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

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Genetic susceptibility testing for clinical purposes has prompted many concerns about the impact of providing risk information, especially to minority groups. We report here on the first study to examine race group differences in a “real-life” genetic susceptibility testing situation. Prior to participants’ enrollment in a randomized clinical trial of a genetic education and counseling program for Alzheimer’s disease (AD), we assessed the following: (1) knowledge about AD, genetics and genetic testing, (2) concerns about developing AD and (3) reasons for and against seeking genetic testing. In this study, we enrolled 321 African American and White adults (79% White; 21% African American; 71% female; mean age=58 years), all with a family history of AD. Results were gathered prior to participants receiving any formal standardized education on these topics. In comparison to Whites, we found that African Americans were less knowledgeable about AD, genetics and genetic testing ($p<0.0001$), and were less concerned about the possibility of developing AD ($p<0.05$). Both racial groups expressed interest in pursuing predictive testing; however, African Americans showed more interest and endorsed more potential benefits for seeking genetic testing than Whites (7.1 vs. 6.3, $p=0.03$). This finding rebuts previous studies that have showed African Americans to be less interested in testing than Whites (Hippis, 2003). At the same time, African Americans held more misconceptions about AD and genetic testing (e.g. higher expectations) and held other beliefs that conflict with and may override these preferences for seeking testing. These findings suggest important distinctions between White and African American volunteers when put in a real-life testing situation without standardized education. It may also give us a glimpse on how different racial and ethnic groups will respond to genetic testing programs.