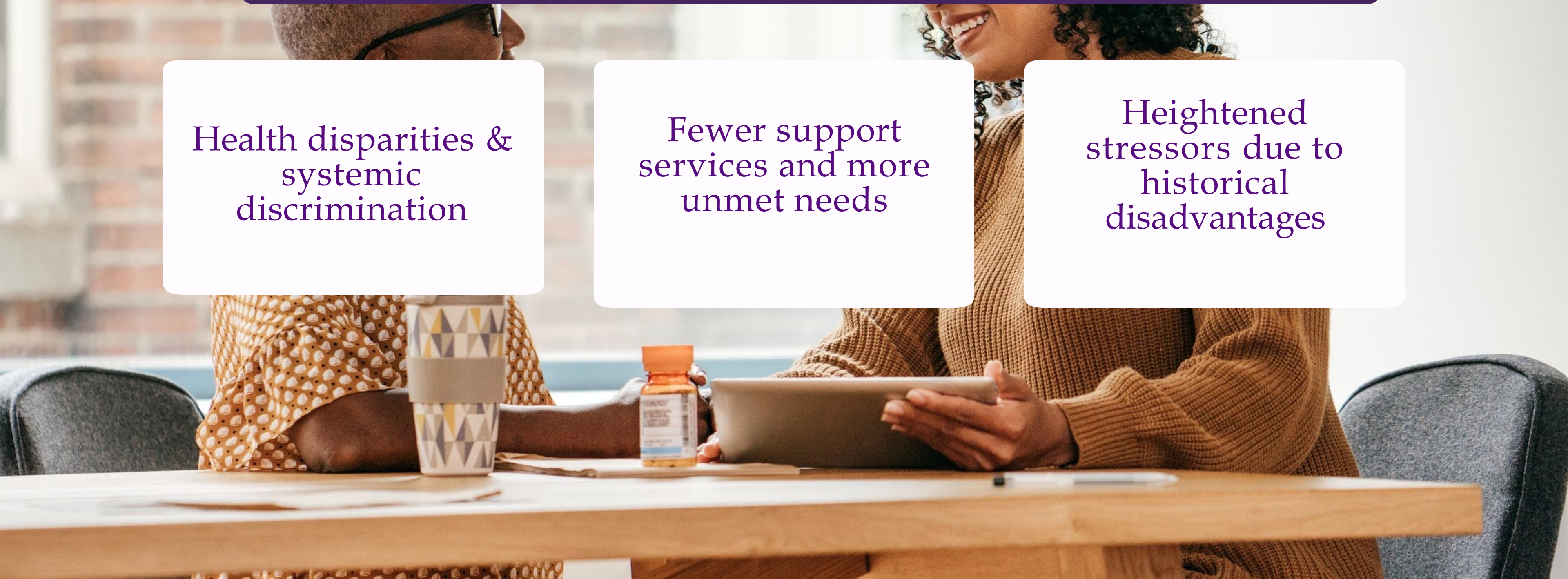
National Institute
on Aging

Unique Experiences of Black Dementia Caregivers

Health disparities &
systemic
discrimination

Fewer support
services and more
unmet needs

Heightened
stressors due to
historical
disadvantages



Unique Experiences of Black Dementia Caregivers



- ❖ Providing care for a family member or friend is challenging, but being a Black caregiver adds an additional layer of challenges and concerns.

(Abramsohn et al., 2019)

- ❖ Due to the disadvantaged social history of Black Americans, several unique stressors, vulnerabilities, and resources inform and affect Black dementia caregivers' experiences and well-being.

(Crewe & Chipungu, 2006)

- ❖ Health and socioeconomic disparities, as well as systemic racism, are factors that serve as barriers to optimal health care access and navigation for caregivers.

(Alexander et al., 2022; Crewe & Chipungu, 2006)

Unique Experiences of Black Dementia Caregivers



❖ Support systems are made up of family, church, and community with limited financial resources.

(Dilworth-Anderson et al., 2012; Abramsohn et al., 2019)

❖ Less access to support services and primary care and more unmet needs for their person living with dementia.

(Abramsohn et al., 2019)

❖ Engage in more hours of intense caregiving and delegate more of their monthly income to caregiving .

(National Alliance for Caregiving & AARP, 2021)

❖ Indicate being disregarded by primary care clinicians which contributes to caregiver burden.

(Alzheimer's Association, 2021)



Received: 21 August 2021 | Revised: 22 November 2021 | Accepted: 1 December 2021

DOI: 10.1111/jgs.17636

ETHNOGERIATRICS AND SPECIAL POPULATIONS

Journal of the
American Geriatrics Society

“Falling between the cracks”: Experiences of Black dementia caregivers navigating U.S. health systems


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Journal of Family Nursing
Volume 28, Issue 3, August 2022, Pages 195–204
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<https://doi.org/proxy.library.umccoy.edu/10.1177/10748407221102465>



Special Issue Article

Experiences of Black American Dementia Caregivers During the COVID-19 Pandemic

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Abstract

Dementia caregivers are responsible for the daily care and management of individuals who are among the most vulnerable to the serious consequences of COVID-19. This qualitative study explores the experience of Black dementia caregivers during the COVID-19 pandemic in the United States. Nineteen Black dementia caregivers were recruited to participate in semi-structured focus groups held in April 2021. Four overarching themes were constructed during analysis: social isolation, decreased well-being, the good and bad of telehealth, and challenges fulfilling health care needs. The results indicate the experience of Black dementia caregivers overlaps with existing literature on the experiences of dementia caregivers of other races during COVID-19. These results can assist in addressing the specific needs and improving the experiences of dementia caregivers in current and future public health crises.

Keywords

care partners, public health crisis, Alzheimer's disease, African American, telemedicine

Problem

Limited culturally
responsive
resources

Increased
vulnerability due to
systemic failures

Higher levels of
stress compared to
other racial groups



A photograph of two women sitting on a grey couch in a bright, modern living room. The woman on the left is Black, with short hair, wearing glasses and a patterned orange and white top. The woman on the right is white, with curly hair, wearing a light blue button-down shirt. They are both looking at each other and talking. In the foreground, on a table, are several medicine bottles. In the background, there is a white shelving unit with various decorative items.

Solution

Develop an education course that is culturally responsive to the unique experiences of Black dementia caregivers.

Focus Groups with Black Dementia Caregivers

Who, What, & When?

- 16 current and former Black dementia caregivers
- 3 virtual focus group sessions between 2022 and 2023

Discussion Topics

- Refine psychoeducation courses to meet the needs of Black caregivers
- Why is a specific course for Black caregivers needed to navigate the healthcare system?

Themes



Limited Accessible
Opportunities for
Education and Resources

“They really don’t understand our culture. And because of that, being a minority, we have to continue to educate in a different way.”
“Our resources are different.”.”

We have our own
Cultural Identity

“We have our own cultural dynamics, and because of being Black in a culture that doesn’t always acknowledge who we are, makes it very stressful at times.”

Creates a Space to
Feel Seen

“It allows people not to feel like they’re in it alone.

A Sense of Empowerment

“It gives the encouragement to still continue to do that extra research and take that extra step to find out what it is that you need for your particular situation.”



Pilot Course

Course Overview



- Asynchronous psychoeducation course to address caregiving needs through a cultural lens
- Focus on key competencies needed to succeed during a pandemic and crisis
- Co-produced by Black caregivers, PLWDs, and healthcare professionals..."For Us, By Us"
- Delivered on Canvas platform with the ability to monitor caregivers' course progress
- 8-10 hours of content in 37 short interactive segments
 - Linked text and video instructional materials



Course Topics

Palliative care & hospice

Caregiver support

Financial scams

Dealing with grief

Preparing to visit the
hospital

Navigating Insurance

Self-care

Resources

Distance caregiving

Combating isolation

How to get an advocate

Document tracking

Life planning/POA

Managing day-to-day life

Financial Planning

Watch the video below to learn more



JORDAN MURPHY
COMMUNITY RESILIENCY MODEL TEACHER



ZANTHIA WILEY, MD
INFECTIOUS DISEASES PHYSICIAN



MATTHEW JOHNSON
CAREGIVER



Black dementia caregivers have expressed that determinants such as class, sex, being a "person of color" and utilizing public health insurance contribute to their difficulties navigating the United States health system.

Deep inequities in the social determinants of health exist in counties highly impacted by



Understanding the Diversity of a Care Team



Additional Resources

- **Study Plan:** Provides time management strategies for caregivers to guide course completion
- **Workbook:** Compiles all worksheets and activities mentioned throughout the course
- **Glossary** of terms used in course
- **Resources** available to compliment lessons

CaREgiving While Black WORKBOOK



Study Plan: CaREgiving While Black

- CaREgiving While Black is a 6-week course that will take approximately 7.75 hours to complete. This guide lays out a suggested plan to complete the course within 6 weeks by dedicating 1.25 hours per week.
- We encourage you to check off each section as you completely them and celebrate your progress as you move through and achieve the goals you set for yourself in participating in the course.
- As you begin this course, take a moment to explore why you want to participant and for whom you are enrolling. Take a moment to answer the following question either on this document or printed out so you see your motivatin every time you come back to this guide: *When you think about yourself as a caregiver, what inspires you to want to become a better caregiver for yourself and for your person?*

1. Week 1 Goals

Course Introduction (~50 mins)

- ☐ Welcome
 - ☐ How to Navigate this Course (~1.5 mins)
- ☐ Introduction to the Course
 - ☐ The Purpose (~8.5 mins)
 - ☐ Dementia in the Black Community (~15 mins)
 - ☐ Public Health Crisis: COVID-19 (~22.5 mins)
 - ☐ Dementia and Risks for COVID-19 (~2.5 mins)

Managing Home Life (~11.5 mins)

- ☐ Introduction (~9.5 mins)
- ☐ Caregivers as Healthcare Providers
 - ☐ The Clinical Role of the Caregiver (~2 mins)

Black/African American Mental Health resources

NAMI

NAMI Focuses On Raising Awareness And Providing Support And Education To Those In Need.

GO

Black Mental Health Alliance

Provides information, resources, and a "Find a Therapist" locator to connect with a culturally competent mental health professional.

Tel. (410) 338-2642

GO

Assessing Your Feelings

Write as many feelings as you have under each topic.
Some of your feelings may seem to contradict themselves.
That's fine, and perfectly normal.

Living with the stress of caring

Thinking about the end of my person's
livespan and my role

Thinking about my days of caregiving

Thinking about the next phase of life

Thinking about how to end my life and my family's
livespan and my role

A photograph of two Black women in a domestic setting. The woman on the left, with voluminous curly hair, is smiling broadly and has her arm around the other woman. The woman on the right, who is older, is holding a tablet and looking at the screen with a gentle smile. They are both wearing sweaters. In the background, a lamp with a white shade and wooden legs is visible, along with a framed abstract artwork on the wall.

Findings



Caregiver Participants

- 75 Black caregivers enrolled in pilot study
 - 64 attempted the course
 - 33 completed the course within 10-week time frame
- Caregivers withdrew due to:
 - personal illness
 - death of care recipient
 - too busy
 - no response

Caregivers who Completed the Course

- 33 caregivers completed the course
- Average age: 54 years
- 94% attended college
- 81% female
- 78% cared for a parent
- 6-30 hours spent on the course (12 hrs average)



Results

- Ability to improve caregivers' emotional well-being and sense of confidence and mastery in their caregiving role.
- T-test comparing pre- and post-course data revealed significant improvement observed in caregivers' feelings of depression ($p = .009$), burden ($p = .034$), and role strain ($p = .029$) within 30 days of course completion.
- Caregiver mastery from baseline to course completion increased on average by 0.42 points with an effect size of 0.26 (Cohen's d).
- In-depth interviews about caregivers' experience taking the course revealed they appreciated the cultural recognition and had feelings of empowerment.


Caregivers who did not complete the course



- Similar demographics to those who completed the course
- Reasons cited for not completing:
 - **Lack of motivation**
 - **Wanted more guidance**
 - **Desired face-to-face interaction**
 - *Preference for face-to-face interaction was echoed by several Black faith communities when pilot results were shared with them

A photograph of a caregiver, a young Black woman with dreadlocks, smiling and hugging an elderly Black woman with glasses and grey hair. They are in a modern kitchen with white cabinets and a range hood. A green plant is visible on the left, and a wooden cutting board is on the counter in the foreground.

Caregiver Testimonies



"I heard Caregiving While Black and chuckled a little, but when I started diving into it a bit, and reading the information on health disparities, dementia myth busters, etc. I got serious, because I realized how important it is to have this course which addresses these harsh realities faced by many in our community."

"Overall, I felt this course was very helpful and very thorough. I had only done one other caregiving course, but this particular course was very helpful because it was created by Black people for Black people. That's empowering."

"All of the speakers looked like me. I could relate to them, they were discussing real life experiences that I could relate to, that was valuable."

Takeaways for Professionals



what's
next?



We are currently conducting an RCT—a two-arm trial in which 140 Black caregivers are randomly assigned to participate in Caregiving while Black or receive the program after a three-month wait.

Assess the efficacy of Caregiving while Black in enhancing caregivers' sense of caregiving mastery (primary outcome), perceived ability to manage care recipients' behavioral and psychological symptoms, and improving their quality of life, health literacy, and emotional well-being (secondary outcomes).

Expand the course into **Caregiving while Black-LIVE**, adding a synchronous facilitator-guided cohort-structured component to the original self-paced asynchronous curriculum material.

Conduct a **prototype test** of the course to assess its preliminary efficacy and its usability, acceptability, and feasibility.

There is an urgent need for culturally responsive education that addresses the unique challenges of Black dementia caregivers.

Education provides an opportunity to empower caregivers, reduce stress, and improve caregiving outcomes.

Resources

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Questions



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Next Steps

CEU Information

- CEU Link will be active for 10 days
- If you have any questions, contact Linda Centeno at **646-744-2923**.

Scan QR CODE for CEU form

