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What Black Women Know and Want to Know About Counseling and Testing for *BRCA1/2*

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Abstract

Black women are just as likely to have hereditary breast cancer mutations as White women, yet their participation in genetic counseling and testing is substantially lower. This study sought to describe Black women's awareness and perceptions of *BRCA1/2* testing and to identify barriers and motivators to seeking *BRCA1/2* services. Fifty intercept interviews were conducted with Black women in public places (a professional women's basketball game, a grocery store, a faith-based community event, and the waiting area at a breast care clinic) in Washington, DC. More than half of the women (54%) were aware that genetic tests to determine risk for certain breast and ovarian cancers exist, but the majority (88%) had never heard of *BRCA1/2* , specifically. After hearing a description of *BRCA1/2* genetic markers, 82% stated that they would agree to *BRCA1/2* testing if it was offered to them. Perceived advantages of testing included cancer prevention and the ability to share information with family members. Perceived disadvantages included emotional distress associated with identification of the mutation and the potential misuse of results to deny healthcare or employment. Physician recommendation, self-care, and known family history were among the motivators for testing. Women listed possible media and venues for intervention. In spite of low rates of *BRCA1/2* testing in the Black community, women in this sample were open to the idea. Interventions that address barriers and include cultural tailoring are necessary.

Keywords

Genetic Counseling; BRCA1/2; Black Women; Health Disparities

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Introduction

Since the mapping of the human genome, there has been a proliferation of genetics research. One of the benefits has been increased access to cancer-related risk information. The discovery of the breast cancer genes, *BRCA1* and *BRCA2* (i.e., *BRCA1/2*) allowed for the mutational analysis of these genes [1, 2]. While hereditary breast cancer is rare and only accounts for 5%–10% of all breast cancer cases, women carrying a risk-conferring *BRCA1/2* mutation have a 55%–85% lifetime risk of developing breast cancer and a 15%–60% lifetime risk of developing ovarian cancer [3, 4]. *BRCA1/2* testing is recommended for women at increased risk of carrying a deleterious mutation, including those with the following medical histories: epithelial ovarian cancer, breast cancer diagnosed at age ≤45, triple negative breast cancer diagnosed at age ≤60, or two primary breast cancers, with one presenting at age ≤50. *BRCA1/2* testing is also recommended for women diagnosed with breast cancer at age ≤50 who have a close (i.e., first or second degree) relative diagnosed with breast cancer at any age; women diagnosed with breast cancer at any age who have a close relative diagnosed with breast cancer at age ≤50; women diagnosed with breast cancer at any age who have two close relatives who were diagnosed with breast cancer or one close relative who was diagnosed with epithelial ovarian cancer; and women diagnosed with pancreatic cancer who have two close relatives who were diagnosed with breast, ovarian, pancreatic, or aggressive prostate cancer at any age [5]. Women with a family history of male breast cancer and those of Ashkenazi Jewish ethnicity are also considered to have an elevated risk for the mutation [5–9]. While *BRCA1/2* testing only identifies risk for one of several hereditary factors [5], the identification of the *BRCA1/2* mutation provides the opportunity for medical management through pharmacologic intervention, increased surveillance, or prophylactic surgery for a vulnerable group [9].

Black women have a lower overall incidence of breast cancer than non-Hispanic White women, but are more likely to have late stage disease and to die from it than Whites [10–14]. Black women's risk for hereditary breast cancer mutations are also the same as White women [15]; yet, despite various research and recruitment efforts over the past decade, Black women have not readily adopted use of genetic counseling and testing services and have substantially lower enrollment rates (15%) into familial cancer genetics registries than White women (36%) [16–18]. It is unclear whether these disparities are due to personal preferences, social norms, and/or cultural beliefs [17, 19, 20]. Some barriers to genetic counseling and testing include lack of knowledge [21–26], negative attitudes regarding genetics and genetics research [22, 25, 27], and concerns about racial, insurance, and employment discrimination[28, 29].

Armstrong and colleagues found that in a sample of women with family histories of breast cancer, Black women were significantly less likely to undergo genetic counseling for *BRCA1/2* testing than White women, but stated that these differences were mostly due to access [30, 31]. Differences have not been explained by socioeconomic factors, risk perception, attitudes, or risk for carrying a *BRCA1/2* mutation in the non-survivor population [32]. Physicians' recommendations have been shown to influence interest in, and uptake of testing in some samples [33, 34]; however, other studies suggest that physician recommendation is not the strongest motivator, with women considering the potential

consequences of testing positive for the mutation to be more influential [35]. Recent data also suggest that having a low confidence in the ability to pursue testing (knowing about services location, payment options, and how to deal with test results) and higher mistrust of medical institutions to use genetic test results strictly for beneficial reasons (e.g., patient care and prevention) were associated with lower participation [36, 37].

Because more information is known about factors that have influenced Black women's mammography screening behaviors, such as spirituality [38–40], fear [39], fatalism [41–43], and family interdependence [44], some of these factors have been incorporated into *BRCA1/2* counseling and testing research [45, 46]. Still, strategies to improve accrual of Black women into breast cancer genomic research have had limited success, and data on determinants of participation are equivocal [16, 47, 48]. One kindred study found that Black women with family histories of breast or ovarian cancers were interested in genetic counseling and testing for *BRCA1/2* [23]; however, multiple studies with Black/White samples have shown that Black women in the general population as well as those with a recent breast cancer diagnosis have lower awareness of, interest in, and uptake of *BRCA1/2* counseling and testing than their White counterparts [3, 36, 49–51]. Studies that have promoted genetic counseling and testing through the use of culturally tailored approaches have shown promise but have nevertheless yielded low participation among Black women [52]. Furthermore, few Black women who agree to be tested, actually choose to receive their test results [20, 53].

Given the recent emphasis on genomic-based medicine, a better understanding of the social norms, and individual values and preferences regarding genetic counseling and testing among Black women is warranted [20, 30]. There are a number of hereditary factors other than *BRCA1/2* that can predispose women to various cancers [5]; gaining insight about the perceptions of genetic testing from individuals in the Black community may help us understand why Black women who may benefit from this type of testing are not receiving it. This paper presents findings from a descriptive study, in which we sought to increase our understanding of Black women's general awareness and perceptions of *BRCA1/2* testing, and to identify barriers and facilitators to use of this service.

Methods

This descriptive study employed intercept interviews, also called "location interviews."—a method used to quickly gain insight into the opinions and behaviors of a population [54–56]. This social marketing research strategy captures information from a convenient, non-random sample in public places where large groups of people congregate [55]. Research staff and the primary investigator received training from an expert in social marketing with extensive experience in conducting intercept interviews.

The Georgetown University Medical Center Institutional Review Board approved this study. Eligible participants were women 21 years of age or older who self-identified as Black/African American. For recruitment, race and age were initially presumed through phenotypic characteristics and were verified during the short demographic survey. Women were recruited at a professional women's basketball game, a grocery store, a faith-based

community event, and the waiting area at a breast care clinic. These locations were selected as they had been previously identified as places where at least 10 Black women could be recruited within a period of two hours. Two research staff attended each event. A table identifying the research team was set up at each site. Brochures on the table featured information on breast health that was tailored for Black women. Information on genetic testing or counseling was not displayed. Approximately every third Black woman who stopped at, or passed by the table was invited to participate. Research staff provided a verbal description of the study; read the consent form aloud; and obtained consent from participants. Interviews lasted approximately 10 minutes. Respondents were given a $10 gift card and general information about breast health for their participation. Women with children were offered healthy snacks (e.g., granola bars), pencils, and notepads. A total of 50 women were interviewed for this study.

Interview Protocol

Intercept interview questions were informed by input from an interdisciplinary research team, a review of the literature, and feedback from survivor advocates. The survey included a combination of closed-ended and open-ended questions. The goal of the interviews was to obtain data on knowledge and perceptions of genetic testing (e.g. “Tell us what you know about genetic testing.”); motivators and barriers to genetic testing (e.g. “What would motivate/prevent you from participating in genetic testing?”); and advantages and disadvantages to genetic testing (e.g. ”What would you say are the advantages/disadvantages to genetic testing?”). Participants were asked four close-ended questions: “Have you heard of genetic testing for breast and ovarian cancer risk?” [yes/no]; “Have you heard of *BRCA1/2* ?” [yes/no]; “If given the opportunity, would you be interested in being tested for *BRCA1/2*?”; and “If given the opportunity, would you be interested in genetic testing for breast and ovarian cancer risk?” [yes/no]. Women were given a brief description of *BRCA1/2* genetic markers before they were asked if they would be interested in *BRCA1/2* testing. Research staff read the questions aloud in an area away from the crowd. Answers to close-ended questions were marked and extensive notes were taken to capture answers to open-ended questions. Important quotes were written in their entirety. Immediately following an interview, research staff augmented interview notes before conducting another interview.

Data Analysis

Demographic items and answers to the four closed-ended questions were analyzed using descriptive statistics to display the distribution and variable factors. The remainder of the survey included narrative responses to specific questions. Based on an initial review of the responses, the research team developed a codebook, which was used to analyze data for each question. Two members of the research team did subsequent coding. Consistent themes were compared among the coders and disagreements regarding codes were discussed until a point of consensus was reached.

Results

Participants

All women self-identified as Black or African American. The sample was highly educated; 48% of the sample had a college degree or higher. Ninety-eight percent had some form of health insurance and 70% were employed full-time. Most women were unmarried (72 %) and 6% were breast cancer survivors (Table 1).

Knowledge: Current and Desired

Women were asked to share what they knew about genetic testing for breast and ovarian cancers. Answers to closed-ended questions can be found in Table 2. While 54% of the participants were aware that genetic testing was available for breast and ovarian cancers, 88% had never heard of *BRCA1/2*. After being told that *BRCA1/2* testing identifies the presence of genetic mutations that signify an increased risk for breast or ovarian cancer, an overwhelming majority of the participants (94%) responded that they would be interested in learning more about the test, and 82% stated that they would be interested in being tested. Additionally, participants wanted more information related to the overall process of genetic testing, such as, how the test is performed; how long it takes; and what it entails. When asked what type of additional information they would want, they said that information on the test's "accuracy" and "benefits" would be key.

Based on the name, women assumed that *BRCA1/2* testing was a genetic assessment used for preventative care, and that it was related to the hereditary nature of breast and ovarian cancers. For example, one participant stated that it "tests to see if you have the gene or are at risk for the disease." Another commented that the procedure was likely a "DNA test" that required "taking blood" in order to gauge breast cancer risk at the "cellular level." Women who were able to provide more accurate descriptions or more details tended to have personal reasons for having this knowledge. Breast cancer survivors demonstrated the most knowledge, followed by women who had relatives that had been diagnosed with breast cancer. A woman who had been through genetic testing offered this summary: "Counseling is given; then, there's blood work for *BRCA1/2*."

Perceived Advantages and Disadvantages

When asked about the advantages of *BRCA1/2* testing, responses included statements, such as, "being able to prevent cancer;" and "the opportunity for early detection, instead of waiting until the cancer develops." Participants identified the ability to take action as the greatest benefit of genetic testing. Potential behavioral changes that might result from identification of the marker included having more mammograms, and living healthier lifestyles. For example, one participant said that if it was discovered that she had the mutation, she could "fine-tune" her life by improving her diet and exercising more. Obtaining information that could be important to family members was frequently cited as another advantage of *BRCA1/2* testing. Increasing public awareness of prevalence was also deemed important.

Most of the disadvantages that participants listed pertained to skepticism about the testing process and procedures. For example, some women cited “the possibility that it won’t work,” and questioned the reliability for Blacks. Others questioned whether there were side effects associated with testing. Women talked about fear and the potential for emotional distress related to identification of the mutation. They also shared concerns that they would face discrimination from the healthcare system or potential employers. Participants worried that after learning that they have the mutation, women might hastily decide to have “unnecessary surgery.” On the other hand, they also worried that women, after learning that they did not have the mutation, might discontinue annual mammograms.

Barriers and Motivators to Participating in Genetic Testing

Primary motivators for participating in genetic testing included known family history, personal health awareness, and physician recommendations. The majority of women reported that they would be motivated to participate in genetic testing if they knew that it was part of their family history. Mothers and women who planned to have children believed that information about genetic risk would be important to have. Other women said that they would be motivated simply because genetic testing is an extension of “health consciousness” and demonstrates the priority of “taking [one’s] health seriously.” Physician recommendation was also cited as being an important motivator. Some suggested that the test should be offered during annual exams or gynecologic visits. Women also mentioned it would be important to have places within their communities where they could be tested, if appropriate, and that these services should be offered on weekends and evenings.

Perceived barriers to genetic testing included “cost,” “insurance coverage,” “transportation,” “personal finances,” and “fear.” One woman commented, “If I have to pay for it, I would skip it and just do my own breast testing (i.e., breast self-exam).” Another stated, “If I had to take off from work to get tested, I wouldn’t go.” Women most frequently reported fear as a barrier, including “fear of knowing that breast cancer is possible”; “fear of results and the unknown”; and “fear of needles and pain.” One woman commented, “I’m thinking of the negative, like I’m going to die.” Some women shared their fears about getting genetic testing and linked it directly to “mistrust of medical science” and the “Tuskegee effect.” They were also fearful of being denied insurance or employment if the mutation was identified. One woman stated, “[The test results] would be given to the healthcare people so that they wouldn’t cover you.”

Women stated that awareness campaigns are necessary to increase knowledge of, and motivation for testing. For example, one woman stated that she was motivated by the “awareness of the high percentage of African American women who were dying [from breast cancer].” They added that pamphlets or guides identifying websites with content about *BRCA1/2* testing would be helpful. They also suggested workshops and free testing promotions as a way to spread the word in the community. Several women commented that survivor and celebrity public service announcements might be effective motivators. At the time of the interviews, a well-known celebrity under the age of 40 had disclosed her breast cancer survivorship status; a few participants mentioned her.

Discussion

The underutilization of genetic testing and counseling services by Black women is well-documented [20, 26, 31, 49]. Improving the rates of genetic counseling and testing in this population may provide opportunities to offer early interventions and thwart disease [57–59]. Data on the perceptions of genetic testing among Black women are key to increasing uptake. This study is one of a few that describe Black women's general knowledge, perceptions, and motivating factors regarding genetic testing for breast and ovarian cancers in a community setting. Including women from non-clinical settings is important because optimal genetic counseling and testing practices will involve engaging individuals who may not be interacting with the healthcare system or with providers who would talk to them about genetic testing [31, 34, 52, 60]. Consistent with previous research done by Pal and colleagues, the women in this sample had a high interest in *BRCA1/2* testing, despite limited exposure [48].

Previous studies with Black women have found an association between recent breast cancer diagnosis and likelihood of participating in genetic testing [50, 51], as well as an association between a family history of breast or ovarian cancers and greater knowledge of genetic testing [49]. Similarly, in the current study, participants who had specific knowledge about the availability of *BRCA1/2* testing tended to be breast cancer survivors. Women with first-degree or second-degree family members who had been diagnosed with cancer also had slightly more knowledge and quite a bit more interest in genetic testing, but had not received any.

Before women can make informed decisions regarding their participation in genetic testing for breast or ovarian cancer, they have to understand their relative risk, the process, and the advantages and disadvantages of testing. The presumed advantages of genetic testing (e.g., breast cancer prevention, greater awareness of risk for self and family) were obvious to all participants; however, women did not have a clear understanding of the process, and lack of understanding could cause women to focus on the disadvantages. A few women were concerned about side effects from testing and the reliability of the tests, specifically when performed on women of color. Furthermore, women were cautious about the potential emotional impact of results, and the steps that one should take in the event of a positive test result were not well understood. While the physical risks associated with genetic testing may be minimal, concerns about negative emotional responses and possible discrimination cannot be easily pushed aside [18, 26]. Previous research suggests that genetic testing outreach efforts targeting the Black community should focus more on the issues of negative emotional reactivity and stigmatization as a primary barrier to genetic counseling participation [26].

In the context of clinically-based trials and interventions, the issue of trust is a complicated one. Previous research on breast cancer, along the care continuum, has shown that medical system mistrust is an issue in the Black community [41, 61]; however, research examining dyadic relationships has shown that Black women have high trust in their personal providers [62, 63]. Along those lines, while women in the current study expressed mistrust of the medical system and insurance providers, and had concerns about the potential misuse of

genetic testing data, they did not report mistrust of their physicians. In fact, participants stated that a physician's recommendation would be an important motivator for *BRCA1/2* testing. Previous research studies with Black women have identified a relationship with a physician as a motivating factor for seeking breast cancer treatment [62] and the decision to seek adjuvant treatment after primary treatment [64]. Physicians are the primary source for health information for many Black women [62, 65]. Most strategies to increase knowledge and awareness about *BRCA1/2* have been targeted towards women at high-risk who are in clinical settings, often as part of research studies [47, 49]. One might assume that individuals who are at increased risk for *BRCA1/2* mutations will be approached or are already aware of genetic testing; however, since most women do not receive care from providers specializing in cancer care or breast health, exposure to information about genetic testing and counseling for breast and ovarian cancers is not guaranteed. Lowstuter and colleagues found that physicians often have low knowledge about genetic testing, particularly as it relates to privacy and the use of results, expressing mistrust regarding the use of genetic information by parties outside of the immediate medical setting [66]. Physician involvement in national and local discourse regarding awareness of genetic services will be vital; however, physician recommendation is only one of many factors relevant to women's decisions to receive or forgo genetic counseling and testing [34].

Armstrong and colleagues described early adopters of testing for *BRCA1/2*, as mostly White women who had heard about it from a source other than their physician and had sought testing because of a personal or family member's cancer diagnosis [33]. In the early initiation of mammography screening, few Black or other minority women were included in the epidemiological studies [67]. Additionally, because the "face" of breast cancer was that of non-Hispanic White women, minority women did not readily adopt mammography use [68]. Previous work by Williams and colleagues [69] showed that Black women who were aware of a family history of breast cancer were more likely to receive mammograms. Our data suggest that, when presented with the option, Black women would be open to *BRCA1/2* testing. Contrary to the numerous studies that report fatalism as a barrier to breast cancer care among Black women [41, 42, 70, 71], they have been shown to be receptive to preventive breast care, as they view it as an extension of primary healthcare [39, 72]. In addition to viewing *BRCA1/2* testing as an aspect of self-care, women in the current study identified the capacity to provide potentially lifesaving information to family members, particularly their children, as a motivator for *BRCA1/2* testing. So far, attempts to reach high-risk women outside of clinical settings have produced less than ideal results [47, 52]. Kinship networks may be useful conduits for spreading information more broadly.

Community-based outreach and intervention strategies have proven to be successful in improving Black women's uptake of mammography [73–76]. Culturally tailored outreach and education activities are needed in the Black community, as Blacks and other minorities have been "left behind" in the important genomic revolution [57, 58, 77]. Basic introduction to the general process, benefits, and risks of testing and counseling for *BRCA1/2* in the Black community may help to inform women and increase their readiness for genomic-based medicine when it is appropriate.

When evaluating results from this study, several limitations should be considered. Women were asked whether they had been diagnosed with breast or ovarian cancer; however, because of the nature and setting of the interviews, it was not appropriate to collect detailed medical histories. Thus, this sample may include women across the risk spectrum (low to high). Women expressed willingness to undergo counseling and testing; however, this does not mean that they will pursue these services in the future. Future studies could use this data collection strategy to recruit women and then follow up with a more detailed screening process. Next, women were recruited from different community venues, and were generally representative of Black women in the District of Columbia metropolitan area; however, this sample may not represent the perspectives of women with less education or lower incomes. Finally, the media presence of celebrities had an impact on our sample, but we cannot draw conclusions about the effectiveness of all celebrity campaigns. The use of celebrities for education on *BRCA1/2* testing, as suggested by participants, warrants further attention.

Given the dearth of data regarding Black women's experiences, this study has several important implications for enhancing Black women's participation in genetics research. Women's receptiveness to this study suggests that our study locations may be acceptable environments for conducting general awareness activities. The method of recruiting women for brief interviews in diverse community settings provides a means to identify women in natural non-clinical settings. To our knowledge, this is the first study to employ this method of participant recruitment for a study about *BRCA1/2*. Certainly, Black women are not alone in their limited awareness of genetic testing, but given their high mortality from breast cancer, high incidence of triple-negative breast cancer, which is more likely to be associated with *BRCA1/2* mutations, high incidence of breast cancer before the age of 45, and limited participation in *BRCA1/2* research, a focus on this group is warranted [3, 10–17, 78].

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Table 1

Description of Participant Characteristics, Washington DC metro area, (N=50)

Participant Characteristics	Percent
Age	
21 – 35	27
36–45	22
46–55	31
56–65	14
65+	6
Marital/Partner Status	
Single	40
Married/Partnered	28
Widowed	10
Divorced	22
Income Level	
$10k–$35K	11
$35,001–$60K	46
$60,0001–85K	20
$85,0001–$100K	7
≥ $100,000	13
Highest Level of Education	
High School/GED	16
Some College	24
Associate Degree	10
Bachelor's Degree	30
Advanced Degree	18
Health Insurance	
Yes	98
No	2
Currently Employed	
Yes	82
No	18
Type of Employment	
Part-time	8
Full-time	70
Breast Cancer Survivor	6

Table 2

Knowledge of Genetic Testing for Breast and Ovarian Cancers

	Yes	No	Missing
Have you heard of genetic testing for breast and ovarian cancer risk?	54.0% (n=27)	46.0% (n=23)	0
Have you heard of *BRCA1/2*?	12.0% (n=6)	88.0% (n=44)	0
If given the opportunity, would you be interested in being tested for *BRCA1/2*?	82.0% (n=41)	16.0% (n=8)	2.0% (n=1)
If given the opportunity, would you be interested in learning more about genetic testing for breast and ovarian cancer risk?	94.0% (n=47)	6.0% (n=3)	0