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Differences Between African Americans and Whites in Their Attitudes Toward Genetic Testing for Alzheimer's Disease

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ABSTRACT

The possibility of predictive genetic testing for Alzheimer's disease (AD) has prompted examination of public attitudes toward this controversial new health-care option. This is the first study to examine differences between Whites and African Americans with regard to: (1) interest in pursuing genetic testing for AD, (2) reasons for pursuing testing, (3) anticipated consequences of testing, and (4) beliefs about testing. We surveyed a convenience sample of 452 adults (61% white; 39% African American; 78% female; mean age = 47 years; 33% with family history of AD). Both racial groups indicated general interest in predictive genetic testing for AD, viewed it as having many potential benefits, and believed it should be offered with few restrictions. However, in comparison to whites, African Americans showed less interest in testing ($p < 0.01$), endorsed fewer reasons for pursuing it ($p < 0.01$), and anticipated fewer negative consequences from a positive test result ($p < 0.001$). These preliminary findings show important distinctions between whites and African Americans in their attitudes toward genetic testing for AD. These differences may have implications for how different racial and ethnic groups will respond to genetic testing programs and how such services should be designed. Future research in real-life testing situations with more representative samples will be necessary to confirm these racial and cultural differences in perceptions of genetic testing.

INTRODUCTION

RAPID ADVANCES IN GENETIC RESEARCH on Alzheimer's disease (AD) have led to the possibility of predictive genetic testing for the disorder (Roses, 1997). Limitations in test sensitivity and specificity, coupled with a lack of treatment options for the disorder, have prompted concerns about the premature introduction of genetic testing for AD (McConnell *et al.*, 1998). However, given the pace of AD research, predictive testing may soon become a viable option for the millions at risk for the disorder. Presymptomatic testing is already available among families with rare early-onset forms of AD (Lennox *et al.*, 1994), and genetic factors in more common later-onset types are under investigation (Lendon *et al.*, 1997). The apolipoprotein E (APOE) E4 allele on chromosome 19 is the first genetic risk factor for sporadic AD to have been identified, with future findings likely to lead to genotype screening (Masters and Beyreuther, 1998).

AD will represent a unique predictive testing scenario. Testing for AD will differ from testing for other disorders by virtue of: (1) the greater prevalence of the disorder (an estimated 14 million cases in the United States anticipated by mid-century), (2) its late age of onset, and (3) the relative uncertainty of its risk information (Brookmeyer *et al.*, 1998; Green, 2001). Furthermore, no prevention or cure options currently exist for AD. Such characteristics distinguish the disorder in important ways from other testing contexts, while also raising complex ethical, legal, and social issues (Post *et al.*, 1997; Post and Whitehouse, 1998). Psychological research may be useful in helping anticipate response to this controversial, complex health-care option (Coon *et al.*, 1999).

Some preliminary surveys have been conducted in this area. In a general population telephone survey, Neumann *et al.* (2001) found that 79% of respondents expressed interest in a hypothetical predictive genetic test for AD. Interest in testing varied by the predictive capacity of the test (*i.e.*, less interest in "partially predictive" testing), but not by age. The vast majority of survey respondents said that a positive test result would prompt behavioral changes, such as signing of advance directives, arrangement of finances, and purchasing of long-term care

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insurance. A survey of 203 first-degree relatives of AD patients in the state of Michigan also found great general interest in predictive genetic testing, as assessed by response to various hypothetical scenarios (Roberts, 2000). In this study, interest in testing varied by situational characteristics (*i.e.*, greater interest in scenarios with greater test accuracy, more immediate risk information, and better available treatments), illness perceptions (greater perceived threat of AD was associated with interest in testing), demographic characteristics (men expressed greater interest in testing than women), and psychological variables (health information-seeking style was associated with interest in testing). Participants rated the following test benefits as most important: (1) informing later-life decisions, (2) helping plan future AD care, and (3) motivating monitoring of AD treatment developments. Test benefits were viewed as much more important than test limitations or risks.

Despite these findings, little work has been done on cultural differences in attitudes toward genetic testing for AD. In fact, this topic has generally been neglected in genetic testing research across all disorders (Croyle and Lerman, 1995). Clinical research suggests that whites are more likely than racial minority groups to pursue genetic testing for cystic fibrosis (Tambor *et al.*, 1994), but comparable investigations on testing for other disorders have generally not been carried out. The aforementioned general population survey (Neumann *et al.*, 2001), which included 16% African Americans, found no significant race group differences in terms of general interest in a hypothetical predictive genetic test for AD. Still, there is a need for studies that examine differences between African Americans and whites not only with regard to their general interest in testing, but also in terms of why they would choose to seek testing and what they expect its consequences will be. The necessity of focusing on African Americans in particular is underscored by research showing that this group may be at particular risk for AD (Green *et al.*, 2002a). Understanding racial differences in perceptions of testing would be important in the design of culturally appropriate genetic education and testing programs (Coon *et al.*, 1999).

METHODS

Procedure

The survey used in this study has been described in a previous publication (Green, 1997). Briefly, survey development included in-depth interviews and a series of focus groups with approximately 70 adults from the Atlanta, Georgia, area. The final survey consisted of a total of 82 questions assessing attitudes, beliefs, and knowledge regarding AD and predictive testing options for the disorder. The survey was distributed to distinct populations of volunteers to achieve a convenience sample with cultural and socioeconomic diversity. The volunteers included: (1) health workers and their family members attending a large caregiver conference in Mobile, Alabama; (2) healthcare workers attending a gerontology education meeting in Pensacola, Florida; (3) persons in rural Georgia who were participating in other public health surveys; and (4) members of church congregations and civic organizations and participants in support groups and health fairs in the Atlanta metropolitan area. A total of 452 white and African-American respondents completed the survey.

Although this was clearly a nonrepresentative sample, efforts were made to ensure diversity with regard to AD family history and racial/ethnic background. African Americans have generally been underrepresented in AD research, in part due to expenses, transportation difficulties, and lack of rapport with clinic staff (Ballard *et al.*, 1993). We made special efforts to overcome these barriers, using principles recommended for recruitment of minority participants in dementia research, such as the use of African-American recruiters and coordinators, and collaboration with African-American church and community leaders (Gauthier and Clarke, 1999).

Measures

Interest in predictive testing: Interest in predictive testing was assessed through a series of hypothetical testing scenarios posed to participants. Each scenario was varied by test accuracy (*i.e.*, 60%, 80%, and 100%). Scenarios also varied by test cost (*i.e.*, free or $200) and available treatment options (*e.g.*, treatment to delay AD onset). Overall, 12 items were included in this measure. Participants responded to each item using a 5-point scale (1 = strongly agree, 5 = strongly disagree). Items that participants endorsed (*i.e.*, responded "strongly agree" or "somewhat agree") were summed to yield an overall index of test interest. Responses to the primary scenario ("If a predictive test for Alzheimer's disease were offered to me, I would want to take it") were also examined separately.

Reasons for seeking testing: Focus group interviews were used to develop a list of 11 reasons for pursuing predictive testing for AD (*e.g.*, "arrangement of my long-term care"; "curiosity"; "the hope that an effective treatment will be developed"). Participants were asked to indicate the extent to which they agreed that the reason would motivate them to take a predictive test (1 = strongly agree, to 5 = strongly disagree). An overall index was created to indicate the total number of items with which participants agreed (*i.e.*, endorsed "strongly agree" or "somewhat agree").

Anticipated consequences of testing: Participants were asked to what extent they agreed with the following statement: "I believe that I could cope with whatever the results of a predictive test were." Participants were also asked to imagine how they would respond to predictive test results indicating a likelihood of developing AD at some point in their life. Participants were asked to indicate the extent to which they agreed that they would have the following reactions to a positive result: (1) become depressed, (2) cry and then get over it, (3) become more aware of my forgetfulness, (4) consider suicide, and (5) continue with my daily living routine. Responses for all items were on a 5-point scale (1 = strongly agree, to 5 = strongly disagree).

Beliefs about testing: Participants were asked to indicate the extent to which they agreed with various beliefs about predictive testing for AD (1 = strongly agree, to 5 = strongly disagree). Items included "Predictive testing for AD should be withheld until there is a cure or treatment available to slow the progression of the disease," "Predictive testing for AD should be available upon request to anyone," and "Pre-test counseling for those who choose to be tested for AD should be required."

Data analysis

Descriptive statistics were used to characterize sample demographics and responses on individual survey items. Differences between African Americans and whites on continuous outcomes of interest were initially examined through *t*-tests; if significant differences were found, an analysis of covariance was conducted using the potentially confounding covariates of age, gender, education level (1 = high school or less, 2 = some college, 3 = college graduate, 4 = graduate/professional school), annual income (below $40,000 *vs.* $40,000 and above), AD family history (yes/no), and caregiving history (yes/no). Chi-square analyses were used to examine race group differences on dichotomous outcomes.

RESULTS

Demographics

Of the 452 respondents, 61% ($n = 278$) were white and 39% ($n = 174$) were African American. The sample had a mean age of 47 years (SD = 14; range, 22–90) and was 78% female. Median education level was college graduate, and median income range was $40,000–$59,999. A total of 33% of participants reported a family history of AD, and 20% reported a caregiving history. On average, whites were older [mean age (white) = 49 years *vs.* mean age (African American) = 44 years, $p < 0.05$] and reported higher levels of education [median education level (white) = college graduate *vs.* median education level (African American) = some college or 2-year degree] and income [median income range (white) = $40,000–$59,999 *vs.* median income range (African American) = $20,000–$39,999]. No significant racial group differences were found with regard to gender, AD family history, or caregiving history.

Intentions toward predictive testing

On average, participants expressed interest in predictive testing in 6 of 12 hypothetical scenarios (median = 5). Whites expressed interest in testing in more scenarios than African Americans [adjusted mean (white) = 6.6 *vs.* adjusted mean (African American) = 5.5., $p < 0.01$]. In the primary hypothetical predictive testing scenarios, 64% of all respondents expressed interest in a test with 100% accuracy, 51% expressed interest in a test with 80% accuracy, and 30% expressed interest in a test with 60% accuracy. Responses in these particular scenarios did not differ by racial group. Overall, interest was highest in the scenario where testing was 100% accurate, with treatment available to delay the onset of AD (80.3% of respondents expressing interest). Interest was lowest in the scenario where testing was 60% accurate and cost $200 (19.6% of respondents expressing interest).

Reasons for seeking testing

On average, participants endorsed 6 out of 11 reasons for pursuing predictive testing for AD. Whites endorsed more reasons for testing than African Americans [adjusted mean (white) = 6.3 *vs.* adjusted mean (African American) = 5.3, $p < 0.01$]. The most commonly endorsed reasons were: (1) arrangement of my long-term care (84.6% of respondents endorsing), (2) arrangement of my personal affairs (83.5% endorsing), and (3) the need to prepare my spouse or children for my illness (79.8% endorsing). Chi-square analyses showed significant differences between white and African Americans on 6 of 11 items. Table 1 presents responses to individual items, stratified by racial group.

Anticipated consequences of testing

Overall, 63% of respondents believed that they could cope with whatever the results of a predictive test were. A vast majority of respondents (76%) also agreed that they would "continue with my daily living routine" in the event of a positive test result. However, a majority of respondents agreed that a positive test result would make them "become more aware of my forgetfulness" (76%) and "become depressed" (59%). Overall, 13% of respondents agreed that a positive test result would

Table 1. Reasons for Seeking Predictive Testing for AD by Racial Group

	Percent endorsing	
	African American	*White*
Arrangement of my long-term care[a]	80	87
Arrangement of my personal affairs[a]	75	89
The need to prepare my spouse or children for my illness[a]	69	87
The desire to do things sooner than I had planned[a]	73	82
The hope that an effective treatment will be developed	61	69
Collecting information that may be useful for genetic planning in my family	53	63
The relief I would anticipate from a negative test result[a]	38	51
Curiosity	41	38
The feeling that I am already showing symptoms of AD	36	37
To confirm the feeling that I am going to get the disease	19	17
The need to plan for suicide in case of a positive result[a]	2	7

[a]Whites > African Americans ($p < 0.05$).

Table 2. Anticipated Consequences of Predictive Testing for AD by Racial Group

If a predictive test indicated that I would eventually develop AD, I would . . .	*Percent endorsing*	
	African American	*White*
Continue with my daily living routine	74	78
Become more aware of my forgetfulness[a]	65	82
Become depressed[a]	43	70
Cry and then get over it	36	36
Seriously think about committing suicide at some point[a]	6	18

[a]Whites > African Americans ($p < 0.05$).

make them "seriously think about committing suicide at some point in the future." Whites were more likely than African Americans to endorse these anticipated negative consequences of testing: (1) would become more aware of forgetfulness [mean % agreeing (white) = 82 *vs.* mean % agreeing (African American) = 65, $p < 0.001$]; (2) would become depressed [mean % agreeing (white) = 70 vs. mean % agreeing (African American) = 43, $p < 0.001$]; and (3) would seriously think about suicide [mean % agreeing (white) = 18 *vs.* mean % agreeing (African American) = 6, $p < 0.001$]. Table 2 presents responses to individual items, stratified by racial group.

Beliefs about testing

The vast majority of respondents agreed that predictive testing for AD should be available upon request to anyone (85%), that pre-test counseling should be required (78%), and that post-test counseling should be required for those who test positive (87%). A majority (54%) disagreed that predictive testing should be withheld until a cure or treatment to slow progression was available. Respondents were equivocal about whether testing should be withheld if a person appears mentally unstable (37% agreed, 36% undecided, 27% disagreed). Whites agreed to a greater extent than African Americans that post-test counseling should be required for those who test positive [mean % agreeing (white) = 92 *vs.* mean % agreeing (African American) = 80, $p < 0.001$]. Table 3 presents responses to individual items, stratified by racial group.

DISCUSSION

This is the first study to examine racial differences in interest in and beliefs about genetic testing for AD. Our findings suggest significant differences between whites and African Americans across several attitudinal domains. When compared to whites, African Americans expressed interest in testing in fewer hypothetical scenarios, saw fewer reasons for pursuing testing, and anticipated less negative consequences from a positive test result. Despite these differences, both groups were generally interested in predictive testing for AD and viewed it as yielding several potential benefits.

Our findings are consistent with related research describing notable distinctions between whites and African Americans in their perceptions of AD (Roberts *et al.*, 2003). Using the same sample described herein, this study found that when compared to whites, African Americans had less awareness of facts about AD, reported fewer information sources, and perceived the disorder as a lesser threat. These findings suggested that AD is a disorder more likely to attract the attention and concern of whites than African Americans. Our current findings are also consistent with this notion; whites showed greater interest in and reasons for pursuing genetic testing for AD, while anticipating more potential negative consequences from testing (*e.g.*, depression, increased "symptom-searching," thoughts of suicide). Although perceptions and intentions do not always translate into behavior, these differences suggest that whites may be more likely than African Americans to seek out genetic testing

Table 3. Beliefs about Predictive Testing for AD by Racial Group

	Percent in agreement	
	African American	*White*
Should be available upon request to anyone	86	82
Pre-test counseling should be required	74	80
Post-test counseling should be required for those who test positive[a]	80	92
Should be withheld if a person appears mentally unstable	37	37
Should be withheld until there is a cure or treatment available to slow progression	19	24

[a]Whites > African Americans ($p < 0.05$).

for AD and to require supportive services to cope with its potential psychological effects.

Our findings are also consistent with previous research on attitudes toward genetic testing for AD (Green *et al.*, 1997; Neumann *et al.*, 2001; Roberts, 2000). As in these prior studies, respondents showed general interest in pursuing testing, but only with the assumption that risk information would be reliable and informative. Also as in prior research, participants viewed testing as beneficial in that it could potentially inform future health and financial planning, later life decision-making, and preparing one's family for the potential burden of future illness.

This study was the first to examine beliefs regarding the ethics of genetic testing for AD. Interestingly, although participants generally endorsed requirements of pre- and post-test counseling (with whites in particular endorsing the importance of post-test counseling), they believed that predictive testing should be offered with few restrictions. For example, participants generally believed that testing should not necessarily be withheld until improved treatment options are available for AD. Such beliefs do not appear to be consistent with the medical community's concerns about premature introduction of genetic testing for AD (Post *et al.*, 1997; McConnell *et al.*, 1998), although it is unclear whether education on the limitations and risks of genetic testing for AD would alter these "consumer" viewpoints.

Our results highlight a particular ethical concern about genetic testing for a severe, incurable disease such as AD: that is, the possibility that it could prompt consideration of suicide. A striking subset of our sample (18% of whites, for example) suggested that they might entertain thoughts of suicide in response to a "positive" test result. While research on genetic testing on Huntington's disease (HD) has shown that pre-test attitudes about suicide rarely develop into post-test suicidal ideation or behavior (Almqvist *et al.*, 1999), these results are nonetheless a cause for concern and suggest that testing programs should offer genetic counseling services to monitor and address potential suicidal ideation. Safety procedures within such programs are likely to be based on the thoughtful guidelines developed in the HD genetic counseling literature (*e.g.*, Quaid, 1992).

Our findings must be interpreted with caution given the nonrepresentative nature of our sample. Also, our statistical controls for education did not take into account quality of education, which often differs across racial and ethnic groups. Another important limitation concerns the hypothetical nature of the testing scenarios posed to study participants. Clearly, responses on a questionnaire are not the same as responses to a real-life testing situation. Research examining responses to a more authentic testing scenario is currently taking place in the REVEAL Study, a multisite randomized clinical trial based at the Boston University Alzheimer's Disease Center (Brown *et al.*, 2000; LaRusse *et al.*, 2000; Green *et al.*, 2002b; Roberts *et al.*, 2002; Green, 2002c).

Rapid advances in genetic research, coupled with the dramatically rising incidence and prevalence of AD, make it increasingly important to explore the social and psychological implications of genetic testing for AD. Health psychological research has long demonstrated the importance of illness-related perceptions in shaping response both to disease burden and available care options (Becker, 1974; Lazarus and Folkman, 1984; Petrie and Weinman, 1997). Thus, further research on cultural differences in attitudes toward genetic testing will be essential in informing future health services and education programs.

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