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Chanita Hughes Halbert
University of Pennsylvania

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Abstract

Genetic testing for susceptibility to breast and ovarian cancer (BRCA1/2 testing) has been available in clinical settings since 1996. Increasingly, such testing is helping women at increased risk make decisions about breast cancer screening and prevention. African American women have participated in genetic counseling and testing programs less than white women, despite greater rates of early onset disease and higher breast cancer mortality. The barriers and motivations for genetic testing among African American women are not well understood. This Issue Brief summarizes a series of studies that systematically explore African American women's beliefs and intentions about BRCA1/2 testing. The findings have been used to tailor genetic counseling programs to better serve this population.

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Leonard Davis Institute of Health Economics

Chanita Hughes Halbert, PhD
LDI Senior Fellow,
Assistant Professor of Psychology
in Psychiatry
University of Pennsylvania

Genetic Counseling and Testing for Breast Cancer Risk in African Americans

Editor's note: Genetic testing for susceptibility to breast and ovarian cancer (BRCA1/2 testing) has been available in clinical settings since 1996. Increasingly, such testing is helping women at increased risk make decisions about breast cancer screening and prevention. African American women have participated in genetic counseling and testing programs less than white women, despite greater rates of early onset disease and higher breast cancer mortality. The barriers and motivations for genetic testing among African American women are not well understood. This Issue Brief summarizes a series of studies that systematically explore African American women's beliefs and intentions about BRCA1/2 testing. The findings have been used to tailor genetic counseling programs to better serve this population.

Racial disparities in the use of BRCA1/2 testing exist, but the reasons for low African American participation are not known

Although hereditary breast cancer accounts for only about 5%-10% of all breast cancer cases, women who carry a BRCA1/2 mutation have a 55%-85% lifetime risk of developing breast cancer, and a 15%-60% lifetime risk of developing ovarian cancer. In addition to providing personal risk information, genetic test results also have important implications for family members. The U.S. Preventive Services Task Force recommends that women with a family history suggestive of hereditary breast cancer be referred for genetic counseling so that they can make informed decisions about whether to undergo genetic testing.

- African American participation in BRCA1/2 counseling and testing programs, and in research about hereditary breast cancer, is low. In a report describing 10,000 consecutive BRCA1/2 laboratory analyses in the U.S., fewer than 2% of blood samples came from women of African descent. A recent study found that African American women with a family history of breast or ovarian cancer were significantly less likely to undergo genetic counseling for BRCA1/2 testing than white women with a similar family history, a disparity that was not explained by the probability of carrying a BRCA1/2 mutation, socioeconomic status, cancer risk perception and worry, or attitudes about BRCA1/2 testing.
- Previous studies have evaluated racial differences in knowledge and attitudes about genetic testing or have compared African American and white women's intentions to be tested. These studies have shown that knowledge about breast cancer genetics and exposure to information about the availability of testing is low among African Americans, whereas expectations about the benefits of genetic testing are high.

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- After considering the benefits and harms of genetic testing and possible preventive measures, not all women at increased risk for hereditary breast cancer will choose to have BRCA1/2 testing. Even if women ultimately decide not to have testing, participation in genetic counseling may be useful for African American women to increase knowledge about breast cancer risk factors and to provide information about options for cancer prevention and control.
 - Barriers to utilization of genetic tests among African Americans may include the cost and availability of testing, concerns about exploitation, and distrust of the medical community. Cultural beliefs and values may also influence decisions about participating in genetic counseling and testing; however, little is known about cultural and attitudinal barriers and facilitators of participation specifically among African Americans.

Communalism and religious coping style may influence genetic testing decisions among African Americans

To explore how cultural beliefs and values might affect decisions about genetic testing among African Americans, Halbert and colleagues interviewed 28 African American women at increased risk for developing breast cancer, based on their family history. The women were recruited through mammography and oncology clinics and were invited to participate in a genetic counseling and testing research program.

- The interviewers explored previously identified aspects of an African American worldview, including communalism (social and familial interdependence), spirituality (religious coping style), and flexible temporal orientation (with an emphasis on both past and present dimensions). In addition, they assessed fatalistic beliefs about cancer, which has been associated with decreased use of cancer screening tests in African Americans.
- Overall, 61% of women accepted genetic counseling and testing, and 39% declined. Test acceptors had higher levels of fatalism about cancer, lower levels of perceived familial interdependence, and were more oriented toward the future.
- Participation rates were lower among women reporting that individuals should not view themselves as independent from family members. Although previous studies suggest that higher levels of spirituality about disease causation may be a barrier to participation in genetic testing, women who reported greater use of working together with God in difficult situations were more likely to accept genetic testing in this study. These findings suggest that beliefs and values regarding communalism and religious coping style could be used as a basis for providing culturally sensitive genetic counseling to African American women.

African American women have a favorable view of genetic testing, but voice concern about its impact on family

Prior to their participation in a randomized study of alternative models of genetic counseling, 74 African American women at high or moderate risk of having a BRCA1/2 mutation were interviewed to evaluate their attitudes about the benefits, limitations, and risks of genetic testing and their intentions to be tested.

- Consistent with previous studies, most women reported positive attitudes about genetic testing. Although the benefits of genetic testing were generally endorsed, only 30% of women indicated that they would definitely be tested. About one-third of women said that they were not considering genetic testing.
 - The most important benefit of genetic testing was to know if additional steps are needed to prevent cancer (88% rated very important) whereas the most important
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limitation or risk of genetic testing was concern about the impact on family members (25% rated very important).

- Adjusting for other factors, women with a personal history of breast cancer and those who perceived themselves at highest risk for breast cancer were more likely to report negative attitudes toward genetic testing than other women. However, women with a high perceived risk were also more likely to consider genetic testing than women with a lower perceived risk. In addition, women with more than two affected relatives, and women who believed that cancer screening generates fear, were more likely to consider genetic testing than other women.

Developing a culturally tailored genetic counseling program

Halbert and colleagues used their findings to develop a culturally tailored genetic counseling (CTGC) protocol for African Americans. CTGC differs from standard genetic counseling in that it incorporates discussion of beliefs and values related to spirituality and religion, temporal orientation, and communalism. The CTGC sessions last about two hours, about a half an hour longer than the standard sessions.

- To address religious and spiritual beliefs and values, women are asked, “What role does spirituality play in your life and what aspect of your religious and spiritual beliefs would influence your decision to have genetic testing?”
- To address values related to temporal orientation, women are asked, “When you make choices about your health care, are you focused on what is going on now or focused on events that may happen in the future?”
- The CTGC protocol also includes probes that encourage women to discuss family concerns. For example, women are asked to describe how their family experiences with breast and/or ovarian cancer influenced their decisions to have genetic counseling, if they talked to any of their family members about participating in genetic counseling, and how they would feel if their family did not want to them to have genetic testing.

Culturally tailored counseling may be beneficial for African American women

The researchers are conducting a randomized study of the effects of CTGC and standard counseling among African American women at increased risk for hereditary breast and ovarian cancer. After extensive outreach efforts in clinics and community events, 62% of eligible women enrolled in the study, and 50% chose to participate in genetic counseling.

- In a sample of 54 women who participated in pre-test education and counseling, women were equally and strongly satisfied with genetic counseling in both the CTGC and standard counseling groups (96% being very satisfied). However, only 26% reported that their worries were lessened and 22% reported that they were able to cope better.
- Women receiving CTGC were significantly more likely to report that their worries were lessened than women receiving standard counseling. In addition, women with household incomes less than \$35,000 were less likely to report that their worries were lessened compared to women with higher incomes.
- These results suggest that discussion of cultural beliefs and values may be beneficial for African American women, especially those with low incomes. Ongoing analyses will compare the effects of CTGC and standard genetic counseling on decisions about genetic testing, psychological functioning, and health behaviors.

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POLICY IMPLICATIONS

As genetic testing for susceptibility to breast cancer becomes integrated into the clinical management of high-risk women, it is critical to identify ways to enhance access to counseling services for women from underserved minority groups. By focusing on values and culture specific to African Americans, these studies have informed the development of counseling services that might be more effective for this population.

- Outreach is needed to improve African American women's knowledge about the availability of genetic counseling and testing for susceptibility to breast cancer. Outreach efforts should include a more elaborate discussion about the impact of testing on family relationships.
- It is likely that cultural beliefs and values that influence participation in genetic testing also influence psychological and behavioral reactions to test results. Therefore, it may be beneficial to incorporate these aspects of the African American cultural worldview into discussions with women after they receive their test results as well.
- Because genetic counseling services are most often prompted by a physician referral, continuing efforts are needed to overcome racial disparities in access to primary and preventive care.

This Issue Brief is based on the following articles: S. Charles, L. Kessler, J.E. Stopfer, S. Domchek, C.H. Halbert. Satisfaction with genetic counseling for BRCA1 and BRCA2 mutations among African American women. Patient Education and Counseling, Oct. 2006, vol.63, pp. 196-204; C.H. Halbert, K. Brewster, A. Collier, C. Smith, L. Kessler, B. Weathers, J.E. Stopfer, S. Domchek, E. P. Wileyto. Recruiting African American women to participate in hereditary breast cancer research. Journal of Clinical Oncology, Vol. 23, Nov. 1, 2005, pp. 7967-7973; C.H. Halbert, L. Kessler, A. Collier, E.P. Wileyto, K. Brewster, B. Weathers. Psychological functioning in African American women at increased risk of hereditary breast and ovarian cancer. Clinical Genetics, Sept. 2005, vol. 68, pp. 222-227; L. Kessler, A. Collier, K. Brewster, C. Smith, B. Weathers, E.P. Wileyto, C.H. Halbert. Attitudes about genetic testing and genetic testing intentions in African American women at increased risk for hereditary breast cancer. Genetics in Medicine, April 2005, vol. 7, pp. 230-238; C.H. Halbert, L.J. Kessler, E. Mitchell. Genetic testing for inherited breast cancer risk in African Americans. Cancer Investigation, no. 4, 2005, vol. 23, pp. 285-295; C. Hughes, G. Fasaye, V. LaSalle, C. Finch. Sociocultural influences on participation in genetic risk assessment and testing among African American women. Patient Education and Counseling, Oct. 2003, vol. 51, pp. 107-114.

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Janet Weiner, MPH, Associate Director for Health Policy, Editor (215-573-9374)

David A. Asch, MD, MBA, Executive Director

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