

C Partners in FTD Care

A quarterly newsletter for
healthcare professionals

Summer 2023

BLACK/AFRICAN AMERICANS AND FTD

While known as a rare disease, frontotemporal degeneration (FTD) is the most common dementia for people under 60. In 2011, researchers estimated 50,000 to 60,000 cases of FTD in the United States¹, but this figure is increasingly understood to be an undercount, for several reasons. For example, FTD is frequently misdiagnosed; additionally, diagnosis takes more than 3.5 years on average, and can often only be confirmed postmortem.

While greater attention has been paid to FTD and FTD research in the years since that study, formal research on the experience of Black/African Americans with FTD has been limited to date. But momentum is growing. This issue of *Partners in FTD Care* draws on perspectives from two FTD care partners and from emergent research, to outline challenges, advance a crucial conversation, and emphasize the need for additional public education, awareness, support, and research.



IN THIS ISSUE

- An Interview with Aisha Adkins and Malcoma Brown-Ekeogu..... 4
- The Alter Program: Bringing Dementia Education to African American Faith Communities..... 6
- Reducing Racial Disparities in FTD Research..... 8
- Understanding FTD Symptoms from a Cultural Context..... 10

BARRIERS TO DIAGNOSIS

For this issue of *Partners in FTD Care*, AFTD interviewed Aisha Adkins and Malcoma Brown-Ekeogu, two Black caregivers for loved ones with FTD (see page 4). They highlighted lack of awareness of FTD and barriers to equitable care as factors leading to challenging diagnostic journeys.

A 2022 study incorporating an analysis of Medicare beneficiary data found that Black/African Americans – alongside Hispanic/Latino and Asian individuals – were “less likely to receive a timely dementia diagnosis.”²

Data from the FTD Insights Survey³ offers additional perspective. African American respondents (n=25, representing care partners and people with FTD) were more likely to report needing to see four or more doctors before receiving a diagnosis (36% compared to 18% of total respondents), and more likely to receive a different initial diagnosis (80% vs. 45%). Notably, just 25 (1.2%) of FTD Insights Survey respondents identified as Black, far

Continues on next page

lower than the percentage they represent in the overall U.S. population (~12 percent), reflecting a need for continued outreach, education, and awareness both for our organization and our field.

SYMPTOMS AND SEVERITY AT THE TIME OF DIAGNOSIS

A recent University of Pennsylvania study⁴ of individuals with FTD (as recorded in the National Alzheimer's Coordinating Center data) showed preliminary data that Black study participants diagnosed with FTD had a higher Clinical Dementia Rating (a widely used measure to rate the severity of dementia), "suggesting that there may be delayed diagnosis of FTD in Black individuals."

Furthermore, Black/African Americans with FTD showed different types of symptoms at the time of diagnosis. Specifically, they were "more likely to exhibit delusions, agitation, and depression but less likely to exhibit apathy at their initial visit." Therefore, they may be more likely to be misdiagnosed "if their symptom profile does not fit within the current clinical criteria."

Black/African Americans with FTD were more likely to initially exhibit delusions, agitation, and depression, but less likely to exhibit apathy.

The study's authors note that Black/African American participants were "considerably underrepresented in this sample," recommending the prioritization of "both equitable access to health care and enrollment in clinical research."

Continued lack of understanding from health professionals about FTD means that families must often serve as their own best advocates in getting an accurate diagnosis. Resources such as AFTD's diagnostic checklists for behavioral variant FTD and primary progressive aphasia can assist families in advocating with physicians for appropriate referrals. Given the emerging understanding of possible diagnostic challenges, be sure to note any additional symptoms (including delusions) above and beyond those listed on these checklists.

SYSTEMIC INEQUALITIES DEEPEN THE CHALLENGES OF FTD

FTD puts a deep strain on every individual and family. For Black/African Americans, systemic inequalities in American society can exacerbate these challenges.

An AFTD-funded study on the social and economic burden of FTD, conducted in 2017 and published in *Neurology*,⁵ found that families facing FTD incur almost double the annual caregiving-related costs for families with an Alzheimer's diagnosis. It's important to note this study did not distinguish between race or ethnicity among respondents. In addition, 58% of caregivers reported that their loved one had made bad choices around money, and two out of three (67 percent) FTD caregivers reported declines in their health. More than half said they incurred higher personal healthcare costs.

Per U.S. Census data,¹⁷ Black/African Americans are impacted by poverty at a rate of 19.5%, compared to the 11.6% rate for Americans overall, suggesting that some Black families facing FTD may have fewer economic resources available to counteract FTD's significant economic impact.

A May 2020 AARP and National Alliance for Caregiving fact sheet⁶ offered a profile of "typical" African American caregivers, identifying multiple areas in which they face deeper challenges. African American caregivers are more likely to be unmarried than all other racial/ethnic groups when taking on caregiving responsibilities; unmarried caregivers have one less resource to call on in a challenging situation. Also, African American caregivers "less often report being in excellent or very good health," the profile said.

The portrait that emerges – of Black/African Americans being more likely to face economic and health challenges, even before experiencing FTD's impact on their finances and well-being – suggests a need for further resources, support, and research.

CHALLENGES IN INTERACTIONS WITH THE U.S. CRIMINAL JUSTICE SYSTEM

Disinhibited behavior among people with FTD can lead to socially inappropriate behavior, misdemeanor offenses (such as shoplifting), hypersexual behavior, and

Continues on next page

traffic violations. A study looking at criminal behavior among individuals with FTD⁷ found that 14% of people with bvFTD were likely to present with criminal behavior, compared with 2% of people with Alzheimer's disease. Additionally, 6.4% of people with bvFTD were more likely to exhibit violence, again compared with just 2% of people with Alzheimer's disease.

In 2021, the American Medical Association⁸ recognized the disproportionate impact of structural racism on Black, Indigenous, and other people of color in experiences of police brutality, suggesting additional concerns for Black families facing FTD, should criminal behavior be a manifestation of an individual's disease. Focusing training for law enforcement and first responders on the different manifestations of dementia can help to reduce risk for all families facing FTD.

A NOTE ON PARTICIPATION IN RESEARCH

This piece cites in multiple areas the importance of additional research to clarify and address the challenges that Black/African Americans face with FTD. Advancing these vital efforts will require continued tending to biases within the research process itself.

A June 2022 study on health disparities in dementia² argues that research efforts in this area need to bear in mind the well-established “lack of representation among ethnoracial groups and limited general results” in dementia research to date, while navigating “increased challenges with recruitment, enrollment and retention” and avoiding sampling/selection bias. In other words, there are clear and obvious gaps in current research on dementia's effects that must be addressed directly and thoughtfully. A 2023 paper published in *Alzheimer's and Dementia*⁹ covers such gaps in FTD-specific research and identifies steps that can be taken to overcome this

current lack of understanding, as does a 2020 FTD Disorders Registry survey¹⁰ on best practices for minority engagement in FTD research (see p. 8).

Additional research is
necessary to clarify and
address the challenges that
African Americans face with FTD.

One initiative already working to address these gaps is the Biomarker Evaluation in Young Onset Dementia from Diverse Populations (BEYONDD) study. BEYONDD works to assess the causes and frequency of young-onset dementia in diverse populations, and seeks to develop scalable, culturally informed research infrastructure in the continental U.S. and Puerto Rico.

MOMENTUM IS GROWING

FTD research – and FTD awareness – are at a pivotal moment. Health professionals, researchers, and advocates are increasingly working to ensure that the needs of all families facing FTD are met. No one should face this disease alone, and tending to every barrier preventing families from accessing a supportive community is vital.

Black families impacted by FTD in the U.S. face unique challenges. Providing necessary information, supports, and opportunities to engage in research is vital, and will require a collaborative effort. AFTD is here to help.

We are dedicated to understanding FTD and advancing research targeting this disease from a full diversity of perspectives, as a vital step toward achieving a world with compassionate care, effective support, and a future free of FTD – for everyone. ■



AN INTERVIEW WITH AISHA ADKINS AND MALCOMA BROWN-EKEOGU

Black/African American families who have shared their stories with AFTD have consistently highlighted difficulties in accessing timely and accurate diagnosis – and that those difficulties represent broader racial disparities in American healthcare. In the following interview, Aisha Adkins and Malcoma Brown-Ekeogu, two Black women and FTD caregivers living in the Atlanta area, talk about aspects of the diagnostic journey, identify ways that health professionals can better prepare families facing FTD for the road ahead, and point out sources of strength they drew from along the way.

AFTD: What challenges did you face in getting an accurate diagnosis?

Aisha: My father and I initially had trouble simply convincing practitioners there was something wrong. Our experience began with urgent care and then a primary care physician. After that, we met with a neurologist, then another neurologist, and one last neurologist who finally gave us a proper diagnosis. The process took years and thousands of dollars.

The first few doctors were very skeptical – even doubtful – of my father and I and our observations about my mother’s behavior. Even when my mother herself reported her own concerns, they had doubts. The initial diagnosis was depression, despite our insistence that the problem ran deeper. Unfortunately, it’s been documented that health professionals’ doubt of Black patients is a systemic issue. Of the physicians we saw, all were men and only one was from a diverse background.

AFTD: Malcoma, does any of that ring true to your experience with diagnosis?

Malcoma: Listening to Aisha, bells were going off in my mind. It was like, Wow! Really? That was me! All these



things were reminding me of how hurtful it felt going through the process to get a diagnosis for my husband.

Hearing Aisha reminded Malcoma “how hurtful it felt going through the process to get a diagnosis for my husband.”

An unfortunate thing for care partners is they may not know someone else going through this, and end up feeling like, “It’s just me.” I’ll call it a club. We’re in a club, and it’s not just us: we just don’t know that. But each of us is experiencing some of the same things.

Our FTD journey began when my husband was hospitalized for a medical emergency with diabetes. Before he was discharged, he said he wanted to walk around the hospital

Continues on next page

for a bit. When the doctor, who was African American, came in to see him, we couldn't find [my husband] anywhere. It turned out he had gone looking for a nurse he met when he was admitted. The doctor told me we needed to see a neurologist. That was my first indication that something was really wrong.

Our primary care doctor said he may be dealing with depression. I knew he was not depressed. I know what depression looks like from other family members. We ended up seeing two neurologists. Every time you see a new doctor, it's like starting over. We eventually went to see a neuropsychologist and spent eight hours in her office. She said, "Based on the MRI and the testing, I'm pretty sure it's FTD."

AFTD: Looking back, what would have helped you be better prepared for FTD?

Malcoma: Doctors need to be more open to learning about non-Alzheimer's forms of dementia. If they had more information – if they even had a checklist of symptoms – it would help families.

AFTD: We need to do a better job to help doctors identify the red flags that say, "This could be FTD."

Malcoma: We have to hit that hard. Bring awareness to where people are and make the information simple so everyday people can easily understand how to get help. Not everyone is willing or able to read densely worded brochures.

Aisha: I also believe that spreading FTD awareness is crucial: PSAs on networks or on radio stations that have large African American audiences. Meeting people where they are, in how and where they consume information – particularly younger people. There are some predominantly Black communities that are healthcare deserts. Folks may not have regular access to a primary care physician. Making materials available in every medical institution, flyers that really emphasize symptoms that are not Alzheimer's.

AFTD: Are there things you want to share about your experience that gave you strength?

Aisha: Being a part of a community. My mother was raised in a very deep faith tradition. One of the ways we realized something was wrong is that my mother didn't want to go to church anymore. Once she was on medications to help mitigate some of the symptoms, church attendance didn't suddenly skyrocket, but her faith tradition was restored. Relying on faith has been a tremendous asset for us, especially going to church within our home and spending time together and worshiping as a family.

AFTD: Did you and your mom find support in the church community?

Aisha: It was difficult for her friends to see her change. I think people can focus on the wrong things. Instead of patience or understanding, people came up to me whispering, "Make sure your mother does this," or, "Make sure she's wearing appropriate attire." I'm appreciative of programs like Alter that educate the faith community on dementia, and how to be a supportive congregation. (See sidebar, page 8.)

Malcoma: My husband and I also found faith to be a tremendous source of strength, even after our church went virtual during the pandemic. The short 10-to-15-minute messages that Alter's Faith Village project posted were just enough for him and were very helpful because of his shorter attention span.

AFTD: Is there anything else you'd like to add?

Malcoma: We should bring awareness to brain donation. We are set up with the University of Miami. In our community, we're shy about brain donation and things like that, but donations are something that help us overall.

Aisha: In regard to reaching practitioners, it would help to have a booklet that describes the feelings that a person with FTD and their family can have. This would help them to understand what people are bringing into their office, and help them to respond with better bedside manner. ■

THE ALTER PROGRAM: BRINGING DEMENTIA EDUCATION TO AFRICAN AMERICAN FAITH COMMUNITIES

by Mia Chester, Alter project director, and Fayron Epps, PhD, Alter founder



Religion provides hope and a framework to find meaning, especially when navigating difficult life events and transitions; it affirms the sacredness of life and the value of a person, even in the face of loss. Even when one's health becomes diminished, or financial or social circumstances change, a person remains defined by their spiritual identity and belongingness to their faith community. Faith communities provide physical, emotional, and social support, along with a positive sense of identity and a social network. For persons living with dementia and their caregivers, spirituality and belonging to a faith community can reduce stress and provide stability and continuity as their circumstances change.

Churches have always been places of refuge and sources of support for many people, but particularly for the African American community, where they have historically served as safe havens during hardships. African Americans are much likelier to reach out to church leaders than medical professionals for mental-health concerns, and pastors and church leaders usually have training in pastoral counseling and can help members find professional help. But faith leaders and communities are not always aware of the needs of families affected by dementia, nor do

they typically know about dementia-specific resources.

In response to this lack of dementia awareness, in 2019 Dr. Fayron Epps and a team of African American health professionals created the Alter™ program. Alter partners with faith communities to create dementia-friendly and inclusive environments to keep the social and spiritual connection strong and vibrant for those living with dementia, and to be a supportive environment for families affected by it.

Alter partners with faith communities to create dementia-friendly environments to keep the social and spiritual connection strong for those living with dementia.

Alter provides guidance and a small stipend to help faith communities with simple but important environmental modifications to make church spaces dementia-friendly. In addition, faith communities are guided to provide culturally

Continues on next page

appropriate dementia and brain-health education and supportive programs to their congregation. The partnership and ongoing support are available at no cost to churches.

Becoming an Alter partner is a unique recognition for African American places of worship, and communicates to those living with dementia and their surrounding community that the church offers a welcoming environment. Churches partnering with Alter are listed in the Alter Church Partner directory as dementia-friendly and inclusive faith communities.

An Alter Partner is a faith community that:

- accepts and values people regardless of cognitive abilities,
- ensures that persons living with dementia and their care partners are supported through their journey,
- makes sure that persons living with dementia, and their care partners, are both spiritually and pastorally supported and nurtured, and
- is open to what people living with dementia have to offer, then supports and encourages using those gifts so that they may participate in the church community.

Having African American faith communities partner with Alter can make a significant impact on families facing FTD. Malcoma Brown-Ekeogu (see interview, page 4) is the care partner for her husband, who is living with FTD. Her faith community has been walking with her on her FTD journey. She described simple gestures of kindness that have sustained her and kept her connected: “Thinking of you” cards, unexpected flowers, meals, phone calls, and in-person visits from friends and clergy. The most impactful support offered by her church are visits by parishioners to spend time with her husband, Kenneth, and provide Malcoma with an hour of much-needed respite. She appreciates her church’s efforts to show empathy and include persons living with FTD and other dementias, although she stressed that much work

remains to destigmatize dementia in the African American community.

By striving to create welcoming, inclusive, and supportive environments for families living with dementia, many faith leaders and congregations are blazing a trail. Their initiative, creativity, and hard work have resulted in modifications to worship services (some have even created new services), the creation of quiet rooms, hosting caregiver appreciation events, and new dementia support ministries.

By striving to create welcoming, inclusive, and supportive environments for families living with dementia, many faith leaders and congregations are blazing a trail.

Places of worship can help members cope with FTD and other dementias by working with them to maintain religious traditions and their connection to a supportive community. Dementia-friendly faith communities are knowledgeable about dementia and are an information resource for families and other parishioners. They help provide respite for caregivers and understand and accept behavior that could be seen as embarrassing. They keep families on the church prayer list. They promote the dignity and value of persons living with dementia and create ways to allow continued church participation. In this way, places of worship can play a vital role in the lives of persons living with FTD and other dementias, as well as their care partners.

AFTD is pleased to partner with the Alter program to share educational materials and resources. If you are interested in learning more about the Alter program, please visit alterdementia.com or call 770-686-7730. ■

REDUCING RACIAL DISPARITIES IN FTD RESEARCH

By Shana Dodge, PhD, AFTD Director of Research Engagement

Healthcare disparities among different racial, ethnic, and socioeconomic groups persist, and are well-documented.^{11,12,13} Individuals with dementia who identify as Asian American, Black/African American, or Latinx are less likely to receive a prompt diagnosis than those who identify as white.^{14,15,16} The more we understand about similarities and differences in the Black/African American FTD journey, especially its initial stages, the better positioned we are to provide early and accurate diagnoses. Timely diagnosis allows families to better plan for the future, access early interventions, and potentially benefit from disease-modifying therapies, such as those for FTD currently in clinical trials.¹⁶

Although African Americans comprise the third-largest racial or ethnic group in the United States, they are underrepresented in FTD research.

Although African Americans comprise the third-largest racial or ethnic group in the United States, they are underrepresented in FTD research, resulting in a lack of knowledge about potential differences in FTD symptoms and experience.¹⁷ Data suggests there is an elevated risk of dementia in African Americans, yet they are less likely to be included in research, despite being just as willing as other racial groups to participate if approached.^{18,19,20} While prevalence rates vary across the globe, FTD is found worldwide, suggesting its presence in all racial groups in the United States.^{21,22}

In a large community survey conducted by AFTD and the FTD Disorders Registry²³ of 1,799 people living with FTD,

biological family members, and past and current care partners, only 25 respondents were African American or responding on behalf of someone who identified as African American. But while small, this cohort gives us some initial insight into how access to FTD diagnoses might differ between racial groups in the United States. Thirty-six percent of African Americans had to consult more than four doctors prior to receiving an FTD diagnosis, compared to only 18% of the overall respondent pool. African Americans were also more likely to receive an initial misdiagnosis (84%) than overall participants (43%). When asked about the first indication that something was wrong, African Americans were more likely to report changes in thinking, spatial reasoning, and delusions/hallucinations compared to all respondents.

AFTD and the FTD field are addressing the need to reach a more representative sample of participants in surveys and other types of research – otherwise, the conclusions made will not generalize to everyone. What is known about the diagnostic journey, for example, comes primarily from non-Hispanic Caucasians who have been able to receive an FTD diagnosis and report on the process. Approaches to genetic counseling and testing are heavily influenced by genomic research on people of European ancestry,²⁴ and most postmortem brain tissue research is conducted primarily on non-Hispanic Caucasian brain donations.^{25,26,27} Diminished access to FTD diagnoses contributes to significantly lower rates of Black participation in FTD research, which leads to a lack of understanding of FTD's natural progression within this community, as well as how they respond to potential interventions.

Studies have examined why researchers have failed to sufficiently engage minority communities. In a 2020 FTD Disorders Registry survey³ (n=17) exploring best practices for minority engagement in research, participating

Continues on next page

A Tribute to Lisa Gwyther, Partners in FTD Care Advisor

This is the last issue of Partners in FTD Care for which Lisa Gwyther, MSW, LCSW, will serve as an advisor. Lisa was a founding member of the Partners in FTD Care Advisory Committee in 2011, and has generously shared with AFTD the expertise she accrued from her many years of working with persons with dementia, particularly young-onset dementias, and their families. She quickly became a champion for families with FTD, recognizing the particular challenges created by misdiagnosis and lack of understanding among healthcare providers. She was a featured speaker at several AFTD Education Conferences and other FTD-focused education events, and never missed an opportunity to leverage her extensive speaking requests or participation on national dementia panels to include information on FTD and AFTD.

Before her recent retirement, she was an associate professor of psychiatry and behavioral sciences at Duke School of Medicine and directed the Duke Aging Center Family Support Program. She founded the Duke Dementia Family Support Program in 1980, building it into a nationally recognized source for dementia information and services.

In 2019, she received a Pioneer Award from the North Carolina Coalition on Aging in recognition of her “lasting



impact in the state and nationally for her groundbreaking contributions in efforts to support individuals with Alzheimer’s and related dementias and their families, and in caregiving advocacy, research and public policy.” Her wise, invaluable contributions to AFTD’s Partners in FTD Care will be missed. Thank you, Lisa!

organizations identified numerous obstacles that prevent research participation by minority communities, including cultural and language barriers, health insurance barriers, lack of awareness, legal status in the U.S., mistrust, and the stigma around dementia.

A 2023 review of global FTD clinical research published in *Alzheimer’s and Dementia*⁹ similarly identified the problem of minority underrepresentation in FTD science. It is known, the study’s authors write, that “diversity in culture, language, education, and socioeconomic factors, among others, impacts clinical presentation, recognition, and diagnosis of bvFTD and PPA, as well as subsequent treatment and care.” But there remain “critical gaps” in our understanding of how those factors impact diverse

populations’ FTD experiences. To help close these gaps, the review calls for future research to focus on multiple areas, including raising global awareness of bvFTD and PPA; modifying current diagnostic criteria and procedures; developing more sensitive cognitive tests targeting these diseases; refining enrollment practices; and conducting additional research into inclusive caregiver interventions.

By familiarizing themselves with FTD and the diverse ways in which FTD symptoms manifest in currently underrepresented groups, healthcare providers are positioned to break down this cycle of exclusion and ensure more equitable and meaningful diagnostic journeys and scientific findings. ■

UNDERSTANDING FTD SYMPTOMS FROM A CULTURAL CONTEXT

Biomedical research continues to study factors at the structural, genetic, and molecular levels that contribute to FTD's wide range of cognitive and behavioral symptoms. More recently, researchers have turned their attention toward understanding how cultural context influences the presentation and perceptions of FTD symptoms.

A recent systematic review by two professional interest areas of the Alzheimer's Association (ISTAART) examined ways in which the clinical presentation of FTD varies internationally by culture, language, education, social norms, and other socioeconomic factors, and identified gaps for further research.⁹ Among the points made:

- “Impaired social cognition is increasingly recognized as a core clinical feature of FTD and has been shown to be associated with abnormal social behaviors. Culture can impact all aspects of social cognition, such as 1) how emotions are perceived and categorized, 2) how social cues are responded to and how empathy is demonstrated, and 3) which behaviors are considered appropriate

according to local social rules and norms.” (p. 6)

- “Shame and stigma are important cultural factors that can impact caregiver burden and quality of life (QoL), and also affect the recognition of symptoms and whether people with FTD obtain a diagnosis.” (p. 8) Examples are given from work in Colombia and China that show the importance of understanding cultural factors that contribute to FTD diagnosis and care.
- “There is shame in seeking help for FTD behaviors such as sexualized behavior, disinhibition, and excessive alcohol drinking. Furthermore, caregivers may perceive these behaviors as deliberate, not recognizing them as symptoms of FTD, which can then delay evaluation, diagnosis, and treatment—with adverse impacts on the levels of caregiver burden. For [primary progressive aphasia] specifically, the loss of communication pertaining to traditions and heritage can contribute to frustration and guilt.” (p. 8)

Continues on next page



The effort to understand these factors internationally is also reflected in efforts to understand FTD across diverse racial and ethnic communities within the United States.

Research is being done to better understand the racial and cultural context for FTD diagnosis, and improve care and support.

Following the 2022 Alzheimer's Disease-Related Dementias Summit, staff from the federal National Institute of Neurological Disease and Stroke²⁸ identified the need to “understand FTD epidemiology and genetics in diverse populations, *including how socioeconomic and ethnocultural status affects disease risk and manifestations*” (italics added). Research following from this imperative will help our field to better understand the racial and cultural context for diagnosis, and improve care and support.

POTENTIAL DIFFERENCES IN NEUROPSYCHIATRIC SYMPTOMS

One example of emerging research in this area examined neuropsychiatric symptoms: changes in mood, thinking, and behavior that are common in FTD. A 2023 study by researchers at the University of Pennsylvania⁴ examined

differences in neuropsychiatric features in Black and non-Hispanic white individuals diagnosed with FTD in the National Alzheimer's Coordinating Center (NACC) data. Prior research suggested there are differences in the symptoms of dementia when comparing Black and white individuals, but this study was the first to focus specifically on FTD. The study explored racial disparities among symptoms at diagnosis, severity, and functional impairment in individuals with a clinical diagnosis of FTD.

The study found differences in the symptom profiles of Black and non-Hispanic white individuals in the cohort. When compared to white individuals at diagnosis, Black individuals more commonly experienced delusions, agitation, and depression. Symptoms were also more severe, suggesting possible delays in accessing diagnosis. The study also found differences in apathy, another common symptom in FTD: Black individuals with FTD were less likely to exhibit apathy at diagnosis, and its severity was lower compared to non-Hispanic white individuals with FTD.

While the authors acknowledge several limitations, this work is important in its efforts to understand how FTD symptoms present in people from different racial and cultural backgrounds. Further research is needed to better understand these potential differences, as well as their causes. ■

PARTNERS IN FTD CARE ADVISORS

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts, and family caregivers. Advisors include:

- **Sandi Grow, RN**, former FTD caregiver, AFTD Board member
- **Lisa Gwyther, LCSW**, Duke Family Support Program (retired)
- **Susan Hirsch, MA**, ProMedica Senior Care
- **Mary O'Hara, LCSW**, University of Colorado School of Medicine
- **Jill Shapira, PhD, RN**, retired

AFTD extends special thanks to Aisha Adkins and Malcoma Brown-Ekeogu for generously sharing their stories, and to Fayron Epps, PhD, RN, FAAN, Alter program founder and associate professor at Emory University.

For permission to reprint this material in whole or in part, contact Esther Kane, AFTD Director of Support & Education, at ekane@theaftd.org. To join the Partners in FTD Care mailing list, or to view the full archive of back issues, visit www.theaftd.org/for-health-professionals/partners-in-ftd-care

References

- Knopman, D. S., & Roberts, R. O. (2011). Estimating the number of persons with frontotemporal lobar degeneration in the US population. *Journal of molecular neuroscience* : MN, 45(3), 330–335. <https://doi.org/10.1007/s12031-011-9538-y>.
- Balls-Berry, J. J. E., & Babulal, G. M. (2022). Health Disparities in Dementia. *Continuum (Minneapolis, Minn.)*, 28(3), 872–884. <https://doi.org/10.1212/CON.0000000000001088>.
- Association for Frontotemporal Degeneration. AFTD. (2021). Frontotemporal Degeneration (FTD): Voice of the Patient Report, Retrieved November 9, 2022, from <https://www.theaftd.org>.
- Jin H, McMillan CT, Yannatos I, et al. Differences in Neuropsychiatric Features in Black and White Individuals Diagnosed with Frontotemporal Degeneration. medRxiv; 2023. DOI: 10.1101/2023.01.27.23284692.
- Galvin, J. E., Howard, D. H., Denny, S. S., Dickinson, S., & Tatton, N. (2017). The social and economic burden of frontotemporal degeneration. *Neurology*, 89(20), 2049-2056.
- AARP, N. A. for C. (2020, May 14). Caregiving in the United States 2020. AARP. Retrieved November 9, 2022, from <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>.
- Liljgren, M., Naasan, G., Temlett, J., Perry, D. C., Rankin, K. P., Merrilees, J., Grinberg, L. T., Seeley, W. W., Englund, E., & Miller, B. L. (2015). Criminal behavior in frontotemporal dementia and Alzheimer disease. *JAMA Neurology*, 72(3), 295–300.
- AMA policy recognizes police brutality as product of structural racism. American Medical Association. (n.d.). <https://www.ama-assn.org/press-center/press-releases/ama-policy-recognizes-police-brutality-product-structural-racism>.
- Franzen S, et al. Gaps in clinical research in frontotemporal dementia: A call for diversity and disparities-focused research. *Alzheimers Dementia*. 2023 Jun 3. doi: 10.1002/alz.13129.
- Youngborg, L., Harlass, S., Reddy, S., Vincent, L., & Hughbanks-Wheaton, D. (2020). *FTD Disorders Registry engagement of minority populations report*. <https://ftdregistry.org/sites/default/files/atoms/files/FTDDR-Minority-Engagement-Report-FINAL-2020.pdf>.
- American College of Physicians. *Racial and Ethnic Disparities in Health Care, Updated 2010*. Philadelphia: American College of Physicians; 2010: Policy Paper.
- Fiscella, K., & Sanders, M. R. (2016). Racial and ethnic disparities in the quality of health care. *Annual review of public health*, 37, 375-394.
- Sealy-Jefferson, S., Vickers, J., Elam, A., & Wilson, M. R. (2015). Racial and ethnic health disparities and the Affordable Care Act: a status update. *Journal of Racial and Ethnic Health Disparities*, 2(4), 583-588.
- Clark, P.C., Kutner, N.G., Goldstein, F.C., Peterson-Hazen, S., Garner, V., Zhang, R., & Bowles, T. (2005). Impediments to timely diagnosis of Alzheimer's disease in African Americans. *Journal of the American Geriatrics Society*, 53(11), 2012-2017.
- Lin, P. J., Daly, A., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., ... & Freund, K. M. (2020). Dementia diagnosis disparities by race and ethnicity: health services research: cost of care and implications for intervention. *Alzheimer's & Dementia*, 16, e043183.
- Tsoy, E., Kiekhofer, R. E., Guterman, E. L., Tee, B. L., Windon, C. C., Dorsman, K. A., ... & Possin, K. L. (2021). Assessment of racial/ethnic disparities in timeliness and comprehensiveness of dementia diagnosis in California. *JAMA Neurology*, 78(6), 657-665.
- United States Census Bureau. (2021, August 12). *Improved race and ethnicity measures reveal U.S. population is much more multiracial*. <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html>.
- National Institute on Aging. (2019). *Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide*. <https://www.nia.nih.gov/sites/default/files/2019-05/ADEAR-recruitment-guide-508.pdf>.
- National Institute of Health and National Institute on Aging. (2018). *National Strategy for Recruitment and Participation in Alzheimer's Disease and Related Dementias Clinical Research*. <https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf>.
- Youngborg L, Harlass S, Reddy S, Vincent L, Hughbanks-Wheaton D. (2020). FTD Disorders Registry engagement of minority populations report. <https://ftdregistry.org/sites/default/files/atoms/files/FTDDR-Minority-Engagement-Report-FINAL-2020.pdf>. Published August 31, 2020.
- Amoo, G., Akinyemi, R.O., Onofa, L.U., et al (2011). Profile of clinically diagnosed dementias in a neuropsychiatric practice in Abeokuta, South-Western Nigeria. *Afr J Psychiatry*, 14, 377–382.
- Onyike, C. U., Shinagawa, S., & Ellajosyula, R. (2021). Frontotemporal Dementia: A cross-cultural perspective. In *Frontotemporal Dementias* (pp. 141-150). Springer, Cham.
- Dodge, S.G., Vincent, L., Dacks, P.A., & Wheaton, D.K.H. (2022). African American experience of Frontotemporal Degeneration (FTD): A sub-cohort assessment of the FTD Insights Survey. Poster presented at the meeting of the Alzheimer's Association International Conference, San Diego, CA.
- National Human Genome Research Institute. (2021). *Diversity in Genomic Research*. <https://www.genome.gov/about-genomics/fact-sheets/Diversity-in-Genomic-Research>.
- Glover, C. M., Shah, R. C., Bennett, D. A., Wilson, R. S., & Barnes, L. L. (2020). Perceived impediments to completed brain autopsies among diverse older adults who have signed a uniform anatomical gift act for brain donation for clinical research. *Ethnicity & Disease*, 30(Suppl 2), 709.
- Lambe, S., Cantwell, N., Islam, F., Horvath, K., & Jefferson, A. L. (2011). Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *The Gerontologist*, 51(1), 28-38.
- National Institute on Aging. (2021). *Brain Donation: A Gift for Future Generations*. <https://www.nia.nih.gov/health/brain-donation-gift-future-generations>.
- Rost, N. (2022). *ADRD Summit 2022 Report*. National Institute of Neurological Disorders and Stroke. https://www.ninds.nih.gov/sites/default/files/documents/ADRD%20Summit%202022%20Report%20to%20NINDS%20Council%20FINAL_508C.pdf.



For more information and to subscribe to future issues of *Partners in FTD Care*, scan the QR code or visit theaftd.org/for-health-professionals/partners-in-ftd-care.