



# Caregiving while Black: Addressing the Cultural Realities

Fayron Epps, PhD, RN, FGSA, FAAN

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# 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.

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# 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

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# 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)

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# 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)
- ❖ Support systems are made up of family, church, and community with limited financial resources. (DiIwirth-Anderson et al., 2012; 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, 2020)
- ❖ Indicate being disregarded by primary care clinicians which contributes to caregiver burden. (Alzheimer's Association, 2020)
- Community and culture help Black caregivers cope with the challenges of caregiving. (DiIwirth-Anderson, Pierre & Hillard, 2012)

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# Informing an Education Program

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## 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

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## 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	Poor Provider Interaction	Payor Source Dictates Care	Discrimination	Broken Health System
• "We used four words: That is not acceptable."	• "Every time I need to go to a doctor I'm given a different story about what he needs and who to call."	• "The insurance that you have, sometimes will dictate the type of services you get."	• "You get a different experience—even if you are a person of color."	• "I believe the healthcare system in America... it is broken."

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## Concerns of Black Dementia Caregivers

Social Isolation	Decreased Well Being	The Good and Bad of Tele-Health	Challenges Fulfilling Healthcare Needs
• "The [pandemic] does get overwhelming. It's depressing and just being in COVID, during that isolation, you need that human interaction."	• "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."	• "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."	• "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."

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

Korah Alexander MPH<sup>1,2</sup> | Susan Oliver BS<sup>1</sup> | Stephanie G. Bennett PhD, RN<sup>1,3</sup> | Janet Hines MPH<sup>1</sup> | Kenneth Stephens PhD<sup>1</sup> | Candice Chongwe DNP<sup>1,4</sup> | Poranne Agbe PhD, RN<sup>1</sup>

**Abstract**  
Dementia caregivers are responsible for the daily care and management of individuals who are among the most vulnerable in the current consequences of COVID-19. This qualitative study captures the experiences of Black dementia caregivers during the COVID-19 pandemic in the United States. Interview data were analyzed to identify the challenges and needs of Black dementia caregivers. The study found that Black dementia caregivers were concerned in particular in their understanding of how to get help, their financial concerns, their social isolation, and their need for support. The study also found that Black dementia caregivers were concerned about their ability to access needed services, their need for support, and their need for help with navigating the health care system. The study also found that Black dementia caregivers were concerned about their ability to access needed services, their need for support, and their need for help with navigating the health care system. The study also found that Black dementia caregivers were concerned about their ability to access needed services, their need for support, and their need for help with navigating the health care system.

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## 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	


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# Pilot Course

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## 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




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## Module 1

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

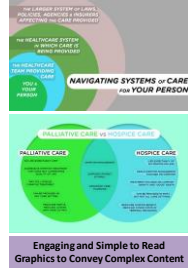
Now let's hear from Dr. Zanthia Wiley as she speaks more about COVID-19 and its impact on the African American community



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## 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	Navigating Your Next Doctor's Appointment
		Entering the Healthcare System
		Pathways of the Healthcare System
Understanding Insurance Coverage Hospice and Palliative Care	Safe Use of the Emergency Department	
	Who are the Key Players Insurance and HIPAA	
	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

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## 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
	Developing Plans of Care	Safe at Home
		Life Planning
		Crisis Planning
Your Emergency Grab and Go Kit		

Answer the following questions as you assess the safety of your home:


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## 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

The community Respite Model is another strategy that can be used to regulate your emotions.

Watch the video below to learn more



I took the self-assessment. Now what?

Depending on what you find in the process of assessing your self-care plan might involve actively seeking help or it might entail more regularly caring for yourself on your own.

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**DR. DeLON CANTERBURY**  
BOARD CERTIFIED PHARMACIST | PharmD, BCOP | CEO, Geriatric Inc.

*Caring for  
White Black*

**Example of an Expert Video**

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### 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

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### 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@geriatric.org](mailto:care.course@geriatric.org) 414-554-0078

Scan the QR Code for More Information

See us at the 2024 Black Health Equity Summit, June 18-20, 2024, at the University of Illinois at Chicago

Funding Sponsor: NPI Funded by NIH

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## Preliminary Findings

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### 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

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### 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)

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## 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.

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## 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*

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## Caregiver Testimonies

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"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."

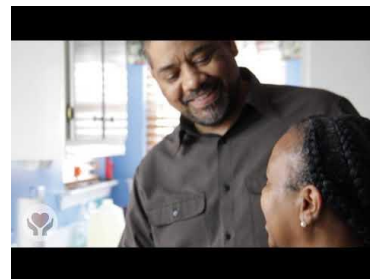
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"I heard Caregiving While Black and I chuckled a little, but when I started diving into it a bit and reading the information on health disparities, dementia myth busters, etc. I got serious, because I realized how important it is to have this course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

"I enjoyed hearing the personal testimonies from other caregivers, like the one who cared for his mother. Hearing his story as well as the other videos made me feel less alone as I care for my mother."

"This course was a life saver and being able to reach out to you all and someone called me right back, that was a lifesaver."

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- 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).

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- 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.

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Now Enrolling for  
the Next  
Rendition of  
**Caregiving While  
Black I**



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## Contact Us

Phone: 678-723-8188  
[care.course@emory.edu](mailto:care.course@emory.edu)

[fepps@emory.edu](mailto:fepps@emory.edu)  
 404-727-6936 (office)  
 @QOL4olderadults

[faithvillage@emory.edu](mailto:faithvillage@emory.edu)  
 Faith Village Research  
 @village\_faith

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