

## In This Issue

According to the Alzheimer's Association, 6.7 million Americans are living with Alzheimer's disease. Family caregivers provide hours of unpaid services and care to people with dementia, with an estimated economic value of \$244 billion dollars per year. Caregivers are often referred to as "silent patients," as the demands associated with caring for a loved one with dementia can put constraints on their ability to focus on their own health and wellbeing. A large body of research has demonstrated that caring for a loved one with dementia is associated with poorer physical and mental health outcomes.

African Americans are disproportionately affected by Alzheimer's Disease and related dementias (ADRD) and are twice as likely to develop late-onset Alzheimer's Disease than White Americans. Research has shown that African American caregivers spend more hours in care-related activities with their loved one and often feel that their concerns are dismissed or under-addressed by medical professionals. African Americans also report more positive attitudes about their caregiving role compared to White caregivers. Access to services, discrimination, distrust in the healthcare system, and other factors add layers of complexity to the ways that people from black communities navigate caring for a loved one with dementia.

In this issue of the E4 Center's Hot Topics Newsletter, we highlight the latest research focused on dementia caregiving in Black/African American communities. These studies advance what is known about the caregiving experience in African American families and illuminate important consideration for culturally-informed interventions and supports.

## Check out these additional resources on caregiving:

- E4 Center Webinars
  - [Proven Strategies to Enhance Caregiver Mental Health and Well-Being](#)
  - [Families Aging with Mental Health and Substance Use](#)
  - [Beyond the Basics: Building Resilience for Informal Caregivers](#)
- Resources for older Veterans and their families and caregivers can be found [here](#).
- Rush Center for Excellence in Aging's [Caring for Caregivers](#) model works to integrate supporting caregivers as part of Age-Friendly Health Systems across the U.S. See the Caring for Caregivers flyer [here](#).

## Dementia caregiving in Black/African American communities

[Empirical evaluation of the "Caregivers Passage Through Dementia" on African American caregivers](#) *Clinical Gerontologist*, January-February, 2023

Duren and colleagues report preliminary data examining a new psychoeducational intervention designed for African American dementia caregivers, called the Universal Dementia Caregiver Boot Camp (UDC). Their results demonstrated that caregivers who participated in the UDC reported increased caregiver knowledge about

dementia, caregiving burden, and coping. At follow-up, caregivers also reported that the program helped them develop confidence, knowledge, and change in attitudes towards themselves and their loved one. They also found that reframing caregiving as a "gift" and empowering caregivers through spirituality were particularly important aspects for their African American participants.

**Cultural and social factors in care delivery among African American caregivers of persons with dementia: A scoping review** *Gerontology and Geriatric Medicine*, January, 2023

Idorenyin Imoh and Charity published a scoping review of 21 publications focused on social and cultural factors studied in African American dementia caregivers. They summarize key themes in the research that influenced care during the COVID-19 pandemic. They highlight cultural beliefs that affect how African Americans view the caregiving role, the influence of racial identity and faith beliefs, and social determinant of health.

**The Senior Companion Program Plus (SCP Plus): Examining the preliminary effectiveness of a lay provider program to support African American Alzheimer's disease and related dementias (ADRD) caregivers** *International Journal of Environmental Research and Public Health*, April, 2023

Xu and colleagues report preliminary effectiveness data on a community-based, peer-led psychoeducation intervention aimed to reduce caregiver burden and enhance knowledge, coping skills, and social support in African American dementia caregivers. The Senior Companion Program (SCP) is one of few culturally-congruent models developed for African American caregivers and is delivered in the home setting. They found that caregivers in the intervention group reported increased knowledge about ADRD, satisfaction with social support, and positive aspects of caregiving, as well as reduced caregiver burden.

**Using a multiple-case study design to explore the worship experiences of black families affected by dementia** *Clinical Gerontologist*, January-February, 2023

Gore and colleagues used a qualitative, multiple-case study approach to characterize experiences of families affected by dementia attending churches committed to creating a dementia-friendly environment. Data from behavioral observation and semi-structured interviews were analyzed. They found that caregivers generally felt that these churches were welcoming and supportive environments for families and individuals affected by dementia. Worship services promoted feelings of connectedness among caregivers and individuals with dementia. Caregivers also reported observing their loved ones to be more attentive and seemed to have more moments of clarity and engagement during and immediately after worship services. These experiences offer support that churches can be important and effective dementia-friendly environments for African American families.

**Tailored music listening in persons with dementia: A feasibility randomized clinical trial** *American Journal of Alzheimer's Disease & Other Dementias*, July, 2023

Petrovsky and colleagues report feasibility, acceptability, and preliminary efficacy data from a tailored music intervention on sleep outcomes in older adults with dementia and their caregivers. Over 90% of participants completed the study, supporting the feasibility of a music-listening intervention for families affected by dementia, particularly in African Americans who constituted over 80% of the sample. Acceptability results were mixed but highlight ways to improve acceptability in future trials. Although both the music intervention and waitlisted control groups both improved on objective measures of sleep, there was a small effect size for sleep duration post-intervention.

**Navigating the complexities of dementia care: The lived experiences of Black American family caregivers** *Journal of Gerontological Nursing*, June, 2023

Ramos and colleagues used an interpretive phenomenology approach to describe the lived experiences of Black women caring for a loved one with dementia. Their focus was on the emotional experiences associated with caregiving in this community. Key themes highlighted included family care obligation, caregiving journey, prioritizing health concerns, coping behaviors, and support needs and challenges. The authors emphasize the importance of considering these themes when providing care and support to this population and when designing culturally-sensitive interventions.



Written for the E4 Center by Susan Buehler, PhD

## Upcoming Events

You can register for these events or learn more by going to our website at [e4center.org/calendar](https://e4center.org/calendar)

APRIL

**Implementing the 4Ms-Behavioral Health: Applying the 4Ms of an Age-Friendly Health System in Mental Health and Substance Use Services**

Speakers: Erin Emery-Tiburcio, PhD, ABPP and Laura Porter, PhD

April 5 @ 12:00 pm - 3:00 pm CDT