



Choosing to be Proactive in the Response to Breast Cancer

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LEARNING OBJECTIVES STATEMENT

By the end of reading this paper, you will be able to:

- Demonstrate knowledge about the Inclusion Pledge Paper Series
- Incorporate facts about family health history, genetic testing, and cancer risk assessments in your sphere of influence

INTRODUCTION

The Tigerlily Foundation collaborates with Dr. Onyinye Balogun, Dr. Melissa Davis, Dr. Erica Warner, Dr. Arnethea Sutton, and Dr. Ogori N. Kalu to highlight the necessity of sharing patient-centered information regarding life before, during, and after breast cancer. This paper series addresses critical questions in the breast cancer sphere that many individuals, particularly Black women, do not have the opportunity to ask or receive answers to. One of the main objectives of this paper series is to include Black patient and health professional voices in disseminating reliable information about breast cancer.

Throughout 2022, the Tigerlily Foundation will publish a series of five papers. These papers will highlight the importance of family health history, genetic testing and risk assessments in communities of color, barriers to diversity in clinical trials, community-based approaches to health, the role of data informatics in the electronic health records, and long-term survivorship in the breast cancer community.

Elevated breast cancer mortality rates in communities of color can be attributed to cultural bias in medicine and healthcare inequities. In this paper series, we hope to provide patient-centered literature that encourages cultural humility, awareness, and sensitivity to the unique challenges of breast cancer in the Black community.

AFRICAN ANCESTRY AND BREAST CANCER

Historically, white women in the U.S. had a higher population-based breast cancer mortality rate than Black women. However, a drastic shift occurred in the 1980s (Jiagge et al. 272). Tamoxifen was introduced in 1977 to improve outcomes of hormone-receptor-positive breast cancers, commonly found in all races. Mortality began to decrease in the 1980s because mammogram screenings at age 40 started in the late 70s, which allowed cancer to be detected and treated earlier. Up until the 1980s, mammograms were only done diagnostically. The disparities in mortality shifted when Black women were not given Tamoxifen at the same rate as white women, and mammogram screenings were not conducted in communities of color. We are currently living in the aftermath of the lack of equitable usage of Tamoxifen and screenings. These issues continue to be a problem facing people of color.

The incidence of breast cancer is higher among white women than Black women in the United States; however, the mortality rate for Black women is much higher (Ellington et al. 44). According to the Breast Cancer Prevention Partners organization, Black women “have a 31% breast cancer mortality rate which is the highest of any racial or ethnic group” in the United States. In addition, young, Black women are also more likely to be diagnosed with triple-negative breast cancer (TNBC) (BCPP 1; Reid et al. 2), a more aggressive, hormone receptor-negative subtype of breast cancer. This, in part, contributes to the high mortality rates for Black women.

Scholars in the last decade have investigated the role of ancestry in breast cancer patients to better understand why it impacts Black women differently. The forced migration of the Trans-Atlantic Slave Trade had created two populations with shared ancestry, demonstrating similar patterns in breast cancer profiles (Jiagge et al. 273; Davis and Newman 219). For example, in both the United States and sub-Saharan Africa, Black women have elevated rates of TNBC compared to their white counterparts (Jiagge et al. 271). In addition, populations in Ghana, Nigeria, and Mali, have reported a higher prevalence of TNBC than those in Eastern and Northern Africa (Davis and Newman 219). Socio-economic status is not the sole determinant for adverse breast cancer outcomes in Black women. Researchers are aware of additional factors including tumor biology, environment, and ancestry (Davis and Newman 219). The study of cellular biology has changed the way scientists have been able to analyze genetics when it comes to breast cancer. Stem cell research is an excellent way to investigate the connection of triple-negative breast cancer in Black women to their African ancestry. Exploring stem cells and biomarker testing would provide more understanding about Black women diagnosed with breast cancer. However, this has not been proven easy because Black women are not represented in clinical research in high enough numbers to produce reliable statistical data (Jiagge et al. 272).

CANCER RISK ASSESSMENT

Recent studies have shown that a critical proactive measure regarding breast cancer is participating in and completing cancer risk assessments. According to Finkelstein et al. (293), there is an underutilization of chemoprevention measures among women deemed high-risk for breast cancer. Primary care physicians should routinely perform breast cancer risk assessments in communities of color, followed by genetic testing for those deemed high risk. Breast cancer risk assessments should be used at higher rates in primary care settings for several reasons (Finkelstein et al. 293).

First, it creates a proactive conversation about breast cancer. Breast cancer risk assessments can be a valuable tool to spark conversations about breast health, as it is likely that patients have questions but do not know what to ask. For high-risk patients, the conversation about preventative measures needs to occur early enough for individuals and doctors to decide on an effective plan. These decisions can involve risk reduction surgery, high-risk screening, or chemopreventative medications, such as

Tamoxifen or Raloxifene (Finkelstein et al. 293). These conversations should also include the risks and benefits of these interventions. More research is needed to determine how patients receive information about their risk for breast cancer and risk reduction interventions in primary care settings (Finkelstein et al. 296).

Second, Black women are less likely than white women to get an early diagnosis of breast cancer. (Reid et al. 3). Early detection is key to increased survival; therefore, creating a dialogue about breast cancer symptoms as early as possible is essential. Primary care providers can create a trusting environment for their patients by having these crucial conversations. A trusting environment includes medical providers listening to and answering questions, allowing patients to process what they are feeling, and offering a safe space (with sufficient patient-provider interaction time) to make informed decisions.

There are many breast cancer risk assessment tools available online that providers can use during the clinical evaluation of their patients. These risk assessment tools use the information on a woman's medical, reproductive, and family history to estimate her chance of developing breast cancer within the next ten years. These tools include the Gail, Tyrer-Cuzick, and MSKCC (Memorial Sloan Kettering Cancer Center) breast cancer risk assessment models.

Unfortunately, most of these models are not as effective for Black women because they were developed and tested with data mainly from white women. Julie Palmer, Sc.D, of Boston University School of Medicine, led the effort to develop the Black Women's Health Study Breast Cancer Risk Calculator. Published in the *Journal of Clinical Oncology* in October 2021, this NCI-funded effort builds on other existing models by adding additional risk factors to estimate the breast cancer risk in Black women. The model was developed using data from multiple extensive population-based studies. Half of the participants identified as Black and then tested the model's performance on a health data set from the Black Women's Health Study (15 years of health data from 52,000 participants). As per Dr. Palmer, this new model performed best for Black women under the age of 40, who most need a personalized tool to guide decisions about screening.

Finkelstein et al. (293) created a model for patients and providers to increase breast cancer risk assessment in the primary care setting. First, the scholars created a website to process preliminary screening of patients. Once the patient was identified as high risk through survey completion, the online BNAV (Breast cancer NAVigation) system notified the doctor that the patient is considered at high risk for breast cancer which prepares the physician for the appointment (Finkelstein et al. 295). This interactive system engages patients by learning more about genetic testing and risk reduction interventions. This platform also tracks the process of what patients have learned through various quizzes and simulations throughout the model. Quizzes and simulations require active engagement from the participants, which helps them retain the information and feel more comfortable relaying it to others. Finally, each patient creates an action plan that the physician reviews, detailing their thoughts about the next steps they would like to pursue.

The risk assessment tool BNAV, when implemented successfully, saw a 37% increase in the utilization of "chemoprevention measures" by high-risk patients at their breast clinic (Finkelstein et al. 295). The purpose of introducing this type of system is "...to increase breast cancer risk assessment and chemoprevention in the primary care setting...[and] promote preventive care and genetic testing based on personalized risk assessment" (Finkelstein et al. 296).

DIVERSITY IN GENETIC COUNSELING AND TESTING

Although there has been an uptick in genetic testing, Black women remain one of the lowest racial demographics to complete it (Reid et al. 2). The data collected from genetic testing helps researchers better understand patterns of hereditary breast cancer (HBC). Since white women are more likely to get genetic testing when compared to women of other races/ethnicities, most of the research regarding HBC lacks diversity as it focuses mostly on white women (Reid et al. 2). Once a high-risk patient is identified through the various risk assessment tools available, it is recommended that the patient be referred to a licensed geneticist/genetics counselor for testing. As stated by Dr. Altovise Ewing, Health Equity Geneticist and Certified Genetic Counselor, during the Tigerlily Foundation Pull Up a Seat event in February 2021, genetic counseling and testing is an informative way for high-risk patients to understand their inherited risk of developing cancer. Genetic counseling explores one's risk by collecting personal and family medical history with the help of a geneticist. That conversation will determine if the individual or another family member is appropriate for genetic testing. Genetic testing examines DNA to determine if there is a genetic mutation that is known to be directly related to an increased risk of developing cancer. Genetic testing can be completed with a blood or saliva sample.

The three types of genetic testing include the following:

- Single-gene testing looks for changes in only one gene.
- Panel testing looks for many changes in genes at once.
- Large-scale genetic or genomic testing analyzes multiple genes or one's entire DNA.

Genetic testing results include positive (genetic mutation shown), variant of unknown significance (VUS, which means a mutation has been detected, but it is unknown if that mutation increases a person's risk of developing cancer), or negative (no gene mutation detected). As scientific research expands and new clinical information becomes available, results can change over time. However, not all patients are notified if it changes. For example, a result of VUS or negative can change to positive because new scientific information directly links a mutation to cancer. Dr. Ewing's medical scholarship and her peers are trying to educate patients on their rights and make sure geneticists and researchers constantly communicate with patients.

CONCLUSION

The increased mortality rates in Black breast cancer patients, in part, can be attributed to disparities in care leading to late-stage diagnosis and delay in treatment. Risk assessment tools have been proven to identify patients at high risk, which can help determine appropriate screening behavior and preventative measures. In addition, genetic counseling and testing for high-risk individuals help them understand their inherited risk of developing cancer which may have further implications for the patient and their family. The Tigerlily Foundation advocates for primary care providers to implement breast cancer risk assessment in communities of color. Utilizing breast cancer risk assessment models and genetic testing is a step towards personalized cancer prevention, which includes early detection of cancer to improve overall outcomes.

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Patient Perspective for Paper 1

Genetic Testing and Risk Assessment

Interviewer: Virginia Leach

Patient Expert: Kiana Wooten

In addition to the Inclusion Pledge Paper Series, breast cancer warriors have been asked to describe their experience with each topic. Patient advocacy-based organizations should want to increase the literature of breast cancer research and create space for patients to share their experiences, inspire others, and build a community of love and support.

Interviewer: When did you notice something did not feel right on your breast?

Kiana: In the spring of 2019, I noticed a small pea-sized lump by my left nipple. Because I had always had cysts in my breast during my monthly cycles, I did not pay much attention to it. That was my biggest mistake! After 4 months, I noticed the lump had gotten significantly more prominent and began to hurt. In addition, I was starting to feel sore all down my shoulder and under my armpit. I quickly made an appointment with my PCP (primary care physician) to get checked. Upon doing a breast exam, she, too, noticed the lump. I flinched as her hands made what seemed like endless circular motions around my breast. And then there was an eerie silence. As I opened my eyes, I could see her facial expression change. She said she was writing me a script to have a mammogram done ASAP. I was very confident that it was nothing more than a cyst or fatty tissue, so I brushed it off. I finally made the appointment two weeks later.

Interviewer: Describe your mammogram experience. How did it compare to the previous ones you had?

Kiana: The day of my mammogram started off like any other ordinary day for me. I was not nervous or anything. I just wanted to get this test over with. However, as they called my name to take me to the backroom for the exam, something felt a bit different. I had the mammogram done and was then taken inside a patient room. I found this to be strange, considering I had had other images done and was never taken into a room afterward. The radiologist informed me that the doctor would come in to talk to me. When he came in and looked over the images, he uttered words that will forever haunt me. He said he was about 99% sure that the lump was malignant. I think I was numb for what seemed like a lifetime. I was confused, upset, distraught, and just couldn't believe what I was hearing. I had so many thoughts that went through my head. "Am I going to die?" "How will my family survive this?" "What do I do now?"

Interviewer: When were you given the results of the mammogram?

Kiana: A definitive diagnosis was needed. I would have to schedule to have a biopsy done. Now I began to panic! Waiting an additional two weeks to get the biopsy done and then waiting for the results. The following weeks were a blur. I finally got the phone call I had been anticipating. On October 1, 2019, I was officially diagnosed with Invasive Ductal Carcinoma. I felt my world closing in on me. I was too young to have cancer, right? WRONG! How could this have happened to me? Why me?

Interviewer: Did your oncology team or primary care physician speak with you about genetic testing?

Kiana: Before getting any type of treatment or surgery, my oncologist felt it was a good idea to have genetic testing. Why, you ask? Before I go any further, I should state that my older sister was also battling breast cancer at the time. So, we thought this was worth doing. I learned so much about my family history through genetic testing that I never knew. I had to have some tough conversations with my family about cancer in our family. It is not a subject that people openly or willingly like to talk about, but it is essential to the point where it can be life-changing.

Interviewer: Did you learn new information while speaking with your family undergoing genetic testing?

Kiana: While talking to my family about my cancer diagnosis and whether we had any other family members who had any type of cancer, I learned that cancer ran rampant on my mother's and father's sides of the family. My mother had two sisters that passed away from cancer. One had gallbladder cancer, and the other sister had cervical cancer. One uncle has colon cancer. There were also a few 1st cousins that had some form of cancer. On my father's side, my paternal grandmother had breast cancer, her daughter (who is my aunt) had breast cancer, and two uncles had some form of cancer. It was like I was living in the twilight zone!

Interviewer: Many people have never heard of genetic testing or know its process. How was your genetic testing experience?

Kiana: Getting swabbed for the test was the easy part. Waiting for the results had me on edge. I had my mother and sister go for genetic testing as well. Turns out that my mother did not have any genetic mutations, and neither did my sister! Unfortunately, I DID. I had a genetic mutation in my RNA. Most people only hear about BRCA 1 or BRCA 2 as far as genetic breast cancer mutations; however, this was not the case for me. My mutation was in my ATM gene. There is also a 50 % chance that I may have passed this gene to my daughter.

Interviewer: Thank you for sharing your experience. This will help several individuals who begin genetic testing. Is there anything you would like to communicate to the Tigerlily Foundation readers and warriors?

Kiana: I really want to reiterate the importance of knowing your family health history. Not only can it save your life, but it could also save other family members' lives. I understand that no one wants to talk about cancer or its risks. Still, these are vital conversations to have. We can change the stigma and narrative about cancer with education and open communication. KNOW YOUR FAMILY HEALTH HISTORY! KNOW YOUR RISKS! KNOW THE SIGNS AND SYMPTOMS! I can guarantee you that if I had known my family history and the risks, I would have gone to the doctor as soon as I found the lump. Then, I would have been diligent about doing monthly breast exams. Cancer does not discriminate against age, sex, race, or religion. Cancer may be a part of you, but it DOES NOT define WHO YOU ARE!

