


# Explanations of AD in Ethnic Minority Participants Undergoing Cognitive Screening

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## Abstract

The purpose of this study was to describe and compare explanations of Alzheimer's disease (AD) of African American, Afro-Caribbean, and European American older adults undergoing cognitive screening. Participants were asked a series of open-ended questions regarding what they knew about AD and if they were experiencing memory problems. Responses were coded and quantized for analysis. Forty percent reported experiencing memory problems. Afro-Caribbeans made significantly more incorrect statements about AD and were less likely to identify memory loss as a symptom. Half the participants said they would seek their physician's advice if the screening was positive; none mentioned a memory disorder center. Misconceptions about AD included the effect of aluminum, brain collapse, relaxed brain, shaking, tremors, and physical illness. More Afro-Caribbeans, all of whom were first generation, had misconceptions about AD. Campaigns to educate the public about AD need to provide culturally sensitive and appropriate information to ethnic minority populations.

## Keywords

African American, Afro-Caribbean, disease construction, dementia, Alzheimer's disease

## Introduction

Alzheimer's disease (AD) has gained visibility through local and national educational campaigns, news stories, and pharmaceutical advertisements. The extent to which this information has reached and been understood by minority populations in the United States is as yet unclear, but there are indications that they are likely to have lower levels of knowledge and more misconceptions about this disease.<sup>1,2</sup> In this study, we asked African American, Afro-Caribbean, and European American adults who were undergoing cognitive screening in community settings a set of open-ended questions related to their understanding of AD.

## Disease Constructions

Individuals' mental constructions of a disease are shaped by their cultural beliefs, norms, and values. Thus the disease constructions of most members of mainstream American culture are likely to be based upon Western biomedicine, while the disease constructions of members of less technically developed societies are likely to be based upon more traditional beliefs.<sup>3</sup> For example, Jang, Kim and Chiriboga<sup>2</sup> found that greater knowledge of AD was related to higher levels of education and acculturation in a sample of 675 Korean American elders. From interviews with 32 caregivers of individuals with dementia, Dilworth-Anderson and Gibson<sup>4</sup> found that the mental

constructions of dementia of caregivers who were European American were most congruent with the Western biomedical paradigm that is the dominant health-related belief system of mainstream American culture. In contrast, more Hispanic and African American caregivers thought dementia was an outcome of a stressful life, and Chinese American caregivers related its occurrence to excessive worry creating an unhealthy imbalance.

## Related Studies

Studies of individuals' understanding of AD have used knowledge tests, semi-structured, and unstructured interviews. For example, Hinton and Levkoff<sup>5</sup> used relatively unstructured interviews to elicit narratives from African American, Irish American, and Chinese American caregivers, generating themes of lost identity and deterioration of the mind that some thought were an expected part of growing old. They also found that, while the Puerto Rican and Dominican families used the

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biomedically derived term AD, their stories focused on tragic loss, loneliness, and family responsibility.<sup>5(p455)</sup>

Aspects of AD frequently addressed in these studies are conceptualization of AD as a disease rather than a part of normal aging, factors associated with its emergence, signs and symptoms, course of the disease, treatment, and prognosis.<sup>6</sup> These categories are similar across both quantitative and qualitative studies. Individuals studied range from 18 years of age to 80 and older. Many studies focused on primary relatives and caregivers of individuals with AD.<sup>7-10</sup> One study included individuals with a diagnosis of AD along with caregivers and noncaregivers.<sup>11</sup>

### *Focus on Family Members*

Probably the most frequently studied segments of the population potentially affected by AD are caregivers and primary relatives who were found to place emphasis on heredity as a causative factor.<sup>9</sup> A sample of 203 primarily White adults, most of whom were involved in care of their relative with AD, achieved a mean score of 84% correct on a 14-item quiz about AD. One third believed God's will has a role in the development of AD, suggesting the importance of spirituality to them. One third also thought that diet and inactivity contributed to the development of AD.<sup>9</sup> Taussig and Mack<sup>8</sup> compared responses of English-speaking and Spanish-speaking caregivers in structured interviews. They found that more Spanish speakers mentioned memory loss as an initial symptom (47% vs 27%), while more English-speaking caregivers mentioned functional (activities of daily living [ADLs]) changes (21% vs 4%). The researchers suggested that the differences may be related to different perceptions regarding these symptoms or differences in understanding of AD. A 2007 survey of 655 caregivers sponsored by the Alzheimer's Foundation of America found that African American and Hispanic American caregivers are more likely to attribute the disease to normal aging.<sup>12</sup>

### *Focus on Other Members of Minority Groups*

Recent interest in knowledge of AD has been directed particularly toward minority populations including African Americans, Hispanic Americans, Chinese Americans, Asian Indians, and Korean Americans.<sup>1,2,4,5,13,14</sup> In general, European Americans have been found to have a higher degree of familiarity with the symptoms, causative factors, and current treatment of AD. For example, Roberts and colleagues<sup>14</sup> found differences in mean scores of White (60% correct) and African American (43% correct) adults (mean age, 47) on a knowledge test. African Americans also reported fewer sources of information about AD and less perceived threat. The researchers suggested that race [sic] was a more important variable than being a caregiver. Ayalon and Areán<sup>1</sup> also found Anglos (ie, European Americans) more knowledgeable than Latinos, Asians, or African Americans, recommending the latter groups be targeted in future educational campaigns. However, their

analysis suggested that education and years speaking English, not ethnicity per se, were responsible for the differences across ethnic groups. The Latinos and Asians held the most stigmatizing views of AD and were more likely to think it could be contagious but curable. In Jang, Kim and Chiriboga's more recent<sup>2</sup> study, only a few Korean Americans thought AD was contagious but half thought it was a normal part of aging. More than 40% thought it a form of insanity and generally fatal. These researchers also called for educational campaigns targeted to minority groups. Similarly, many Asian Indian Americans, age 18 to 81, who were presented with a vignette ascribed AD to loneliness and mental illness.<sup>13</sup> Otilingam and Gatz<sup>13</sup> noted that most of the knowledge questions they used were answered correctly by less than half of their sample of 255 Asian Indian Americans.

### *Summary*

Most of the studies reviewed found that European Americans, variously called Anglos or whites, were most knowledgeable, holding disease representations that most closely reflect the Western biomedical conceptualization of AD. Members of US ethnic minority groups were more likely to believe that AD is a normal aspect of aging or a mental illness and the result of stressful life experiences.

No studies involving individuals presenting for cognitive screening or involving Afro-Caribbean participants were found.

## **Methods**

### *Participant's Recruitment*

Cognitive screening was offered to individuals attending community programs, primarily group meetings, and exercise programs at neighborhood senior centers in South Florida. Adults who wished to be screened were eligible for the study unless they were too impaired to be able to understand the purpose of the study and provide consent by institutional review board (IRB) guidelines (none were excluded on this basis).

A brief interview employing open-ended questions was conducted prior to screening. Participants were asked the following questions:

- Are you familiar with the term "Alzheimer's disease"? Can you tell me what it means?
- Can you tell me what happens to people who develop AD?
- Have you had any concerns about your memory?
- What would you do if you were told you might have a memory problem?

Responses were recorded verbatim and transcribed. Information that could affect coding decisions, including age, gender, and ethnic group membership, was removed from the transcriptions for the purposes of analysis.

## Data Analysis

Open coding was used in this analysis.<sup>15</sup> Two of the investigators read and reread the participant responses and created the coding system from these responses. They then coded each participant's responses independently, compared assigned codes, and reconciled any disagreements that were found. Response exemplars were also identified for the purposes of illustrating the coding categories. These are reported in the Results section. The major coding categories created were incorrect statements, explanations of the disease, signs and symptoms of AD, treatment of AD, personal concerns about memory loss, and emotions expressed by the individuals related to AD. Finally, these codes were quantized,<sup>16</sup> codes were merged with descriptive quantitative data on each participant (age, Mini-Mental State Examination [MMSE] score,<sup>17</sup> years of education, and so forth) and subjected to quantitative analysis employing chi square for categorical data (gender, ethnicity, and the coded variables) and analysis of variance (ANOVA) for interval data (number of incorrect statements made by participants, years of education, age, and MMSE scores).

## Sample

Altogether, 72 participants were interviewed and screened for evidence of cognitive impairment. Of these, 29 were African American, 23 were Afro-Caribbean, and 20 were European American. All of the African American participants were black, English speaking, and born in the United States. The Afro-Caribbean participants were also black, but all were born in Caribbean countries, none in the United States. All were fluent in English but 15 reported that their first language was Creole. All of the European American participants were white, English speaking, and born in the United States. None of the participants were Spanish speaking or of Hispanic descent.

Participants ranged in age from 46 to 89. Average age was 71 (SD = 7.83). There was no significant difference in age across the ethnic groups  $F(2, 69) = 0.46, P = .63$ . The majority (81%) of the sample was female. While the differences were not statistically significant, a greater proportion (35%) of the European American group were male, while only 14% of the African American group and 13% of the Afro-Caribbean group were male.

The ethnic groups did differ, however, in terms of education and MMSE scores. The average years of education for the sample as a whole was 13.50 (SD = 4.51) with a wide range of 2 to 21 years. The mean number of years of education completed by the European Americans and African Americans was similar: 15.10 (SD = 2.88) and 15.44 (SD = 3.88), respectively. The mean for the Afro-Caribbean group was lower at 9.56 (SD = 4.07)  $F(2, 69) = 18.85, P < .001$ . The Afro-Caribbean participants also had a lower average MMSE score, mean 24.56 (SD = 3.87) compared with 26.40 (SD = 3.66) and 26.89 (SD = 2.31) for the European American and African American participants, respectively. The range of unadjusted MMSE scores for the sample as a whole was 15 to 30. The

difference was significant  $F(2, 69) = 3.47, P = .03$ . Given the well-known sensitivity of MMSE scores to the level of education<sup>18</sup> and substantial correlation of education and MMSE scores in this sample ( $r = .31, P = .007$ ), the unadjusted MMSE scores were compared using analysis of covariance (ANCOVA) controlling for education. With the level of education controlled, the difference in MMSE scores between ethnic groups was not significant  $F(3, 68) = 0.86, P = .42$ . The adjusted means for the European Americans, African Americans, and Afro-Caribbeans were 26.15, 26.59, and 25.15, respectively.

There were no differences between the ethnic groups in terms of marital status, but a smaller proportion of Afro-Caribbean participants lived in single-family residences (55% vs 85% for the European Americans and 88% for the African Americans). None of the participants lived in retirement communities or were institutionalized.

## Results

### Memory Concerns of Participants

Participants were asked whether they were concerned about their memory. Forty percent said that they were concerned about their memories or had experienced a memory-related problem. For example:

- Sometimes I go to the kitchen for something, then can't remember what I went for. I keep forgetting.
- I have a lot of memory problems. I rely on my 16-year-old daughter to remember things.
- I have started to forget small things.

The proportion acknowledging a memory concern or problem did not differ across ethnic groups. In fact, it was 39% for the Afro-Caribbeans, 40% for the European Americans, and 41% for the African Americans.

### Signs and Symptoms of AD

The most frequently mentioned sign of AD, by 89% of the sample, was memory loss or change in memory. Fewer Afro-Caribbean participants mentioned this than members of the other 2 groups, a difference that was significant  $\chi^2(2, N = 73) = 7.25, P = .02$ . Impact on ability to think, to function independently, and to remain oriented to one's surroundings were each mentioned by several participants as well but there were no differences in the proportions within each ethnic group. Problems communicating were mentioned by 3 Afro-Caribbean participants, not by any European Americans or African Americans. Two Afro-Caribbean participants said that they had no idea what the signs and symptoms of AD were.

### Explanations of Underlying Disease Mechanisms

Few respondents offered any description of the pathophysiological changes associated with AD or the underlying mechanisms

leading to its inception. None mentioned vascular changes, 1 mentioned plaques. Another mentioned dendrites but said they were “not encouraged to work” which was also coded as a misconception.

One third (32%) of the sample related the onset of AD to age. For example:

- Everyone should be concerned by a certain age (50s).

There were no differences in relating AD to age by ethnic group membership.

In all, 11% termed AD a disease and 18% believed that measures can be taken to prevent its occurrence (15% of the European Americans, 35% of the African Americans, and none of the Afro-Caribbeans). A typical response was “If I catch it in time, maybe I can keep it at a minimum.”

The difference in belief that measures can be taken to prevent AD across ethnic groups was significant  $\chi^2(2, N = 73) = 10.48, P = .005$ .

### *Incorrect Explanations of AD*

In addition to coding for specific answers described above, we also noted statements and explanations that were clearly incorrect or counter to current thinking about AD. In all, 71% of the sample made no clearly incorrect statements. Examples of statements coded as incorrect include the following:

- Your brain has partially collapsed.
- Like a baby . . . .
- Shaking all the time.
- Too much aluminum in the brain.
- It also causes physical illnesses but I’m not sure what they are.
- The brain becomes so relaxed and needs to be stimulated.

In contrast, several provided answers reflecting their having more information:

- A form of dementia discovered by Dr Alzheimer from Europe. Very, very devastating to people. Senility used to call it that. [I] saw this on TV.
- I don’t understand why people should lose their short-term memory before their long-term memory . . . . It should be easier to remember something that just happened.

There was a difference in the number of incorrect responses offered by members of each ethnic group,  $F(2, 69) = 3.11, P = .05$ . The largest number of incorrect statements came from the Afro-Caribbean participants.

### *Treatment*

Half (50%) of the sample said they would see a physician if they screened positive for memory impairment. More African Americans and Afro-Caribbeans specifically mentioned seeing

a physician, while more European Americans specifically mentioned obtaining medication. These differences were not statistically significant. Few other treatments were mentioned by more than 1 person. In all, 5 (7%) mentioned exercise, 5 (7%) mentioned some type of cognitive stimulation, and 3 mentioned games. One European American said nothing could be done:

- Sometimes things are best left alone because sometimes tests trigger other conditions.

Two other European Americans mentioned diet. Only 1 mentioned turning to God, an Afro-Caribbean participant who said “Pray to God and ask for healing.”

### *Emotional Response*

Several who were already experiencing problems were frightened by them. One respondent said, “It frightens me. I didn’t realize where I was going and it was 8 pm.”

Several more expressed concern: 4 (20%) of the European Americans but only 1 African American and 1 Afro-Caribbean participant. This difference was not statistically significant  $\chi^2(2, N= 73) = 4.94, P = .08$ . None of the male participants expressed concern or fear.

### *Discussion*

An analysis of coded and quantized qualitative data was conducted. Responses from individuals who participated in cognitive screening offered at senior centers in South Florida were coded and analyzed as categorical data. All the participants were African American, Afro-Caribbean, or European American. Forty percent were already experiencing some difficulty related to memory. The 3 ethnic groups did not differ in terms of age or proportion who already had a concern about their memories. The 3 ethnic groups did differ, however, in terms of years of education and MMSE scores. The difference in MMSE scores was related to educational level.

In general, the Afro-Caribbean participants, all of whom were first-generation Americans, appeared to be less knowledgeable about AD than either the European American or African American participants. Fewer Afro-Caribbeans mentioned memory as a symptom of AD. They also held more misconceptions about AD, a difference sustained even when controlling for the differences in education.

The misunderstandings expressed suggest that all understood that AD affects the brain but many were not clear about the type of damage that occurs. Few had any in-depth knowledge of the pathophysiological changes that occur, but this level of understanding is not to be expected in a community sample. The signs and symptoms of the disease mentioned by participants were generally accurate with the exception of tremors, shaking, and becoming like a baby again. Their descriptions of the tremors and shaking suggest they were not familiar with the differences between Parkinson’s disease and AD. Many participants had personal acquaintance with a

family member or friend with AD and referred to the experience of this known individual. Others referred to the media, particularly to what they had seen on television, as the source of their information.

There were some unexpected findings. The older African American population's strong spirituality and trust in God for healing<sup>19</sup> was not evident in these responses. Only 1 participant, an Afro-Caribbean, mentioned God or leaving the problem to God.

Traditionally, it was assumed that being diagnosed with AD was a devastating event<sup>20</sup> yet volumes of research have indicated that the diagnosed individual usually is able to cope with the diagnosis, sometimes expressing relief at knowing what is wrong.<sup>21</sup> This is reflected in the expression of concern, as opposed to fear, from participants.

The finding that half the participants would seek help from a physician if they screened positive is consistent with the findings from 2 other studies.<sup>22,23</sup> Consistent with that of Demirovic and colleagues,<sup>22</sup> we found more minority participants reporting that they would seek help from a physician than did the European Americans. When Boustani and associates<sup>23</sup> compared African Americans to whites, they found an interesting pattern related to age: African Americans over 80 declined diagnostic testing more frequently than whites; but among those younger than 80, the opposite pattern was evident.

Sometimes what is not said is as important as what is said in response to open-ended questions. In this study, not 1 participant mentioned consulting a memory disorder center to obtain a definitive diagnosis if their screen was positive. The 3 urban South Florida counties in which this study was conducted have 6 memory disorder centers that specialize in providing expert evaluation and diagnosis. It appears that their existence is not as well known to the general public as are the signs of AD. Instead, participants indicated that they would consult their general physician. This suggests that primary care providers, especially those with a preponderance of older adults in their practice, need to be well prepared to recognize the signs and symptoms of early AD and prepared to manage it.<sup>24</sup> Yet the accuracy of general practitioners' diagnoses and their ability to distinguish AD from depression may be of some concern.<sup>25</sup>

An objective test would not have brought out the misunderstandings noted in this study. Two measures of knowledge have been published recently but they were not developed from qualitative data. Carpenter and colleagues<sup>6</sup> created a 30-item dichotomous test "The Alzheimer's Disease Knowledge scale" that measures "risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management,"<sup>6(p236)</sup> developed from items used in other scales (some of which were designed for students or professionals). Only 2 items were similar in content to the misconceptions expressed by our participants (shaking as a symptom and short-term memory loss). Ayalon and Areán<sup>1</sup> used a 17-item, dichotomous assessment of "the nature, the consequences, and the cure of AD."<sup>1(p52)</sup> Only 1 of their items, about aluminum, was similar to the misconceptions voiced by our participants.

### Limitations

We used primarily open-ended questions that place a greater demand on participants to generate answers that represent all of their knowledge and gaps in their knowledge. What is not said remains unknown and the addition of some closed-ended questions might generate information on additional misconceptions and more information about the prevalence of specific misconceptions verbalized by our participants. Employing open-ended questions, on the other hand, does uncover misconceptions that currently available objective tests have not uncovered.

Sample strategies also deserve further study. Our participants were volunteers and randomly selected participants might have produced different results. Those with no knowledge of AD or a high level of fear of AD may not have volunteered for the cognitive screening.

Differences between Afro-Caribbeans and African Americans are likely related to differences in culture and life experiences as well as educational background. Samples that are more equivalent in regard to education could help clarify the source of the difference. A sample with balanced numbers of males and females would provide the opportunity to better explore gender differences. More detailed sociodemographic variables and measures of acculturation should be included to make it possible to more thoroughly examine their relationship to knowledge levels.

### Additional Comments

Campaigns to educate the public about AD need to target ethnic minority populations. Health educators should focus on dispelling misunderstandings and providing information about cognitive impairment, diagnostic resources, treatment options, and possible preventive actions such as maintaining a healthy brain with lifestyle changes including diet, stress reduction, and exercise.<sup>26</sup> Such information should be provided in a culturally appropriate format and should address the specific misconceptions held by the targeted population.

Readiness for information about AD was evident from participants' responses. When addressing the health information needs of older African Americans and particularly older Afro-Caribbeans, health educators should not assume that all will either be familiar with the term AD or know how to recognize the symptoms. The information presented should include a description in laymen's language of the signs and symptoms; the changes that occur in the brain and why they are thought to occur. Include information on treatments that are currently available, both pharmacological and behavioral. Likely misconceptions about what happens within the brain (eg, too "relaxed" or brain "collapse") and distinctions between the effects of AD and other neurodegenerative diseases such as Parkinson's should also be addressed. If done in a small group or individual format, participants should be encouraged to voice their own explanations and concerns so that the educator can understand the extent to which their disease construction is congruent with current research and can address particular concerns that have been raised.

Given the numbers of older adults projected to develop cognitive impairment in the future and the higher risk of minority populations, which may be mediated by lower levels of education and other early life disadvantages,<sup>27</sup> educational campaigns that will reach older adults from diverse backgrounds need to be developed. Knowledge is available about the potential for prevention through lifestyle changes that may reduce the number of older adults who become impaired. Early detection and treatment can delay the progression of cognitive impairment thereby reducing costs and improving quality of life. Further research can be used to monitor the effectiveness of the dissemination of this knowledge to those who need it most. Our research is encouraging in that participants were generally aware of AD and optimistic about the value of seeking help for cognitive decline. Through education about the causative factors, symptoms, prevention, and available treatments, older adults can be empowered to maintain cognitive health, recognize symptoms early, and seek appropriate treatment.

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