Perceptions of Risk Factors for Alzheimer's Disease Among Community-Dwelling, Non-Demented Older African Americans

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Introduction

Older African Americans may be at higher risk of developing Alzheimer's dementia compared to older non-LatinoWhites.[1,2] Given the projected growth of the older African American population,[3,4] potentially heightened Alzheimer's disease (AD) risk represents an important racial disparity in aging. Partly due to community-based interest and media attention, factual knowledge about AD risk factors is growing among African Americans in general. For example, age and genetics (e.g. APOE ε4 allele) represent the most well-known AD risk factors among African Americans.[5] Despite this increased knowledge, misconceptions regarding AD continue to exist. For instance, compared to non-Latino Whites, African Americans are more likely to endorse memory loss, a hallmark symptom of AD, as a natural part of aging.[5–9] Older African Americans as a sub-population have exhibited less AD-related factual knowledge and lack awareness regarding their increased AD risk potential.[9] Outside of age, genetics, and other AD risk factors such as heart disease; an open question remains about other variables that older African Americans may perceive as AD risk factors.

Perception represents a type of knowledge or way of knowing but remains distinct from factual knowledge.[10, 11] At its simplest, perception refers to a person's recognition, organization, and interpretation of stimuli or information within his or her environment. While factual knowledge can inform a perception, a perception also stems from the delivery

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of information– including who, how, and where or context- and a person's previous thoughts about and experiences with the information and its delivery.[10, 12] Hence, a perception may be factually inaccurate and discrepant from established (medical) knowledge.[13–15]

It may be reasoned that both factual knowledge and perceptions regarding AD risk factors guide how a person thinks about his or her cognitive health and engages in health-related behaviors.[14, 16, 17] Previous research has mostly focused on factual knowledge related to AD risk factors. Much less is known about perceptions of AD risk factors.[18] Of the smaller body of literature that has focused on perceptions of AD risk factors, most has pertained to perceptions held by younger adults. As older African Americans are arguably at higher risk for developing AD, it is important to understand what they perceive as risk factors of AD. By systematically soliciting and understanding variables that older African Americans perceive as potential AD risk factors, researchers and others may develop both effective and culturally competent (i.e. the understanding and application of norms, knowledge, and prior experiences related to a particular group such as older African Americans) education materials and intervention strategies to facilitate meaningful engagement with older African Americans about AD.

The purpose of the current study was to expand existent literature by examining perceptions of potential AD risk factors among older African Americans without dementia. More specifically, we aimed to understand the relative importance that older African Americans place on certain risk factors in the development of AD. Although often grouped as a single population, older African Americans do not represent a monolithic group and may possess differing perceptions of potential AD risk factors based on key demographic characteristics. Previous research has indicated that demographic heterogeneity among African Americans is an important source of variability that may shape knowledge and perceptions. For example, while perceptions of AD risk factors have not been the subject of intense investigation, previous research with African Americans has suggested that educational attainment may impact AD-related beliefs.[7, 18] Similarly, perceptions of other common conditions such as cancer have been shown to be impacted by age among African Americans.[19] Hence, we sought to understand the role of salient demographic characteristics (i.e. age, years of education, and gender) in perceptions of potential AD risk factors among older African Americans. Additionally, given the central importance of cognition to AD, we also aimed to explore the role of global cognitive level and its association with perceptions of potential AD risk factors. Overall, we postulated that age, years of education, gender, and global cognitive level among older African Americans without dementia would differentiate perceptions of AD risk factors in the development of AD.

Methods

Participants

Participants belonged to the Minority Aging Research Study (MARS) - an ongoing, longitudinal epidemiologic study of aging in older African Americans. MARS recruits from churches, senior buildings, and social organizations that cater to African Americans in an urban city in the Midwest. MARS examines risk factors for cognitive and motor decline and began enrollment in 2004. All participants take part in an annual, structured, uniform clinical

evaluation including demographic characteristics, review of medical history, psychosocial factors and lifestyle behaviors, a complete neurologic examination, and performance-based cognitive and motor function tests.[20] Based on the clinical evaluation, a clinician classifies persons with respect to dementia using established criteria,[21] which require a history of cognitive decline and evidence of impairment in at least two cognitive domains. Eligibility for the current analysis was restricted to persons who: 1) were free of dementia at the baseline interview, 2) self-identified as non-Latino African American, and 3) completed a scale regarding perceptions of potential AD risk factors. MARS was approved by the Rush University Medical Center Institutional Review Board and all participants provided written informed consent.

Perceptions about Alzheimer's Disease Risk Factors

We used a modified scale to assess participants' perceptions of potential AD risk factors. [22–24] The original scale[22] assessed the perceived importance of seven potential risk factors (i.e. stress, exposure to toxic materials, God's Will, problems with brain chemistry, lifestyle, genetic make-up, and lack of mental activity) in relation to developing AD among a sample of first degree relatives of persons living with AD, largely consisting of White women (mean age = 53.5 years). The original scale[22] had a Cronbach's alpha of 0.63. The scale was later converted to a 10-item[23] and 3-item[24] version with 2 separate samples consisting of mostly White women with mean ages of 47 years[23] and 64.4 years.[24] To our knowledge, the scale has not been used exclusively with older African Americans.

The version used in the current study, provided by the scale authors, was very similar to the 10-item version with slight modifications including relabeling of some risk factors and the addition of risk factors thought to be more relevant for community-dwelling adults. Nine items measured how important participants perceived the following factors in increasing their chances of developing AD: genetics or hereditary factors (passed down through your family), mental illness, stress, old age, God's Will, head injury, exposure to toxins (such as drinking out of aluminum cans), drinking too much alcohol, and smoking too much. Responses were coded using a Likert-type scale with endpoints 1 (not at all important) to 4 (extremely important).

Demographic Characteristics

All participants self-reported their race (i.e. African American/Black) and ethnicity (i.e. Latino: yes or no) based on categories from the 1990 U.S. Census Bureau[25] as well as date of birth, years of education, and gender.

Global Cognition

Participants completed a battery of 19 cognitive function tests.[20, 26–28] One test, the Mini-Mental State Examination (MMSE), was only used for descriptive purposes. The remaining 18 performance-based tests assessed 5 domains of cognitive function[20, 26–28] including: 1) episodic memory - measured using the CERAD Word List Memory, Recall, and Recognition tests; and immediate and delayed recall of the East Boston Story and Story A from Logical Memory; 2) semantic memory - measured using a 15-item version of the Boston Naming Test, a 15-item reading recognition test from the Wide Range Achievement Test, and a

Verbal Fluency test (animals and fruits/vegetables); 3) working memory - measured using Digit Span Forward, Digit Span Backward, and Digit Ordering; 4) perceptual speed - measured using the oral version of the Symbol Digit Modalities Test, two indices from the Stroop Test, and Number Comparison; and 5) visuospatial ability - measured using a 15-item version of Judgment of Line Orientation and a 17-item version of Standard Progressive Matrices. To create the composite, raw scores from the 18 performance-based cognitive measures were converted to *z* scores using the baseline mean and standard deviation of all subjects enrolled in MARS. Each participant's standardized *z* scores were then averaged to yield a composite global cognition score, as previously described.[20, 26–28]

Analyses

We first examined responses to scale items across the overall sample using basic descriptives including frequency distributions. We then stratified the sample based on age, years of education, and gender. For age, we performed a median split with participants who were median age and younger in one group and participants who were older than median age in another group. For years of education, we stratified participants based on having a high school diploma or less (12 or fewer years of education) compared to having more than a high school diploma (13 or more years of education). For gender, participants were grouped according to their self-identified gender – either female or male. Afterward, we examined basic descriptives for each scale item by median split age, stratified years of education, and gender. We then performed *t*-tests to gain a basic understanding of potential differences in responses to each scale item by those same groupings. We also performed Spearman correlations to examine the relationship between global cognition and each scale item.

Lastly, in an effort to understand the impact of each predictor variable - age, years of education, gender, and global cognition - while adjusting for the others, we performed either proportional odds models or generalized logit models. We used proportional odds models when the assumption of proportional odds was accepted (i.e. outcome responses were treated as ordered) and generalized logit models when the assumption of proportional odds was rejected (i.e. outcome responses were treated as nominal or unordered). We performed separate models for each scale item; hence, we performed nine distinct models. All models included terms for all predictor variables. All analyses were conducted using SAS software, version 9.3 of the SAS system for Linux.

Results

Participant Characteristics

Of 742 participants, 24 met criteria for dementia, 3 identified as Latino, and 105 had not yet completed their clinical evaluation by the time of these analyses; hence, 132 participants were excluded from analyses. The total number eligible for current analyses was 610 participants. Participants had a mean age of 74.5 (SD=6.4) years, 14.9 (SD=3.4) mean years of education, an average global cognition score of 0.08 (SD=0.57), and an average MMSE score of 28.0 (SD=2.0). Almost one-quarter (24%) of the sample were men. The median age was 73.6 years with a range of 61.6 to 98.8 years, and 173 (28%) participants had a high school diploma or less (12 years of education or less). See Table 1.

Perceptions about AD Risk Factors in the Overall Sample

Almost 50% of participants indicated that genetics and old age were important risk factors for AD. Nearly 40% of participants rated God's Will as an important risk factor for AD. More than 60% of participants believed exposure to toxins was not an important risk factor for AD. See Table 2.

Perceptions about AD Risk Factors by Median Split Age

Based on mean responses, the two median split groups – age 73.6 years and younger, and older than 73.6 years; did not differ on the following AD risk factors: genetics, stress, old age, head injury, drinking too much alcohol, or smoking too much. However, participants in the younger aged group were more likely to indicate mental illness (2.5 vs. 2.3, p=0.05) and exposure to toxins (2.2 vs. 2.1, p=0.04) as important AD risk factors compared to those in the older aged group. Conversely, participants in the younger aged group were less likely to indicate God's Will (2.2 vs. 2.4, p=0.02) as an important AD risk factor compared to those in the older aged group. See Table 3.

Perceptions about AD Risk Factors Stratified by Years of Education

Based on mean responses, the two stratified groups – those with 12 or fewer years and those with 13 or more years, did not differ on the following AD risk factors: genetics, mental illness, stress, old age, head injury, exposure to toxins, or smoking too much. However, participants with 12 or fewer years of education were more likely to indicate God's Will (2.5 vs. 2.2, p=0.001) and drinking too much alcohol (2.5 vs. 2.3, p=0.02) as important AD risk factors compared to those with 13 or more years of education. See Table 4.

Perceptions about AD Risk Factors by Gender

Based on mean responses, the two groups – female and male – did not differ on any AD risk factor.

Perceptions about AD Risk Factors by Global Cognition

Global cognition was not correlated with the following AD risk factors: genetics, mental illness, stress, old age, head injury, or exposure to toxins. Global cognition was correlated with God's Will ($r= -0.13$, $p= 0.001$), drinking too much alcohol ($r= -0.16$, $p< .0001$), and smoking too much ($r= -0.15$, $p< .0005$). Participants with higher global cognition were less likely to indicate God's Will, drinking too much alcohol, and smoking too much as important AD risk factors compared to participants with lower global cognition. See Table 5.

Statistical Models for Perceptions of AD Risk Factors

The assumption of proportional odds was accepted for some AD risk factors; hence, we used separate proportional odds models to examine the relationship between predictor variables and the following AD risk factors: mental illness, old age, God's Will, head injury, exposure to toxins, and smoking too much. The assumption of proportional odds was rejected for other AD risk factors; hence, we used generalized logit models to examine relationships between predictor variables and the following AD risk factors: genetics, stress, and drinking

too much alcohol. We report differences in perceiving AD risk factors as very important and extremely important.

Age and education were significant predictors for genetics and God's Will as AD risk factors. Participants who were younger aged were more likely to indicate that genetics were very important (est. = −0.06, p= 0.02) and extremely important (est. = −0.06, p= 0.02) compared to those who were older aged. Additionally, participants with more years of education were more likely to indicate that genetics were very important (est. = 0.14, p= 0.02) and extremely important (est. = 0.14, p= 0.02) compared to those with fewer years of education. For God's Will, participants with more years of education were less likely to indicate God's Will as very important (est. = −0.14, p= 0.001) and extremely important (est. = −0.14, $p < .0005$) compared to those with fewer years of education. We did not find significant associations for global cognition or gender with any of the AD risk factors in these models.

Discussion

In this study of over 600 older African Americans without dementia enrolled in MARS, we aimed to understand perceptions of potential AD risk factors. As postulated, we found differences in perceptions based on age, years of education, and global cognition. Notably, participants who were at the older end of the age range, had fewer years of education, and had lower global cognition perceived God's Will as more important compared to their counterparts who were at the younger end of the age range, had more years of education, and had higher global cognition. After controlling for other predictors, differences due to years of education remained for God's Will. Additionally, in fully adjusted models, participants who were at the older end of the age range and had fewer years of education perceived genetics as less important compared to those who were at the younger end of the age range and had more years of education. We did not find any differences in perceptions based on gender.

Current study findings add to existent literature by exclusively focusing on the perceptions of older African Americans regarding risk factors for the development of AD. Previous research has largely focused on AD-related knowledge.[29] Genetics[5, 22–24] and old age[5] are commonly and accurately endorsed as AD risk factors among African Americans, in general – similar to current study findings. However, African Americans as a whole[23, 24, 30] and older African Americans in particular[9] possess less factual knowledge regarding AD in comparison to their White counterparts. Conversely, perceptions represent another type of knowledge – separate from but possibly informed by factual knowledge as well as other factors including a person's previous thoughts and experiences. We are aware of one prior study specifically focused on perceptions of AD-related risk factors among older African Americans. Rovner and colleagues[9] found that almost 50% of older African Americans believed that God's Will served as an AD risk factor. Current study participants also perceived God's Will as an important risk factor for AD. God's Will was endorsed more by current study participants at the older end of the age range, with fewer years of education, and lower global cognition. Hence, education materials focused on AD, especially targeting specific subgroups of African Americans, should address potential religious beliefs in

relation to AD. God's Will is not a factor that can be, arguably, evidenced through research. However, current findings suggest that practitioners, researchers, and others should, at the least, acknowledge participants' religious and spiritual beliefs. For example, while it is important to focus on evidence-based information regarding risk of AD, conversations and outreach materials might mention that the established risk factors do not fully explain the risk of AD and there is much that is unknown at this point. It is important to note that across levels of education, God's Will has served as a tool for people to understand and cope with illnesses related to the brain including AD.[31] In communities such as older African Americans, a historical lack of access to resources surrounding health including AD may have facilitated the pronounced role of God's Will as a means for knowledge and understanding.

Current study findings also indicated that participants endorsed AD risk factors less established in previous literature. Current study participants with fewer years of education and lower global cognition were more likely to cite drinking too much alcohol as an important AD risk factor compared to their counterparts with more years of education and higher global cognition. Current study participants who were at the younger end of the age range also reported mental illness and exposure to toxins as more important AD risk factors compared to those who were at the older end of the age range. Lastly, current study participants with lower global cognition also noted smoking too much as a more important AD risk factor compared to those with higher global cognition. Previous research has postulated that high levels of alcohol consumption,[32] depression,[33] environmental toxins,[34] and cigarette smoking[35] may place people at increased risk for developing AD and other dementias. Our results suggest that AD-related education materials geared toward older African Americans may highlight common perceptions of AD risk factors that are evidence-based while simultaneously debunking misconceptions regarding AD and its risk factors that are no longer fully supported in the literature.

As older African Americans are arguably at higher risk for developing AD in relation to older non-Latino Whites, it is important to include older African Americans in research regarding AD and assess and address their perceptions of AD risk factors. What older African Americans perceive as causes of AD may indicate prioritization of AD for individuals and families, recognition of AD symptoms, openness to lifestyle and behavioral changes, and ways to frame AD-related education materials and outreach efforts. In so doing, researchers and others may be able to develop effective and culturally competent education materials and strategies for engagement and intervention regarding AD and its potential risk factors. Culturally competent education materials and strategies for engagement and intervention may be more effective when working with older African American communities regarding AD and cognitive aging.[7, 29, 36] Importantly, researchers and others should not consider older African Americans as a monolithic group as our results demonstrate that age, years of education, and global cognition may impact their perceptions of AD-related risk factors. Future research should continue to examine perceptions of AD risk factors among older African Americans and subgroups within older African Americans.

This study has important limitations. First, our participants comprised a volunteer cohort in the Midwest, and tended to be physically and cognitively healthier and more highly educated

than the average older African American adult. Second, a growing body of literature has focused on the role of gender in AD development. However, we did not find significant gender differences in perceptions of AD risk factors potentially due to being underpowered for older African American men. Hence, our findings may not be generalizable to older African Americans across the United States and should be replicated in a population-based sample specifically with increased numbers of older African American men. However, a main strength of this study includes a large, well-characterized cohort of older African Americans across broad older age and education ranges to demonstrate perceptions of AD risk factors.

Conflicts of Interest and Source of Funding:

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Table 1.

Demographic Characteristics and Scores for Cognition Across All Participants (N=610)

Demographic Characteristic	
Age	Mean = 74.5 (SD = 6.4)
	Median = 73.6
	Range = 61.6 – 98.8
Years of Education	Mean = 14.9 (SD = 3.4)
	12 years = 173 (28%)
Men	146 (24%)
Cognition	
Global Cognition	Mean = 0.08 (SD = 0.57)
	Range = −2.06 – 1.79
MMSE	Mean = 28.0 (SD = 2.0)
	Range = 19 – 30

Table 2.

Frequencies and Means for the Overall Sample (N=610) Endorsing Each Alzheimer's Disease Risk Factor

	Not at all Important[1]	Somewhat Important[1]	Very Important[1]	Extremely Important[1]	Mean[2]
Genetics	9.2	37.4	29.5	19.5	2.6
Mental Illness	15.9	38.2	27.7	13.8	2.4
Stress	10.7	42.1	29.2	13.6	2.5
Old Age	9.8	38.0	32.8	14.9	2.6
God's Will	32.3	23.9	18.5	20.8	2.3
Head Injury	18.0	34.8	29.3	13.4	2.4
Exposure to Toxins	26.9	36.9	21.8	10.0	2.2
Drinking Too Much Alcohol	21.5	32.0	27.5	14.6	2.4
Smoking Too Much	27.1	31.6	22.6	14.3	2.3

[1]Frequency Percentages

[2]Mean refers to the average of each participant's response for a potential AD risk factor (e.g. genetics); response options were: 1=Not At All Important, 2=Somewhat Important, 3=Very Important, and 4=Extremely Important

Table 3.

Means[1] for Perceptions about Alzheimer's Disease Risk Factors by Median Split Age

	Median Age[2] (n=299)	> Median Age[2] (n=284)	Z-value, *p*-value
Genetics	2.7	2.5	NS
Mental Illness	2.5	2.3	−1.98, 0.05
Stress	2.5	2.5	NS
Old Age	2.5	2.6	NS
God's Will	2.2	2.4	2.32, 0.02
Head Injury	2.4	2.4	NS
Exposure to Toxins	2.2	2.1	−2.05, 0.04
Drinking Too Much Alcohol	2.4	2.4	NS
Smoking Too Much	2.3	2.2	NS

[1] Mean refers to the average of each participant's response for a potential AD risk factor (e.g. genetics); response options were: 1=Not At All Important, 2=Somewhat Important, 3=Very Important, and 4=Extremely Important

[2] Mean Age = 73.6 Years

Table 4.

Means[1] for Perceptions about Alzheimer's Disease Risk Factors Stratified by Years of Education

	12 or Fewer Years (n = 165)	13 or More Years (n = 418)	Z-value, *p*-value
Genetics	2.6	2.6	NS
Mental Illness	2.5	2.4	NS
Stress	2.5	2.5	NS
Old Age	2.6	2.5	NS
God's Will	2.5	2.2	3.22, 0.001
Head Injury	2.4	2.4	NS
Exposure to Toxins	2.2	2.1	NS
Drinking Too Much Alcohol	2.5	2.3	2.34, 0.02
Smoking Too Much	2.3	2.2	NS

[1] Mean refers to the average of each participant's response for a potential AD risk factor (e.g. genetics); response options were: 1=Not At All Important, 2=Somewhat Important, 3=Very Important, and 4=Extremely Important

Table 5.

Spearman Correlations and Significance Values between Global Cognition and Each Alzheimer's Disease Risk Factor

	Global Cognition
Genetics	NS
Mental Illness	NS
Stress	NS
Old Age	NS
God's Will	$r = -0.13$ $p = 0.001$
Head Injury	NS
Exposure to Toxins	NS
Drinking Too Much Alcohol	$r = -0.16$ $p < 0.0001$
Smoking Too Much	$r = -0.15$ $p < 0.0005$