

# Knowledge of Alzheimer's disease in four ethnic groups of older adults

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## SUMMARY

**Objectives** The present study evaluated knowledge of Alzheimer's disease (AD) in four ethnic groups of older adults.

**Methods** Ninety-six Anglo, 37 Latino, 30 Asian, and 30 African American older adults completed a short survey about AD.

**Results** Results indicated that Anglo older adults are significantly more knowledgeable about AD than African American, Asian, and Latino older adults. Level of education partially accounted for differences in knowledge of AD between Latino and Anglo older adults. After controlling for age, number of years of speaking English was associated with knowledge of AD in Asian older adults.

**Conclusions** The results suggest that certain ethnic minority groups do not have sufficient information about AD, and this may explain the lack of AD service use by minorities. Extensive evaluation of barriers to knowledge of AD is needed in order to specifically target minority groups and educate them about AD and the importance of early intervention. Copyright © 2004 John Wiley & Sons, Ltd.

**KEY WORDS** — African Americans; Latino; Asian Americans; Caucasian Americans; dementia; acculturation; education

## INTRODUCTION

Cognitive enhancers, such as Aricept (donepezil) or Exelon (rivastigmine) as well as behavioral interventions, such as cognitive rehabilitation or memory training may be beneficial in slowing the rate of cognitive decline. These interventions are most effective when administered early in the course of the disease, thus, early recognition of Alzheimer's disease (AD) is crucial (Burns *et al.*, 1999; De Vreese *et al.*, 2001). While AD is more prevalent among ethnic minorities (Teng *et al.*, 1998), ethnic minority elderly are likely to receive the diagnosis of AD at later stages of the disease, following a long and debilitating course (Gallagher-Thompson *et al.*, 1997; Guo *et al.*, 2000; Hinton *et al.*, 2000) and, therefore, are less likely to

access early interventions and benefit from available treatments.

It is important to disseminate knowledge of AD and its course to the community. Theoretically, the more one knows about AD, the more likely one is to seek help for the disease. Education and dissemination programs for other diseases, such as HIV and hypertension, have found that community awareness of the disease, its causes and presentation can influence the rate at which community members seek diagnostic testing and treatment (Zimmerman *et al.*, 1986; Toro-Alfonso *et al.*, 2002). If older adults had accurate information about AD, they may be more inclined to discuss the disease with their medical doctors and to initiate treatment early.

Cross-ethnic research on knowledge of AD is limited and those studies that exist have relied primarily on qualitative methodology. It has been argued that, even though the biomedical model of AD is available, ethnic minorities tend to use folk models to explain AD symptomatology (Hinton and Levkoff, 1999; Levkoff *et al.*, 1999; Dilworth-Anderson and Gibson, 2002). The stigma of AD is prevalent among ethnic

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minorities and, at times, AD is seen as a punishment from God (Gallagher-Thompson *et al.*, 2000; Hinton *et al.*, 2000). Although the relationship between these beliefs and whether or not minorities receive a diagnosis early enough to benefit from treatment has not been established, it seems logical that these cultural beliefs are partly responsible for the under-use of cognitive enhancers and behavioral interventions among ethnic minorities.

While the above data are compelling, they have been derived primarily from qualitative interviews and thus may not be entirely representative of all minority elderly. This very useful information should be followed up with more rigorous methods to determine if knowledge of AD truly is variable between ethnic groups. The use of quantitative methods is important because it allows direct comparisons between ethnic groups about the accuracy of knowledge of AD as well as cultural beliefs and values associated with AD. It also confirms what aspects of AD knowledge vary between ethnic groups. The goals of the present study were twofold: (a) to evaluate ethnic group differences in knowledge of AD by the use of a close-ended AD questionnaire; and (b) to identify the role that level of education and level of acculturation play in ethnic group differences in knowledge of AD. Based on previous qualitative research, we hypothesized that: (a) Anglo older adults have more accurate knowledge of AD and higher levels of education than African American, Latino, and Asian elderly; and (b) ethnic group differences in knowledge of AD are accounted for by levels of education and acculturation.

## METHODS

### *Participants and procedure*

The sample consisted of 100 Anglo, 38 Latino, 30 Asian, 31 African American, and 10 ethnically unidentified older adults. Participants were recruited from four public sector primary-care clinics in San Francisco and were randomly selected from clinic logs for a survey study of distress in older minority medical patients (Areán and Alvidrez, 2001). Participants had to be 55 years of age or older and to speak English or Spanish in order to participate in the study. As part of the parent study, participants were administered the AD quiz by trained research assistants. This survey was administered at the end of the parent survey. Because of vision and literacy issues, all questions were read to participants. Interviews were conducted primarily in English. Interviews in Spanish were conducted with 27 of the Latino participants.

### *Measures*

*Knowledge of AD* was assessed by 17 true–false questions. The questionnaire was constructed in several steps. First, a list of questions was generated based on face validity. Second, the list was reviewed by AD and survey experts for wording. Last, the quiz was shown to a representative group of older adults for clarity. The quiz includes questions about the nature, the consequences, and the cure of AD. Correct answers were determined based on empirical evidence and clinical observations. The maximum total score on the quiz is 17. In the present study, moderate reliability was evident across all four ethnic groups (Cronbach's  $\alpha$  African American = 0.76; Cronbach's  $\alpha$  Asian = 0.84; Cronbach's  $\alpha$  Latino = 0.86; Cronbach's  $\alpha$  Anglo = 0.80).

*Acculturation* was defined in this study as years living in the United States and years speaking English. This information was derived from patient's self-report. Although this is a crude measure of acculturation, we needed a measure that could be applied uniformly to several ethnic groups, as most measures of acculturation are specific to the ethnic group for which they were developed and cannot be compared easily across groups. Most of the African Americans and Anglos in the present study were born in the United States. Therefore, we could not use years in the United States and years of speaking English as proxies of level of acculturation in these groups. It also is important to note that most of the Asians in the present study spoke English prior to coming to the United States. Therefore, years of speaking English may also be considered as an indicator of quality of education among Asian elderly.

*Education* was derived from patient's self-report.

*Ethnicity* was assessed by a multiple-choice format (1 = Other; 2 = Black; 3 = White; 4 = Asian; 5 = Latino).

*Other demographic information* marital status, place of birth, and age were derived from patient's self-report.

## RESULTS

### *Characteristics of the sample*

Participants who had incomplete information on the AD quiz and/or did not identify as Latino, Asian, African American, or Anglo were excluded from analysis ( $n = 16$ ). Significant ethnic group differences in level of education were found ( $F(3, 189) = 21.81$ ,

$p < 0.01$ ), with the Latino ( $t(189) = 8.06, p < 0.01$ ) and the African American ( $t(189) = 2.54, p < 0.05$ ) samples being significantly less educated than the Anglo sample. No significant differences in level of education were found between the Anglo and the Asian samples ( $t(189) = 1.73, n.s.$ ). Significant ethnic group differences in age were found ( $F(3, 189) = 4.26, p < 0.01$ ), with the Asian sample being significantly older than the Latino ( $\Delta = 4.99; SE = 1.76, p < 0.05$ ) and the African American ( $\Delta = 6.20; SE = 1.85, p < 0.05$ ) samples. Significant ethnic group differences in the sex distribution ( $\chi^2(3, n = 193) = 13.12, p < 0.01$ ) and in marital status ( $\chi^2(15, n = 193) = 49.03, p < 0.01$ ) also were found. The sample characteristics are summarized in Table 1.

*Ethnic group differences in knowledge of AD*

To assess ethnic group differences in knowledge of AD, a one-way analysis of variance (ANOVA) was conducted with the total score on the AD quiz as the dependent variable and ethnic group affiliation as the independent variable. Significant ethnic

group differences in knowledge of AD were found  $F(3, 189) = 35.68, p < 0.01$ . As expected, orthogonal comparisons of the Anglo sample to the Latino ( $t(189) = 8.76, p = 0.01$ ), the Asian ( $t(189) = 7.55, p < 0.01$ ), and the African American ( $t(189) = 2.84, p < 0.01$ ) samples indicated that the Anglo sample was significantly more knowledgeable about AD than the other ethnic groups. While 78.1% of Anglo elderly correctly answered at least 50% of the questions, only 20.0% of Asian elderly, 21.6% of Latino elderly, and 53.3% of African American elderly correctly answered at least 50% of the questions.

A summary of the percentage of people who responded correctly to the questions of the AD quiz by ethnic group affiliation is presented in Table 2. Low levels of knowledge of AD were prevalent across all four ethnic groups. The majority of older adults in all four groups had significant misperceptions about the prevalence, the etiology, the diagnosis, the financial coverage of AD treatments, and the course of AD. The majority of Latino and Asian older adults viewed AD as contagious and believed that AD was curable. Significantly more Latino, Asian, and

Table 1. Demographic characteristics of the four ethnic groups of older adults

Demographic variables	Ethnicity				Significant difference <sup>a</sup>
	African American ( <i>n</i> = 30)	Asian ( <i>n</i> = 30)	Latino ( <i>n</i> = 37)	Anglo ( <i>n</i> = 96)	
Age					
Mean	65.0	71.2	66.2	67.4	Asian > African American**
Standard Deviation	6.5	5.3	7.2	7.8	
Gender					
Male	25 (83.3) <sup>b</sup>	18 (60.0)	15 (40.5)	61 (63.5)	$p < 0.01^{**}$
Female	5 (16.7)	12 (40.0)	22 (59.5)	35 (36.5)	
Marital Status					
Married	5 (16.7)	19 (63.3)	15 (40.5)	13 (13.5)	$p < 0.01^{**}$
Separated	3 (10.0)	0 (0)	3 (8.1)	2 (2.1)	
Divorced	7 (23.3)	4 (13.3)	6 (16.2)	34 (35.4)	
Widowed	5 (16.7)	5 (16.7)	5 (13.5)	17 (17.7)	
Single	9 (30.0)	2 (6.7)	8 (21.6)	30 (31.3)	
Born in the United States	28 (93.3) <sup>b</sup>	1 (3.3)	6 (16.2)	82 (85.4)	$p < 0.01^{**}$
Years lived in the United States					
Mean	64.6	15.1	26.5	63.6	
Standard Deviation	6.7	17.2	19.2	12.5	
Years spoken English					
Mean	65.1	55.4	15.7	66.3	Anglo* > Asian, Latino; African American*, Asian* > Latino
Standard Deviation	6.5	18.0	23.1	8.8	
Years of Education					
Mean	11.5	12.2	7.4	13.6	African American*, Asian*, Anglo* > Latino
Standard Deviation	3.3	4.5	3.8	4.0	

<sup>a</sup>Significant differences on interval variables were identified using a one-way analysis of variance. Orthogonal comparisons and post-hoc analyses were then conducted. For nominal variables chi-square analyses were conducted. \* $p < 0.05$ , \*\* $p < 0.01$ , < > indicates direction of difference.

<sup>b</sup>Results are reported as frequency (percentage).

Table 2. Knowledge of AD among four ethnic groups of older adults

Knowledge of AD/Ethnicity	Percentage of people who responded correctly				Significant difference <sup>a</sup>
	African American (n = 30)	Asian (n = 30)	Latino (n = 37)	Anglo (n = 96)	
1. AD could be contagious ( <i>False</i> )	73.3	<b>46.7<sup>b</sup></b>	<b>48.6</b>	84.3	Anglo > Asian**, Latino**
2. All humans if they live long enough, will probably develop AD ( <i>False</i> )	66.7	<b>36.7</b>	<b>18.9</b>	77.0	Anglo > Asian**, Latino**
3. AD is a form of insanity ( <i>False</i> )	60.0	<b>36.7</b>	<b>35.1</b>	90.6	Anglo > Asian**, Latino**, African Americans**
4. AD is a normal process of aging, like graying of hair or wrinkles ( <i>False</i> )	50.0	<b>16.7</b>	<b>24.3</b>	65.6	Anglo > Asian**, Latino**
5. There is currently no cure for AD ( <i>True</i> )	63.3	<b>30.0</b>	<b>43.2</b>	80.2	Anglo > Asian**, Latino**
6. Persons with AD develop physical and mental problems ( <i>True</i> )	73.3	60.0	59.5	78.1	Anglo > Latino*
7. The major symptom of AD is memory loss ( <i>True</i> )	83.3	70.0	59.5	90.6	Anglo > Asian*, Latino**
8. In people over 75 years of age, forgetfulness is indicative of the beginning of AD ( <i>False</i> )	<b>40.0</b>	<b>13.3</b>	<b>24.3</b>	73.9	Anglo > Asian**, Latino**, African American**
9. When a spouse of someone elderly dies, the survivor can suffer a type of depression that appears as if it was AD ( <i>True</i> )	60.0	<b>43.3</b>	<b>32.4</b>	50.0	n.s.
10. Stuttering is an inevitable part of AD ( <i>False</i> )	53.3	<b>23.3</b>	<b>5.4</b>	62.5	Anglo > Asian**, Latino**
11. Elderly men are more likely to develop AD than elderly women ( <i>False</i> )	<b>20.0</b>	<b>13.3</b>	<b>16.2</b>	<b>43.1</b>	Anglo > African American*, Asian**, Latino**
12. AD is generally fatal ( <i>True</i> )	<b>23.3</b>	<b>16.7</b>	<b>37.8</b>	<b>41.6</b>	Anglo > Asian*
13. The majority of people that suffer from AD live in institutions, like asylums ( <i>False</i> )	70.0	<b>20.0</b>	<b>13.5</b>	71.8	Anglo > Asian**, Latino**
14. Aluminum has been identified as a significant cause of AD ( <i>False</i> )	<b>33.3</b>	<b>13.3</b>	<b>8.1</b>	<b>33.3</b>	Anglo > Asian*, Latino**
15. AD can be diagnosed with a blood test ( <i>False</i> )	<b>26.7</b>	<b>23.3</b>	<b>5.4</b>	<b>44.7</b>	Anglo > Asian*, Latino**
16. The costs of institutionalization, like an asylum, are paid by Medicare ( <i>False</i> )	<b>16.7</b>	<b>10.0</b>	<b>0</b>	<b>30.2</b>	Anglo > Asian*, Latino**
17. High blood pressure (hypertension) medication can cause symptoms similar to those of AD ( <i>True</i> )	<b>23.3</b>	<b>23.3</b>	<b>24.3</b>	<b>23.9</b>	n.s.
Mean total score (Standard deviation)	8.36 (3.61)	4.96 (3.89)	4.56 (3.94)	10.41 (3.02)	Anglo > Asian**, Latino**, African American**
Maximum total score = 17					

<sup>a</sup>Significant difference was calculated using a one-way analysis of variance. Orthogonal comparisons were calculated to test the initial hypothesis that Anglos would be more knowledgeable of AD than the other three ethnic groups. \* $p < 0.05$ , \*\* $p < 0.01$ , < > indicates direction of difference.

<sup>b</sup>Bold digits indicate that less than 50% of the sample responded correctly.

African American older adults than Anglo older adults viewed AD as a form of insanity. In addition, the majority of African American, Latino, and Asian older adults thought that forgetfulness was indicative of AD in older adults.

### The role of level of education

To assess the mediating role of level of education in ethnic group differences in knowledge of AD, a three-step mediating regression analysis was conducted (Baron and Kenny, 1986). The first two steps of the analysis are described above (i.e. assessing eth-

nic group differences in knowledge of AD and in level of education). If the first two steps of the analysis are significant, regression analysis with the total score on the AD quiz as the dependent variable, ethnic group affiliation as the independent variable, and level of education as a mediator is conducted (see Table 3). Level of education was partially responsible for higher levels of knowledge of AD among Anglo elderly relative to Latino elderly. Level of education did not account for differences in knowledge of AD between Anglo and African American elderly. Because there were no significant differences in level of education between Anglo and Asian elderly, level

Table 3. The role of level of education in ethnic group differences in knowledge of AD

Ethnic Group	Ethnicity			Education			R <sup>2</sup>
	B	SE B	$\beta$	B	SE B	$\beta$	
Anglo vs Latino	-2.39	0.38	-0.51**	0.17	0.07	0.19*	0.41
Anglo vs African American	1.75	0.64	0.22*	0.14	0.07	0.17	0.09

\* $p < 0.05$ , \*\* $p < 0.01$ .

Table 4. The role of level of acculturation in knowledge of AD among Asian and Latino older adults

Ethnic Group	Age			Years in the U.S.A.			Years of speaking English			R <sup>2</sup>
	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$	
Latino	0.10	0.09	0.19	0.03	0.05	0.17	0.01	0.04	0.08	0.07
Asian	-0.11	0.12	-0.16	-0.02	0.04	-0.11	0.09	0.03	0.46*	0.26

\* $p < 0.05$ , \*\* $p < 0.01$ .

of education was not studied as a mediator of group differences in these groups.

#### *The role of level of acculturation*

To assess the role of level of acculturation, regression analyses, with knowledge of AD as the dependent variable, years of speaking English and years in the United States as independent variables, and age as a control variable, were conducted for the Latino and the Asian samples, separately (see Table 4). For the Asian sample, years of speaking English, but not years in the United States predicted knowledge of AD. For the Latino sample, neither years in the United States nor years of speaking English predicted knowledge of AD. In addition, there was no significant difference in knowledge of AD between Latinos who chose to have the interview in English ( $M = 6.10$ ;  $SD = 3.75$ ) to those who were interviewed in Spanish ( $M = 4.00$ ;  $SD = 3.93$ ;  $t(35) = 1.45$ , *n.s.*).

## DISCUSSION

### *Ethnic group differences in knowledge of AD*

The main hypothesis of the present study was that Anglo older adults would have more accurate knowledge of AD than Latino, Asian, and African American older adults. This hypothesis was supported. Of the numerous misconceptions held by all four ethnic groups in the present study, stigmatization (e.g. the view of AD as contagious or as a form of insanity) and normalization of AD (e.g. the view of AD as non-fatal or as part of normal aging) are the views most likely to impede access to services (Guo *et al.*,

2000; Hinton *et al.*, 2000) and are the ones most prominent among the three ethnic minority groups in the present study. These views may seem contradictory. However, it is possible that the normalizing views of AD are more prevalent in the initial stages of the disease when AD symptoms are less severe, whereas the stigmatizing views of AD become more prevalent as the disease progresses and behavioral and cognitive symptoms become more prominent (Hinton *et al.*, 2000). It also is possible that relative to Anglo older adults, ethnic minority older adults hold a more stigmatizing view of aging in general and, therefore, believe that as people age they are likely to lose their memory and to become insane.

It is important to note that in addition to misconceptions about AD, numerous economic, linguistic, geographic, and cultural factors may hamper access to services among ethnic minorities. However, for educational campaigns aimed at increasing early detection and treatment of AD in minority populations, these data suggest that such campaigns would do well to inform the public that AD is not a normal part of aging and is not contagious, but is a serious condition which early treatment can forestall.

### *The roles of level of education and level of acculturation*

Our findings indicate that not ethnicity *per se*, but other factors associated with ethnicity, such as level of education and years of speaking English, account for the group differences identified. As expected, level of education partially explained differences in knowledge of AD between Latino and Anglo older adults. In addition, after controlling for age, years of speaking

English, but not years in the United States were associated with knowledge of AD among Asian elderly. Most of the Asians in the present study spoke English prior to immigrating to the United States. Therefore, years of speaking English can be considered as an indicator of quality of education among this group as well as an indicator of level of acculturation. The results suggest that level of education of Latinos and level of acculturation/quality of education of Asians are correlated with Western knowledge of AD. Based on these findings, it is suggested that among Latino and Asian elderly, those most at need for education about AD are of lower levels of education and acculturation. For African Americans, education did not explain differences in knowledge of AD. Possibly, other variables, such as place of residency, income, or parental achievements are responsible for the group differences identified.

The sample in the present study was limited to a small sample of older adults residing in the San Francisco Bay Area. Future research should replicate the study with a larger group of older adults from a variety of locales. In addition, level of acculturation was assessed only in the Latino and the Asian samples. Future research will benefit from a more comprehensive assessment of acculturation level and its role in knowledge of AD. Another potential limitation is the fact that the study design allowed for Latinos who spoke either English or Spanish to participate, while Asians who did not speak English were excluded from the study. This may have resulted in less educated Latinos than Asians. However, we did not find significant differences between Latinos who chose to be interviewed in English to those who were interviewed in Spanish, confirming that at least for the Latino sample, language of interview was not an important factor in determining knowledge of AD. In addition, while literacy level may have accounted for some of the differences in knowledge of AD identified, we attempted to overcome this potential problem by having representative older adults review the AD quiz for clarity during the measurement development stage and by conducting the survey in an interview format, allowing participants to receive on-going assistance. Last, the study did not assess the relationship between knowledge of AD and service use and did not assess how older adults access information about AD.

The uniqueness of the present study is the use of quantitative methods to assess knowledge of AD in four ethnic groups of older adults. Evaluating the role of education level and acculturation level in knowledge of AD also is an important contribution of this

study. Overall, the study confirms qualitative research that has found low levels of knowledge among older adults. Even though all four groups held significant misconceptions about AD, Latino and Asian elderly and to a slightly lesser degree African American older adults held the most stigmatizing and the most normalizing views of AD. These views are most likely to hamper access to services. The study also suggests that different pathways are responsible for the acquisition of knowledge in the different ethnic groups studied. Level of education accounted for differences in knowledge of AD between Anglos to Latinos, while level of acculturation/quality of education accounted for differences in AD knowledge among Asian elderly.

The Alzheimer's Association, as well as other local organizations, offer extensive educational materials and psychoeducational workshops about AD, in a variety of languages, designed to accommodate the needs of a wide range of ethnic groups. These interventions have shown to reduce distress and frustration among dementia caregivers and to increase a sense of control (Gallagher-Thompson *et al.*, 2001; Stolley *et al.*, 2002). Despite the availability of accurate information about AD, our study suggests that many older adults remain ill-informed about the disease. Because ethnic minorities demonstrated the lowest levels of knowledge of AD in the present study, efforts should specifically focus on identifying barriers to knowledge of AD in older ethnic minorities and on identifying their means of gaining information about AD.

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