

PROJECT ECHO MINISERIES:

# BEST PRACTICES IN DEMENTIA CARE

*Hosted in collaboration with the*  
Alzheimer's Association



**Seven weekly sessions**

Thursday, 3 – 4 p.m. ET | March 7 – April 18

[nhpco.org/projectecho](https://nhpco.org/projectecho)

# Providing Information, Education, and Support to Patients and Families

March 21, 2024

# Disclosures

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## Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

## Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

## Evaluation

Please complete program evaluation materials following each session.

# Ground Rules and Video Teleconferencing Etiquette

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- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

# Today's Agenda

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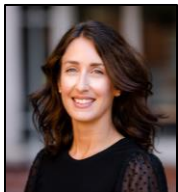
- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

# Project ECHO Team



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# Session Faculty

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**Fayron Epps, PhD, RN, FGSA, FAAN**

Professor | Karen & Ronald Herrmann Distinguished Chair  
in Caregiving Research

Fellow | Betty Irene Moore Fellowship Program for Nurse  
Leaders and Innovators

UT Health San Antonio, School of Nursing, TX



# Didactic Presentation



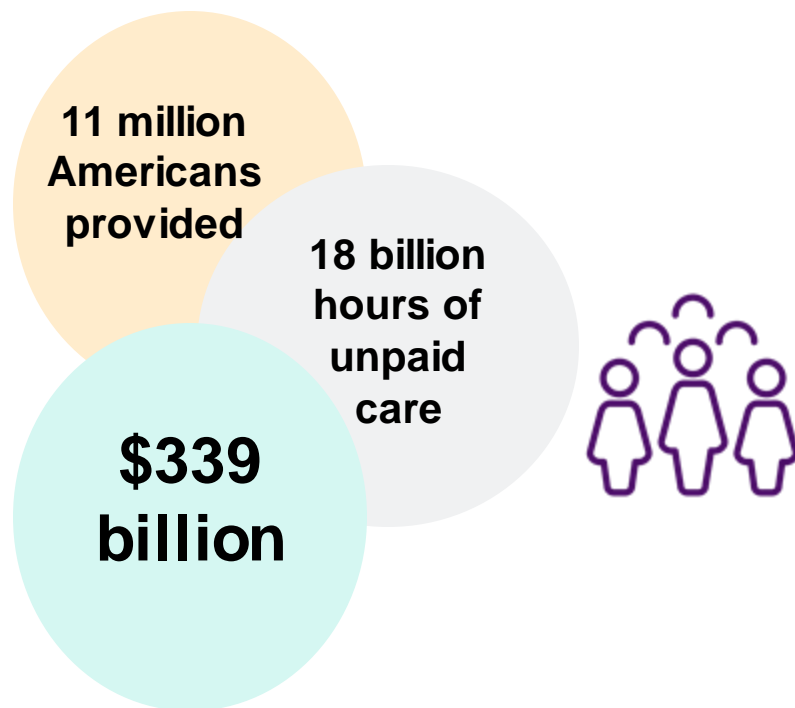
# Disparities in Alzheimer's

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- Black individuals >65yo are 2x as likely to develop Alzheimer's disease and Hispanic populations are about 1.5x more likely to develop Alzheimer's disease
- Earlier age of onset on average
- Missed or delayed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among White older adults
- Black and Hispanic populations will eventually make up 40% of all patients with Alzheimer's disease in the United States, some statistics state this could be as soon as 2030

# Caregiving

## Who Are the Alzheimer's Caregivers?



- **Two thirds** are women and **one third** are daughters
- **One in three** is age 65 or older
- **More than half** take care of their parents
- One quarter of dementia caregivers are in “sandwich generation” of caregivers
- **41%** of caregivers have a household income of **\$50,000 or less**
- **66%** live with the care recipient in the community

# Alzheimer's Caregivers Report High Emotional and Physical Stress

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- Nearly 6 in 10 (59%) family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high.
- 74% of caregivers reported they were “somewhat concerned” to “very concerned” about maintaining their own health.
- 30% increase in depressive symptoms while caring for a spouse.
- 59% of caregivers felt they were “on duty” 24 hours a day in the year before the death of the person with the disease.
- 72% of family caregivers experienced relief when the person with Alzheimer's or another dementia died.
- Compared with non-dementia caregivers, dementia caregivers indicate a greater decrease in their social networks.

# Race, Ethnicity and Caregiving

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- Black caregivers were more likely to provide over 40 hrs of care per week than white caregivers
- Black dementia caregivers — 69% less likely to use respite services compared with white caregivers.
- Hispanic, Black, and Asian American dementia caregivers indicate greater care demands, less outside help/formal service use, and greater depression when compared with white caregivers.
- Support from family and friends is associated with better self-rated health for Black dementia caregivers, but not for White or Hispanic caregivers.

# Dementia Care Practice Recommendations

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- Provide education and support early in the disease to prepare for the future
- Encourage care partners to work together and plan together
- Build culturally sensitive programs that are easily adaptable to special populations
- Ensure education, information, and support programs are accessible during times of transition
- Use technology to reach more families in need of education, information, and support

# Tailoring Information and Education

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- Factors that affect families' information and education needs
  - PWD stage of dementia
  - PWD co-existing medical conditions
  - What the family already knows
  - Literacy levels
  - Language
  - Culture
  - Computer comfort level and access
  - Willingness to attend information and education opportunities and access available information

# Supporting African American Families facing Dementia through Meaningful Programs



# What is Alter?

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- The Alter program is working toward bringing resources and supportive services to African American communities.
- We provide dementia-related education to African American faith-based communities and equip them with the resources they need to better serve their members and the surrounding community who have been impacted by dementia.
- Evidence-informed three-pronged approach:
  - Education/Awareness
  - Support
  - Worship





# Examples of Initiatives & Activities:

## SUPPORT



Memory Cafe

Support Groups

Resource Library

Respite Programs

Supportive education/trainings

Supply Closet for families

## EDUCATION



Memory/Purple Sunday

Virtual Dementia Experience

Dementia or Brain Health Education (to include youth)

## WORSHIP



Shorten service length

Offer a high proportion of music

Familiar prayers & use of visual aids

MORE THAN

80

PARTNERS



## Partnership Details

- 2-year partnership
- Welcome box
- Memorandum of Understanding
- Financial contribution/Monetary support
- Agree to implement 16 suggested initiatives/activities and modifications
- Opportunity to renew partnership/legacy partners

HAVE INVESTED MORE THAN

\$120K

IN OUR FAITH COMMUNITIES

# How Can You Help?

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## STAY CONNECTED



Sign up for quarterly newsletters  
Become a Volunteer  
Follow us on social media

## BECOME A PARTNER



Attend a virtual informational session  
Complete an application and onboarding packet  
Identify an ambassador within your congregation

## PARTICIPATE IN EDUCATION



Host and/or attend a:  
Community forum  
Dementia-Friendly Workshop



[Home](#) [About](#) [Alter Resources](#) [Contact](#)

[Partner with Alter](#)

# Creating Dementia Friendly Congregations

Inspiring and Equipping Faith Communities

[Partner with Alter](#)

[Subscribe to Newsletter](#)

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[www.alterdementia.com](http://www.alterdementia.com)





*Alter guides and equips predominantly African American places of worship to become trailblazing dementia-friendly faith communities.*



**Partner**

To learn how you can Alter your faith community, join us for one of our monthly informational meetings.

Meetings are held on the 3rd Thursday of each month @ 6 pm EST



**Alter Dementia Summit**

The Summit will equip faith communities with practical tools and resources needed to support their members living with dementia and their caregivers.

Pre-Register or Sponsor Below  
April 25th-27th  
House of Hope Atlanta



**Consultation**

We provide consultation for faith communities and organizations serving families affected by dementia.



<https://bit.ly/AlterProgramInfo>



<https://alterdementia.com/summit-2024/>

**Contact Us**

 (770) 686-7730

 [Outreach@alterdementia.com](mailto:Outreach@alterdementia.com)



# Why Caregiving while Black?



- Providing care for a family member or friend is challenging, but being a Black caregiver adds an additional layer of challenges and concerns.
- 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.
- 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 healthcare access and navigation for caregivers.
- Less access to support services and primary care and more unmet needs for the person living with dementia.
- Community and culture help Black caregivers cope with the challenges of caregiving.

# Course Overview

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- 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"
- 8-10 hours of content in an asynchronous series of 37 short interactive segments.
- The course employed linked text and video instructional materials and faculty-monitored exercises and covered topics related to navigating the healthcare system, managing home life, and caregiver self-care.
- 40 brief (7-15 minute) videos of Black healthcare professionals, caregivers, and persons living with dementia sharing their experiences.

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

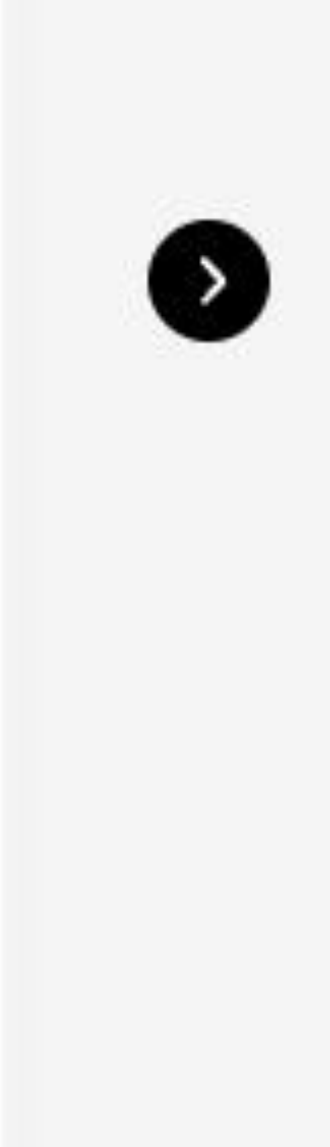




# Understanding the Diversity of a Care Team



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# PILOT STUDY RESULTS

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- 33 caregivers completed the course
- 94% attended college
- 78% cared for a parent (12 hrs average)
- 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 felt empowered.

Average age: 54 years

81% female

6-30 hours spent on the course

"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."

"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."

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

"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."

# Didactic Presentation Q&A

# Attendee Location Poll

# Case Study Presentation:

## Disparities in Community Services and Caregiver Support

# Situation

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- Mrs. T is a 73 year old pleasant lady with progressive neurocognitive (memory) decline for the past 5 years (Alzheimer's Dementia Type)
- The memory decline now impacts her activities of daily living (she needs additional support for cooking and household activities). She is also experiencing behavioral disturbances, a tendency to disrupt others and wander on her own
- Mrs. T refuses to wear or embrace any sort of safety assist device that would help track her location
- As a result of the above, she is often left home with a family member or caregiver and misses social interactions

# Background

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- Social interactions in the community and at Church have been a significant part of Mrs. T's definition of quality of life.
- As a result of her progressive symptoms, she now feels alienated and lonely. She misses singing for the Church choir.
- Mrs. T also has some chronic medical conditions including Diabetes Mellitus Type II, chronic kidney failure stage 3, obesity and high blood pressure
- She is often irritable and refuses care but insists on Mr. T being in her presence all the time.



# Assessment

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- Mr. T is 70 years old, with functional mobility issues (has arthritis, uses walker).
- Mr. T is verbalizing caregiver fatigue
- What other assessments would be useful ?
- How could the community/church help in this situation?
- What unique experiences is Mr. T living through (consider race, ethnicity, background)?

# Discussion and Recommendations

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- When is it appropriate to focus solely on the patient's needs and when is it appropriate to focus on the caregiver's needs as well?
- What are some other examples of community (and tailored) programs that could benefit caregivers?
- Where does the role of respite care fall?
- Consider the role of caregiver training and sharing printed materials/ specific instructions. These tools tend to ease the burden of critical thinking and problem solving for the caregiver and also offer a sense of community and support.
- Disease specific support groups can be highly resourceful for the caregiver
- Remember to encourage planning and discussion early on. Many of these planning discussion and "what-if" scenarios can be included in early and often advance care planning and goal of care discussions -> between patient/ family and providers
- Offering community resources and community health workers/ providers who sound and look like the patient/ caregiver facilitate building trust and long lasting relationship.

# Key Takeaways

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- Culturally relevant/responsive programs are important in dementia care
  - One size does not fit all
- It is critical to recognize the culture of all those we are trying to serve
  - Education provided by people who look like those we are serving is often better received
- Black individuals are more likely than others to develop Alzheimer's type Dementia
  - On an average, the onset of disease is early
- Compared to caregivers of patients with non-dementia related diagnoses, caregivers of patients with dementia related diagnoses have higher levels of stress, are more isolated and have felt a sense of relief after the patient dies
- Best practice recommendations suggest that it is important to ensure that information, support and resources are available at a time of transition, and that partners work together to plan care early on.
- When caregiving for persons with dementia, literacy, language and cultural sensitivity are key factors for a successful and high-quality experience.

# References

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- Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2023;19(4). DOI 10.1002/alz.13016. <https://www.alz.org/alzheimers-dementia/facts-figures>
- Zarit Burden Interview (ZBI) [https://eprovide.mapi-trust.org/instruments/zarit-burden-interview#need\\_this\\_questionnaire](https://eprovide.mapi-trust.org/instruments/zarit-burden-interview#need_this_questionnaire)
- Archangels Caregiver Intensity Index <https://www.archangels.me/for-organizations>

# Session Evaluation and Certificate of Completion

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- Your feedback is valuable as we plan upcoming sessions! Please complete the [Project ECHO Dementia Care Miniseries Post-Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who attend at least five live sessions and complete all session evaluations as well as a final miniseries evaluation

# Upcoming Sessions

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Date: March 28, 2024

Topic: Transitions in Care and Coordination of Services

Date: April 4, 2024

Topic: Best Practices in Dementia Care Session 5

# Additional Information

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NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

For more information:

[projectecho@nhpc.org](mailto:projectecho@nhpc.org)