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Table of Contents

Final Report: Award Number DAMD17-00-1-0639

Title: Development of the Harlem Witness Program for Educating Urban African American Women about Genetic Testing for Breast Cancer

Investigator: Heiddis Valdimarsdottir, Ph.D.

The major goal of the proposed study was to develop an innovative method of community outreach and education, geared toward both understanding and then reducing the barriers that African American women have toward genetic testing for breast cancer susceptibility. Although there are a number of risks associated with testing (e.g., insurance discrimination, distress) there are also a number of benefits, including that the information may help women decide upon specific steps to prevent the disease or to detect it at earlier, more curable, stages [1]. As the vast majority of research in this area has focused on White women, it is not clear what hinders African American women in undergoing genetic counseling and testing. In addition, most of the published studies that included African American women in their samples did not focus on culture-specific factors that may affect African American women's decisions to undergo genetic counseling/testing. The possibility that African American women may have unique concerns that influence their decision-making was raised by Hughes et al. [2] findings that compared to White women, a greater proportion of African American women endorsed the following items as risks of BRCA testing: a) modern medicine is not trustworthy, b) death from cancer is inevitable, c) testing would be too difficult to handle emotionally, and d) testing might have a significant effect on family members. Similarly, our preliminary data indicate that African American women who refused genetic counseling were significantly more likely than women who went for counseling to indicate that if they were found to be mutation carriers they would feel ashamed, singled out, less healthy and worry more that their results would not be kept confidential. These studies suggest that limited acculturation to the dominant culture, historical mistrust of the medical community, and health-related or other culturally based beliefs and practices may all influence the attitudes that African American women have toward genetic counseling and testing. Therefore, the major aims of the proposed research were:

Aim 1: To identify culturally-specific attitudes and beliefs related to breast cancer and genetic testing that may represent barriers to BRCA counseling/testing among African American women.

To achieve this aim, educational materials were developed and presented in a focus group format by Erica Wahl, M.S., a genetic counselor. These facts and myths about breast cancer and genetics were presented to African American women with a personal or family history of breast cancer. Four African American women ranging in age from 36-60 (mean age of 47.2) years took part in the focus group. All participants had completed high school and were born in the United States. Three were breast cancer survivors while the other had a first-degree relative who had lost her life to breast cancer.

Knowledge levels of genetics and breast cancer ranged from very little to a considerable amount among the participants, as expressed in the following statements:

- "Before today I heard nothing about genetic testing and counseling"
- "I wasn't aware of the susceptibility gene"
- "I knew about it because I was diagnosed with cancer"

Participants also expressed the fact that they did not think a lot of other women were aware of the existence of genetic mutations that may increase their susceptibility for breast cancer.

Participants' feelings and concerns about genetic testing also varied. For example, one woman expressed the fact that she did not want to undergo genetic testing because "she had enough to deal with" regarding her cancer diagnosis. Fear of being tested was expressed by most of the women, including the fear of discrimination and that their results would not remain confidential.

Aim 2: To use the information provided in the focus groups to develop an education and outreach program (i.e., the Witness Project® of Harlem (WPH)).

The WPH represents a culturally sensitive educational effort that requires collaboration with the church, a powerful and far-reaching institution in the African American community. This program has been modeled after the Witness Project® developed by Dr. Erwin and her associates at the University of Arkansas for Medical Sciences. The Witness Project® is a culturally competent breast and cervical cancer education program for African American women. It is designed to increase adherence to recommended screening guidelines. The Project trains breast cancer survivors, referred to as Witness Role Models (WRMs), to share their own experience of cancer diagnosis and treatment. Additionally, Lay Health Advisors (LHAs) are trained to work with the WRMs in the education component of the program. The program is based, in part, on the African American cultural and spiritual practice of "witnessing", or sharing personal stories of struggle, faith, and empowerment. Programs are primarily conducted in church settings. The Arkansas Witness Project's WRMs and LHAs are all African Americans and it has been demonstrated that ethnic and cultural similarity between Project presenters and their audience enabled more extensive exploration of variables thought to be barriers to cancer screening in many African American women.

Based on the information provided by the focus group, we have developed materials on genetic counseling and testing (see attached) and have added this to the Witness Project® of Harlem, as planned. Since the WPH was established, we have been able to recruit and train 25 team members; 7 Witness Role Models and 18 Lay Health Advisors. In addition, we have ongoing efforts in place to work with and present programs at faith- and community-based organizations throughout Northern Manhattan. We have conducted 7 programs in 2001, reaching over 120 women.

On-going efforts have been made to establish working relationships with additional faith- and community-based organizations located in northern Manhattan. These efforts include, but are not limited to, the creation and dissemination of informational flyers, print and radio public service announcements and conducting informational presentations. The creation of such ties will increase awareness about WPH and facilitate the recruitment of volunteers and sites for conduction WPH programs.

1. Baum A, Friedman AL, Zakowski SG. Stress and genetic testing for disease risk. Health Psychology 1998;16:8-19.
2. Hughes C., Gomez-Caminero A, Benkendorf J, Kerner J., Isaacs C, Barter J *et al.* Ethnic differences in knowledge and attitudes about BRCA1 testing in women at increased risk. Patient Educ Couns 1997;32:51-62.

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Revised Fact Sheet:

Breast Cancer and Genetics

for presentation to Witness audiences

Breast Cancer and Genetics

Inherited Breast Cancer

- In a small number of families, breast cancer is inherited
- In these families…
  - Breast cancer is more common
  - There are often multiple family members with breast cancer
  - Breast cancer is diagnosed at younger ages
  - Cancer is passed on from generation to generation
  - Rare cancers, like breast cancer in men, are more common
  - There may also be family members with ovarian or bilateral breast cancer (breast cancer in both breasts)
- 5-10% of all breast cancer cases are inherited

Breast Cancer Susceptibility Genes

- Scientists have discovered that changes, called mutations, in breast cancer susceptibility genes are passed down from generation to generation in these families.
- These genes are called BRCA1 and BRCA2 – BRCA for BReast Cancer.
- Genes are found in every cell in our body. They are like our bodies' instruction manual – every gene has a job.
- When there is a mutation in a gene, the gene can't do its job.

Myths About Inherited Breast Cancer

- Even if I have the genetic change, I can't do anything about it
- Cancer runs in my family, so I already know that I probably have the genetic change
- A woman can't get the genetic change from her father
- I've already had breast cancer, so knowing whether or not I have the genetic change isn't relevant for me

African American Women and Genetic Counseling and Testing

- Compared to other women, fewer African American women have genetic counseling
- African American women are underrepresented in genetic research

Genetic Counseling

- Genetic counseling is currently available.
- Women can meet with a genetic counselor to...
  - Discuss their family history of cancer
  - Discuss the genetics of breast cancer
  - Discuss the risks and benefits of testing
  - Help decide if genetic testing is appropriate
- There are no national guidelines stating that all women with a family history of breast cancer should be tested. The decision to have BRCA1 and BRCA2 testing is a personal choice.

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Revised Fact Sheet:

Breast Cancer and Genetics

for training of Witness Lay Health Advisors

Breast Cancer and Genetics

Inherited Breast Cancer

- In a small number of families, breast cancer is inherited
- 5-10% of all breast cancer cases are inherited
- In these families...
  - Breast cancer is more common
  - There are often multiple family members with breast cancer
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  - There may also be family members with ovarian or bilateral breast cancer (breast cancer in both breasts)
  - Breast cancer is diagnosed at younger ages
  - Cancer is passed on from generation to generation

Breast Cancer Susceptibility Genes

- Genes are found in every cell in our body. They are like our bodies' instruction manual – every gene has a job
- These genes that are related to breast cancer in some families are called BRCA1 and BRCA2 – BRCA for BReast CAncer
- The job of the BRCA1 and BRCA2 genes is to control cell growth
- Scientists have discovered that changes, called mutations, in breast cancer susceptibility genes are passed down from generation to generation in these families
- Mutations in BRCA1 and BRCA2 can lead to the development of cancer
- Women who have a BRCA1 or BRCA2 mutation have an increased risk to develop breast and ovarian cancer
- All first-degree relatives (parents, brothers, sisters, and children) of an individual with a BRCA1 or BRCA2 mutation have a 50% chance of also having the mutation

African American Women and Genetic Risk for Breast Cancer

- A lot is unknown because African American women are underrepresented in genetic research

Myths About Inherited Breast Cancer

- Even if I have the genetic mutation, I can't do anything about it
- Cancer runs in my family, so I already know that I probably have the genetic mutation
- A woman can't get the genetic mutation from her father
- I've already had breast cancer, so knowing whether or not I have the genetic mutation isn't relevant for me

Genetic Counseling and Testing

- Genetic counseling about BRCA1 and BRCA2 is currently available
- Testing for mutations in BRCA1 and BRCA2 is also available; it is a blood test
- In the genetic counseling session, the genetic counselor will…
  - Discuss your family history of cancer
  - Discuss the genetics of breast cancer
  - Discuss the risks and benefits of testing
  - Help you to decide if genetic testing is appropriate for you

African American Women and Genetic Counseling and Testing

- Compared to white women, fewer African American women have genetic counseling

- Medical options are available to women who test positive, including...
  - Increased screening, including more frequent clinical breast examinations and transvaginal ultrasounds to screen for ovarian cancer.
  - Preventive surgery, including mastectomy (removal of the breast) and oophorectomy (removal of the ovaries).
  - Preventive medications, including Tamoxifen. Tamoxifen is a medication that reduces the risk of developing breast cancer.

Pros and Cons of Genetic Counseling and Testing

- Pros
  - Obtain knowledge
  - Peace of mind
  - Sense of control
  - Helps women make decisions about their medical care
  - Can provide important information for family members
- Cons
  - Concerns about insurance/employment discrimination
  - Concerns about confidentiality
  - Concerns about how the results will affect family members
  - A positive test result may make some women feel "singled out"

Important Information to Consider

- There are no national guidelines stating that all women with a family history of breast cancer should be tested. The decision to have BRCA1/BRCA2 testing is a personal choice.
- If a woman decides to have testing, we recommend that she avoid commercial testing facilities because many do not provide counseling before testing.

Witness Success

The Witness Project® of Harlem is a program that can save lives. If you want to know what you can do- or if you want to have a program in your church or organization please let us hear from you:

(212) 659-5517

Through the support of the Witness Project® of Harlem, the following organizations are largely responsible for its success:

- Derald H. Ruttenberg Cancer Center
- University of Arkansas Cancer Research Center
- Department of Defense
- Gloria Heyison Breast Cancer Foundation, Inc.
- The Greater New York City Affiliate of The Susan G. Komen Breast Cancer Foundation, Inc.

Current national expansion of the Witness Project® is supported by:

- The Centers for Disease Control and Prevention

We are interested in offering this program to more communities, but we need more volunteer "Witnesses". A training program is available for women who want to help us, as is a videotape- "If I Can Help Somebody-Witnessing to Save Lives".

To learn more, please call or write to:
The Witness Project® of Harlem
Mount Sinai School of Medicine
The Derald H. Ruttenberg Cancer Center
One Gustave L. Levy Place, Box 1130
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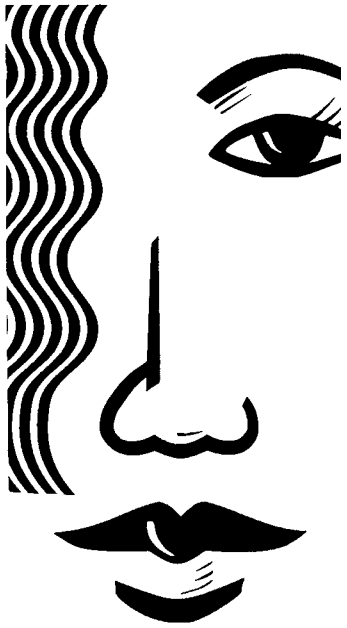
email: info@witnessprojectharlem.org
Web address: http://www.witnessprojectharlem.org

Witnesses



In Church,
People Witness
to Save Souls.

At the
Witness Project®,
They witness
to Save Lives.

Witnesses for Life

The Witness Project® of Harlem is a health program for Black women in faith-based and community settings. It features a group of Black women who each "witness" about their triumph over breast or cervical cancer. Together, they spread the good news that cancer doesn't have to be an automatic death sentence. The key is to catch it early and get it treated.

Body and Soul

The Project offers more than just hope, though. It also teaches women some simple things they can do in their own lives to protect themselves against breast and cervical cancer. Things like breast self-examination.

Trained health instructors at each program use special models to show the audience how they can check themselves for signs of breast cancer. The audience members then get a chance to practice what they've learned by examining the models for lumps.

In addition, the instructors answer questions about things like the Pap test (a test to find cervical cancer) and mammograms (a special kind of x-ray to look for breast cancer). Women will have a chance to find out where in their community they can have these tests done for low (or in some cases no) cost.

The Witness Project®
It's Good for Both Body and Soul.