

Re-examining ethnic differences in concerns, knowledge, and beliefs about Alzheimer's disease: results from a national sample

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Objective: This study aims to evaluate ethnic group differences in concerns, knowledge, and beliefs about Alzheimer's disease (AD) in three ethnic groups of older adults (White, Latino, and Black).

Methods: The Health and Retirement Study is a US national representative study of older adults over the age of 50 years and their spouse of any age. The study is based on the 2010 wave.

Results: Analysis is based on data from 939 White, 120 Latino, and 171 Black respondents who completed a special module about AD concerns, knowledge, and beliefs. There were significant ethnic differences on 7 of 13 items. However, after the adjustment for education, gender, age, having a family member with AD, depressive symptoms, and medical comorbidity, only four items showed significant ethnic group differences; relative to White respondents, Black respondents were less likely to report that having a parent or a sibling with AD increases the chance of developing AD and that genetics was an important risk for AD. In addition, relative to White respondents, both Black and Latino respondents were more likely to perceive stress as a potential risk for AD. Latino respondents were less likely to perceive mental activity as a protective factor.

Conclusions: The study found limited ethnic group differences, with most items showing a similar pattern across groups. Nevertheless, the nature of the ethnic group differences found might be associated with a differential pattern of health service use. Copyright © 2013 John Wiley & Sons, Ltd.

Key words: ethnic differences; ethnic gap; dementia; knowledge; beliefs; attitudes

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There are documented ethnic gaps in Alzheimer's disease (AD) assessment and treatment. For instance, research has shown that the prevalence of dementia is higher in Blacks and that they are more likely to use expensive inpatient care (Husaini *et al.*, 2003). Others have found ethnic minorities to be less likely to receive pharmacological interventions (Mehta *et al.*, 2005; Zuckerman *et al.*, 2008). To address this ethnic gap, a substantial body of research has focused on ethnic differences in concerns, knowledge, and beliefs about AD as potential variables of importance (Ayalon and Areán, 2004; Hinton *et al.*, 2005; Mahoney *et al.*, 2005; Connell *et al.*, 2007; Carpenter *et al.*, 2009; Fornazzari *et al.*, 2009; Gray *et al.*, 2009; Lee *et al.*, 2010; Schrauf and Iris, 2011; Tappen *et al.*, 2011). Past research has shown that ethnic minorities are more likely to view AD as a normal part of life

(Ayalon and Areán, 2004; Connell *et al.*, 2009; Gray *et al.*, 2009), to believe AD is contagious (Ayalon and Areán, 2004), and to view AD as a form of insanity (Lee *et al.*, 2010). The theoretical rationale behind this line of research is that the way people think about and interpret events (including physical or cognitive symptoms) determines their emotional and behavioral responses (Leventhal, 1984; Lobban *et al.*, 2003).

Although highly informative, most of this research was based on nonrepresentative samples of caregivers, older adults, or lay persons, with very few studies being based on representative samples (Connell *et al.*, 2007). The different wording and constructs evaluated in the various studies also make it difficult to compare across studies and to draw conclusions about the state of knowledge and beliefs among different groups in the

population (Anderson *et al.*, 2009). These shortcomings have led a recent review on the topic to conclude that "critical next steps are needed to better understand knowledge, beliefs, and concerns about cognition among the general public, particularly in diverse social and cultural groups (Anderson *et al.*, 2009)."

In contrast to much of past research, the present study provides a representative data of the US population. The study also uses selected questions that were in use in past research to allow for easy comparisons across studies. In addition, in contrast to much of past research that did not control for important variables (e.g., education) that might explain ethnic group differences in concerns, knowledge, and beliefs about AD (Anderson *et al.*, 2009), the present study controls for demographics and clinical variables of potential importance.

To evaluate the relative role of ethnicity in concerns, knowledge, and beliefs about AD, I first examined unadjusted ethnic group differences, then adjusted for potential variables that differ across ethnic groups to examine potential mediating effects, and finally, adjusted for additional variables that might also be of importance when considering AD concerns, knowledge, and beliefs, even if these variables do not differ across ethnic groups. On the basis of past research, I expected White respondents to report concerns, knowledge, and beliefs about AD that are more consistent with current scientific views compared with ethnic minorities. I also expected ethnic differences to be largely accounted for by other demographic variables that might differ across ethnic groups, such as level of education or familiarity with AD. The sociodemographic and clinical variables evaluated in the present study were selected because these variables were hypothesized to differ across ethnic groups (e.g., level of education) and/or to relate differently to concerns, knowledge, and beliefs about AD (e.g., individuals with higher medical comorbidity are more knowledgeable about AD because of greater exposure to medical settings and knowledge, or individuals with higher levels of depressive symptoms are more likely to report perceived risks for AD due to their mental status).

Methods

The study is based on the 2010 wave of the Health and Retirement Study (HRS, <http://hrsonline.isr.umich.edu/>), a representative national sample of US residents over the age of 50 years and their spouse of any age. There is an oversampling of Blacks, Latinos, and residents of Florida. The HRS is sponsored by the National Institute of Aging and is conducted by the University of Michigan. The study is reviewed and

approved by the University of Michigan's Health Sciences institutional review board. Participants take part in a biennial interview that covers a range of topics including income, wealth, work, retirement, health, and health-care utilization.

The present cross-sectional study is based on the 2010 wave, which included a module on AD concerns, knowledge, and beliefs. A total of 1252 were randomized to this module. Because of the small number of respondents who self-identified their ethnicity as "other" (22), this group was excluded, and analysis was restricted to data from 939 White, 120 Latino, and 171 Black respondents. A total of 654 face-to-face interviews were conducted, and the remaining interviews were conducted over the phone.

Measures

Concerns about AD. Respondents were asked to rank three questions regarding their concerns about AD (e.g., worry about getting AD) on a five-point scale (1 = strongly agree; 5 = strongly disagree). Similar items were used in past research to evaluate concerns about AD (Roberts *et al.*, 2003); see Table 2 for details.

Knowledge about AD. Four true/false items addressed knowledge about AD (e.g., prescription drugs that prevent AD are available). The psychometric properties of these items were previously evaluated (Carpenter *et al.*, 2009); see Table 2 for details.

Beliefs about factors that increase the risk for AD. Two items, ranked on a three-point scale (1 = very important; 3 = not at all important), addressed beliefs about factors that increase the risk for AD (e.g., stress). These items were used in past research (Carpenter *et al.*, 2009; Roberts and Connell, 2000); see Table 2 for details.

Beliefs about factors that decrease the risk for AD. Four items, ranked on a three-point scale (1 = very important; 3 = not at all important), addressed beliefs about factors that decrease the risk for AD (e.g., vitamins). Similar items were used in past research (Connell *et al.*, 2009; Roberts *et al.*, 2003); see Table 2 for details.

Sociodemographic variables. Ethnicity (White, Latino, and Black), age (>75 years), gender, education (>12 years of education), and whether or not one had a family member with AD were gathered on the basis of self-report.

Depressive symptoms. Symptoms were evaluated using the Center for Epidemiologic Studies Depression Scale (Radloff, 1977), a common eight-item measure of depressive symptomatology, often used in large epidemiological studies. A cutoff of 4 or higher was considered as indicative of depression (Steffick, 2000).

Medical comorbidity. Respondents were asked to indicate whether a physician told them they suffer from any of the following four medical conditions, which are considered risk factors for AD: stroke, hypertension, diabetes, and heart condition. The sum of all four conditions was dichotomized to represent the presence of no or one condition versus more than one condition.

Analysis

Because responses on continuous items were skewed and to maintain consistency with past research (Connell *et al.*, 2009), all nonbinary AD concerns and beliefs items were recategorized; items addressing concerns about AD were recategorized as 1 = strongly agree or somewhat agree versus 0 = neither agree nor disagree, somewhat disagree, or strongly disagree. AD beliefs items were recategorized as 1 = very important or somewhat important versus 0 = not at all important. To determine the independent association of ethnicity, chi-square analyses were calculated. Next, to test for mediation, a series of logistic regressions were employed with the AD concerns, knowledge, and beliefs items as outcome variables. Ethnicity served as an independent variable, and age, education, and depressive symptoms were separately adjusted for, as these three variables differed across ethnic groups. Next, ethnicity served as an independent variable, and all covariates were entered simultaneously into the model. This analysis allows examining the unique contribution of ethnicity after controlling for all other potential predictors. All analyses

were weighted and stratified, using STATA's SVY (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP.) command to account for the complex sample design employed by HRS.

Results

Table 1 outlines the characteristics of the sample by ethnic group. The majority of the sample consisted of White (939), followed by Black (171) and Latino (120) respondents. The Latino sample was significantly younger than the other ethnic groups. In addition, the White sample was the most educated and the least likely to be classified as depressed. There were no ethnic group differences in gender distribution, in whether or not one had a family member with AD, or in medical comorbidity.

Bivariate analyses

Concerns about AD. The majority of the sample, across ethnic groups, reported a wish to know their chance of having AD. There were no ethnic group differences on this item. There were ethnic differences in the perceived chance of getting AD, with the White sample being the least likely and the Latino sample being the most likely to believe they will get AD. Between one-quarter to one-third in each ethnic group reported worrying about getting AD. There were no ethnic group differences on this item (Table 2).

Knowledge about AD. There were significant ethnic group differences on all four knowledge items (Table 2). Most Latino and to a slightly lower degree Black and White respondents thought that people with AD are not capable of making informed decisions. About a third of the White sample, but almost 50% of the Black sample and a little over half of the Latino sample,

Table 1 Sample characteristics by ethnicity

	White (<i>n</i> = 939) <i>n</i> (%)	Latino (<i>n</i> = 120) <i>n</i> (%)	Black (<i>n</i> = 171) <i>n</i> (%)	χ^2	<i>df</i>	<i>p</i> -value
Age (>75 years)	308 (24.5)	18 (8.8)	51 (23.4)	12.2	2	<0.01
Female	519 (51.6)	73 (53.0)	117 (60.2)	2.9	2	0.29
Education (>12 years)	467 (54.1)	25 (24.6)	61 (38.3)	38.0	2	<0.001
Have a family member with AD	119 (20.3)	14 (23.5)	27 (29.5)	3.0	2	0.15
Medical comorbidity (>1)	327 (31.9)	46 (30.5)	82 (43.1)	5.9	2	0.09
Depressive symptoms (≥ 4)	101 (10.9)	25 (18.5)	28 (16.7)	7.4	2	0.04

AD, Alzheimer's disease; *df*, degree of freedom.

Frequencies and percentages, *n* (%), are reported; chi-square analyses were conducted.

Table 2 AD attitudes, knowledge, and beliefs

Dependent variables	White n (%)	Latino n (%)	Black n (%)	χ^2	df	p-value
Concerns about AD ^a						
Wish to know the chance of having AD (strongly agree or somewhat agree)	521 (57.0)	69 (57.0)	103 (63.3)	1.6	2	0.51
Believe will get AD (strongly agree or somewhat agree)	184 (19.9)	40 (33.9)	47 (27.8)	12.4	2	<0.01
Worry about getting AD (strongly agree or somewhat agree)	259 (27.1)	44 (36.5)	44 (24.2)	4.4	2	0.10
Knowledge about AD ^b						
People with AD are not capable of making informed decisions (F)	296 (34.4)	13 (7.2)	29 (22.4)	33.8	2	<0.001
Prescription drugs that prevent AD are available (F)	552 (63.4)	49 (46.7)	80 (51.6)	14.4	2	0.02
It is safe for people with AD to drive as long as they have a companion (F)	799 (88.2)	94 (76.9)	146 (86.8)	10.2	2	0.02
Having a parent or sibling with AD increases the chance of developing it (T)	620 (71.0)	79 (62.9)	86 (48.4)	22.8	2	<0.001
Beliefs about factors that increase the risk for developing AD ^c						
Stress (very important or somewhat important)	517 (55.6)	92 (77.2)	130 (82.5)	41.0	2	<0.001
Genetics (very important or somewhat important)	823 (90.7)	101 (87.0)	133 (84.0)	5.3	2	0.10
Beliefs about factors that lower the risk for AD						
Physical activity (very important or somewhat important)	821 (90.0)	103 (83.6)	137 (87.3)	3.7	2	0.15
Mental activity (very important or somewhat important)	878 (95.2)	107 (84.4)	143 (88.2)	23.4	2	<0.001
Healthy diet (very important or somewhat important)	807 (89.2)	101 (84.1)	137 (86.2)	2.9	2	0.27
Vitamins (very important or somewhat important)	659 (74.2)	87 (74.9)	121 (82.0)	3.0	2	0.24

AD, Alzheimer's disease; *df*, degree of freedom.

^aFrequency and percentage of those endorsing strongly agree or somewhat agree in response to the concerns about AD items.

^bFrequency and percentage of those endorsing false (F) or true (T) in response to the AD knowledge items.

^cFrequency and percentage of those endorsing very important or somewhat important in response to factors that increase or lower the risk for AD.

reported that prescription drugs that prevent AD were available. A little over 10% of the White and Black samples, but over 20% of the Latino sample, thought that it was safe for people with AD to drive as long as they had a companion. Most White and Latino respondents, but a little less than half of the Black sample, thought that having a parent or a sibling with AD increased one's chances of developing AD.

Beliefs about factors that increase the risk for having AD. There were ethnic group differences in the belief that stress is a risk for AD, with the White sample being the least likely to acknowledge stress as a very important or somewhat important risk factor. There were no ethnic group differences in the belief that genetics was a risk for AD, with most respondents across ethnic groups identifying genetics as a risk factor (Table 2).

Beliefs about factors that lower the risk for having AD. Chi-square analyses were conducted to examine the relationship between ethnicity and beliefs about factors that lower the risk for AD. There were ethnic group differences on only one item (mental activity as a protective factor against AD), with the other three items showing no difference across groups. Most respondents thought that mental activity was a protective factor

against AD, but Whites were the most likely to report it as a protective factor and Latinos were the least likely. In addition, most respondents, unrelated to ethnic group, believed that physical activity, keeping a healthy diet, and taking vitamins were protective against AD (Table 2).

Ethnic differences adjusted for age, education, or depressive symptoms, separately

All significant ethnic group differences evident in bivariate analyses were evident after adjusting for age or depressive symptoms, separately. After the adjustment for education, some of the ethnic group differences evident in bivariate analyses were not maintained; there were no significant ethnic differences on the item "believe will get AD," adjusted Wald test, $F(2, 51) = 1.56$, $p = 0.22$, and on the item "prescription drugs that prevent AD are available," adjusted Wald test, $F(2, 51) = 1.05$, $p = 0.35$. In addition, there were no significant differences between Black and White respondents, OR [95% CI] = 0.65[0.39–1.09], $p = 0.10$, on the item "people with AD are not capable of making informed decisions," but Latino versus White differences were maintained, OR [95% CI] = 0.24 [0.09–0.65], $p < 0.01$; adjusted Wald test, $F(2, 51) = 5.10$, $p < 0.01$. Finally, after the adjustment for education, there were no significant differences

between Whites and Latinos in the belief in stress as a risk for AD, OR [95% CI] = 1.79[.97–3.29], $p = 0.06$, but differences between White and Black respondents remained significant, OR [95% CI] = 3.38[1.87–6.11], $p < 0.001$; adjusted Wald test, $F(2, 51) = 9.54$, $p < 0.01$. In all of these instances, education was a significant correlate of the outcome variables examined, suggesting that it mediates some of the ethnic differences observed. Further results are available upon request.

Ethnic differences adjusted for age, gender, education, having a family member with AD, depressive symptoms, and medical comorbidity

Concerns about AD. After the adjustment for covariates, there were no ethnic group differences on these three items (Table 3).

Knowledge about AD. After the adjustment for covariates, of the four knowledge items, only one remained significantly different across ethnic groups, with Black respondents being significantly less likely to acknowledge that having a parent or a sibling with AD increases one's chances of developing AD (Table 3).

Beliefs about factors that increase the risk for having AD. After the adjustment for covariates, both Latino and Black respondents were more likely than Whites to believe that stress was a very important or somewhat important risk for AD. In addition, Black respondents were significantly less likely than White respondents to acknowledge genetics as a risk for AD (Table 3).

Beliefs about factors that decrease the risk for having AD. After the adjustment for covariates, Latino respondents were less likely to identify mental activity as a protective factor against AD. There were no ethnic differences on the other items (Table 3).

Discussion

The present study evaluated concerns, knowledge, and beliefs about AD in three ethnic groups of older adults over the age of 50 years. In the unadjusted model, seven of the items differed across ethnic groups. However, once adjusted for sociodemographic variables, only four items showed ethnic group differences. The level of education in particular seems to play a role in mediating ethnic group differences. These findings point to the important role of education in determining one's concerns and knowledge about AD. The study suggests that the educational interventions might prove useful

in closing the ethnic gap in relation to concerns and knowledge about AD.

The present findings should be contrasted with much of past research that did not account for other sociodemographic variables when examining ethnic group differences (Ayalon and Areán, 2004; Gray *et al.*, 2009). This may account for the fact that past research has found more consistent evidence for ethnic differences. Moreover, some questions that have shown to differ across ethnic groups, such as the belief that AD is a punishment by God or the belief that AD is a normal part of life (Ayalon and Areán, 2004), were not addressed in the present study. As such, the study was somewhat limited in replicating past ethnic differences that might be of importance.

A consistent ethnic difference concerning the attribution of genetic factors to AD emerged. Blacks were significantly less likely to agree with the statement that having a parent or a sibling with AD increased one's chances of developing AD and less likely to perceive genetics as an important risk factor for AD. There has been a growing debate about the role of genetics in AD (Bertram *et al.*, 2007). Nevertheless, it is expected that those who attribute a genetic component to AD will be more likely to seek consultation if their family member has AD. As such, it is possible that Blacks will be particularly hesitant to seek consultation under these circumstances. Therefore, educational interventions concerning the role of genetics in AD might be particularly beneficial for Blacks.

Relative to White respondents, both Latino and Black respondents were more likely to believe that stress was a risk for AD, and Latino respondents were less likely to believe that mental activity was a protective factor against AD. These findings imply a different disease model in Whites versus Latinos and Blacks. Given past research that has consistently documented a relationship between one's illness beliefs, illness behaviors, and clinical outcomes, these findings have important practical implications (Petrie *et al.*, 2007). Attributing AD to stress might put the responsibility for the condition on the individual and as a result might be associated with greater stigma and lower probability of seeking formal assistance. Attributing AD to mental activity, on the other hand, may encourage individuals to engage in various mental activities (e.g., crossword puzzles and online games) as a means to prevent or ameliorate the effects of the disease, whereas a lack of such perception might result in opposite behaviors. Further education concerning the role of stress in AD is warranted; especially as scientific knowledge about it becomes more conclusive. In addition, Latino older adults could benefit from further knowledge about

Table 3 Logistic regression of ethnic differences in AD attitudes, knowledge, and beliefs adjusted for age, gender, education, having a family member with AD, medical comorbidity, and depressive symptoms

Dependent variables	Adjusted OR (95% CI) ^a	Black	Latino	Adjusted Wald test $F(2, 51)$ ^b	p-value
Concerns about AD ^c					
Wish to know the chance of having AD (strongly agree or somewhat agree = 1)	1.30 (0.59–2.89)	1.25 (0.78–2.00)		0.66	0.52
Believe will get AD (strongly agree or somewhat agree = 1)	1.12 (0.59–2.10)	1.05 (0.53–2.06)		0.07	0.93
Worry about getting AD (strongly agree or somewhat agree = 1)	1.18 (0.63–2.19)	0.61 (0.35–1.05)		2.05	0.13
Knowledge about AD ^d					
People with AD are not capable of making informed decisions (F = 1)	0.31 (0.08–1.16)	0.65 (0.31–1.37)		2.01	0.14
Prescription drugs that prevent AD are available (F = 1)	0.79 (0.34–1.83)	0.78 (0.43–1.41)		1.35	0.26
It is safe for people with AD to drive as long as they have a companion (F = 1)	0.66 (0.27–1.60)	1.37 (0.59–3.15)		0.73	0.49
Having a parent or sibling with AD increases the chance of developing it (T = 1)	0.79 (0.33–1.92)	0.32 (0.19–0.53)		10.75	<0.001
Beliefs about factors that increase the chance of developing AD ^e					
Stress (very important or somewhat important = 1)	2.41 (1.22–4.77)	4.66 (2.22–9.72)		11.85	<0.001
Genetics (very important or somewhat important = 1)	0.55 (0.18–1.71)	0.34 (0.14–0.82)		3.45	0.04
Beliefs about factors that lower the chance of AD					
Physical activity (very important or somewhat important = 1)	0.44 (0.18–1.12)	1.08 (0.48–2.47)		1.62	0.21
Mental activity (very important or somewhat important = 1)	0.22 (0.08–0.56)	0.41 (0.17–1.01)		7.00	<0.01
Healthy diet (very important or somewhat important = 1)	0.71 (0.23–1.13)	0.57 (0.24–1.38)		0.88	0.42
Vitamins (very important or somewhat important = 1)	0.62 (0.30–1.29)	1.57 (0.76–3.25)		2.33	0.10

OR, odds ratio; AD, Alzheimer's disease.

^aWhite respondents represent the reference category; odds ratios and 95% confidence intervals are reported.^bAdjusted Wald tests examine the overall effects of ethnicity in the adjusted models.^cA value of 1 represents a response of strongly agree or somewhat agree on the concerns about AD items, whereas 0 represents neither agree nor disagree, somewhat disagree, or strongly disagree.^dA value of 1 represents the more accurate response to the knowledge about AD items, either false (F) or true (T) as indicated in parentheses. A value of 0 reflects an inaccurate response.^eA value of 1 represents a response of very important or somewhat important to the factors that increase or lower the chance of developing AD. A value of 0 represents a response of not at all important.

leisure activities, which have shown to reduce the risk for AD (Helzner *et al.*, 2007).

Finally, consistent with past research (Connell *et al.*, 2009; Roberts *et al.*, 2003), results demonstrated that most respondents wished to know their risk for developing AD but did not believe they would get AD and did not worry about getting AD. This approach was consistent across ethnic group and showed little variability after the adjustment for sociodemographic and clinical variables. Whereas these beliefs could facilitate early diagnosis, the belief one would get AD or worries about developing the condition could also result in high levels of stress that might serve as a barrier to service use. Further research is necessary to evaluate the associations of these items with actual service use.

Despite its notable strengths, the study has several limitations that should be noted. First, although the questionnaire addressed several domains, including AD concerns, knowledge, and beliefs, each domain contained only a few items. The division of the items to the three domains was somewhat arbitrary. For instance, the item "Having a parent or sibling with AD increases the chance of developing AD" could have been classified under either the beliefs about risk factors domain or the knowledge domain. In addition, some of the questions addressed in this study do not offer a clear-cut answer even in the scientific literature (e.g., stress as a risk factor for AD). As such, it is not clear how to address these concepts in future educational interventions. Another limitation concerns the lack of representation of Asians in the HRS dataset. Nevertheless, despite its limitations, the study has several strengths that should be noted. This is one of very few national samples to address the topic of AD concerns, knowledge, and beliefs and the only one to target individuals over the age of 50 years, who are considered important stakeholders either as carers or as patients. Another advantage of this study is the adjustment for a variety of sociodemographic variables to better contextualize the role of ethnic group differences. Finally, the fact that the measures used in the present study have already been used in other studies and, thus, allow for relatively easy comparisons across studies is another advantage. The present study found limited ethnic group differences, with most items showing a similar pattern across groups. This suggests that overall, educational campaigns can be largely consistent across ethnic groups. The specific items that did show ethnic group differences might be associated with a different pattern of illness representations and health behaviors in these three ethnic groups and, therefore, should receive specific targeted attention in future educational interventions.

Key points

- Ethnic differences in concerns, knowledge, and beliefs about Alzheimer's disease were evident on 7 of 13 items.
- After the adjustment for sociodemographic variables, only four items significantly differed across ethnic groups.
- Education has an important role in mediating some of the ethnic differences found.
- Educational campaigns can be largely consistent across ethnic groups, with only several deviations based on ethnicity.

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Conflict of interest

None declared.

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