Improving Minority Access to Genetic Counseling for Cancer Risk

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The Second Annual Robert H. Lurie Comprehensive Cancer Center Health Policy Symposium, held last year in Chicago, was entitled “Cancer, Reaching Medically Underserved Populations: Low Literacy and Culturally Specific Barriers.” This is the fourth in a series of reports on the conference presentations, prepared for ONI by researchers at Northwestern Medical School, that will put the discussions into a broader context. This month’s article reviews a presentation by Chanita Hughes, PhD, Georgetown University Medical Center, Lombardi Cancer Center, Washington, DC.

Introduction

CHICAGO—Disparities in cancer incidence and mortality between whites and ethnic minorities in the United States persist,[1] suggesting a need for targeted efforts to increase cancer screening and prevention measures among ethnic minorities and the medically underserved. Such efforts include increasing minority participation in cancer prevention trials (see ONI September 2000, page 3) and implementing new technologies for cancer screening and early detection, some of which have only recently become available to the public.

One such technology is genetic screening for mutations in cancer susceptibility genes. Such screening accompanied by genetic counseling enables individuals to assess their risk of developing cancer and decide which type of cancer screening and cancer prevention measures to take. Unfortunately, genetic screening may not be accessible to all, especially to ethnic minorities and the medically under-served, who may lack essential knowledge about cancer screening or who may be unfamiliar with genetic testing.

In addition, minority communities may have significant concerns about being used as guinea pigs for new medical tests and procedures. These concerns may lead to underutilization of genetic screening for cancer risk.

This paper will address the work of Chanita Hughes, PhD, of Georgetown University Medical Center, on ethnic differences in knowledge and attitudes about genetic testing for breast cancer risk, as presented at the Robert H. Lurie Comprehensive Cancer Center’s Symposium on Cancer: Reaching Medically Under-served Populations.

Goals of Genetic Counseling

Approximately 5% of women diagnosed with breast cancer each year carry a mutation in the BRCA1 gene.[2] Women with a BRCA1 mutation have a nearly eightfold higher (80% to 85%) lifetime risk of developing breast cancer and up to 30-fold higher lifetime risk of developing ovarian cancer (approximately 44%), compared with women in the general population (about 11% and 1.5% to 2%, respectively).[3]

Genetic testing to detect mutations in BRCA1 and assess cancer risk is becoming available to an increasing number of women. To provide information and alleviate patient distress about genetic testing, pre- and post-test counseling and patient education are crucial.

According to Dr. Chanita Hughes, the goals of pretest education and counseling include providing education about genes, inheritance, susceptibility, and risk assessment. In addition, counseling sessions should address the benefits and risks of testing, including confidentiality issues, effects on family members, and the potential for insurance discrimination.[4]

In pretest counseling sessions, Dr. Hughes’ goal is not to encourage or discourage testing but rather to provide information so that women can make an informed decision about whether to pursue genetic testing.

Goals of post-test counseling include discussing disclosure, risks of developing cancer, and
recommendations for screening and surveillance. Supportive counseling is also available.

**Cultural Influences on Testing**

In a series of studies on cultural influences on genetic testing, Dr. Caryn Lerman, Dr. Hughes, and their colleagues show that black and white women have different views and levels of knowledge about genetic testing, and respond differently to education and counseling interventions prior to undergoing genetic testing for BRCA1 mutations.[4,5]

In one study, Hughes et al found that white women reported more exposure to written and verbal materials about genetic testing than did black women. A greater percentage of white women had used genetic testing, and they had significantly greater knowledge levels about breast cancer genetics and genetic testing.

In a second study, participants were randomized to receive either a genetic testing education intervention alone or an education intervention accompanied by counseling about genetic testing. Education efforts focused on identifying individual risk factors and patterns of inheritance, and addressed the benefits, limitations, and risks of genetic testing. Counseling topics included women’s experiences with cancer in their families, the anticipated impact of positive/negative results or of declining testing, and coping resources and skills.

**Black Women’s Concerns**

In this study, black and white women in both intervention arms were found to have similar attitudes about the benefits of genetic testing, although black women tended to rate the benefits of testing significantly higher than did white women. However, black and white women in both intervention arms had very different views on the negative aspects of genetic testing. Black women were considerably more concerned about the effects of testing on their family members and reported more emotional strain.[4,5]

When the counseling and education intervention arm was compared with the education intervention arm, the researchers found that counseling increased the number of concerns and decreased the number of benefits that participants identified.

For black women, education and counseling led to a greater increase in intention to undergo genetic testing, compared with education alone, while for white women there was no difference in the impact of the two intervention arms.

Because differences between the black and white women persisted after controlling for sociodemographic factors, the observed differences may be ascribed to cultural beliefs and values. For example, women from diverse ethnic and cultural backgrounds may have different attitudes toward temporal orientation (eg, emphasizing the present rather than the future); cancer fatalism; religion and spirituality; and family relationships.

**Conclusion**

Reported differences between black and white women in knowledge levels and attitudes about genetic testing raise the concern that education and counseling efforts for women at increased risk for cancer are not reaching black women.[4]

In addition, counseling and education efforts about the benefits, limitations, and risks of genetic testing may not address the specific concerns of black women regarding genetic testing, such as their distrust of the medical community and concerns about the effects of testing on family members.[4,5]

Targeted genetic counseling programs addressing the specific cultural beliefs and concerns of participants may successfully increase knowledge about and awareness of genetic testing.

**References:**


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