

Caregiving while Black: Addressing the Cultural Realities

Fayron Epps, PhD, RN, FGSA, FAAN

Wisconsin Alzheimer's Institute Annual Update in ADRD

November 11, 2022



1

Faith Village Research Lab



Our mission is to improve access to resources and awareness of Alzheimer's disease and related dementias in African American and faith communities by conducting research and providing education.

2

Meet the Team

Primary Investigator:

- Dr. Fayron Epps

Co-Investigators:

- Dr. Kenneth Hepburn
- Dr. Carolyn Clevenger
- Dr. Stephanie Bennett

Coordinators:

- Kevin Crawford
- Kiran Raina
- Nkosi Cave

PhD Students and Graduate Research Assistants:

- Karah Alexander
- Mayra Sainz
- Sloan Oliver
- Emani Williams

3

Disclosures & Funding

- RRF Foundation for Aging [2020213]
- Betty Irene Moore Fellowship Program for Nurse Leaders and Innovators
- Career Development Award from the National Institute on Aging [K23AG065452]



RRF | Foundation for Aging

UC DAVIS
HEALTH

Betty Irene Moore Fellowship
for Nurse Leaders and Innovators



4



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 not only contribute to an increase in dementia risk in Black Americans, but also serve as barriers to optimal health care access and navigation for caregivers.

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

5



Unique Experiences of Black Dementia Caregivers

❖ 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)

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

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

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

(Alzheimer's Association, 2021)

Community and culture help Black caregivers cope with the challenges of caregiving.

(Dilworth-Anderson, Pierre & Hillard, 2012)

6

Informing an Education Program

7

Focus Groups with Black Dementia Caregivers

- April 2021
- 19 Black American caregivers from 4 states
- 2 virtual focus group sessions
- **Discussion topics:**
 - COVID-19 Pandemic & the impact on caregiving experience
 - Navigating the U.S. Health Care System
 - Experiences of discrimination in health care

8

Concerns of Black Dementia Caregivers

"Gaps in the health systems lead to people falling between the cracks & prevents access to the care, services, and resources one needs"

Forced Advocacy

- "We used four words: That is not acceptable."

Poor Provider Interaction

- "Every time I need to go to a doctor I'm given a different story about what he needs and who to call."

Payor Source Dictates Care

- "The insurance that you have, sometimes will dictate the type of services you get."

Discrimination

- "You get a different experience- even if you are a person of color."

Broken Health System

- "I believe the healthcare system in America... it is broken."

9

Concerns of Black Dementia Caregivers

Social Isolation

- "The [pandemic] does get overwhelming. It's depressing and just being in COVID, during that isolation, you need that human interaction."

Decreased Well Being

- "You have...so many decisions to make...for yourself as well as for the person for whom you're caring...all this stuff gets in your head."

The Good and Bad of Tele-Health

- "It's time to look at him [care recipient]; it's time to touch him. It's time to know what's going on with him."

Challenges Fulfilling Healthcare Needs

- "One of my biggest fears during COVID, was that if my [care recipient] got sick...[in the hospital]...I would not be able to look after him...or speak for him."

10

Received: 21 August 2021 | Revised: 22 November 2021 | Accepted: 5 December 2021
 DOI: 10.1111/sps.17636

Journal of the American Geriatrics Society
 ETHNOGERIATRICS AND SPECIAL POPULATIONS

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

Karah Alexander MPH¹ | Sloan Oliver BS² | Stephanie G. Bennett PhD, RN³ | Jenyl Henry MPH⁴ | Kenneth Hepburn PhD¹ | Carolyn Clevenger DNP⁵ | Fayron Epps PhD, RN¹

Journal of Family Nursing
 Volume 28, Issue 3, August 2022, Pages 195-204
 © The Author(s) 2022, Article reuse Guidelines
<https://doi.org/10.1177/10748407221102465>

SAGE journals

Special Issue Article

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

Sloan Oliver, MPH¹, Karah Alexander, MPH¹, Stephanie G. Bennett, PhD, MBA, RN^{1,2}, Kenneth Hepburn, PhD¹, Jenyl Henry, MPH³, Carolyn K. Clevenger, DNP, RN, GNP-BC, FAANP, FGSA, FAAN¹, and Fayron Epps, PhD, RN, FAAN¹

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

Caregiver Recommendations for Course Topics

Palliative care & hospice	Dealing with grief	Self-care	Combating isolation
Life planning/POA	Caregiver support	Preparing to visit the hospital	Resources
How to get an advocate	Managing day to day life	Financial scams	Navigating insurance
	Distance caregiving	Document tracking	

Pilot Course

13

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



14

Module 1

Key Section	Topic Within Sections	Lessons
Course Introduction	Welcome	How to Navigate this Course
	Introduction to the Course	The Purpose
		Dementia in the Black Community
		Dementia and Risk for COVID-19
		Public Health Crisis: COVID-19

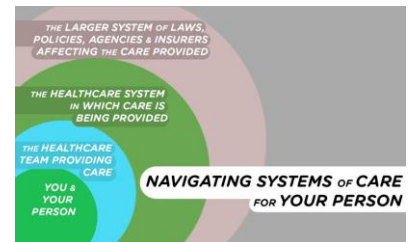
Now let's hear from Dr. Zanthia Wiley as she speaks more about COVID-19 and its impact on the African American community



15

Module 2

Key Section	Topic Within Sections	Lessons
Navigating the Healthcare System	Introduction Effective Communication in Healthcare Setting	Introduction
		Health Literacy
		Talk Like Members of Your Healthcare Team
	Navigating the Hospital System	Navigating Your Next Doctor's Appointment
		Entering the Healthcare System
		Pathways of the Healthcare System
		Safe Use of the Emergency Department
	Understanding Insurance Coverage Care Coordination Hospice and Palliative Care	Who are the Key Players
		Insurance and HIPPA
		Having a Good Plan of Care
		Discharge Planning
		Home Care vs Home health
		Palliative Care vs Hospice



Engaging and Simple to Read Graphics to Convey Complex Content

16

Module 3

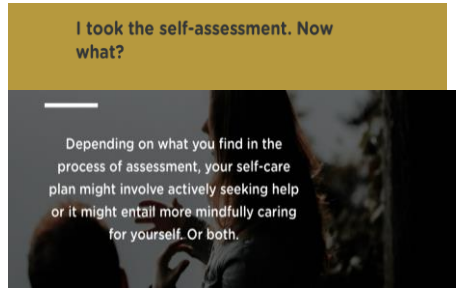
Key Section	Topic Within Sections	Lessons
Managing Home Life	Introduction	Introduction
	Caregivers as Health Providers Guiding your Person's Day	The Clinical Role of a Caregiver
		The Challenges of Disease Progression
		Planning your Person's Day
	Identifying, Assessing and Using Resources	Reliable Information, Fake News, and Scams
		Accessing Resources
		Medication Management
		Safe at Home
	Developing Plans of Care	Life Planning
		Crisis Planning
Your Emergency Grab and Go Kit		



17

Module 4

Key Section	Topic Within Sections	Lessons
Caregiver Self-Care	Introduction	Introduction
		COVID-19 and Caregiving
	Mental Well Being	Assessing for and Combating Isolation
		Assessing Your Feelings
	Deeper Dive Self-Care Strategies	Implementing Self-Care
	Respite Care	What Does "Respite Care" Mean?
	Religiosity and Spirituality	Feeding Your Spirit
	Dealing with Death and Grief	Dealing with Your Person's Death



18



Example of an Expert Video

19

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

20

Pilot Study

- No-control longitudinal study to test prototype course
- **Study Duration for individual caregivers:** 24 weeks
- **Key study outcomes:** measures of caregiver psychological well-being & confidence in their ability to provide effective care to the PLWD
- Caregivers engage in baseline, midpoint, & end of study data collection interviews
- Honorarium provided after each interview
- Optional post-course completion interview (qualitative)

BLACK DEMENTIA CAREGIVERS NEEDED

For a 6-week Culturally-Appropriate Caregiver Training & Education Course

What will you learn?

- Managing Home Life with Dementia
- Health Care Navigation
- Caregiver Self-Care



Are you eligible?

- Identify as Black/African American
- Caring for a person living with dementia
- Have a way to access the course online

This course is part of research. For more information or to see if you are eligible, [click here](#) or contact us at:

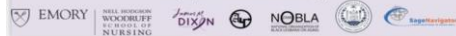
care.course@emory.edu
404-251-0078

Scan the QR Code for More Information



You will receive a \$40 gift card for each pre and post 30-minute interview completed.

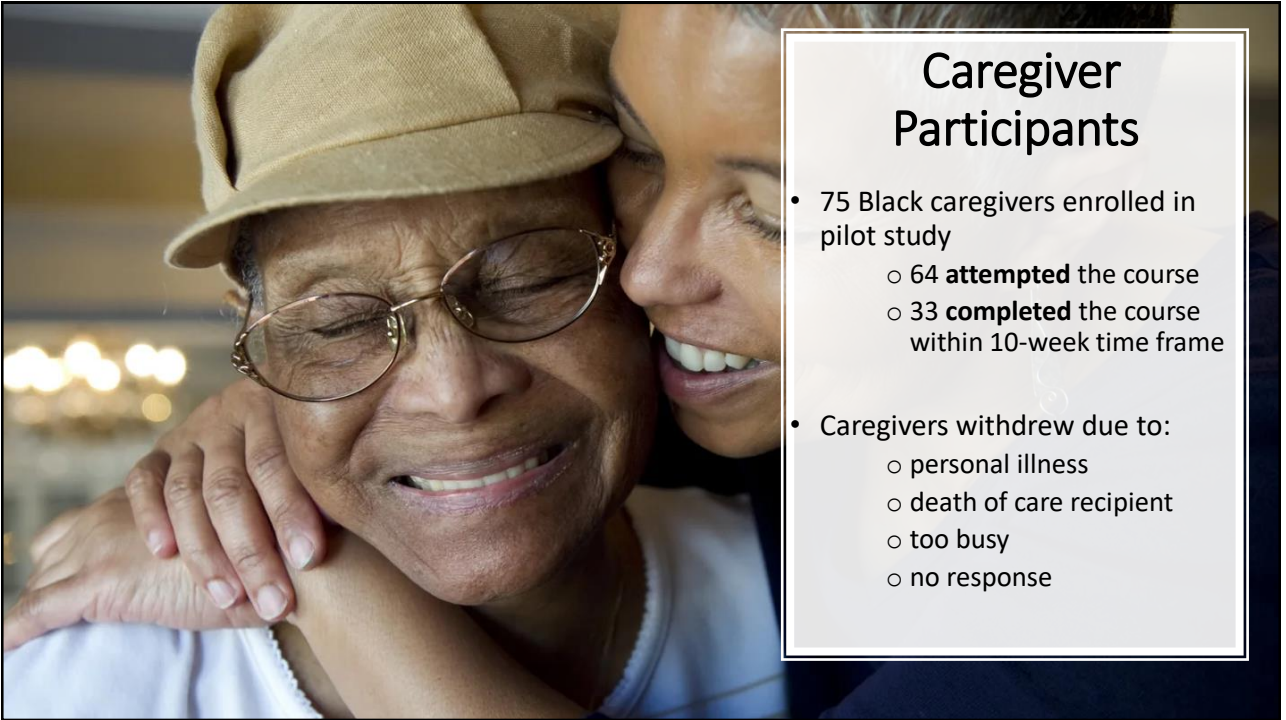
Funding Sponsor: RRF Foundation for Aging



21

Preliminary Findings

22



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

23

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)

24

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.

25

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*

26

Caregiver Testimonies

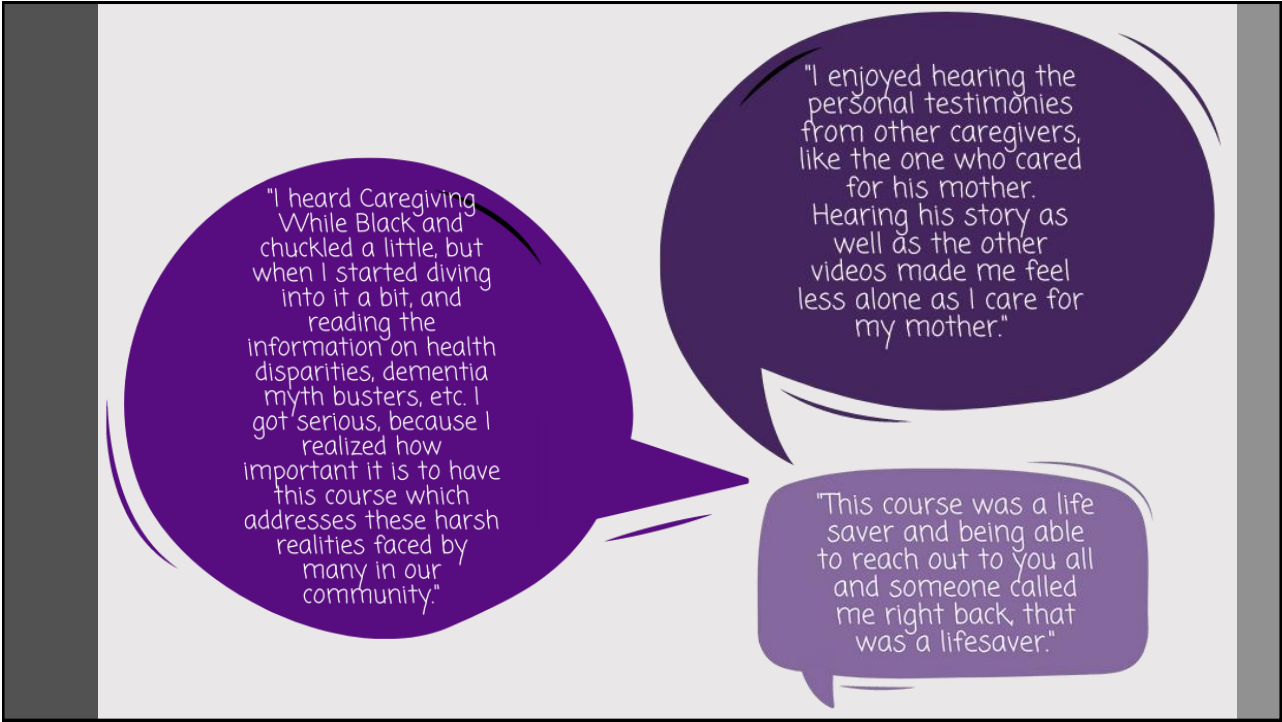
27

"I no longer felt alone, I saw I have a whole community-caregivers, medical professionals-who all care."

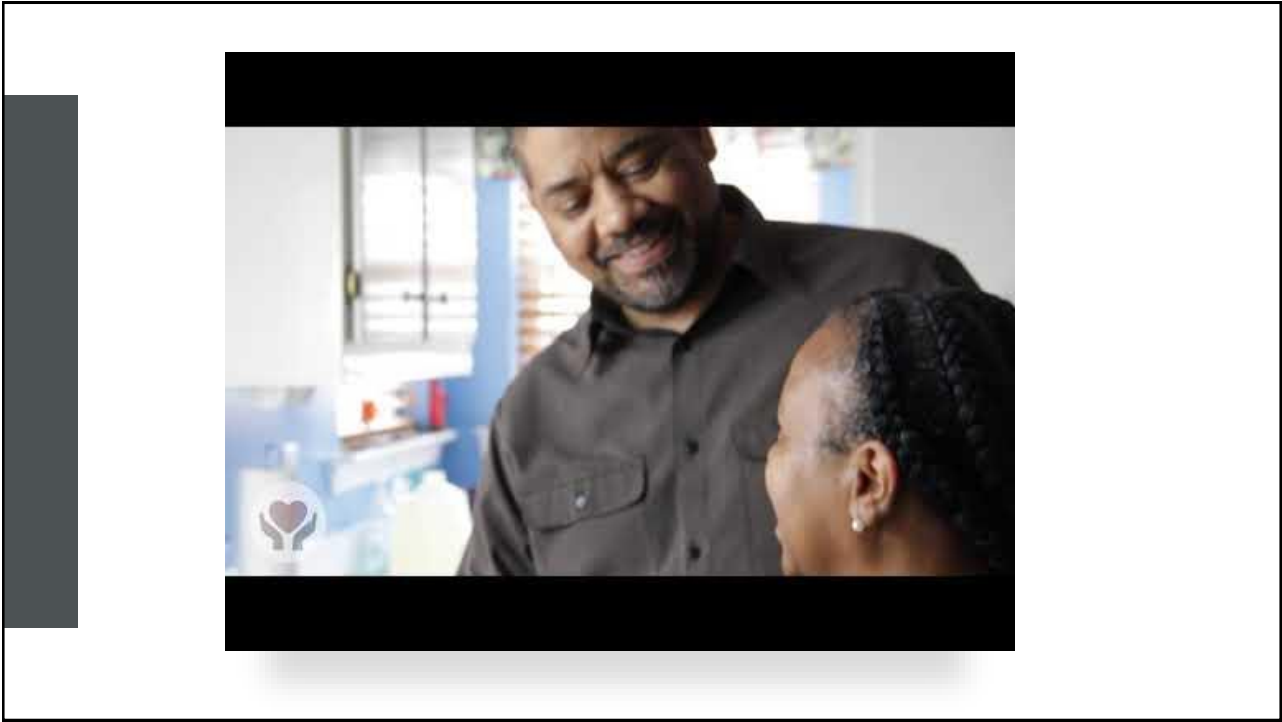
"All of the speakers looked like me. I could relate to them, they were discussing real life experiences that I could relate to, that was valuable."

"Overall, I this felt 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."

28



29



30



31

- Use **caregiver feedback** to direct the revision of the *Caregiving while Black* course
- Conduct a **two-arm trial** in which 140 Black caregivers will be randomly assigned to participate in *Caregiving while Black* or receive the program after a wait of 3 months.
- **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).

32

- Employ an iterative user-centered design approach to reconfigure *Caregiving while Black* and expand it 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.

33

Now Enrolling for
the Next
Rendition of
Caregiving While
Black !



34

References

Crewe SE & Chipungu, SS. Services to support caregivers of older adults. In: Berkman B, 413 ed. Handbook on Social Work in Health and Aging. New York: Oxford University; 414 2006:539– 550.

Abramsohn ME, Jerome J, Paradise K, Lostas T, Spacht AW, Lindau TS. Community 400 Resource Referral Needs Among African American Dementia Caregivers in an 401 Urban Community: A Qualitative Study. BMC Geriatrics 2019; 19:311-321.

National Alliance for Caregiving & AARP. Caregiving in the U.S. Available 416 at: <http://www.caregiving.org/data/04finalreport.pdf>. Accessed October 16, 2022.

Alexander K, Oliver S, Bennett GS, Henry J, Hepburn K, Clevenger C, Epps F. Falling between the cracks: Experiences of Black dementia caregivers navigating U.S. Health Systems. Journal of American Geriatric Society 2022;20(2): 592-600.

Oliver S, Alexander K, Bennet GS, Henry J, Hepburn K, Clevenger C, & Epps F. Experiences of African American dementia caregivers during the COVID-19 pandemic. J of Family Nurs: Special Issue on COVID-19 2022.


Special Report. Race, Ethnicity, and Alzheimer's in America. Alzheimer's Association 434 (online) Available at: <https://www.alz.org/media/Documents/alzheimers-facts-and-figures435-special-report.pdf>. Accessed October 16, 2022.

Dilworth-Anderson P, Pierre G, Hilliard TS. Social Justice, Health Disparities, and Culture in 409 the Care of the Elderly. JLME 2012;40(1):26-32.

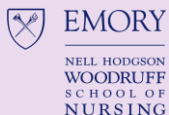
35

Contact Us

Phone: 678-723-8188
care.course@emory.edu

fepps@emory.edu
404-727-6936 (office)
 @QOL4olderadults

faithvillage@emory.edu
Faith Village Research 
 @village_faith



36