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ORIGINAL RESEARCH

Differences Between African American and White Research Volunteers in Their Attitudes, Beliefs and Knowledge Regarding Genetic Testing for Alzheimer's Disease

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Abstract Genetic susceptibility testing for common diseases is expanding, but little is known about race group differences in test perceptions. The purpose of this study was to examine differences between African Americans and Whites in knowledge, attitudes, and motivations regarding genetic susceptibility testing for Alzheimer's disease (AD). Before enrolling in an AD genetic testing research trial, 313 first-degree relatives of AD patients (20% African American; 71% female; mean age = 58 years) were surveyed regarding: (1) knowledge about genetics and AD risk; (2) concerns about developing AD; and (3) reasons for seeking testing. In comparison to Whites, African Americans were less knowledgeable about genetics and AD risk ($p<.01$) and less concerned about developing AD ($p<.05$), with lower levels of perceived disease risk ($p=.04$). The results suggest that African Americans and Whites differ notably in their knowledge, beliefs, and attitudes regarding genetic testing for AD. Additional research with more representative samples is needed to better understand these differences.

Keywords Genetic testing · African Americans · Alzheimer's disease · APOE · Risk assessment · Susceptibility testing · Health beliefs · Health literacy · Health disparities

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Introduction

The number of people with Alzheimer's disease (AD) has nearly doubled since 1980, with greater than four million Americans living with the disease (Alzheimer's Association 2008). Genetic tests that identify individual susceptibility to several common adult-onset diseases, including AD, are now commercially available, and medical advances in genetic research on AD have brought about the possibility of genetic susceptibility testing for asymptomatic individuals (Masters and Beyreuther 1998; Peters et al. 2004; Roses 1997). Susceptibility alleles are distinct from Mendelian variations for conditions such as Huntington's disease in that they are typically more prevalent but much less strongly associated with disease expression (Farrer et al. 1995b). The Apolipoprotein (APOE) ε4 allele on chromosome 19 is a well-established genetic risk factor for AD (Kim et al. 2009).

Limitations in test sensitivity and specificity coupled with the lack of treatment options for the disorder have prompted concerns about introducing this type of genetic testing for AD into clinical practice (AGSEC 2001; Farrer et al. 1995a; McConnell et al. 1998; NIA et al. 1996; Post et al. 1997). However, predictive testing is already available for families with rare early-onset forms of AD (Lennox et al. 1994) and susceptibility testing, along with predictive testing using neuroimaging results and other biomarkers, may one day become a viable option for the millions of first-degree relatives of patients with AD who are at increased risk for developing this disease (Roberts and Tersegno 2010).

There is some evidence that the incidence of AD, the impact of risk factors causing the disease, and the impact of family history may differ between African Americans and Whites (Farrer et al. 1997; Gurland et al. 1999; Tang et al. 1998, 2001). A focus has been placed on African Americans due to recent research suggesting that this group is at heightened risk for developing AD in comparison to Whites (Green et al. 2002). Epidemiological studies have consistently supported a higher age specific prevalence of dementia (Gurland et al. 1999), higher cumulative risk of AD (Tang et al. 1998) and higher incidence rates of AD (Tang et al. 2001) among African Americans compared with Whites. The ε4 allele is an important risk factor for AD in African Americans, particularly among those younger than 70 years of age (Graff-Radford et al. 2002). It has been suggested that *APOE* information can be used in a research setting to offer genetic counseling to family members of patients with AD (Green 2002).

Clinical research suggests Whites are far more likely than ethnic minorities to pursue genetic counseling and genetic susceptibility testing (Armstrong et al. 2005) for conditions such as hereditary breast and ovarian cancer syndrome, and that this disparity may be attributable to differences in exposure to genetic information and referrals by health care providers (Hughes et al. 2003). However, there has been little research done on race/ethnic group differences in attitudes toward, and interest in genetic susceptibility testing. To date, only a few studies have been conducted in this area, and most have relied on hypothetical test scenarios as opposed to actual test situations (Neumann et al. 2001; Roberts 2000). In a study done by Hipps et al. (2003), attitudes toward genetic testing for AD were investigated in a racially diverse sample, with African Americans showing less interest in testing, endorsing fewer reasons for pursuing it, and anticipating fewer negative consequences from a positive test result than their White counterparts. Conversely, a telephone survey conducted by Singer et al. (2004), found that Latinos and African Americans were more likely to express preferences for prenatal and adult genetic testing in comparison to Whites. Reasons for these differences are not fully understood but may be attributable to the different sampling techniques and survey methods employed by these studies. The current study represents a real-life genetic testing situation with a sample of participants who volunteered to receive APOE results and genetic susceptibility information related to AD. The purpose of this study was to investigate race group differences in knowledge about and attitudes towards genetic testing prior to receiving standardized education that was provided as part of the protocol.

Methods

Participants and Procedures

Data utilized in this analysis were from the second in a series of randomized controlled clinical trials, known as the REVEAL (Risk Evaluation and Education for Alzheimer's Disease) Study, investigating the impact of risk assessment in asymptomatic family members of AD patients. In this study, adult children and siblings of patients with AD received education, genetic counseling and risk assessments regarding their own chances of developing AD. Participants were given personalized risk information based on their age, race, gender, family history of AD, and APOE genotype (Cupples et al. 2004). The study was conducted with Institutional Review Board approval at four sites including: Boston University, Case Western Reserve University, Weill Medical College of Cornell University and Howard University. Most study participants heard about the REVEAL Study through the media, the Internet, other research studies, public presentations, or word-of-mouth. A few participants were recruited through AD research registries at the participating sites, or while attending memory assessment clinics with their affected family member.

Adults over the age of 18 who had one living or deceased first-degree relative with AD were eligible for this study. Individuals who had more than one affected first-degree relative were excluded from the study, as risk estimates were not developed for that higher-risk population. Additionally, we excluded individuals with first-degree relatives who developed the disease before the age of 60 given the study's focus on risk for late-onset AD. Individuals over the age of 85 were also excluded because there were insufficient data to produce AD risk estimates beyond the age of 85.

Project staff members, who were primarily master's level research assistants trained in study procedures, collected basic demographic information from potential participants by telephone in order to assess their study eligibility prior to enrollment in the REVEAL Study. Eligible individuals then proceeded to the second step of the study where informed consent was obtained; more detailed demographic information was collected, and knowledge and attitudes regarding AD, genetics, and personal risk of developing

AD (including most of the data for this paper) were assessed. Participants willing to proceed further into the study were then randomized into one of two different education and AD risk disclosure arms. Data used in this study were collected on an individual basis over a 3-year period. Primary outcomes of this randomized trial will be reported elsewhere and are not addressed in this paper.

Measures

Knowledge

At baseline, participants were asked four general knowledge questions (see Table 2) regarding AD and genetic testing developed as part of a study of a racially diverse sample of older adults in the Boston and Birmingham, AL areas (Moscarillo et al. 2007). Responses to each question were analyzed and correct responses were then individually summed to create an overall knowledge score ranging from 0 to 4.

Concern About AD

At baseline, participants were also asked five questions over the phone regarding their concern about developing AD (see Table 3). These questions were drawn from prior work on attitudes toward genetic testing for AD, including a large community-based survey in the Southeast that oversampled African Americans (Green 2002; Roberts 2000). Participants were asked to indicate the extent to which they agreed with each item using a 5-point Likert type scale (1 = "strongly disagree" to 5 = "strongly agree") and each of the five items were examined independently. Additionally, we dichotomized (1 = agree; 0 = did not agree) responses to each question by grouping answers of agreement (i.e. 1 = participants responded "somewhat agree" or "strongly agree") versus answers of "neutral" or disagreement (i.e., "somewhat disagree," or "strongly disagree"). In a separate analysis, participants were also asked to provide a numerical estimate of what they thought their chances were of developing AD throughout their lifetime, rating their estimates by choosing a number between 0 and 100%.

Reasons for and Against Seeking Genetic Susceptibility Testing

Prior to attending their education session, participants were asked to rate the importance of twelve possible reasons why they might seek genetic risk assessment for AD (Table 4) (Roberts et al. 2003). These reasons covered personal, family, altruistic, pragmatic and financial motivations. Participants were also asked to rate the importance of ten possible reasons not to seek genetic testing for AD (Table 5). Reasons offered included unwanted distress and emotional reactions, lack of definitive results, lack of a cure or prevention medication, and others. Both scales demonstrated a high level of internal consistency reliability in the current study (Cronbach alpha = 0.82 for reasons for seeking testing scale, 0.81 for reasons against seeking testing scale).

Participants were asked to indicate how important the listed factors were to them personally by using a 5-point scale (1 = "not at all important" to 5 = "extremely important"); these items were analyzed individually. Dichotomous responses (1 = important vs. 0 = not important) were created by grouping responses indicating the question was important (1 = "very important" or "extremely important") vs. neutral or not important. These dichotomized responses were used to create summed scores representing the total number of reasons endorsed for and against seeking genetic testing.

General Anxiety

The Beck Anxiety Inventory (BAI) is a 21-item measure designed to distinguish common symptoms of anxiety from those of depression and to be sensitive to treatment change (Beck et al. 1988). It has been extensively validated and has shown excellent test-retest reliability and internal validity (Wetherell and Arean 1997). The BAI is scored on the basis of self-reported severity of a given symptom over the past week from 0 (not at all) to 3 (severe), yielding a total score from 0 to 63.

Data Analysis

All analyses were conducted using SAS 9.1 software. Descriptive statistics were used to characterize sample demographics and responses on individual survey items. Chi-square analyses were used to examine race group differences on categorical items. Analyses of covariance were used to examine race group differences on continuous summed items adjusting for the following covariates: age, gender, years of education [range: 0 (no formal education) to 20 (doctoral degree)], and baseline BAI score. Logistic regression analyses were performed on the dichotomized individual items on (a) the AD concern scale, (b) the reasons for seeking genetic testing scale, and (c) the reasons against testing scale, adjusting for the same covariates listed above. Income level was not included as a covariate given its collinearity with education level. Additionally, including income would require removing a significant number of participants with missing income responses, thus decreasing our sample size and statistical power. A *post hoc* analysis among subsamples matched by socioeconomic status assessing ethnic group differences between participants in

a low SES vs. a high SES group produced results following the same trends we observed in analyzing the total sample (data not shown).

Results

Demographics

A total of 313 African American and White participants were enrolled in the study at the pre-education stage (See Table 1), after excluding 7 participants with other race and 9 participants with missing responses (response rate 97% among participants at pre-education). All of these participants were adult children or siblings of persons with AD, and the majority of participants were White (80%), female (71%) and college-educated (mean = 16 years of education). Most participants were in a high median income bracket ($70,000–99,000), and had health insurance upon entering the study (96%).

Of the 313 participants, 20% (n=64) were African American, and there were significant demographic distinctions between the two race groups (see Table 1). African Americans differed from Whites in years of education, gender distribution, and income level. African Americans had lower mean education levels (mean = 15.0 years, SD= 3.0, vs. mean = 16.2 years, SD=2.4, $t_{(84.16)}=-3.05$, $p<.01$), were more likely to be female (86% vs. 68%, $\chi^2_{(1`)} = 8.48$, $p<.01$), and had lower income status in comparison to Whites (median = $50,000–69,999 vs. median = $70,000–99,999, $\chi^2_{(5)} = 31.28$, $p<.01$). The group comparison on income excluded the 20 participants (90% of whom were White) with missing data on this survey item.

Knowledge

A summary of participant responses on the knowledge scale can be found in Table 2. The adjusted mean population knowledge score for the entire sample was 2.3 (out of a possible 4); however, there were significant race group differences with Whites scoring higher than African Americans (2.5 vs. 1.8, $F_{(1,279)}=14.52$, $p<.001$). Our results suggest that Whites were more likely to know: (1) the APOE genetic test does not predict AD with certainty ($\chi^2_{(1)} = 17.99$, $p<.0001$); (2) the average person's lifetime risk of AD is 10–15% ($\chi^2_{(1)} = 5.01$, $p=0.03$); and (3) being APOE ε4 positive only makes the chances of developing AD somewhat higher ($\chi^2_{(1)} = 9.12$, $p<.01$). Fewer than half of African Americans correctly answered three of the four knowledge questions, while 62% of Whites answered questions correctly. The question most commonly answered incorrectly by both groups was "What is the average person's lifetime risk of getting AD?" (52% correct responses overall).

Table 1 Sample demographics

Demographic characteristics	African Americans (n=64)	Whites (n=249)	Total sample (N=313)
Mean Age, Years (SD);	58.6 (10.4)	58.0 (10.8)	58.1 (10.7)
Range	36–86	33–86	33–86
Sex[a]			
Female. #(%)	55 (86%)	168 (68%)	223 (71%)
Male, #, (%)	9 (14%)	81 (32%)	90 (29%)
Mean years of education (SD)[b]	15.0 (3.0)	16.2 (2.4)	16.0 (2.6)
Range	3–20	7–20	3–20
Site, # participants (%)			
Boston University	9 (14%)	92 (37%)	101 (32%)
Cornell	2 (3%)	84 (34%)	86 (28%)
Case Western	6 (9%)	63 (25%)	69 (22%)
Howard	47 (73%)	10 (4%)	57 (18%)
Median income bracket[b]	$50,000–69,999	$70,000–99,999	$70,000–99,999
Health insurance			
# (%) w/health insurance	60 (94%)	240 (96%)	300 (96%)
# (%) w/out health insurance	4 (6%)	9 (4%)	13 (4%)
Long term care (LTC) insurance			
# (%) w/LTC insurance	15 (23%)	55 (22%)	70 (22%)
# (%) w/out LTC insurance	49 (77%)	194 (78%)	243 (78%)

[a] African American > White; $p<.01$

[b] White > African American; $p<.01$

Table 2 Participant responses to knowledge items on questionnaire

Questionnaire items (response choices, with correct answer in bold)	African Americans (n=64)	Whites (n=249)	Total sample (N=313)
	% Responding correctly		
Can the APOE genetic test predict with certainty whether one will get AD?[a] (Yes; ***no***; undecided)	28%	58%	52%
What is the average person's lifetime risk of getting AD?[a] (>75%; 45–50%; ***10–15%***; 1–5%)	36%	52%	48%
How are people's chances of developing AD different if they have an affected parent or sibling? (*the same as everyone else;* ***somewhat higher than people in general;*** *much higher than people in general*)	70%	75%	74%
How does having APOE ε4 affect one's chances of getting AD?[a] (*there is no effect,* ***makes one somewhat more likely to get AD,*** *makes one much more likely to get AD*)	40%	62%	57%
Mean knowledge items answered correctly, out of four (SD)[a]	1.8 (1.1) 0–4	2.5 (1.1) 0–4	2.3 (1.1) 0–4

[a] White > African American; $p<.05$

A closer look at the data showed significant differences in how African Americans and Whites answered some of these knowledge questions. African Americans were more likely to choose the "undecided" response when asked if the APOE genetic test can predict with certainty whether a person will get AD($\chi^2_{(1)} = 7.18$, $p<.01$).

Perceived Concern

A summary of participant responses on the AD concern scale can be found in Table 3. Because of a low reliability score on this scale, (Cronbach alpha <.60) we analyzed individual items only. Seventy-five percent of all participants endorsed (i.e., marked "somewhat agree" or "strongly agree") items indicating concern about developing AD; however a significantly greater percentage of Whites endorsed this statement in comparison to African Americans (77% vs. 63%, $\chi^2_{(1)} = 5.31$, $p<.05$). Multivariate logistic regression analyses also suggested that women were more concerned than men ($\chi^2_{(1)} = 13.23$, $p<.001$) and that younger age ($\chi^2_{(1)} = 8.11$, $p<.01$) was associated with higher concern. Race group differences were not found for any of the other items measuring concern (Table 6).

With regard to participants' quantitative estimates of perceived lifetime risk of developing AD, the estimated adjusted group mean was 56.8%. Race group differences were found as Whites estimated a higher lifetime chance of developing AD than African Americans (57.4 vs. 49.7, $F_{(1,279)}=6.02$, $p<0.05$), despite being at lower objective risk as a group (Cupples et al. 2004). The average lifetime risk ultimately disclosed to Whites was 32.9%, compared to 54.5% for African Americans.

Reasons for Seeking Genetic Testing

A summary of participant responses on this scale can be found in Table 4. Greater than 60% of respondents endorsed as "very" or "extremely important" five of the possible twelve reasons for seeking genetic testing. The most commonly endorsed reasons were: (1) to know more about my risk in case better treatments become available (84%); (2) to seek information on preventive measures (82%); (3)

Table 3 Participant responses on perceived concern about Alzheimer's disease scale

Scale items	African Americans (n=64)	Whites (n=249)	Total sample (N=313)
	% "Agree" or "Strongly agree"		
I am concerned that I'll develop AD[a]	63%	77%	74%
I am concerned that I will develop AD in the next 5 years	20%	16%	17%
I'd like to know if I am going to develop AD at some point in my life	88%	91%	90%
I believe that I will develop AD	33%	42%	40%
AD is the worst disease I can think of	52%	49%	49%

[a] White > African American; $p<.05$

Table 4 Participant ratings of importance of reasons for seeking genetic testing

Questionnaire items	African Americans (n=64)	Whites (n=249)	Total sample (N=313)
	% Endorsing as very or extremely important		
The need to prepare my family for my possible illness	65%	54%	56%
The need to arrange my personal affairs	66%	63%	64%
The desire to start doing things sooner than I had planned to	47%	48%	48%
To know more about my risk in case better treatments become available	84%	84%	84%
The need to make arrangements for my long-term care	61%	64%	63%
To give information about my children's possible risk of AD	66%	46%	51%
The desire to contribute to research	84%	76%	78%
To put my mind at ease if I found out I was not at risk for AD	63%	49%	51%
To confirm the feeling that I might already be developing AD[a]	42%	21%	25%
To plan for suicide if I test positive	0%	1%	1%
To seek information on preventative measures	84%	82%	82%
Curiosity	61%	39%	44%
Mean items endorsed (SD)	6.8 (3.2)	6.3 (1.1)	6.5 (2.9)
Range	0–11	0–11	0–11

[a] African American > White; $p<.05$

the desire to contribute to research on AD (77%); (4) the need to arrange my personal affairs (64%); and (5) the need to make arrangements for my long-term care (63%). Participants endorsed as "very/extremely important" an average of 6.5 out of 11 reasons for seeking genetic testing for AD. On average, African Americans and Whites endorsed roughly the same amount of reasons for testing (6.8 vs. 6.3). As Table 4 indicates, African Americans and Whites differed on numerous items; however, after adjusting for covariates in our multivariate analyses, the only difference that remained statistically significant was that African Americans were more likely to endorse "to confirm the feeling that I might already be developing AD" ($\chi^2_{(1)} = 4.46$, p=.03). Greater than 80% of all participants identified "the need to know of personal risk in case better treatment became available," and "the need to seek information on preventative measures," as important reasons for seeking genetic susceptibility testing.

Table 5 Participant importance ratings of reasons against seeking genetic testing questionnaire

Questionnaire items	African Americans (n=64)	Whites (n=249)	Total sample (N=313)
	% Endorsing as very or extremely important		
It would be too upsetting to find out I'm at risk for AD[a]	19%	8%	11%
The test does not give me a definite answer about whether or not I might get AD	15%	10%	11%
The test procedure would be too burdensome	3%	3%	3%
It could make me worry about my children's risk of getting AD	13%	8%	9%
The test results might upset my loved ones	17%	10%	12%
The results could affect my health insurance[b]	16%	29%	26%
The results could change how people look at or act towards me	8%	10%	10%
The results could affect my employment	14%	9%	10%
There is no way to cure or prevent AD[a]	26%	13%	15%
My family does not think it is a good idea for me	2%	3%	3%
Mean items endorsed (SD)	1.2 (1.9)	1.1 (1.6)	1.1 (1.6)
Range	0–9	0–8	0–9

[a] African American > White; $p<.05$

[b] White > African American; $p<.05$

Reasons Against Seeking Genetic Testing

A summary of participant responses to items on the scale assessing reasons against seeking genetic testing can be found in Table 5. Only one of 10 provided reasons against seeking genetic testing was endorsed as "very" or "extremely important" by greater than 20% of all respondents: "The results could affect my health insurance." Participants endorsed an adjusted average of only 1.1 out of a possible 10 reasons against seeking genetic testing for AD (26% endorsed). A significantly greater percentage of Whites specifically selected the "effects on health insurance" item as a reason against seeking testing in comparison to African Americans ($\chi^2_{(1)} = 3.73$, p=.05). African Americans were more likely than Whites to endorse:"There is no way to cure or prevent AD" ($\chi^2_{(1)} = 6.90$, p<.05), but only 15% of participants overall endorsed this as a reason not to pursue testing. Overall, there were only two statistically significant differences between African Americans and Whites in their reasons not to pursue genetic testing. Table 6 presents a summary of multivariate analyses examining factors associated with our outcomes of interest.

Discussion

Prior research has found race/ethnicity to be a powerful variable in explaining differences in how people view AD and genetic testing (Hipps et al. 2003; Peters et al. 2004; Thompson et al. 2003); however, much of the literature relies on responses to hypothetical testing scenarios. This is one of the first reports to describe race group differences in the context of a "real-life" clinical trial offering genetic susceptibility testing to research volunteers. Our findings suggest race group differences in knowledge and perceptions of AD, perceived threat of developing AD, and reasons for and against seeking genetic susceptibility testing.

In our study, African Americans were less knowledgeable of established facts concerning AD and genetic testing in comparison to Whites, and these findings are consistent with similar research on other medical disorders. For example, previous studies on cancer and hypertension show that African Americans were less knowledgeable than Whites about risk factors, symptoms, causes, detection and treatment (Armstrong et al. 2002). A number of factors (e.g. socioeconomic barriers, institutional racism, and mistrust of the medical system) may play a role in African Americans being less likely to access medical services, research opportunities and medical topics in the lay literature, thereby constraining awareness of information about AD (Connell et al. 2001; Welsh et al. 1994). There may also be less knowledge about AD among African Americans because more attention is paid to conditions such as diabetes and hypertension in the African American community, and educational efforts and programs may focus on these diseases rather than on AD. This lack of knowledge may cause African Americans to make decisions about genetic testing without full awareness of its benefits, limitations and potential risks. Recent research indicates that even though African Americans endorsed intentions to pursue genetic testing to a greater extent than Whites, they also shared beliefs that conflicted with this desire (Singer et al. 2004). African Americans often express less confidence in American institutions and less trust in their doctors and health practitioners (Singer et al. 2004). In any given situation, these sentiments may well override their desire for genetic testing.

Our results also suggest that African Americans are generally less concerned about the possibility of developing AD in comparison to their White counterparts. This lower level of concern is consistent with previous studies which have shown that African Americans perceive AD as a lesser threat than Whites (Roberts et al. 2003), and that AD poses a lower personal burden to African American caregivers (Lawton et al. 1992). Dementia may be considered a less fearful condition to African Americans for several reasons including: African Americans having greater access to extensive support networks (e.g., family, church), a greater

Table 6 Analyses of covariance examining factors associated with knowledge and attitude scales

		Combined knowledge score		Quantified perceived lifetime chance of developing AD		Summed score of reasons to pursue genetic testing		Summed score of reasons against pursuing genetic testing		I will develop AD someday	
Variable	df	Beta	p value	Beta	p value	Beta	p value	Beta	p value	Beta	p value
Race (Black)	1	**−0.645**	**<0.001**	**−7.71**	**0.015**	0.504	0.227	0.104	0.676	**−1.15**	**0.001**
Age	1	−0.004	0.519	**−0.359**	**0.003**	−0.015	0.358	−0.010	0.313	**0.040**	**0.004**
Sex (female)	1	−0.050	0.742	4.49	0.113	0.657	0.081	−0.118	0.598	**1.15**	**<0.001**
Yrs of Educ	1	**0.065**	**0.015**	−0.036	0.942	**−0.143**	**0.030**	0.009	0.810	0.004	0.948
BAI baseline score	1	−0.019	0.184	**0.883**	**0.001**	0.072	0.041	0.039	0.065	**0.072**	**0.026**

reliance on assuaging coping methods such as prayer, an ability to adapt to adversity, a more positive outlook on aging, and a greater value placed on familial roles than on cognitive skills (Gallagher-Thompson et al. 2000). These lower levels of concern about AD risk suggest that African Americans may anticipate fewer negative consequences regarding genetic testing that conveys personal risk for AD. Interestingly, Whites in this study greatly overestimated their lifetime risk of developing AD, a phenomenon that was not observed in African Americans. This biased view of personal risk may reflect Whites' greater anxiety about the potential consequences of AD.

In examining reasons for and against pursuing genetic susceptibility testing, prior research on real-life "deterministic" DNA testing for early onset familial AD and frontotemporal dementia revealed that the most commonly endorsed reasons for seeking testing were for assistance with organizing family affairs, financial planning, anxiety relief, and other themes not directly related to medical care (Steinbart et al. 2001). The present results similarly show that at-risk participants pursue susceptibility testing for practical, financial, familial and altruistic reasons. However, in this sample, the strongest reasons participants cited for pursuing susceptibility testing concerned medical treatment and prevention. These results may illustrate a societal shift from the fatalistic ideology that there is nothing that can be done about AD to a more proactive stance where people now believe there are, or will soon be, preventive measures and treatments to avert or delay the onset of this disease.

The findings also showed that on average, African Americans endorsed a similar number of reasons to pursue genetic testing as Whites. These results are inconsistent with those of other related studies where race group differences in attitudes toward genetic testing were evident (Hipps et al. 2003). The present results may be attributed to the differential design and samples studied, as our study was querying a sample of African Americans already self-selected on the basis of initial interest in genetic testing (i.e., those skeptical of or negative toward genetic testing would likely not have been included in our sample). Studies in the breast cancer literature have documented higher levels of interest in undergoing genetic testing among African Americans compared to Whites; however these studies have also referenced lower levels of awareness of genetic testing among African Americans (Hughes et al. 1997). Other studies have evaluated genetic testing intentions and have shown that knowledge and exposure to genetics is low among African Americans, whereas expectations about the benefits of genetic testing are high (Halbert et al. 2005). The lower knowledge scores we observed may suggest that responses are being given by African Americans about genetic testing for AD with incomplete understanding of risks and benefits.

For example, a reason more commonly endorsed by African Americans is the need to confirm feelings of already developing AD, which medical research describes as "anticipatory dementia" or anxiety among asymptomatic first-degree relatives about developing the disorder (Cutler and Hodgson 1996). Our findings extend similar research in this area and further illustrate that some people may pursue susceptibility testing not only to help in making practical decisions (e.g., arranging personal affairs), but also to answer questions of curiosity and to address fears and anxiety about developing this disease (Roberts et al. 2003). In this sample, 43% of African Americans said that they pursued genetic testing in order to confirm feelings of already developing AD, in comparison to only 20% of Whites. Since APOE genotype cannot, in fact, provide such confirmation, this seemingly mistaken belief about the benefits of genetic susceptibility testing may cause African Americans to have higher expectations of this procedure that would not be fulfilled [Others (Hughes et al. 2003) have also reported higher expectations about the positive outcomes of genetic testing among African American women]. The present finding also indicates that genetic testing protocols for AD will have to take into account the understandable, but potentially unfounded anxieties that participants who seek such services may display.

At the opposite end of the spectrum, only a small percentage of participants endorsed reasons not to pursue testing. This is an expected finding given this was a study of individuals who had proactively volunteered to be tested in a research protocol. Notwithstanding this bias, the item endorsed most frequently as a deterrent to testing (by approximately one quarter of the sample) was "the results could affect my health insurance," with Whites significantly more likely to endorse this item than African Americans. It should be noted that these data were collected prior to 2008, when the Genetic Information Nondiscrimination Act (GINA) was signed into law, prohibiting discrimination by employers and health insurers based on genetic information (Hudson et al. 2008). It remains to be seen what impact GINA will have on the provision of genetic susceptibility testing for AD, but our results suggest that Whites may be more concerned about the implications of this information on their insurance status, at least prior to formal education on this topic. Long term care coverage currently remains very expensive and if genetic testing for AD becomes more customary, insurance companies may attempt to protect themselves from adverse selection by requesting genetic information (Zick et al. 2005).

These differences in attitudes towards genetic testing may represent differences in knowledge about genetic testing and related issues that were not accounted for by the brief measures used in this study. A recent public opinion survey suggested African Americans are in fact, more concerned

about the possible misuses of genetic information and are more concerned about privacy with reference to the government (Singer et al. 2004). A recent study in Detroit found that even among those with access to health care, African Americans were less likely to participate in a research project offering multiplex genetic susceptibility testing and education about risk of eight common health conditions (Hensley Alford et al. 2011). Such findings suggest that awareness of the potential risks and limitations of genetic testing for AD may make reasons against seeking genetic testing among African Americans more pronounced.

Study Limitations

There are several limitations of this study. Our sample was predominantly White, female, highly educated and of high socioeconomic status. Importantly, our results reflect those of persons who were willing, and in some cases, aggressively volunteered, to pursue genetic testing for AD. Our statistical adjustment for education did not take into account quality of education, which often differs across and within racial and ethnic groups. Furthermore, reported race group identity may be a proxy for numerous social factors that were not assessed in this study. For the majority of questions, we used a forced-choice answer format that might have affected our data, as the questions might have been unclear and the cultural validity of certain items might have varied. For the few questions, where "I don't know" or "undecided" was an option, we found a greater percentage of African Americans answered with one of these choices. If we had provided this option more often, particularly with the knowledge questions, our results might have been different.

Practice Implications

The results of this study suggest a potential need for increased outreach and education about AD genetics for African Americans. Even among this well-educated sample in which mean education level was equivalent to a bachelor's degree, many participants demonstrated limited awareness of important facts surrounding AD and genetic testing. Existing cancer research has demonstrated that education efforts that increase general knowledge are directly associated with health behavior changes and better decision-making (Lerman et al. 1999; Millon-Underwood and Sanders 1990). The addition of personalized genetic counseling may lead to greater increases in awareness of limitations and risks of testing compared with education alone. Our results suggest that culturally sensitive educational initiatives should be considered for genetic testing of late-onset Alzheimer's disease.

Research Recommendations

The results of this study suggest that while African Americans may be less concerned about AD, in our sample of research volunteers they endorsed just as many reasons for pursuing genetic susceptibility testing as Whites. Due to structural inequalities in society and the U.S. healthcare system, African Americans may be less knowledgeable about the inherent limitations of genetic testing and may therefore be less aware of potential negative consequences of testing. Future analyses are planned to examine whether the knowledge levels and attitudes of both groups towards genetic testing persist after they receive formal education and counseling and after they receive their personal AD risk estimates.

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