Use of Cancer Genetics Services in African-American Young Breast Cancer Survivors

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Introduction: African-American women have higher rates of early-onset breast cancer compared with their Caucasian counterparts; yet, when diagnosed with breast cancer at a young age, they underuse genetic counseling and testing to manage their risk of developing future cancers.

Methods: Self-reported baseline data were collected between September 2012 and January 2013 and analyzed in 2014 from a subpopulation of 340 African-American young breast cancer survivors (YBCSs) enrolled in an RCT. YBCSs were diagnosed with invasive breast cancer or ductal carcinoma in situ between ages 20 and 45 years and were randomly selected from a statewide cancer registry. Logistic regression examined predictors of using cancer genetics services.

Results: Overall, 28% of the sample reported having genetic counseling and 21% reported having genetic testing, which were significantly lower ($p \leq 0.005$) compared with white/other YBCSs participating in the parent study. In a multivariate analysis, income was positively associated with counseling (B=0.254, $p \leq 0.01$) and testing (B=0.297, $p \leq 0.01$), whereas higher education levels (B=−0.328, $p \leq 0.05$) and lack of access to healthcare services owing to cost (B=−1.10, $p \leq 0.03$) were negatively associated with genetic counseling. Lower income and lack of care because of high out-of-pocket costs were commonly reported barriers.

Conclusions: Despite national recommendations for genetic evaluation among women with early-onset breast cancer, few African-American YBCSs reported undergoing genetic counseling and testing. Most reported that their healthcare provider did not recommend these services. Interventions addressing patient, provider, and structural healthcare system barriers to using genetic counseling and testing in this population are needed.

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Introduction

Racial and ethnic health disparities in breast cancer mortality in younger women are well documented.[1–3] The incidence of early-onset breast cancer and mortality are higher among African-American women compared with Caucasian women.[3,4] There are significant racial disparities in breast cancer survival among women diagnosed with breast cancer at a younger age.[3] It is the second leading cause of death among African-American and Caucasian women aged between 20 and 49 years; the mortality rate for younger African-American women is double that of younger Caucasian women (14.3 vs 7.1 per 100,000).[3] This disparity in health outcomes has been attributed to lower SES, cultural

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factors, delay in accessing care,[5–7] and biological differences in breast cancers between African-American and Caucasian women.[1,2] African-American women are diagnosed with tumors that are more aggressive at presentation, characterized by higher grade, and poorly differentiated, with a greater likelihood of triple-negative breast cancer.[2,8]

Although *BRCA1* and *BRCA2* are associated with majority of the hereditary breast and ovarian cancer (HBOC) syndrome cases, other less common genes confer a moderate risk.[9,10] The prevalence of these mutations varies considerably among ethnic groups and geographic areas.[9,10] Inherited mutations in HBOC-associated genes predispose individuals to a significantly higher risk of breast and ovarian cancer.[11] Based on observations primarily of Caucasian women, *BRCA1* or *BRCA2* mutation carriers have a fourfold increased relative risk of developing a contralateral breast cancer.[12] *BRCA* mutation carriers also have a greater likelihood of early-onset disease, with higher-grade tumors often characterized as triple-negative.[1]

The National Comprehensive Cancer Network recommends HBOC genetic risk assessment in individuals aged younger than 50 years diagnosed with breast cancer.[13] Identifying an HBOC-associated mutation in these individuals is critical for quantifying future cancer risks, developing a personalized prevention and surveillance plan, and advancing family members' understanding of their own cancer risks.[14,15] Despite these benefits, there is documented underutilization of cancer genetics services among African-American women,[16–21] who are less likely to use cancer genetics services than Caucasian women,[15,22–24] despite the highly reported prevalence of *BRCA* and other gene mutations among them.[7,14,17]

Studies assessing barriers to use of genetic services among African-American women reported limited knowledge about genetic counseling,[25] concerns about genetic discrimination and medical mistrust,[20,26,27] high cost,[20] underuse among HMO participants compared with those with private insurance plans,[24] and lack of provider referral despite meeting eligibility criteria.[19] However, few of these studies have been conducted exclusively in African-American women diagnosed with early-onset breast cancer (young breast cancer survivors [YBCSs]). Given that a diagnosis of early-onset breast cancer is a hallmark of HBOC,[28] it is imperative that more studies are conducted in this population to elucidate factors that impact utilization of cancer genetics services. The primary aims of this study are to: (1) conduct an in-depth examination of factors associated with use of cancer genetics counseling and testing among African-American YBCSs; and (2) examine age-related differences in self-reported utilization of these services.

Methods

Study Design

This secondary analysis used baseline data from a prospective RCT that tested the efficacy of two interventions designed to increase breast cancer surveillance and use of cancer genetics services among YBCSs and their high-risk female relatives in the state of Michigan (ClinicalTrials.gov ID: NCT01612338).[29] An expanded version of the Theory of Planned Behavior (TPB) guided the parent study[29] and informed this secondary data analyses (Appendix Figure 1, available online). The TPB posits that knowledge and attitudes toward a behavior, subjective norms regarding the behavior, and perceived control over the behavior predict one's intention to engage and perform the health behavior.[30] Family support, which has been shown to facilitate one's decision to have genetic testing,[29,31] was also incorporated into the TPB for the parent study.[29,31] TPB has been successful in predicting and explaining behaviors such as mammography screening[32,33] and physical activity in breast cancer survivors.[34,35]

Sample

Details about recruitment process and enrollment criteria for the parent study have been published elsewhere.[29] Briefly, a random sample of 3,000 YBCSs (with unilateral or bilateral invasive breast cancer or ductal carcinoma in situ between ages 20 and 45 years) diagnosed between 1994 and 2008 were identified and recruited from the Michigan Cancer Surveillance Program with linkage to vital records.[29] The initial sample was stratified by race (African American versus white/other) to oversample African-American YBCSs. Data collection from YBCSs occurred from September 2012 to January 2013 and analyses for this secondary analysis occurred in 2014. The IRB at Duquesne University approved this secondary data analysis of 340 African-American YBCSs who returned the baseline survey. Use of cancer genetic services among white/other YBCSs participating in the parent study are presented to support conclusions of this secondary analysis.

Measures

Previously described validated measures assessed factors associated with use of cancer genetics services.[29] Reliability of all measures was examined in this sample of African-American YBCSs (Cronbach's $\alpha > 0.70$) (Table 1). Demographics, clinical characteristics, and self-reported use of cancer genetics services were assessed with a baseline survey developed by the core research team of the parent study based on the Behavioral Risk Factors Surveillance System Survey[36] and previous studies conducted by the core research team.[37,38] Cancer genetics services were defined as follows: "Genetic services usually involve meeting with a genetic counselor or doctor who takes your family history, talks about your risk of hereditary cancer, and gives you information about genetic testing and cancer screening and genetic testing uses a sample of saliva or blood to examine DNA, it tells us if we have a deleterious mutation that increases our risk for cancer due to heredity."[38] Age at the time of the study was dichotomized to: (1) <50 years and (2) >50 years. The personal age of a patient could reflect whether they value and accept genetic counseling and testing, with a greater likelihood of uptake of genetic testing among younger survivors. It is also important to note that the mean year