

Susan G. Komen Research Grants – Fiscal Year 2014

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Identification and education of low-income women at risk for hereditary breast cancer

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Lead Organization: University of California, San Francisco

Grant Mechanism: KS Grant ID: SAC110049

Public Abstract:

Women with the BRCA1/2 gene mutations have an extremely high chance of getting breast or ovarian cancer. Fortunately, the mutations can be found with a simple blood test. Women who test positive can actually avoid getting breast cancer if their mutation is discovered before cancer occurs or they can find it earlier than they would have otherwise. Breast cancer patients who test positive may be able to obtain more appropriate treatment and importantly, they can help save their children and grandchildren from getting cancer. African American women experience the highest mortality due to breast cancer but there has been little education in their communities about genetic cancer even in areas where risk services are available free.

Our study is designed to bring education on hereditary breast cancer (caused by a gene mutation) to African American women and their families through their church. We used systematic methods to develop and pilot test a culturally appropriate workshop and educational materials including videos, brochure, bingo game, a facilitator guide, and a family history score sheet (that helps women determine if they might be at high risk). Our study includes recruiting church health ministry leaders from our existing faith partnerships, and training them to conduct workshops on hereditary breast cancer. The purpose is to raise awareness about genes, health, and disease, and to identify high risk women and connect them with the services that could save their lives.

Our research question is: What is the feasibility and appropriateness of education on hereditary breast cancer for African American women in an urban church setting? We study this by attending the church workshops and conducting observations ("fly on the wall" observing how the workshops go; what re their strengths and limitations?) We also conduct surveys with participants before and after each workshop to measure how much new information they learned and what they will do with it. In the workshops, women also fill out family history "score sheets" that help them determine if they are at high risk and could benefit from meeting with a genetic counselor.

The successful outcome of our study can lead to large-scale educational programs in communities across the country that will help women at very high risk prevent breast and ovarian cancer. It will also be a foundation for future research and education related to new genetic developments that will enable African Americans to obtain the highest quality care and thus further reduce the disparities that have long affected their communities.