



Black Americans' perceptions of Alzheimer's disease, a healthy brain, and strategies for brain health promotion

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ABSTRACT

Objectives: Lack of awareness of Alzheimer's disease (AD) among Black Americans may undermine their ability to identify potential AD risk. We examined Black Americans' perceptions and knowledge of AD, and views of a healthy brain, which may contribute to the development of effective and culturally sensitive strategies to address racial disparities in AD.

Methods: We conducted a mixed-methods study, integrating a cross-sectional survey of 258 older (>55 years) Black participants and qualitative interviews with a sub-sample of $N = 29$. Both data sets were integrated to inform the results.

Results: Participants endorsed having little knowledge of AD. While most participants reported practicing a healthy lifestyle to promote a healthy brain, the range of activities listed were limited. Participants made several suggestions to increase AD awareness, which includes using AD educational materials containing information that would benefit the whole family, not only older adults. Outreach approaches that address both individual behaviors and structural factors were also encouraged.

Conclusion: Our findings identify ongoing needs to improve AD awareness among traditionally under-represented groups.

Innovation: The study utilized novel approaches to examine participants' perspectives of AD that included a diverse sample of research naïve participants, and integrated exploration of participants' views of AD and brain health.

1. Introduction

As the number of older adults in the United States (U.S.) is rapidly growing, there is increased need to promote healthy aging and to address challenges and disorders associated with the aging process, such as risks for Alzheimer's disease (AD). AD causes loss of memory and

cognitive functioning (i.e., thinking and reasoning), significant impairment in ability to carry out daily activities, and changes in personality and behavior. It leads to functional decline and significant economic burden for patients, caregivers, and society [1,2]. As of 2021, AD affected 6.2 million Americans and that number is expected to increase to 14 million by 2060 [3].

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Previous studies demonstrate that, despite widely disseminated AD awareness campaigns and community education programs, several gaps remain in public knowledge of AD, especially among racially and ethnically minoritized communities [4-8]. For example, in one study, non-Hispanic White Americans exhibited higher level of AD knowledge than their Black counterparts [9-11]; and Black Americans were more likely to inaccurately view memory loss as a normal part of aging [9,12]. Lack of awareness and misperceptions regarding AD among Black Americans may limit recognition of AD symptoms and engagement in healthy lifestyle habits that can prevent AD and support brain health, broadly defined as the ability to perform all mental processes and functions [13]. They may also curtail the development of tailored interventions to improve outreach efforts, prevention strategies, and management of the disease in Black communities. Therefore, understanding of Black Americans' views and perceptions of AD is an essential first step in promoting AD awareness in this group.

In the present study, we examined older Black adults' knowledge and perceptions of AD and understanding of brain health. While knowledge of AD, that is, factual, established medical information about the disease, is critical for promoting early awareness, diagnosis, and treatment of AD symptoms, one's *perceived* knowledge of AD is also critical and is in fact, a prerequisite to behavior change. Perceived knowledge represents one's way of knowing and organizing one's world [14,15]. Indeed, according to socio-cognitive and behavior theories, such as the Theory of Planned Behavior [16], perceived knowledge, whether it is accurate or not, influences behavioral intention, which in turn shapes behavior [16]. For example, perceived knowledge of AD might be one's interpretation, understanding, or mental representation of AD signs, symptoms, and risks, which are influenced by their lived experiences and sociocultural contexts, such as cultural beliefs. Additional contextual factors such as one's identities, cultural knowledge, communication patterns, and worldviews of health and healthcare may also shape perceptions of AD and brain health. To further illustrate, communities may use different terminologies, emotions, communication frames or cognitive schemas (e.g., cultural representations) to describe AD [17]. They may see AD as a loss of personhood, a normal part of aging, a biomedical construct, or a mental illness [18]. Individuals across sociocultural groups may have differing perceptions of risk factors associated with AD, when and where to seek care, and varying views of how to manage caregiving for persons afflicted with the disease (e.g., who provides care, how, and what type of care is prioritized) [18-20].

Yet, most studies examining populations' views of AD are primarily quantitative and have relied on factual knowledge measures, typically assessed through a series of closed-ended questions and a predefined list of perceived risks [12,21]. In so doing, they may not fully capture participants' perceptions of AD, and the sociocultural contexts, values, belief systems, and norms that may shape their perceptions. Indeed, AD knowledge assessed through perceptions rather than factual statements may yield different findings. As Glover and colleagues argue, understanding of Black Americans' *perceptions* of AD may contribute to the development of both effective and culturally sensitive intervention strategies to facilitate meaningful engagement about AD [7]. Therefore, in the present study, we explored both participants' perceived and factual knowledge of AD. Moreover, we examined their perceptions of brain health to gain insight into how they understand the connection between healthy lifestyle behaviors, brain health, and AD prevention strategies.

Given the various factors that may shape ones' perceptions of AD, the sociocultural and geographical heterogeneity of Black Americans, research exploring the views of AD in this diverse group is warranted. In the context of this study, we used the term Black as a broad category to refer to individuals of African ancestry, including those of multiracial backgrounds, who resided in the Indianapolis Metropolitan area in the state of Indiana. We acknowledge the sociohistorical contexts and limitations associated with the use of the term Black in health-related research [22]. We view this study as a first step to document

perceptions of AD in a subgroup of Black individuals, which could facilitate future studies into the cultural and geographical variations in the larger Black U.S. population, including non-US born individuals of African heritage. In summary, understanding how older Black adults view ways to maintain brain health provides the foundation for developing strategies for future outreach and educational efforts promoting cognitive function, AD knowledge awareness, and disease prevention among this population.

2. Methods

2.1. Study design

This study is part of the AD-REACH research project [23,24], which aimed to identify drivers of engagement and barriers to participation in AD biomarker research. As shown in Fig. 1, the AD-REACH project incorporated a sequential explanatory mixed methods study design [25], integrating a cross-sectional survey of older Black and White adults and qualitative interviews with a subset of Black participants. In the present analysis, we used the same approach, but focused on Black participants only to provide a deeper and nuanced understanding of this group's perceptions of AD and brain health. We examined Black participants' self-reported knowledge of AD, their views of "a healthy brain," and suggested strategies to promote brain health and increase AD awareness.

2.2. Participants and recruitment procedures

Participants in the present study were self-identified Black adults, aged 55 or older, who resided in the Indianapolis metropolitan area and who were research naïve (i.e., they had never participated in an AD research study prior to their enrollment in AD-REACH). Participants were recruited from September 2021 to April 2022 using electronic health records at Indiana University Health and affiliated All IN for Health research registry, and the Richard L. Roudebush VA Medical Center. We invited potential participants identified through the electronic health records to the study by mail followed up by a phone call. Recruitment strategies also included online advertisement, community outreach events, and snow-ball techniques [26] - asking study participants to refer others to the study.

2.3. Instruments and data collection procedures

2.3.1. Survey development

The survey was developed through a participatory, iterative process that included focus groups with community members, existing research participants from the Indiana Alzheimer's Disease Research Center, and community advisory board (CAB) members. We also conducted semi-structured and cognitive interviews [27] with two distinct groups of community members that met the same study criteria listed above.

2.3.2. Survey administration

Data collection for the study was guided by the Theory of Planned Behavior [16,28], which asserts that attitudes, perceived social norms, and perceived behavioral control influence behavioral intentions, that in turn predict subsequent behavior. Potential survey participants were screened for eligibility, and, following verbal consent, they then completed the AD-REACH survey online or over the phone. The survey explored participants' views of AD biomarker research and AD research participation and included questions about perceived knowledge of AD and behaviors for maintaining a healthy brain.

2.3.3. Interviews

In the larger study, a purposive, subsample of Black survey completers who expressed hesitancy about research participation on the survey were invited to participate in qualitative interviews to expand on

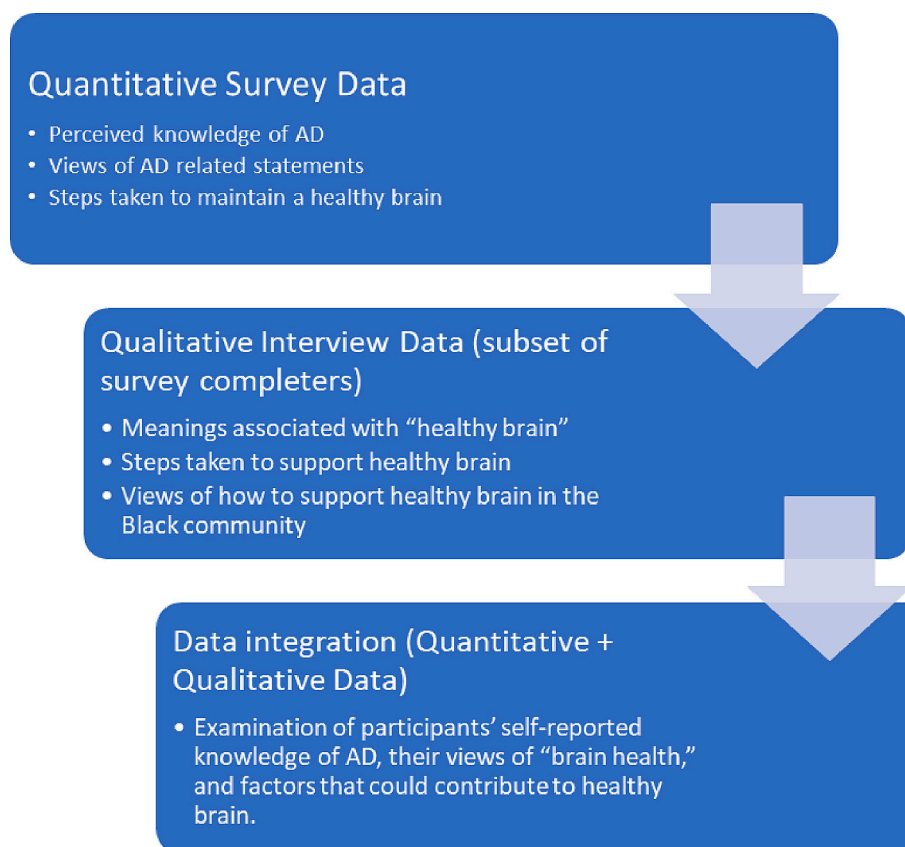


Fig. 1. Sequential explanatory mixed methods study design.

the survey results. This subgroup of participants was selected to better understand reasons for research hesitancy and how to address them. In the present analysis, we focused on participants' responses to interview questions about AD perceived knowledge, brain health, and suggested strategies to promote AD knowledge and brain health. Examples of the questions included: "When you hear the phrase 'keep your brain healthy' – what does that mean to you?" "When you are asked what you are doing to keep your brain healthy – how would you respond?" "What would help support the steps you are taking to keep your brain healthy?" "From your perspective, what do you think would be most helpful to help the Black community keep their brain healthy?" Interview questions were purposefully left broad and open-ended so that participants could interpret the sentences and provide their perspectives. The first author (JE) and two research assistants trained in qualitative research conducted the interviews, which lasted 30 to 60 min. The Indiana University Institutional Review Board and Richard L. Roudebush VA Medical Center Research and Development Committee approved the study. Participants provided informed consent prior to study participation and received \$35 for completing the survey and, if applicable, an additional \$35 upon interview completion.

2.4. Data analyses

We summarized participants' demographics and survey results using descriptive statistics. Semi-structured, qualitative interviews were audio recorded and transcribed for analysis. A team of four analysts, including the first two authors, and 2 trained research assistants analyzed the data using a rapid data analysis approach [29-31], which involved summarizing the interview data using a templated matrix. The matrix included participants' demographics (e.g., sex), a priori domains of inquiry (e.g., participants' views of healthy brain), and a summary of each participant's answers, which facilitated comparisons across participants. Each

individual transcript was independently summarized by two analysts. To ensure analytical rigor and trustworthiness, the analytical team reviewed and discussed the content of each summary, resolving inconsistencies by consensus. The larger team then collaboratively consolidated the summaries by domain to identify commonly occurring themes and to allow comparisons across participants until data saturation was reached [32]. The team also incorporated several bracketing methods [33,34] to reduce bias, facilitate reflexivity, and enhance the study's methodological rigor, including analysts' preparation of analytical memos [35] and peer debriefing [36] facilitated by a co-author (KAC) who was not involved in the data collection and coding process. To integrate the mixed-methods data, we reviewed the quantitative and qualitative data iteratively and identified qualitative themes that helped explain, expand on, and complement the quantitative findings.

3. Results

3.1. Participants' demographics

A total of 258 Black participants completed the AD-REACH survey. As shown in Table 1, survey participants were mostly female (53%), >65 years of age (58%), single (57%), and had <16 years of education (73%). The purposive subgroup of interview completers was primarily male (65%), over >65 years old (72%), single (52%), and had <16 years of education (76%).

In Table 2, we summarized the mixed methods results and included exemplar quotes for the three main themes identified: perceived and factual knowledge of AD, actions taken to maintain a healthy brain, and proposed strategies to promote brain health and increase AD awareness. Additional data from the survey are included in Table 3.

Table 1
Participants' demographics.

Survey Completers	Black older adults n = 258% (n)
Age (years)	
55-64	42.2 (109)
>65	57.8 (149)
Sex	
Female	53.5 (138)
Male	46.5 (120)
Veterans	
Education	19 (50)
< 16 years	73.3 (189)*
Grades 1-11	6.2 (16)
Grade 12/GED	22.5 (58)
Vocational/training/some college	30.6 (79)
Associates degree	14 (36)
≥16 years	26.7 (69)*
College grad/BA - BS	12.4 (32)
Some professional school	3.5 (9)
Master's degree	9.3 (24)
Doctoral degree	1.6 (4)
Relationship	
Partnered	42.6 (110)*
Single	57.4 (148)*
Interview Completers	Black older adults n = 29% (n)
Age (years)	
55-64	27.6 (8)
>65	72.4 (21)
Sex	
Female	34.5 (10)
Male	65.5 (19)
Education	
< 16 years	75.9 (22)
≥16 years	24.1 (7)
Relationship	
Partnered	48.3 (14)
Single	51.7 (15)

3.2. Knowledge of AD

While most survey participants reported having some knowledge of AD (60%), only 12% endorsed knowing what causes it and even fewer (4%) stated that they know how to manage and prevent it. Five percent of participants reported knowing “nothing at all” about AD. Most correctly agreed with the statements that AD can affect younger people in their 40s and 50s (73%), and that exercise and diet can reduce risk of AD (63%). However, most survey participants incorrectly agreed with the statement that “changes in memory and thinking are always normal as people get older” (71%), and incorrectly disagreed with or were unsure about the statement that “Black people are at higher risks of developing dementia compared to Whites” (59%).

Consistent with responses obtained in the larger survey, interview participants explained that most individuals in the Black community have little knowledge of AD, unless they have direct experiences working with patients with AD or caring for a loved one with the disease. They estimated that 5% to 30% of their community members know what AD is. Some noted that stigma, misconception of AD as a mental illness, and lack of effective communication about AD have hampered understanding of the disease. Interview participants also maintained that even those with family members afflicted with the illness may not fully understand the condition or know how to manage it. Some noted that AD is a growing health crisis that is becoming more visible in the Black community.

3.3. Actions taken to maintain a “healthy brain”

In survey responses, most participants (75%) reported practicing a healthy lifestyle to promote a healthy brain. Over 70% reported 1) limiting alcohol use or smoking, 2) socializing with others, and 3) managing chronic conditions such as high blood pressure. However,

Table 2
Mixed Methods Integration.

	Summary of Quantitative Data	Summary of Qualitative Data	Exemplar Quotes
Perceived knowledge of AD	<ul style="list-style-type: none"> 60% of participants reported having some knowledge of AD. 12% reported they know what causes it and 4% shared that they know how to manage or prevent it. 71% of participants viewed changes in memory and thinking in old age as normal. 59% reported being unsure of or disagreed with the statement that Blacks had relative higher risks of AD compared to Whites. 	<p>Most participants noted that knowledge of AD in their community is minimal. They identified stigma, myths about mental illness, and lack of AD education as barriers to individuals' understanding of the disease.</p>	<p>I don't know anything about (AD). I know people that has it in my family... We know very little about it. I think we are very uneducated about Alzheimer's and or dementia. -1894Female</p> <p>I don't think too many [people] really think about it as much unless it hits them personally... some Black people look at it like mental illness, [it] is taboo. -1668Male</p> <p>I think that there's whispers about it... But I don't think it's well-known and I don't think it's known as how truly dangerous it is. ... the Black community doesn't fully understand I think the implication. Not like cancer. -1440Male</p> <p>That means that there should be certain mental activities that you do in order to cause your brain to process information... I'm thinking of a crossword puzzles, reading, writing, being in social groups, maybe even speaking in public, learning new things, learning new hobbies. -1337Male</p> <p>It means feed yourself, feed your mind with things that are conducive to learning. I'm thinking of</p>
Actions taken to maintain a healthy brain	<ul style="list-style-type: none"> 75% of participants reported practicing a healthy lifestyle to promote a healthy brain. Fewer, 56%, reported engaging in stress management and staying mentally active (66%) as strategies for promoting brain health. 72% female participants vs. 59% male reported engaging in mental activity. 	<p>In response to “What does keep your brain healthy mean to you?” most participants describe what one could do or what they are doing to promote brain health. They cited primarily doing puzzles, followed by adopting a healthy lifestyle which included healthy eating and vitamins, exercise and stress management.</p>	

(continued on next page)

Table 2 (continued)

	Summary of Quantitative Data	Summary of Qualitative Data	Exemplar Quotes
			reading. I'm thinking of meditation. I'm thinking of healthy foods. -2009Male
Proposed strategies to promote brain health and increase AD awareness			
Exemplar Quotes			
Theme 1: Invest in the Black community's well-being throughout the lifespan		<ul style="list-style-type: none"> I think if they're aware at a younger age, maybe they would keep more active and be more attuned to it [AD] or what could happen down the line. -1006Female I've been noticing more libraries in the Black community. And then and that's good... We need more grocery stores that sell healthy foods, more fresh vegetables, and that sort of thing. The Black community could benefit from paying more attention to diet... I'd like to also see art museums and that sort of thing. To kind of stimulate the brain in that way, music, the arts, math. -1086Male I think young people don't get the exposure to culture and experiences out in the world that would help a lot to stimulate the brain... We're talking about generations of young Black people and even older Black people who don't have the knowledge about Alzheimer's, and how it affects our community... I think starting out at any time you know is going to be helpful to future generations who would not have that knowledge... even know about there was any type of research done.... So, I think that it would help a lot. -1135Female 	
Theme 2: Proactively reach out to the Black community		<ul style="list-style-type: none"> They don't publicize it [AD], you know on TV. They don't have any classes where you can get knowledge. And unless you talk to people or someone with Alzheimer's disease, you know nothing...I feel everybody watches TV. Everybody might not read. They're making movies about irrelevant stuff. They need to focus on important stuff like this so people can be aware of it. And not wait till it happens to their loved one or someone you know because if you know what to look for and the signs then you know they may have some medicine that can help you. -2007Female Talk to the people, even though they ain't in there [clinic] for it [AD]. Maybe in their early 30s or 40s. Make them aware of it at an early age. -1005Male 	
Theme 3: Integrate information about AD and brain health into broader culturally appropriate wellness campaigns		<ul style="list-style-type: none"> The best way to really to engage African Americans or Blacks would be to talk about what feeds the brain...then we could get into reading, meditation, and good eating. You talk about that in a roundabout kind of way you could say you know things like that do ward off Alzheimer's. So, you can't lead into the conversation "let's talk about Alzheimer's." You enter into it in a circuitous or roundabout kind of way. And then bring it up somewhere within or at the end of the conversation. I guess you want to give him the sizzle before you give them the steak. -2009Male I think that if we put it [AD information] like on the TV and that sort of thing it would become a Black people problem and that's not necessarily true. But I think when more awareness like when people do go to the health care that when they go and see the doctor and that sort of thing, I think that information given to them by way of pamphlet or something to read about it would bring more awareness to that problem. -1086Male 	
Theme 4: Improve health, healthcare, and research equity		<ul style="list-style-type: none"> If there's no clinic where they can afford it, it's not much you can do either. So, there needs to be more clinics. More awareness ...putting it on the radio and stuff like that. -1342Female There are issues of access to quality food. ... I have four Dollar stores, ...multiple gas stations... They ain't selling produce of any sort. They got a basket with you know three-day old bananas and some spongy apples. ... The closest thing to a grocery store in my neighborhood is [Name] bodega...The issues with regard to brain health, particularly in [CITY], are poverty and poor nutrition....You're seeing that like not even some basic needs are difficult or impossible to be met... I don't drive. So, I either have to take public transit or I have to get a Lyft... and for those people 	

Table 2 (continued)

	Summary of Quantitative Data	Summary of Qualitative Data	Exemplar Quotes
			<p>who don't have a credit or debit card, they gotta call a cab or ride the bus...so you get to the .store, now you have spent 60 dollars or 70 dollars, now you ...You gotta carry it. The issues are just compounded. We're not willing to fix the poverty. 1919Female</p> <ul style="list-style-type: none"> People come into our community and are clueless about who we are and what we're all about. And have not made any effort in learning about our community, but only relying on what the media has put in front of them as this is what the African American community should look like. And, if that's your only source about the African American community, you are extremely ignorant. Well, you need to know that you... to overcome years and years of a group of people being taken advantage of in all different ways. For instance, are you familiar with the wealth gap?... education gap?... the health gap?...social justice issues. ... And if you have a problem with those things, you're not gonna do well within an African American environment, because it's gonna show. 1337Male

fewer reported managing stress (56%) and staying mentally active (66%) as part of their healthy lifestyle for promoting brain health.

Analyses of the qualitative interviews corroborate these findings and provide insight into participants' views of what it means to "keep your brain healthy," as well as proposed examples of how to do so. A few interviewees stated that they did not know what it means to "keep your brain healthy." Most opted to describe what one could do to maintain brain health or what they were currently doing, which included engaging in activities that would stimulate cognitive processes. Interviewees primarily cited doing puzzles, as well as reading and other forms of "mind aerobics." Only one participant discussed "writing and learning new things." In participants' narratives, the second most common response to what it means to "keep their brain healthy" was adoption of a healthy lifestyle, which included discussions of healthy eating, vitamins, and to a lesser degree, limiting drugs and alcohol. A few participants also discussed engaging in regular exercise, which consisted of "working around or staying active at home," stress reduction (e.g., positive thinking), and socialization.

3.4. Proposed strategies to promote brain health and increase AD awareness

Our qualitative analysis identified four main sub-themes regarding strategies to promote brain health and increase AD awareness in the Black community: 1) Invest in the Black community's well-being throughout the lifespan; 2) proactively reach out to the Black community; 3) Integrate information about AD and brain health into broader culturally appropriate wellness campaigns, and 4) improve health, healthcare, and research equity.

3.4.1. Invest in the black community's well-being throughout the lifespan

Participants viewed investment in the general wellbeing of individuals in the Black community as integral to brain health in later life. They emphasized that brain health education and promotion should start early in life, with encouragement for individuals to learn about their family health history at a younger age, and promotion and sharing of health information that can benefit multiple generations. They further emphasized the importance of youth education being comprehensive and well-rounded, promoting reading and math skills, the arts, and healthy habits, as well as better education to promote nutrition and physical exercise, all of which can improve mental stimulation and contribute to ongoing brain health.

Table 3
Percentage of responses for each survey question. *N* = 258.

Perceived knowledge of AD	
Q1: On a scale of 1 to 5, how would you rate how much you know about AD?	
Statement	Total, n, %
I know nothing at all	14, (5.4)
I have heard of AD, but I am not sure what it is	48 (18.6)
I know what AD is	146, (60.5)
I know what AD is and what causes it	30 (11.6)
I know what AD is, what causes it, and how to manage and prevent it	10 (3.9)
Q2: Alzheimer's disease can affect younger people, even in their 40s and 50s	
Statement	Total, n, %
Disagree	18 (7.0)
Agree	188 (72.9)
Unsure	52(20.1)
Q3: Exercise and a balanced diet can reduce the risk of Alzheimer's disease	
Statement	Total, n, %
Disagree	13 (5.0)
Agree	171 (66.3)
Unsure	74 (28.7)
Q4: Changes in memory and thinking as people get older are always normal	
Statement	Total, n, %
Disagree	49 (19.0)
Agree	184 (71.3)
Unsure	25 (9.7)
Q5: Black people are at higher risk of developing dementia, including Alzheimer's disease, compared to Whites	
Statement	Total, n, %
Disagree	43 (16.7)
Agree	107 (41.4)
Unsure	108 (41.9)
Q6: What are you doing to keep your brain healthy? (check all that apply)	
Statement	Total n (%)
Practice a healthy lifestyle (e.g., eating a healthy diet, getting enough sleep, and exercising regularly)	194 (75.2)
Limit alcohol use; Limit or avoid smoking	184 (71.3)
Reduce stress (for example, meditating or doing relaxation exercises)	145 (56.2)
Stay mentally active	170 (65.9)
Spend time regularly with family and friends	188 (72.9)
Take medications for your medical conditions (such as high blood pressure) as prescribed	199 (77.1)

3.4.2. Proactively reach out to the Black community

Participants emphasized the importance of proactively providing information about AD and brain health in the community, as opposed to providing information when someone engages with the healthcare system. They noted the importance of active community engagement from Black individuals as well as those who seek to support the community. Such localized interactions may be able to address the fear and stigma that many face related to AD, which makes it difficult for some to engage in discussions about AD and brain health.

3.4.3. Integrate information about AD and brain health into broader culturally appropriate wellness campaigns

Participants discussed the need for creation of culturally appropriate, accessible, and targeted AD information to meet the needs of Black individuals. They suggested that researchers and health educators “give them the sizzle before you give them the steak,” which involves providing “bite-size” information and integration of AD materials as part of

broader wellness or health education campaigns. Integration of information may also provide the opportunity to present information about AD and brain health in a non-judgmental or threatening way that fosters individuals’ sense of self-efficacy, “ego,” empowerment, and dignity. A participant explained:

The male ego tends to have a tendency not want to step back and look at it without putting their manhood in any kind of situation where someone’s telling them what to do or how they’re supposed to think ... They want to do the right thing, fine. But if they don’t, I say, fine... I would say, you give them a choice of how to be able identify it [AD] and then be able to act on it, if they should feel to do that. 1860 Male Veteran.

3.4.4. Improve health, healthcare, and research equity

Discussions about how to improve brain health in the Black community centered on issues related to health equity for many participants as they discussed the need for improved access to social resources to meet basic needs, greater access to healthcare and preventive medicine, and more equitable treatment in health services. For example, a few participants discussed their experience with food deserts, which “makes simple health decisions a challenge for people without transportation,” and noted how poverty, homelessness, and other unmet social needs contribute to emotional stress and undermine their abilities to practice a healthy lifestyle. Relatedly, some participants added how violence, the legal/justice system, and toxic environments (e.g., environment affected by lead and chemicals) are barriers to healthy brain. Several participants commented that better access to healthcare would facilitate early diagnosis of AD and better quality of care to manage the illness.

4. Discussion and conclusion

4.1. Discussion

The present study examined older Black adults’ perceived knowledge of AD, views on how to keep the brain healthy, and perspectives on how to increase awareness and knowledge of AD and brain health in the Black community in [BLIND] metropolitan area. Using a mixed-methods approach, results showed misconceptions and uncertainty about AD are common and that there are some gaps in the understanding of healthy brain behaviors. However, there was strongly expressed recognition of the importance of increasing community education about AD and brain health, which suggests openness to AD outreach activities. Participants provided rich perspectives about how these current gaps in knowledge impact the Black community and voiced actionable recommendations for future AD and brain health outreach and awareness campaigns. These findings point to opportunities for collaborations with community members to identify and implement tailored solutions that meet their AD educational needs.

Our findings also indicate that participants reported limited perceived knowledge of AD. Participants’ discussions highlight their lack of awareness of AD knowledge gaps that still exist in their communities, which contributes to their perceived sense of health inequities [24]. For example, they linked lack of knowledge of AD in their community to limited prevention efforts, delayed AD diagnosis, and barriers to accessing health services and other resources to manage the disease. While there have been various and ongoing efforts to increase AD awareness [37,38], our findings indicate more work needs to be done to reach traditionally under-represented groups.

Furthermore, our findings on participants’ views of specific AD-related statements corroborate previous reports of relatively limited factual knowledge of AD among Black individuals [5,9,10,12,39]. For example, some participants endorsed the inaccurate view that changes in memory and thinking are normal signs of aging, which has been noted in previous publications [9,12]. Most participants were unaware of disparities in rates of AD among Blacks, which highlights lack of

information about AD among those who are most vulnerable to the disease.

Participants' suggestions for increasing AD awareness and promoting brain health add to growing calls to develop culturally sensitive messages and tailored approaches for diverse communities [40,41]. Participants discussed using a family-oriented approach where education starts early in life and educational materials contain information that would benefit the whole family, not only older adults. They also recommended infusing AD knowledge into health education across the lifespan. Indeed, increasing AD-awareness and integrating a trans-generational or community-wide perspective is the first step to improving research participation and fostering dementia friendly communities [42,43]. A step towards this approach may involve embracing a life course perspective in AD awareness campaign and engaging diverse health partners such as clinicians, health educators, and health promotion advocates, to discuss brain health and AD across the life span.

Most participants reported engaging in activities and behaviors that promote brain health, which is a strength and a solid foundation for health promotion, but they also revealed areas for improvement. Approximately three quarters of participants endorsed living a generally healthy lifestyle, and specifically discussed incorporating healthy eating habits and limiting substances for brain health. Cognitive stimulation was also frequently mentioned as important for maintaining brain health. However, participants provided few examples of activities outside of "puzzles and games" that support cognitive stimulation. While puzzles and games can support mental stimulation and therefore brain health, outreach and educational efforts may encourage individuals to build and expand on alternative activities for brain health promotion. Such activities also may facilitate person-centered discussions on how individuals can build on their personal interests, such as gardening or learning a new skill, and use available resources within their communities to engage in brain health promoting activities.

Few participants spontaneously mentioned stress management, exercise, and socialization as part of their lifestyles for brain health, which suggest that they may not systematically link these behaviors to brain health and AD prevention. These are potential areas for interventions as well as a focus on risk reduction for chronic diseases and other factors associated with aging. Indeed, AD education could be integrated in ongoing efforts to increase physical activity, social and emotional wellbeing in diverse communities. These are consistent with the Centers for Disease Control Health Brain Roadmap recommendations that call for the integration of brain health education into existing health communications that promote health and chronic condition management for people across the life span [44].

Participants' recommendations for increasing AD awareness and promoting brain health integrated individual responsibilities, such as adopting a healthy lifestyle, with larger historical, sociocultural contexts that impact health, including limited access to quality healthcare and meeting basic needs. Indeed, increasing AD awareness and promoting brain health require a multi-pronged approach that goes beyond influencing individual behaviors. These findings, however, should be interpreted within the context of this study and its limitations, which include a non-representative sample of Black Americans in one geographical region, limited data on the participants' ethnic backgrounds, sociocultural contexts, and communication styles about AD.

However, comprehensive approaches that address both individual behaviors as well as systemic and structural factors are needed to have positive, long-lasting impacts on community's health. As the participants suggested, addressing social determinants of health and ensuring access to high quality and equitable healthcare, education, nutrition, and housing are necessary for wellness and brain health. Thus, multi-systems partnerships and strategies that are rooted in principles of health equity and community collaboration may provide a roadmap for success.

4.2. Innovation

Studies examining populations' views of AD are primarily quantitative and have relied on factual knowledge measures. In this study, we used innovative approaches that incorporated quantitative and qualitative research methods to capture participants' perceived knowledge and views of AD. This approach facilitated a deeper understanding of participants' views of AD and perceived need for brain health promotion. Moreover, we examined participants' views of brain health to gain insight into their current strategies for AD prevention and recommendations to increase AD awareness in the Black community. Furthermore, given increasing efforts to recruit individuals from the community in AD research, we focused in this study on older Black adults and included Black men from diverse socioeconomic backgrounds. Our diverse sample of research naïve participants highlights another innovative feature of our study, which brings to fore the views of individuals who have been traditionally underrepresented in AD research.

4.3. Conclusion

Findings from this study have several implications that could help advance policies, research, and clinical practice to promote AD awareness and brain health. At a policy level, interventions are needed to increase equitable access to healthcare care, to facilitate access to community resources that foster wellbeing, and to address structural and socio-determinants of health. Specifically, participants underscored that brain health requires long-term socioeconomic investment in communities and overall wellbeing across the lifespan. Thus, to address risk of AD and reduce the burden of this disease on society, interventions may need to go beyond individual, healthcare, and aging solutions. Researchers and health educators have opportunities to meet participants' expressed need for AD education, and to develop comprehensive and targeted approaches that promote brain health in Black communities across the life span.

Future studies could investigate how to best work with community partners to increase knowledge of AD, research participation, and self-efficacy to manage AD risk factors. Investigations of the relationship between perceptions of AD and actual engagement in AD-related beliefs and behaviors across the lifespan are also needed. Clinicians are well positioned to address participants' limited engagement in brain health promoting activities. They could offer targeted and dedicated discussions about brain health with their patients to incorporate a wide range of social and health promoting activities. Overall, the study results offer some guidance for policymakers, researchers, and healthcare practitioners to integrate a community and strength-based approach as well as a health equity framework in their AD outreach and educational efforts.

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CRediT authorship contribution statement

Johanne Eliacin: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Angelina Polsinelli:** Writing – review & editing, Formal analysis. **Kenzie A. Cameron:** Writing – review & editing, Supervision, Formal analysis, Conceptualization. **Andrew J. Saykin:** Writing – review & editing, Funding acquisition. **Sophia Wang:** Writing – review & editing, Resources, Project administration, Methodology,

Investigation, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Andrew Saykin reports financial support was provided by National Institute on Aging. Johanne Eliacin reports financial support and administrative support were provided by US DEPARTMENT OF VETERANS AFFAIRS (VETERANS HEALTH ADMINISTRATION). Andrew Saykin reports a relationship with Avid Radiopharmaceuticals Inc. that includes: board membership and consulting or advisory. Sophia Wang reports a relationship with APPI and DSMB that includes: consulting or advisory. Kenzie Cameron reports a relationship with EPI-Q, Inc. that includes: consulting or advisory. Andrew Saykin reports a relationship with Bayer Oncology (Scientific Advisory Board) that includes: board membership. Andrew Saykin reports a relationship with Eisai (Scientific Advisory Board) that includes: board membership. Andrew Saykin reports a relationship with Siemens Medical Solutions USA, Inc. (Dementia Advisory Board) that includes: board membership. Andrew Saykin reports a relationship with Springer-Nature Publishing that includes: board membership. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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