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African American Women's Limited Knowledge and Experiences with Genetic Counseling for Hereditary Breast Cancer

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Abstract

Genetic counseling and testing for hereditary breast cancer have the potential benefit of early detection and early interventions in African American women. However, African American women have low use of these services compared to White women. We conducted two focus groups with African American women diagnosed with breast cancer (affected group, $n=13$) and women with at least one first-degree relative with breast/ovarian cancer (unaffected group, $n=8$). A content analysis approach was employed to analyze interview data. Breast cancer survivors had more knowledge about genetic counseling and testing than participants who were unaffected with cancer. However, knowledge about genetic counseling was limited in both groups. Barriers to pursuing genetic counseling and testing included poor understanding of the genetic counseling and testing process, fear of carrying the mutation, concerns about discrimination, and cost. Motivators to participate in genetic counseling and testing included desire to help family members, insurance coverage, and potential of benefiting the larger African American community. Education efforts are needed to increase genetic counseling and testing awareness in the African American community.

Keywords

Provider; minority; African American women; genetic counseling and testing; hereditary breast cancer

Genetic counseling and testing (GC/T) services to detect harmful mutations of *BRCA1* and *BRCA2* (*BRCA1/2*) breast-ovarian cancer susceptibility genes have been available since

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1996 (Lee et al., 2002). However, the use of GC/T varies widely, with minority women having lower rates of use than White women (Hall & Olopade, 2005; Sherman, Miller, Shaw, Cavanagh & Gorin, 2013). Approximately 5% to 10% of hereditary breast cancers in the United States are thought to be due to germline mutations, with *BRCA1/2* accounting for a significant proportion (John et al. 2007; Malone et al. 2006; McClain, Palomaki, Nathanson, & Haddow, 2005). In women with a *BRCA1/2* mutation, the probability of developing breast cancer is 50% to 85%, and ovarian cancer is 10% to 40% (Narod & Salmena, 2011; Thompson & Easton, 2002; U.S. Preventive Services Task Force, 2005). For each first-degree relative that has breast cancer before the age of 50, the risk of breast cancer increases 1.2 fold in a woman with a *BRCA1* mutation, and 1.7 fold in a woman with a *BRCA2* mutation (Metcalfe et al., 2010).

Genetic testing and counseling for hereditary breast cancer have the potential benefit of facilitating early detection and early interventions. Genetic counseling and testing for mutations of the *BRCA1/2* genes can provide individuals with information about breast and ovarian cancer risk and may influence decision making about cancer prevention options (i.e., prophylactic surgery, chemoprevention, risk avoidance), promote screening, and provide information to family members to define their risk (Grann et al. 2002; MacNew, Rudolph, Brower, Beck, & Meister, 2010). For example, women with *BRCA1/2* mutations who have prophylactic mastectomy or pre-menopausal prophylactic oophorectomy reduce their risk for breast cancer by 90% (Rebbeck et al. 2004) and 50% (Rebbeck et al. 2002), respectively. Implementation of risk-reducing surgery reduces mortality in individuals with *BRCA1/2* mutations (Rebbeck et al. 2004).

Hereditary breast cancer is characterized by: (a) early age of onset < 50 years of age; (b) having close family members diagnosed with the disease or family members with multiple cases of breast cancer and/or both breast and ovarian cancer; (c) a high incidence of contralateral breast cancer in young (< 50 years) Black women; and (d) association with other malignancies (Metcalfe et al. 2011; Newman et al., 2006). A *BRCA* mutation affects clinical management, increases the likelihood of developing contralateral breast cancer and/or ovarian cancer, and has implications for therapies (i.e., PARP inhibitors) (Antoniou et al. 2003; Fong et al. 2009; Ihnen et al., 2013; Nathanson & Domchek, 2011; Tutt et al. 2010).

Despite evidence supporting the clinical utility of GC/T for mutations of the *BRCA1/2* genes, factors contributing to underuse GC/T by high-risk African American women are poorly understood (Halbert et al. 2006). African American women are less likely than White women to undergo genetic counseling and testing after controlling for family history of breast cancer (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Haffty, Silber, Matloff, Chung, & Lannin, 2006; Honda, 2003). Participation in genetic testing is limited among African American women even after undergoing genetic counseling (Halbert et al., 2006; Susswein, Skrzynia, Lange et al., 2008; Thompson et al., 2002). Genetic testing may be especially important for African American women because of earlier age of diagnosis, higher rates of mortality, and worse prognosis compared to White women (American Cancer Society, 2011; Glanz, Croyle, Chollette, & Pinn, 2003; Simon et al. 2006). Indeed, John et al. (2007) found that African American women diagnosed at a younger age had a two-fold

higher rate of *BRCA1* mutations than young White women. In high-risk African American families, *BRCA1/2* rates that are similar to those of White families have been found. *BRCA1/2* mutations prevalence rates of up to 28% have been reported in African American women who are at high-risk (Chen et al. 2002; Gao et al. 2000; Nanda et al. 2005).

Reasons for the difference in use of genetic counseling and testing among African Americans and White women are varied, and explanations to date remain inconclusive. Overall, the most consistent predictors of uptake of genetic counseling and/or testing across populations include having a personal or family history of breast or ovarian cancer, greater perceived risk of developing breast or ovarian cancer, and greater cancer-specific distress (NCI, 2013). Explanations for the lower use of genetic counseling and testing in African American women include: limited knowledge, lower perception of breast cancer risk, perceived barriers to GC/T, anticipated negative emotional reactions and stigma concerns (Kinney et al. 2006; Simon & Petrucelli, 2009; Thompson et al., 2002), concerns related to cost (Pal et al. 2008), fear of discrimination (Simon & Petrucelli, 2009), distrust of the medical community, and concerns about exploitation due to carrier status. Further, some researchers suggest the low rate of GC/T seen in African Americans may be related to cultural beliefs and values, including fatalism, temporal orientation, and religious and spiritual faith (Meiser et al. 2001; Hughes, Fasaye, LaSalle, & Finch, 2003; Sherman et al., 2013). Greater use of spiritual coping has been associated with a perception of lower breast cancer risk (Ma et al., 2008).

Studies examining African American women's interest in genetic testing for the cancer susceptibility genes have shown that there is a high interest, but the actual uptake of testing ranges from 26% to 80% in those individuals at high risk (Halbert et al. 2006; Ropka, Wenzel, Phillips, Siadat, & Philbrick, 2006). In one study the perception of the benefits of genetic testing was higher in African American women than White women (Hughes et al. 1997). Kinney et al. (2001) found that a large percentage of African American men and women (82%) who had a family history of breast cancer indicated they intended to participate in genetic testing if it was available. Despite the perceived benefits and high interest in genetic testing among African American women, some studies have found that the actual uptake of genetic testing is low. For example, Susswein et al. (2008) reported that the uptake of genetic testing for breast cancer was lower in African American women even when barriers such as cost and access were minimized. Lerman and colleagues (1999) found that low-moderate risk African American women were less likely than Whites to undergo genetic testing after an education-counseling intervention. Despite African American women's high interest in GC/T, the reasons for their low participation relative to their risk profile or in comparison to their White counterparts remain unclear.

Purpose of the Study

Descriptive qualitative research may enhance our current understanding of the barriers and motivators for African American women to obtain GC/T and identify potential target factors for further research. Barriers and motivators related to the use of *BRCA1/2* genetic counseling and testing will likely occur within the socio-cultural context of our health care delivery system (Sheppard et al., 2013). This study builds upon current knowledge by

assessing awareness of and exploring socio-cultural factors such as values, experiences, and beliefs that influence African American women's participation in GC/T. A better understanding of barriers and motivators for African American women's participation in GC/T is critical to developing effective strategies to improve the use of genetic counseling and testing in all at-risk populations (Armstrong et al., 2005; Halbert et al. 2010). The purpose of this study was to explore perceived barriers that may limit GC/T participation as well as motivators for participation from the perspective of African-American women (affected and unaffected with breast cancer); and to explore the influence of socio-cultural factors on their decision regarding obtaining or not obtaining GC/T.

Methods

Participants

Purposive sampling was used. Participants were recruited from the greater Washington, D.C. metropolitan area by word of mouth and/or through fliers disseminated at community activities sponsored by the Capital Breast Care Center (CBCC), African American Public Health Network, and cancer ministries at local churches. The flyers indicated the opportunity to participate in a focus group to gather opinions about genetic counseling and testing for breast and ovarian cancer. Flyers also included the eligibility criteria, compensation, and research team contact information. Women from prior research studies unrelated to GC/T were also invited to participate. Nine participants were recruited from community based organizations, three through word of mouth, and nine from previous research studies. Criteria for participant eligibility included women who self-identified as African American/Black race, were able to speak and understand English and were at moderate to high risk for hereditary breast cancer. Women were considered at risk for hereditary breast cancer if (a) they were diagnosed with breast/ovarian cancer at 50 years of age or at 50 years of age with either one first degree relative or two second degree relatives with breast and/or ovarian cancer (affected group); or (b) healthy women with 1 first-degree relative affected by breast and/or ovarian cancer (unaffected group). A total of 35 women were contacted. From those 35 women, 11 did not meet eligibility criteria, 3 were lost to follow-up, and 21 women participated in the focus groups. The sample and focus groups were stratified to represent two groups: affected women ($n=13$) and unaffected women ($n=8$). All procedures were approved by the MedStar Oncology IRB.

Procedure

Before beginning the focus groups, women consented to be in the study. In November 2008 two trained facilitators conducted two focus groups that lasted approximately 2 hours at the Martin Luther King Library in the District of Columbia. The two facilitators had extensive experience conducting focus groups and they co-lead both focus groups. Women received a \$40 American Express gift check for participating.

Instrumentation

Using 18 semi-structured questions (see Appendix), the facilitator elicited awareness, thoughts, attitudes, and perceptions about genetic counseling and testing. Motivators and barriers were also discussed. We developed questions that tapped into relevant themes and

topics previously identified in the literature (e.g. Thompson et al., 2002). Examples of questions included: *Have you ever heard about genetic counseling for breast and ovarian cancer? What would motivate you to get genetic counseling for breast and ovarian cancer? What kinds of things would prevent you from getting genetic counseling for breast and ovarian cancer?* The same questions were subsequently asked for genetic testing. Other specific questions revolved around the role of cultural beliefs including spirituality in decisions to participate in GCT (*How would your spiritual beliefs, if any, play a role in your decision to get genetic counseling and/or testing for breast and ovarian cancer/BRCA 1/2?*) and follow-up questions derived from participants' replies to the general open-ended questions. We obtained feedback about the focus group questions from two breast cancer survivors and from genetic counselors and other medical providers (Graves et al., 2011) and refined the questions accordingly. All focus groups were audio-taped and transcribed verbatim by a professional transcriptionist.

Data Analysis

Two of the investigators with experience in qualitative analysis (JC and VS) analyzed the transcripts for major themes pertaining to motivators and barriers to genetic counseling and genetic testing. NVivo version 8 was used to code, sort, and display data summaries from transcripts (QSR International Inc. 2008). Transcripts were coded using established methods of qualitative content analysis (Pope, Ziebland & Mays, 2000). The two investigators read the transcripts independently in their entirety to identify initial codes. They met to reconcile differences and to develop a coding taxonomy that included broad categories with exemplar text and definitions to guide the remaining coding of the transcripts. These codes were refined in an iterative process that involved a further examination of the data through a constant comparison process until the coding taxonomy was finalized. The two research members independently coded the data from the focus groups by placing key words, phrases or content areas into the broad categories and met bi-weekly to reconcile differences. Data for each focus group were analyzed separately; however, consistent categories were compared between the groups. Disagreements regarding categories led to refinement of codes through consensus of the investigators.

Results

Sample Characteristics

Most participants were US born (90%), currently employed (62%), not currently married or in a relationship (e.g. divorced, widowed, never married) (71%), had completed some college or more (86%), had insurance (95%) and were between 56–65 years of age (38%) (See Table 1). While insurance rates closely align with the African American population in the Washington DC area (92%), the educational attainment of the sample was higher compared to the DC female African American population (52% completed some college or more) (US Census Bureau, 2011).

Interview Categories

Several codes emerged from the data and were organized into the following four categories: (1) Motivators and Barriers to GC/T, (2) Desired Information about GC/T, (3) Women's

Attitudes towards GC/T, and (4) Information Seeking and Knowledge about GC/T. In some instances, identified factors were both barriers and motivators. In these cases, we provide examples of both. In general, most participants expressed some level of familiarity with the concept of genetic testing related to breast cancer but fewer women demonstrated any knowledge or experience regarding what counseling related to breast cancer mutations would entail. Most examples from participants concerned testing rather than counseling, demonstrating the general lack of awareness and/or knowledge of the genetic counseling piece. We use GC/T when the comments are general and pertain to both counseling and testing and GT when they specifically relate to testing. Selected quotes exemplify the codes in the Results section and additional quotes are presented in Table 2.

Category 1: Motivators and Barriers to GC/T

Motivators: Both affected and unaffected participants stated that the primary motivators to participating in genetic counseling and testing were concern for family members, having insurance, and test availability. Affected women named specific family members such as sisters, daughters, nieces, and granddaughters as primary motivators for getting genetic counseling and testing. In particular they were interested in reducing their family members' risk of breast cancer. One affected woman commented:

“I have two daughters and about eight nieces. I was the first one diagnosed with breast cancer in my family, so I would be concerned about it for their sake to find out what was going on...so that's what would motivate me, family.”

Interestingly, another woman affected with breast cancer mentioned that having male relatives would be a strong motivator for her to pursue GT. She highlighted the fact that most people usually do not consider males as being at risk for breast cancer; however, their risk should also be considered as they could potentially suffer similar outcomes as women. She stated:

“We keep saying our nieces and granddaughters, but the men in our families need to know too, because they are the ones that get it [breast cancer] and die...we get it and they [doctors] find it; prayerfully everyone here had it and they found it, but they [the men] get it and they die.”

Benefits of participation in GT to the larger African American community were also discussed. One woman commented: “...[what would motivate me] is the African-American community, period, because...there's so much research being done for others and we seem not to have enough people to participate in these type of things [cancer research studies].” One unaffected woman stated:

“if a relative had breast cancer, a close, close, relative then I would be curious to see if I'm carrying that gene or maybe if I was expecting a child and had it [genetic mutation] I would want to know if I was passing...or likely to pass it [to my child].”

Insurance coverage of GC/T was very important to both groups of women and one unaffected woman commented that “insurance would be a huge motivator in order for me to consider getting GC/T.” Accessibility of the test was also important to both groups. For

example, both affected and unaffected women stated that they would be motivated to have GC/T if they had easy access (close location, easy transportation, and parking options) to the counseling and testing facility. Unaffected women were more concerned about having to get referrals from their primary care providers for GC/T. One woman shared that she would be motivated if GT was *“made easily accessible instead of having to get a recommendation or referral from [my] provider.”*

Barriers: Both affected and unaffected women reported cost, lack of insurance coverage, discrimination, fear of knowing they had cancer, risk-management decision making, and family as primary barriers to not getting GC/T. Lack of knowledge of hereditary breast and ovarian cancer and *BRCA1/2* was a significant barrier to women unaffected with cancer. All of the unaffected women shared that they had no knowledge of genetic counseling or testing for *BRCA1/2* before participating in the focus group. In contrast, most affected women did report knowledge of GC/T but only as a result of their personal history with cancer. One woman commented, *“I heard about it [GC/T] when I was diagnosed, but I didn’t know what it was all about...I just didn’t know.”* Although both groups expressed interest in GC/T, one unaffected woman commented *“You would have to come up with a way to pay for it [GT]...you might really, really want it but if you don’t have five thousand dollars to pay for this test...that’s gonna prevent you no matter how bad you want it.”* Neither group saw the possibility of receiving GC/T without adequate coverage, as the test was viewed as being *“very expensive.”*

Both affected and unaffected women mentioned concerns about discrimination. Interestingly, affected women expressed more concerns about issues of discrimination related to stigma than unaffected women. These concerns appeared related to affected women’s experiences of their own cancer diagnosis and having to deal with other people’s reactions. Specifically, affected women associated participation in GT with possible “stigma” and possible employment discrimination. According to one affected woman, *“some employers if they find out you had something, they’re not gonna hire you for fear that you’ll get sick and they are gonna have to pay for it.”* Additionally, affected women were concerned that their genetic profiles would be stored on computers and used against them in the future.

In general unaffected women reported more fear towards participating in GT than affected women. They expressed more concerns about learning that they would carry a mutation and could possibly have cancer. According to one unaffected woman it was the fear of the unknown that held her back and commented, *“sometimes you just don’t wanna know.”* Fear of decisions about how to manage increased breast and ovarian cancer risk also emerged as a barrier for unaffected women. Many commented that they did not want to have to think about having to make decisions they would need to make if their *BRCA1/2* test results came back positive. One unaffected woman commented, *“I keep seeing a lot of breast cancer as of late, and it’s about having preventive mastectomy...I think about it for myself and I thought, ‘I would not want to think about that’.”*

Category 2: Desired Information about GC/T—Unaffected women, being unfamiliar with genetic counseling and genetic testing, shared that they were interested in obtaining

information about the reliability of the genetic test's results in predicting risk. Additionally, unaffected women were interested in knowing whether or not the process of GC/T required multiple visits, the length of time it would take to receive test results, if testing was painful, if there were potential risks involved when participating in testing, whether it would make them sick, and whether or not they would have to make the choice of losing their breasts as a result of participating in GT. As one unaffected woman inquired: *"Is it one-time testing or is it a series of days or...months."* Affected women desired information regarding test interpretation and knowing what to do with their results. They were also interested in knowing specifically how participating in GT actually cures or prevents cancer, as one woman noted: *"Once you've have all the test, what are the procedures now to stop or fix or heal...that's gonna prevent this other disease or whatever it is from coming your way ...you told me I'm a candidate for this, now what?"* Both groups were interested in learning about any potential side effects that would be associated with their participation in GT.

Category 3: Women's Attitudes towards GC/T—Both affected and unaffected women held positive attitudes about GT. Some women discussed their attitudes about breast cancer mutations and genetic testing within the context of their spirituality or their relationship with God. For example, one woman commented that if she were to learn that she had the mutation, this is how she would handle it, *"If I get a negative test result...praise Jesus; thank you so much...but if it is positive all I can say is, 'God I'm a need ya to hold me through this'."* Another woman commented, *"God was a major part of my treatment...just having the faith and believing and trusting in God that everything will be alright brought me through...so if I was to have the mutation, He would do the same [bring her through]."* Thus, overall, women's spiritual beliefs were not described as barriers to seeking genetic services but as a potential source of hope and coping. Many unaffected women shared a desire to participate in GC/T but also voiced concerns that participation would not be possible without insurance or the ability to cover the costs associated with counseling and testing. While affected women were also concerned about costs related to co-pays, most strongly voiced that participation in GC/T was too important to allow factors such as cost or insurance to deter them. As one woman commented, *"If I make up in my mind to get it, I would definitely get it...I don't worry about insurance."*

Category 4: Information Seeking and Knowledge about GC/T—Affected women demonstrated more knowledge about GC/T than unaffected women. Some of the affected women stated that they heard about GC/T as a result of either their diagnosis or because of a family member's diagnosis of breast cancer. Women in both groups stated that they had heard information about GT as a result of a national newscaster who shared her breast cancer experience in the media. A few women also had learned about genetic testing and prophylactic mastectomy from an actress who had shared her story on television (Christina Applegate). These cases discussed in the media represented the first exposure to GC/T-related information for virtually all of these participants (e.g. testing for a breast cancer gene, having a breast removed as a result of testing positive for the gene). Thus, TV was the main source of GC/T information rather than healthcare providers. The TV generated awareness about GC/T and treatment decisions as we can see by the comments of one participant (probably referring to Robin Roberts): *"she chose voluntarily to have her breasts*

removed although she didn't have cancer." However, there was some confusion among participants as to whether or not mastectomies were purely prophylactic. Participants in both groups agreed that it would be important to provide women with more education about GC/T.

Discussion

This study explored barriers and motivators to genetic counseling and testing in African-American women both affected and unaffected by breast cancer using focus group methodology. We found that only one woman in our study had received both genetic counseling and testing for *BRCA1/2*. This finding was concerning because study eligibility included moderate- to high-risk group of women who were likely appropriate clinical candidates for *BRCA1/2* genetic counseling.

Our study findings were striking in participants' low level of knowledge about genetic counseling and testing for *BRCA1/2* mutations. Participants were more familiar with genetic testing service than they were with the genetic counseling service. Thus, our study supports and expands upon related research reports of low awareness and knowledge about *BRCA1/2* mutations in African Americans (Armstrong et al. 2002; Baty et al., 2003; Donovan & Tucker, 2000; Hughes et al. 1997; Skinner et al., 2002). Previous studies suggest that low awareness and knowledge about *BRCA1/2* mutations in African Americans may influence decision making about genetic counseling and/or testing (Armstrong, Weber, Ubel, Guerra, & Schwartz, 2002; Donovan & Tucker, 2000; Hughes et al. 1997). For example, Thompson et al., (2002) found that high-risk African American women with less knowledge about breast cancer genetics rejected both genetic counseling and testing. Although numerous resources exist for providing genetic counseling and risk education to diverse populations (Hall & Olopade, 2005), the disconnect appears to be reaching the women who would benefit from these empirically-tested risk counseling and risk communication materials.

Our present results indicate that even though some women had heard about GC/T, mainly through TV, there was a lack familiarity and knowledge and confusion, especially about genetic counseling -- suggesting the need to integrate risk assessment within more routine clinical encounters and to provide clearer information from diverse sources (e.g. healthcare providers) to understand GC/T and its impact on treatment decision-making. For example, healthcare providers (oncologists, primary care physicians) who provide care to African American women at risk for carrying a *BRCA1/2* mutation may not provide the needed recommendations for genetic counseling, or if they do, may not specifically follow-up to see if referrals resulted in actual appointments with genetic counselors (Graves et al., 2011).

Uniquely, our results further indicate that referrals and/or risk counseling interventions would benefit from attention to women's personal cancer history as the information needs and perceived barriers to GC/T differed within our sample by affected status. For instance, affected women, who were more familiar with GC/T, desired more information about the interpretation of test results and subsequent actions, whereas unaffected participants desired more information about the whole process. Exploring different types of information needs among affected versus unaffected women can be an important area for future research to

inform targeted efforts to improve knowledge about GC/T among different types of women who would benefit from GC/T.

We also found differences in the emotional reactions to GC/T, as unaffected participants noted more fear (e.g. possibility of being a mutation carrier, fear of the unknown, fear of having to make treatment decisions) than affected women. This difference may be explained by participants' different degree of exposure to cancer. For affected women, GC/T may be interpreted as one more step in the cancer survivorship continuum, whereas GC/T for unaffected women brings up novel and unfamiliar potential experiences (e.g. the possibility of developing cancer). Beyond fear of the unknown with *BRCA1/2*, particularly among unaffected African American women, other beliefs such as fear of discrimination appear salient for both affected and unaffected women as a potential barrier to accessing GC/T.

We further support prior findings across populations that women fear stigmatization and employment discrimination for being mutation carriers (Durfy, Bowen, McTiernan, Sporleder, & Burke, 1999; Eijenzaga et al., 2013; Kinney et al. 2001; Lipkus, Iden, Terrenoire, & Feaganes, 1999; Short, Vasey, & Tunceli, 2005). Fear of stigma, as well as other anticipated negative emotions (e.g. family related guilt, shame), have been related to lower rates of participation in GC/T (Newman et al. 2006; Thompson et al. 2002). However, previous research suggests that once African American women participate in GC/T, cancer-specific worries and fear are reduced (Ford, Alford, Britton, McClary, & Gordon, 2007; Kessler et al. 2005; Lerman et al. 1999). Thus, designing interventions that target anticipated emotions prior to counseling is warranted.

Both affected and unaffected women related their perceptions of breast cancer mutations and genetic testing to their spirituality or their relationship with God. Religion is an important part of the African American culture and it is used as a coping mechanism for African Americans in the general population and women diagnosed with breast cancer (Banks-Wallace & Parks, 2004; Bourjolly, 1998; Henderson, Gore, Davis, & Condon, 2003). The use of religious coping among African American women at increased risk for having a *BRCA1/2* mutation is underscored in a study by Weathers et al. (2009) who also found that African American women overall reported a high utilization of religious coping strategies. We found that women's spirituality was described as an anchor to help participants deal with a positive result rather than a deterrent to seek counseling and testing because of their faith. This finding supports prior studies that concluded that spiritual beliefs did not lead African American breast cancer patients to delay treatment (Sheppard, Adams, Lamdan, & Taylor, 2011; Sheppard, Davis, Boisvert, Jennings, & Montalvo, 2011) and Hughes and colleagues (2003) research that found a trend for women endorsing working with God as a coping mechanism being more likely to participate in GC/T. Thus, our results are contrary to other studies that suggest that African American women's spiritual beliefs would cause them to delay breast screening and/or treatment (Gullate, et al., 2010; Hughes et al., 2003).

One of the primary motivators for participating in genetic counseling and testing for affected and unaffected women was concern for family members which supports previous research (e.g. Thompson et al., 2002). Thus, understanding the importance of family as a motivator can help shape both public health awareness campaigns and development of patient-level

education materials related to appropriate use of GC/T among at-risk women. Family-based education strategies that have been employed to improve functional breast cancer literacy may be relevant (Williams, Mullan, & Fletcher, 2007). Assisting women to make connections between their individual risk and the risk of their family members may be another way to capitalize on African American women's motivation to pursue GC/T based on family needs. Indeed, Lerman et al., (1999) reported that when African Americans were given the opportunity to discuss family issues and their concerns about being tested, the uptake of genetic testing was increased, suggesting that African American women may benefit from genetic counseling. Participating in genetic counseling can increase prevention awareness even if testing is not pursued, as Ford and colleagues' (2007) qualitative study found that African American women who participated in genetic counseling expressed self-efficacy in reducing breast cancer risks through lifestyle factors (screening, diet, exercise).

Implications

Genetic providers – particularly genetic counselors—have a unique role in providing risk assessment to African American women. Increasing physicians' awareness of referral options to genetic counselors may be useful (Graves et al. 2011). Referral to genetic counselors will provide African American women with the needed information to make an informed decision about genetic testing and risk management. Our data suggest the majority of African American women are interested in GC/T participation yet most have not had an opportunity to do so. Strategies to potentially increase health care providers' referrals to genetic specialists and genetic counselors include: implementation of standard family history collection forms to identify at-risk individuals; development of specialized genetic services within settings that provide medical services to large numbers of African American women (Graves et al. 2011); and provision of potential "talking points" for physicians to use when describing the process and benefits of genetic counseling with patients based on participants identified motivators and concerns. For instance, talking points should include the potential benefit of GC/T for family members, recognition of the importance of spirituality, clarifying the distinction between genetic counseling and testing, and information about the Genetic Information Nondiscrimination Act (GINA) law to dissipate fear of discrimination. Other strategies genetic counselors could use to raise awareness include presentations at support groups of newly diagnosed breast cancer patients with significant African American membership and the development of culturally tailored brochures that show intergenerational families. Moreover, given the higher incidence of early onset breast cancer among African American women compared to Caucasian women (American Cancer Society, 2009), outreach efforts to groups that provide information and support to younger breast cancer survivors may reach African American survivors.

Study Limitations

This study had certain limitations. The lack of knowledge and familiarity with genetic counseling prevented us from discussing the differences between women's perceptions of genetic counseling versus testing as most of the comments revolved around testing. The small size of the sample and the small number of focus groups conducted did not allow us exploring if GC/T perceptions varied among other subgroups (e.g. cancer family history) and did not guarantee that we reached data saturation. Although focus groups constitute an

appropriate method to gather rich information that emerges from participant's interactions, social desirability in a group setting and having a large number of participants in one of the focus groups may have limited participation from some individuals and our possibility of capturing some nuanced responses and participant's individual differences. The volunteer nature of the sample may introduce a sampling bias limiting the study generalizability. Women in our sample were highly educated and were mostly insured. Although insurance coverage paralleled those in the DC area, results might not be generalizable to their less educated and uninsured counterparts in other regions.

Despite the limitations, the present study extends prior findings by highlighting lack of awareness of genetic counseling as a key barrier to *BRCA1/2* GC/T. Our results related to fears and concerns, particularly the differences between affected and unaffected African American women, can contribute to our knowledge of specific factors that may be important to this group (Halbert, Kessler, & Mitchell, 2005; Hughes et al. 2003; Kinney et al. 2001; Suther & Kiros, 2009; Thompson et al. 2002). The need for more work focused on African American women and to identify unique characteristics that may exist within groups is summarized in a comment from one participant that, "*so much is being done for others but not us*," which points to some of the culturally specific aspects associated with GC/T that may be at the heart of disparities. As we consider ways to ensure that the benefits of technological advances are equitable for all women, awareness of and referral and access to GC/T in African American women must be considered.

Research Recommendations

Interventions to improve GC/T uptake in African American women have produced mixed results (Halbert et al., 2010; Kendall, Kendall, Catts, Radford, & Dasch, 2007; Thompson, Valdimarsdottir, Jandorf, & Redd, 2003). Thus, other efforts are needed to test potential explanations of GC/T underuse in African American women and new interventions that tackle aspects that have been understudied such as emotional management (Sherman et al., 2013). A deeper understanding of the role of different anticipated emotions in women's decisions to undergo GC/T warrants further attention. Future research should explore GC/T barriers and limitations in more diverse samples of African American women including women with lower education, no insurance, and different levels of *BRCA1/2* risk status. These types of studies could help inform targeted interventions to improve awareness and use of GC/T services. Future efforts to reduce disparities in breast cancer mortality, particularly in young African Americans, should address disparities in GC/T participation (Gonzalez-Angulo et al. 2011).

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Appendix. Focus Group Core Questions

Knowledge and Awareness about Genetic Counseling Testing

- 1 Have you ever heard about genetic counseling and testing for breast and ovarian cancer or *BRCA 1/2* the gene that has been associated with breast cancer?
- 2 Have you ever received genetic counseling for breast and ovarian cancer/*BRCA 1/2*? If yes, from where did you receive genetic counseling? Please describe your experience.
- 3 Have you ever received genetic testing for breast and ovarian cancer/*BRCA 1/2*? If yes, from where did you receive genetic testing? Please describe your experience.
- 4 if you had a choice, where would you prefer to receive genetic counseling and testing for *BRCA 1/2*?

Motivators/Barriers about Genetic Counseling Testing

- 5 What would motivate you to get genetic counseling for breast and ovarian cancer/*BRCA 1/2*?

- 6 What kinds of things would motivate you to get genetic testing for breast and ovarian cancer/BRCA 1/2?
- 7 What kinds of things would prevent you from getting genetic counseling for breast and ovarian cancer/BRCA 1/2?
- 8 What kinds of things would prevent you from getting genetic testing for breast and ovarian cancer/BRCA 1/2?
- 9 What kind of information would you like to have about genetic testing and counseling for breast and ovarian cancer/BRCA 1/2 to feel better informed and would make you want to participate in it?

Usefulness of Results, Cultural Beliefs and Self Efficacy associated with genetic counseling and testing

- 10 if you decided to participate in genetic counseling and testing for breast and ovarian cancer/BRCA 1/2, what would you do with the information that you learned? Would you know what to do?
- 11 What would you do if the results were positive? Do you understand what that means?
- 12 What would you do if the results were negative? Do you understand what that means?
- 13 Some women share test results with their family or a trusted friend, with whom would you share your test results for breast and ovarian cancer/BRCA 1/2 (spouse, extended family, friend—**rank according to importance**)?
- 14 How would your spiritual beliefs, if any, play a role in your decision to get genetic counseling and/or testing for breast and ovarian cancer/BRCA 1/2?
- 15 if you were to decide to get genetic counseling and/or testing for breast and ovarian cancer/BRCA 1/2, can you think of anyone in your immediate family or a close friend that might discourage you from getting genetic counseling and/or testing? If yes, who and what do you think would be some of their objections?
- 16 Most people are afraid of the unknown, if you decided to get genetic counseling and testing for breast and ovarian cancer/BRCA 1/2 what types of concerns would you have?
- 17 Do you feel confident that if you wanted to get genetic counseling and testing for breast and ovarian cancer you could go and get it? Please explain.
- 18 Is it important for you to think of yourself as a person who can choose whether or not to receive genetic counseling and testing for breast and ovarian cancer/BRCA 1/2? Please explain.

Table 1

Demographic Characteristics of Study Participants

Demographics	N (%)
Age	
21–35	4 (19)
36–45	3 (14)
46–55	3 (14)
56–65	8 (38)
65 and older	3 (14)
Insurance	
Uninsured	1 (5)
Currently Insured	20 (95)
Income	
\$10K	1 (5)
\$10,001–35K	1 (5)
\$35,001–\$60K	10 (48)
\$60,001–\$85K	4 (19)
\$85,001–\$100K	2 (9)
>\$100K	3 (14)
Marital Status	
Married/Partnered	6(29)
Divorced	6 (29)
Separated	2(9)
Widowed	2(9)
Single/Never Married	5(24)
Education	
Completed High School	3(14)
Some College or More	18 (86)
Currently Employed	13(62)

Table 2**Major Themes and Exemplar Domains**

Motivators to GC/T
<p>Family “I had [GC] counseling when I was diagnosed with breast cancer because I had had another cancer prior to this breast cancer and I was curious to find out what was making this happen because the majority of my family are women so I wanted to know what was the risk to my nieces and my sisters and great nieces.” “I wanted to know everything I could possibly know so that I would have a complete package to take back to my nieces and my sisters and tell them ‘this is what you’d have to be mindful of; these are the things you have to look for’ because my mom had breast cancer...I had it...I had sisters and nieces that were grown women that needed to know...[I didn’t care about the cost] it was like the death of my sisters and my nieces...I didn’t care one way or the other even if I had to mortgage the house.”</p>
<p>Insurance “What would motivate me [to get GC/T] is if it were covered by insurance.”</p>
<p>Affordability “What would motivate me would be the availability of getting these kinds of tests [locally]...I had one test done [and] only one lab in California that did that test and when I saw what my insurance paid...I just about had a stroke...so being able to get something [GC/T] locally at a reasonable cost would motivate me.”</p>
Barriers to GC/T
<p>Access “Ohm, after I was diagnosed, my daughter who just turned 31-years-old...she tried to get a mammogram...that’s when I found out about this <i>BRCA1</i> and 2 and it took tooth and nail fighting with her insurance company so that she could get it [GC/T].”</p>
<p>Insurance “See that’s not bad [a co-pay of \$2500] for a woman that has insurance but for a woman that has five kids and taking care of them without insurance that’s another issue; and that’s the thing, you have to have it [insurance].”</p>
<p>Discrimination “the stigma [would stop me from getting tested] because you always have a concern that somewhere this information is gonna reside on a computer somewhere; it may prevent you from getting employment, future insurance, or any number of things so that’s [my] concern. That is one thing that has stopped me from going ahead with testing.” “I would never think that a credit report would stop you from getting employment and a credit report does so that’s why personally this [getting GC/T] is a concern because all of us know that this information is gonna be on a computer in someone’s database somewhere so the whole world can see.”</p>
<p>Family “...my mother [would discourage me from getting GC/T] because she is from the old school...those type of things are frightening for her; just mention the word genetic and you don’t have to say anything else...she sees someone messing with your cells...you gonna be a guinea pig or somebody’s gon give you something and you not gonna know what they giving you.” “They [older generation] don’t always trust these doctors...they think you’re messing with God.” “...my grandmother is from the islands so she believes in like spirits and all sorts of things...if I did get it [GC/T] and I was positive she would give me tons of teas to drink...from her upbringing they treated everything with something they grew in the ground...so she might not be as objective and would be the first to say, ‘why do you need this?’”</p>