

An Examination of Dimensions of Perceived Behavioral Control Regarding Genetic Counseling and Testing for *BRCA 1* and *BRCA 2* in African-American Women at Moderate to High-Risk for Breast Cancer

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(ABSTRACT)

Breast cancer affects thousands of women each year and among those diagnosed, African-American women (AAW) make up a significant proportion that are diagnosed with early onset disease, have larger tumors, greater lymph node involvement, higher mortality and lower survival rates. Studies examining factors associated with greater breast cancer morbidity and mortality in this group have suggested that they may differ from Caucasian women in terms of certain risk factors for breast cancer; however, other evidence suggests that the risk of developing breast cancer is similar among African-American and Caucasian women who have a family history of breast cancer. As such, access to genetic counseling and testing (GC/T) services would be an important part of cancer control for this group but in this fast moving area of medicine African-American women are being “left behind”.

It is unclear why AAW have not readily adopted these preventive services. In light of the paucity of evidence regarding explanations of underuse, it is possible that important factors such as perceived behavioral control (PBC) in the Theory of Planned Behavior may help explain African-American women’s lack of participation in genetic counseling and testing for *BRCA 1/2*. The goals of this mixed methods study were twofold; first, to explore levels of perceived behavioral control and general motivations regarding genetic counseling and testing for *BRCA 1/2* in African-American women at moderate to high-risk for breast and ovarian cancer and second, to explore the dimensionality of the perceived behavioral control construct from the Theory of Planned Behavior (TPB) and its utility in understanding underuse of *BRCA 1/2* genetics services in this group.

Overall, women had high levels of perceived behavioral control, low knowledge and positive attitudes towards genetic counseling and testing for BRCA 1/2. Results from the principal components analysis lent support for the dimensionality of the perceived behavioral control construct suggesting that it indeed could be thought of as made up of the constructs perceived control [P-C] and perceived difficulty [P-D]. Only perceived control was found to be associated with genetic testing intentions suggesting that it was a better predictor. Neither scale was associated with genetic counseling intentions.

Future research should focus on educational efforts geared towards highlighting the utility of genetic counseling in addition to genetic testing for BRCA 1/2. Theoretical implications include using two measures to assess aspects of perceived behavioral control (perceived difficulty [P-D] and perceived control [P-C]) instead of one PBC measure. Additionally, studies using the TPB model should include the constructs of spirituality and knowledge when trying to understand underuse of BRCA 1/2 genetic services in African-American women at moderate to high-risk for breast cancer.

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## Chapter 1

### *Introduction*

Breast cancer affects thousands of women each year. Among those diagnosed, African-American women (AAW) make up a significant proportion who are diagnosed with early onset disease, have larger tumors, greater lymph node involvement, higher mortality and lower survival rates (American Cancer Society, 2007; Halbert, et al., 2005b; Newman, et al., 2006; Olopade, et al., 2003). These observed disparities have been attributed to socioeconomic and biologic factors but, to date, they have not adequately accounted for the disparities seen in this group (Ashton, et al., 2003; Joslyn, 2002; O'Malley, et al., 2003; Shavers & Brown, 2002).

Several studies conducted to identify factors associated with greater breast cancer morbidity and mortality among African-American women have suggested that they may differ from Caucasian women in terms of certain risk factors for breast cancer (e.g. age at menarche, birth rates, oral contraceptive use and obesity) (Bernstein, et al., 2003). However, another body of evidence suggests that the risk of developing breast cancer is similar among African-American and Caucasian women who have a family history of breast cancer (Halbert, et al., 2005b). As such, efforts are being directed toward developing a better understanding of genetic risk factors for breast cancer among African-Americans. Although hereditary breast cancer is rare and accounts for about 5%-10% of all breast cancer cases, women who are found to carry a risk conferring *BRCA 1* or *BRCA 2* (*BRCA 1/2*) gene mutation have a 55%-85% lifetime risk of developing breast cancer and a 15%-60% lifetime risk of developing ovarian cancer (Antoniou, et al., 2003; Halbert, et al., 2005b).

It was once thought that the prevalence of *BRCA 1* mutations was low in African-American women enrolled in population-based case control studies (e.g. Newman, Mu, Butler, Millikan, Moorman, King, 1998). Evidence within the last decade has shown that the prevalence of *BRCA 1/2* mutations is similar to other ethnic groups who have a personal and family history of breast and/or ovarian cancer (Frank, et al., 2002; Halbert, 2005b). Work by Olopade and colleagues (2003) have

uncovered distinct mutations in the *BRCA 1 and BRCA 2* genes that have been found in both African-American and West African families suggesting evidence for founder mutations. These findings would be useful in helping to identify appropriate cancer preventive screening options for African-American women. As such, access to genetic counseling and testing (GC/T) services would be an important part of cancer control but in this fast moving area of medicine African-American women are being “left behind” (Easton, 2005).

The US Preventive Services Task Force (USPSTF) and the American Society of Clinical Oncology (ASCO) recommend referral for *BRCA1/2* counseling and testing for women with at least a 10% risk for carrying a mutation (ASCO, 1996; US Preventive Services Task Force, 2005). Despite these guidelines, African-American women significantly underutilize genetic counseling and testing for *BRCA 1/2* compared to their white counterparts (Armstrong, et al., 2005; Hughes-Halbert, 2006; Kinney, et al., 2001; Olopade, et al., 2003). Even after accounting for actual risk of carrying a mutation, African-American women remain far less likely to receive genetic counseling and testing for *BRCA 1/2* compared to Caucasians (Hughes-Halbert, 2006). The etiology of low participation in genetic counseling and testing for African-American women is not very well understood. However, evidence suggest that underuse may in part be due to lower perceived personal risk, low awareness and knowledge of genetic services and negative attitudes towards genetic services (e.g. Armstrong, et al., 2002; Hughes, et al., 1997; Kinney, et al., 2001).

In light of the paucity of evidence regarding explanations of underuse, it is possible that important factors such as perceived behavioral control (PBC) in the Theory of Planned Behavior may help explain African-American women’s participation in genetic counseling and testing for *BRCA 1/2*. The theory of planned behavior (TPB) postulates that an individual’s behavioral intention is the most proximal determinant of their behavior. Furthermore, constructs of attitudes (attitude towards GC/T), subjective norms (influence of important others regarding GC/T), and perceived behavioral control (factors affecting how “doable” GC/T seems) are postulated to independently influence

behavioral intention (Ajzen & Fishbein, 1980; Ajzen, 1991, 2002). The TPB has been used in many studies to predict behavioral intentions to perform health behaviors (e.g. exercising, breast screening delay, condom use, consuming soy products) and can be useful in understanding genetic counseling and testing intentions as it has been underutilized in African-American women.

Perceived behavioral control has been defined as the belief that one has and can exercise control over performing a specific behavior. This construct has been relatively unexplored in African-American women in reference to genetic counseling and testing for BRCA 1/2. Perceived behavioral control can be an important factor in understanding African-American women's breast cancer screening behaviors and may impact their willingness to participate in genetic counseling and testing services. According to some studies, Ajzen's conceptualization of the PBC construct reflects dimensions of perceived difficulty [P-D] (ease or difficulty of performing a behavior) and controllability [P-C] (extent to which performing the behavior is up to the individual) (Armitage & Conner, Terry & 1999; Manstead & van Eekelen, 1998; Terry & O'Leary, 1995; Trafimow, et al., 2002). Thus, this study presented an opportunity to clarify the relationship of the hypothesized dimensions of the PBC and also examine the impact of perceived behavioral control on African-American women's genetic counseling and testing intentions.

#### *Summary and Study Aims*

Given that most studies of hereditary breast cancer have primarily focused on Ashkenazi Jewish and non-Hispanic Caucasian women, this study is among the first to explore African-American women's genetic counseling and testing participatory intentions. Guided by the Theory of Planned Behavior, data from this study will begin to fill the gap in the literature regarding factors that influence African-American women's participation in genetic counseling and testing and knowledge regarding the PBC construct.

A two-phased mixed methods study was conducted. In phase one, qualitative methods were employed to assess African-American women's levels of perceived behavioral control and other

factors related to getting genetic counseling and testing for *BRCA 1/2*. In phase two, data from a cross-sectional survey with African-American women at moderate to high-risk for *BRCA 1/2* were used to examine the dimensionality of PBC and assess the predictive utility of the dimensions on women's intentions to get genetic counseling and testing for breast and ovarian cancer. The study aims were as follows:

### **Phase I: Qualitative Phase**

To conduct two focus groups with moderate to high-risk African-American women to explore their expressed levels of perceived behavioral control and general motivations regarding genetic counseling and testing and to refine a quantitative survey.

### **Phase II: Quantitative Phase**

**Aim I:** To explore relationships among the perceived difficulty [P-D] and perceived control [P-C] scales and participant demographic (socio and psychosocial) characteristics.

**Aim II:** To determine if there is a difference in the mean scores of perceived difficulty [P-D] and perceived control [P-C] based on affected status in moderate to high-risk African-American women.

**H<sub>1</sub>:** Women who were unaffected with cancer will have a higher score on the perceived difficulty [P-D] scale.

**H<sub>2</sub>:** Women who have been affected by cancer will have a higher score on the perceived control scale [P-C].

**Aim III:** To use factor analysis to determine whether the two dimensions of perceived behavioral control, that is, perceived difficulty [P-D] and perceived control [P-C], are distinct factors.

**H<sub>3</sub>:** The six items of the P-D scale will load into one factor and the three items of the P-C scale will load into another factor, showing that they are distinct constructs.

**Aim IV:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic counseling** while controlling for relevant demographic factors.

**Aim V:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic counseling**.

**H<sub>4</sub>:** The perceived difficulty scale will be a better predictor of **genetic counseling** intentions in moderate to high-risk African-American women than the perceived control scale.

**Aim VI:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic testing** while controlling for relevant demographic factors.

**Aim VII:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic testing**.

**H<sub>5</sub>:** The perceived difficulty dimension will be a better predictor of **genetic testing** intentions in moderate to high-risk African-American women than the perceived control dimension.



## Chapter 2

### *Review of the Literature*

#### *Introduction*

This chapter will provide an overview of breast cancer and address general information regarding hereditary breast and ovarian cancer syndrome (HBOC) and the associated *BRCA 1* and *BRCA 2 (BRCA1/2)* gene mutations. A discussion of clinical management options including genetic counseling and testing for BRCA mutation carriers will follow. Additionally, a detailed discussion regarding HBOC syndrome, *BRCA 1/2* mutations, and genetic counseling and testing in African-American women will be provided. Factors associated with disparities in participation in genetic counseling and testing uptake will also be identified, followed by a proposed theoretical framework that could account for the observed underutilization of genetic counseling and testing among African-American women at moderate to high-risk for breast and ovarian cancer.

#### *Background*

Breast cancer is the most common cancer among women in the United States other than skin cancer and is the second leading cause of cancer death in women, after lung cancer. For example, in 2008, approximately 182,460 new cases of invasive breast cancer were diagnosed and about 40,480 women died from the disease (National Cancer Institute, 2009). Breast cancer results from genetic and environmental factors that lead to accumulation of mutations in essential genes. These mutations can be sporadic or germline events. More specifically, sporadic breast cancers are those which hereditary factors do not appear to contribute to the cancer risk. For sporadic breast cancer, the affected individual will not have a family history of the disease; therefore, the genetic element of the disease results from mutations that occurred in a specific cell resulting in a tumor. Sporadic breast cancers are the most common and account for 90-95% of breast cancers in women. Conversely, hereditary breast cancer is rare and results from a mutation in the germline (the sex cells found in

eggs or sperm). As such, every cell in the body has the mutation, not just the tumor cell; consequently, adverse events in the mutated cell increase the likelihood that cancer will develop.

#### *Hereditary Breast and Ovarian Cancer Syndrome*

Studies estimate that cancer risk in 5%-10% of women with breast cancer and 10%-15% of women with ovarian cancer is associated with germline mutations in the highly penetrant susceptibility genes, breast cancer gene 1 and breast cancer gene 2 (*BRCA 1/2*) otherwise known as hereditary breast and ovarian cancer (HBOC) syndrome (American Cancer Society, 2007; Rebbeck, et al., 2002; Rebbeck, et al., 2004). Studies from high-risk families suggest that women harboring a mutation in either gene have up to an 87% lifetime risk of developing breast cancer and a 20%-44% lifetime risk of developing ovarian cancer. Breast cancer survivors with inherited mutations in either *BRCA 1* or *BRCA 2* genes are at a substantially increased risk to develop a second breast cancer as well as ovarian cancer and other types of cancers (Ford, et al., 1998). Women of Ashkenazi Jewish descent are also at an increased risk for carrying the mutation such that the frequency is about five times higher than that found in the general population. Additionally, men who carry a *BRCA 1* or *BRCA 2* mutation are at an increased risk to develop breast, prostate and pancreatic cancer (Simon & Petrucelli, 2009).

#### *Clinical Characteristics of Hereditary Breast Cancer*

Several clinical characteristics may distinguish an inherited form of breast cancer from a sporadic breast cancer. Generally, these include an age of onset which is 10 to 20 years earlier than the average age of onset, bilateral breast cancer, an increased occurrence of a second breast cancer, male breast cancer and the occurrence of additional cancer diagnoses (e.g. ovarian, colon, prostate) in a single individual or among close relatives (Bozzone, 2007; Olufunmilayo, Olopade & Fackenthal, 2000). See Table 1 for a complete list of established risk factors for HBOC.

**Table 1. Established Risk Factors for Hereditary Breast/Ovarian Cancer (HBOC)**

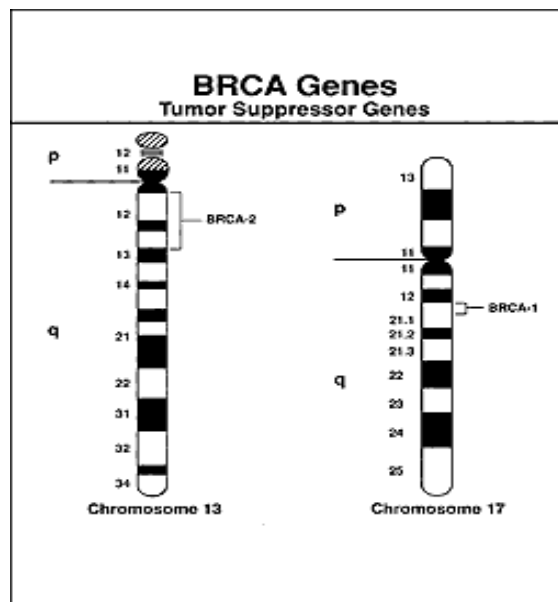
- 
- Breast cancer before age 50
  - Ovarian cancer at any age
  - Multiple primary cancers
  - Bilateral occurrences of breast cancer
  - Male breast cancer at any age
  - Ashkenazi Jewish (central/eastern European) ancestry
  - Co-morbidities associated w/genetic syndromes (Li-Fraumeni syndrome, Cowden disease, Muir-Torre syndrome, Peutz-Jeghers syndrome, and ataxia telangiectasia)
  - Multiple affected family members from one lineage (maternal or paternal)
- 

Adapted from Simon & Petrucelli, 2009, fair use

Most of the aforementioned characteristics may be explained by Knudson's (1971) two-hit model of carcinogenesis which suggests that cancer develops through loss of function of both the maternal and paternal alleles (copies) of a cancer susceptibility gene. In inherited forms of cancer, there is a mutation in either the maternal or paternal allele within the egg or sperm at conception, thus every daughter cell thereafter has 'one hit' or mutation in a specific site. A mutation in the remaining allele or 'second hit', may occur in time as the result of an environmental trigger or by chance during DNA replication. In contrast, sporadic cancers begin with two normal copies of a cancer susceptibility gene which require two successive acquired mutational events ('two hits') occurring in a single cell at each allele of a cancer susceptibility gene for cancer to develop. This process requires more time and generally occurs only once in a single cell.

#### *BRCA 1 and BRCA 2 Genes*

In 1994, the first gene associated with breast cancer — *BRCA1* (for **BR**east **CA**ncer 1) was identified on chromosome 17. A year later, a second gene associated with breast cancer — *BRCA 2* — was discovered on chromosome 13 (See Figure 1). *BRCA 1* and *BRCA 2* belong to a class of human genes known as tumor suppressors which maintain genomic integrity to prevent uncontrollable proliferation. The multi-factorial *BRCA 1 and BRCA 2* protein products are involved in DNA damage repair, ubiquitination (tagging specific proteins for degradation), transcriptional regulation and other cellular monitoring functions (Boulton, 2006; Starita & Parvin, 2003).



**Figure 1. BRCA 1 & BRCA 2 Tumor Suppressor Genes**  
National Cancer Institute, 2009

#### *Who is at Risk for BRCA Mutations*

According to estimates of lifetime risk, about 13.2 percent (132 out of 1,000 individuals) of women in the general population will develop breast cancer, compared with estimates of 36 to 85 percent (360-850 out of 1,000) of women with an altered *BRCA 1* or *BRCA 2* gene (National Cancer Institute, 2009). Women with an altered *BRCA 1* or *BRCA 2* gene are 3 to 7 times more likely to develop breast cancer than women without alterations in those genes. Lifetime risk estimates of ovarian cancer for women in the general population indicate that 1.7 percent (17 out of 1,000) will get ovarian cancer, compared with 16 to 60 percent (160-600 out of 1,000) of women with altered *BRCA 1* or *BRCA 2* genes (National Cancer Institute, 2009). Overall, the carrier frequency for *BRCA 1* in the general United States population is probably 1 in 1000 and is about 3% to 5% in the general population of women with breast cancer (Couch & Hartmann, 1998; Malone, et al., 2006; Newman, et al., 1998). The proportion of breast cancer families with *BRCA 1* mutations vary from 7% in the families with breast cancer only to 40% in families with breast and ovarian cancer (Olufunmilayo, et al., 2000).

In population-based studies of women with breast cancer, *BRCA 1* mutation rates vary from 3.3% to about 8% in women with early-onset disease (Couch, et al., 1998; Malone, et al., 2006; Newman, et al., 1998). According to Olufunmilayo and colleagues (2000), these numbers are much lower than previously predicted. These data can be interpreted in many different ways. However, the evidence suggests that *BRCA 1/2* testing is not appropriate for women in the general population. For individuals who are affected with breast cancer younger than age 50 years, ovarian cancer at any age or for individuals from families at increased risk for *BRCA 1* or *BRCA 2* mutation, genetic counseling and testing are appropriate and should be offered to such individuals (Olufunmilayo, et al., 2000). These data also suggest that there may be other unidentified breast cancer-susceptibility genes and that current technologies are inadequate to detect all genetic mutations that confer increased risk for breast cancer.

According to the American Society of Clinical Oncology (ASCO, 1996), patients should undergo genetic testing for breast cancer susceptibility if the patient's family exhibits any of the following: (1) One first-degree relative age of onset less than 30 years; (2) Two first-degree relatives if age of onset for one is less than 50 years or for both is less than 60 years; (3) Two first-degree relatives one with bilateral disease; (4) One first-degree relative and one second-degree relative, if the sum of their ages of onset is less than 110; (5) One first-degree relative and one second-degree relative, one with bilateral disease; (6) Two second-degree relatives, either both maternal or both paternal, if the sum of their ages of onset is less than 80; (7) One first-degree relative with breast cancer and one first-degree relative with ovarian cancer with age of onset less than 70 years; (8) Two first-degree relatives with ovarian cancer; (9) One first-degree with male breast cancer. A first-degree relative is a parent, sibling, or child. A second-degree relative is an aunt or uncle, nephew or niece, half-sibling, grandparent, or grandchildren.

*Genetic Counseling/Testing for BRCA 1 & BRCA 2*

Genetic Testing (GT) to identify deleterious *BRCA 1/2* mutations became commercially available in 1996. This process can provide individuals with information about cancer risk as well as the opportunity to influence decisions regarding risk reduction strategies and enable other family members to better define their own risk. Genetic testing for *BRCA 1/2* analyses is solely conducted through Myriad<sup>®</sup> Laboratories Inc. in Salt Lake City, Utah. Genetic counseling (GC) for hereditary breast and ovarian cancer is available in the United States although there is paucity in the number of genetic counselors across the country. Genetic counseling provides individuals with pre/post test counseling including pedigree or family history interpretation and cancer risk assessment, a discussion regarding the risks, benefits and limitations of GT if medically indicated, and the ordering, interpretation and disclosure of genetic tests and results (Brown, Moglia, Gromet, 2007). Currently, the gold standard for genetic counseling is that it is conducted with a trained genetic counselor.

Comprehensive genetic counseling services can be provided using various models but one of the most common models discussed in the literature is the Two-Visit model as described by Roche, Lucas and Hughes (2001). The two-visit model provides genetic services using a genetic counselor, an oncologist, and a mental health professional. In this model, the genetic counselor gets the medical and family history, constructs a family pedigree, provides a risk assessment, and assesses the patient's risk and discusses screening and prevention options. The medical oncologist then joins the genetic counselor and expands the discussion of medical management options and also possibly performs a physical examination. While the genetic counselor and oncologist will have begun a psychological assessment, a mental health professional can be asked to further evaluate the patient's anxiety, if necessary and provide strategies for coping. Comprehensive genetic counseling and testing sessions for breast cancer genetics risk assessment includes multiple components as shown in Table 2 (see Appendix A for a description of the genetic counseling and testing process).

**Table 2. Genetic Counseling Sessions (Two-Visit Model): Pre- and Post-test**

**Pre-visit**

- Call triaged
- Intake completed
- Genetic Counselor (GC) calls patient to schedule appointment
- Patient is sent appropriate forms (i.e., appointment letter, brochure, medical release forms—if necessary, billing and insurance information)
- Patient returns medical release form
- Medical records reviewed
- Genetics chart assembled and forms filed
- GC calculates cancer risk using statistical model if available
- Discuss case at conference if available
- Contact lab/send patient pre-authorization for insurance if necessary

**Visit 1**

- Patient meets with GC to review and/or discuss the following:
  1. contracting/review of consents (if applicable)
  2. review of medical/family history
  3. genes/inheritance
  4. cancer susceptibility genes
  5. appropriateness of testing (especially if proband unaffected)
  6. review of medical management screening and prevention options
  7. prophylactic surgery
  8. risk of genetic discrimination/review of HIPAA and state laws
  9. pros and cons of genetic testing
  10. family communication issues
  11. logistics of blood draw and availability of results –turnaround time
- Patient meets with physician:
  1. history and physical
  2. review of history
  3. more in-depth medical management discussion
- Blood drawn and sent for testing if appropriate
- If blood drawn provide option to schedule visit 2
- Review adjunct research options that may be available to patient

**Between visit 1 and 2**

- GC writes clinic note and/or patient letter
  - Results received, copied, and filed
  - Patient scheduled for visit 2 if not done so already
-

**Table 2. Genetic Counseling Sessions (Two-Visit Model): Pre- and Post-test (Cont'd)**

**Visit 2 (if genetic testing is undertaken)**

- Patient meets with GC and physician to discuss/review the following:
  1. results
  2. cancer risks
  3. surveillance and prevention options
  4. risks and disclosure to relatives
  5. testing of at-risk family members
  6. referrals—physicians and/or psychologists
  7. adjunct services provided and/or scheduled

**After visit 2**

- Second chart note and/or patient letter written per patient's permission/HIPAA compliant—results and/ or letter sent to referring physicians and/or appropriate providers
- Patient chart updated with information
- Follow-up phone call 2–3 weeks after results provided if possible

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There are two scenarios by which women may be referred for genetic testing and counseling; based on ASCO guidelines and/or actively seeking out the services. Typically, medical professionals specializing in oncology or gynecologic oncology may refer women affected with cancer to get genetic testing if they meet testing criteria based on ASCO guidelines (e.g. 1<sup>st</sup> or 2<sup>nd</sup> degree relatives affected by breast or ovarian cancer). Additionally, women who have been affected with breast or ovarian cancer and those who have not been affected but are concerned about their risk due to their family history may choose to inquire about genetic testing through the oncologists. Primary care physicians (i.e. family medicine physicians and gynecologist) can also refer women interested in genetic testing if they meet ASCO guidelines. Because genetic counselors are not recognized as “providers” by insurance companies, they cannot directly bill patients for their services but may bill for services through the physician responsible for the initial referral.

*Clinical Management Options for Carriers of the BRCA Mutation*

Women at increased risk of breast cancer are currently offered the following options: (1) **Increased Surveillance.** For example, women may start monthly breast self-exams at age 18 and annual or semi-annual clinical breast examinations beginning at age 25. Or, yearly mammography



and magnetic resonance imaging beginning at age 25. Women may also receive annual or semi-annual trans-vaginal ultrasound and testing for CA-125 to detect ovarian cancer beginning at age 25.

(2) **Chemoprevention.** Women may opt to take drugs such as Tamoxifen (shown to significantly reduce the risk of breast cancer both in affected and unaffected mutation carriers) or oral contraceptives which are associated with up to a 60% risk reduction for ovarian cancer; and (3)

**Prophylactic Surgery** such as preventative mastectomy which has been associated with a >90% risk reduction for breast cancer or ovarian cancer and/or oophorectomy which has been shown to provide a 96% risk reduction for ovarian cancer and up to a 68% reduction in breast cancer risk (Olufunmilayo, et al., 2000; Simon and Petrucelli, 2009).

Additionally, women with a family history of breast cancer should receive counseling about genetic testing from their health care providers. Genetic counseling for breast cancer risk through a genetic counselor or some other trained health professional is designed to offer clarity about genetic risk and treatment options; however, it is not without its complexities and may be cost prohibitive for many women. Genetic counseling typically costs around \$200-\$400 and may be covered by insurance for high-risk women. Costs for genetic testing can run up to \$3,000 and is covered (e.g. average patient usually pays 10% out-of-pocket) by most insurance companies for high-risk women (Olufunmilayo, et al., 2000; Myriad<sup>®</sup> Laboratories Inc., 2009).

#### *BRCA 1/2 Mutation Analyses among Women of African Descent*

The majority of genetic testing for *BRCA 1/2* mutations has been conducted among women of Caucasian ancestry (Simon & Petrucelli, 2009). Several reports have shown that genetic counseling and testing for hereditary breast and ovarian cancer syndrome is underused among high-risk African-American women (Armstrong, et al., 2000; Kinney, et al., 2001; Olopade, et al., 2003). It is thought that the shared genetic background of Africans and U.S. born African-American individuals contribute to greater susceptibility to early onset breast cancer in both groups of high-risk women (Olopade, et al., 2003). Reviews by Olopade and colleagues (2002) found striking similarities

between *BRCA 1* related breast cancers and breast cancers that occur in young African-American women (e.g. early onset, poorly differentiated tumors, hormone receptor negative and high frequency of p53 mutations) (Couch, et al., 1998; Marcus, et al., 1996). Breast cancers in young African-American women are also more likely to have aggressive clinical and pathologic features (Grann, et al., 2005; Joslyn, 2002; Jones, et al., 2004; Li, et al., 2003).

Several studies have evaluated high-risk African-American and African women for unique mutations in the *BRCA 1* and *BRCA 2* genes (Pal, et al., 2004; Haffty, et al., 2006; Malone, et al., 2006; Haffty, et al., 2009). Early studies found that the prevalence of *BRCA 1* mutations was low in African-American women enrolled in population-based case control studies, however, recent data has shown that the prevalence of *BRCA 1/2* mutations is similar to other ethnic groups who have a personal and family history of breast and/or ovarian cancer (Frank, et al., 2002). For example, Frank and colleagues (2002) reported that the prevalence of mutations was 19% and 16% in African-American and non-Ashkenazi European individuals, respectively. A recent review on hereditary breast cancer in African-Americans reported that 26 different *BRCA 1* mutations and 18 distinct *BRCA 2* mutations have been identified in Africans or African-American individuals; most of which are unique mutations although a few recurrent mutations have been identified (Olopade et al., 2003; Frank, et al., 2002; Gao, et al., 1997; Mefford, et al., 1999).

In a study of high-risk African-American women at the University of Chicago, five of nine probands (i.e. affected participant; See Appendix B for a complete list of defined terms) had germline *BRCA1* mutations three of which were found to be unique and two were found in probands from unrelated families (Gao et al., 1997). Other investigators have identified novel *BRCA 1* mutations including one found in two unrelated African-American families and another identified in one African-American kindred (Fitreal, et al., 1994; Castilla, et al., 1994; Miki, et al., 1994).

In another study of 45 high-risk women diagnosed with breast cancer at Howard University and 92 ethnically matched population based community controls, two protein truncating mutations in

*BRCA 1* were identified (Panguluri, et al., 1999). The 943ins10 mutation had been reported previously in a family from the Ivory Coast and in three other families of African ancestry (Stoppa-Lyonnet, et al., 1997; Arena, et al., 1996; Mefford, et al., 1999). The 3450del4 mutation also had been reported in one Norwegian and two Canadian families. In another analysis of the *BRCA 1* gene among 54 African-American women with breast cancer unselected for family history or age, one novel frame shift mutation was found (Shen, et al., 2000). In a study of 70 high-risk premenopausal women with breast cancer from Nigeria, of which the majority had no known family history of cancer, 4% were found to have deleterious mutations including two novel *BRCA 1* mutations and one protein-truncating mutation in *BRCA 2* (Gao, et al., 2000).

The results from these studies suggest that *BRCA 1/2* mutations are relatively common among high-risk individuals of African descent raising the possibility of a link to one or more common African ancestor(s). Another notable feature of these studies is the unique presence of a wide spectrum of sequence variations and mutations in the *BRCA 1* and *BRCA 2* genes, which is consistent with a high-level of genetic diversity among individuals of African ancestry (Simon & Petrucelli, 2009; Shen, et al., 2000). In the study by Gao and colleagues (2000), 23% of the participants had sequence variants. These findings support the presence of *BRCA 1* and *BRCA 2* mutations among women of African descent and strengthen the need to improve the availability of genetic counseling and testing for hereditary breast and ovarian cancer among high-risk African-American women.

#### *Genetic Counseling/Testing in African-American Women (AAW)*

Genetic counseling and testing for hereditary breast and ovarian cancer (HBOC) may be especially important for African-American women (AAW) due to their higher rates of early onset breast cancer and higher breast cancer mortality rates (Halbert, et al., 2005b; Simon, et al., 2006; Weir, et al., 2003). Use of genetic counseling and testing for hereditary breast and ovarian cancer is not common in AAW; however, several studies have documented the presence of *BRCA 1/2*

mutations in high-risk African-American women (Olopade, et al., 2003; Ademuyiwa & Olopade, 2003). Results of these studies suggest that the prevalence of *BRCA 1* and *BRCA 2* mutations in African-American hereditary breast cancer families may be similar to those seen in Caucasian hereditary breast cancer families.

According to Simon and colleagues (2009), there are no clinical or medical reasons why high-risk African-American women should not be referred for genetic counseling and testing for hereditary breast and ovarian cancer. In a study of 155 high-risk women that underwent genetic counseling and testing at the University of Chicago and other centers that participated in the Myriad Genetics beta testing of *BRCA 1/2* from 1992 to 2003, African-American women participants were found to have a higher rate of DNA sequence variants than non African-American participants (44.2% vs. 11.5%) but lower rates of deleterious mutations (27.9 vs. 46.2%). There were no racial differences in the ability of the statistical program (BRCAPRO) to predict the likelihood of a *BRCA 1* or *BRCA 2* mutation among African-American versus non African-American participants suggesting that similar clinical criteria can be used to select African-American women and Caucasian women for genetic testing for hereditary breast and ovarian cancer (Nanda, et al., 2005). More widespread use of genetic counseling and testing for hereditary breast and ovarian cancer among high-risk African-American women has the potential to increase early detection, introduce the option of preventive measures and lower cancer mortality rates.

#### *Underuse of Genetic Counseling/Testing in African-American Women*

Studies have shown that genetic counseling and testing for hereditary breast and ovarian cancer syndrome is underused among high-risk African-American women (e.g. Olopade, et al., 2003; Hughes-Halbert, 2006; Armstrong, et al., 2005; Kinney, et al., 2001). Evidence suggest that the underuse may in part be due to lower perceived personal risk, low awareness and knowledge of genetic services and negative attitudes towards genetic services (Hughes, et al., 1997; Kinney, et al., 2001; Armstrong, et al., 2002; Lipkus, et al., 1999; Hall and Olopade, 2005; Thompson et al., 2002;

Furr, 2002; Bates, et al., 2005). Notwithstanding the explanations offered, the reasons for this underutilization of genetic services are not well understood even in light of a small body of evidence that suggest factors such as affected status, family history, worry about possible stigmatization and anticipation of familial guilt may be important (Armstrong, et al., 2005; Thompson et al., 2002; Kinney et al., 2001).

One of the most often cited studies that explored racial disparities in utilization was a case control study conducted by Armstrong and colleagues (2005). Their goal was to explore racial disparities in utilization of genetic counseling for primary prevention of breast and ovarian cancer in the University of Pennsylvania Health System. Their findings suggested that African-American women were much less likely to undergo genetic counseling for *BRCA 1/2* testing than white women. These findings persisted even after controlling for confounding factors such as the probability of carrying a *BRCA 1/2* mutation, SES factors (i.e. age, marital status, education, income and insurance) and psychological factors (e.g. risk perception and cancer worry).

An editorial by Hall and Olopade (2005) examining genetic testing disparities suggested that one explanation for the racial disparities may be in the area of perceived risk. They cited results from the 2000 National Health Interview Survey which showed that in the three areas of perceived risk (*BRCA* mutation, breast cancer and ovarian cancer) average risk African-American women had consistently lower scores (a greater proportion reported “less than average” risk) than their white counterparts. The average African-American woman underestimates her risk of breast cancer and is less aware of genetic testing technologies as a means of assessing personal risk. Other studies (Armstrong, et al., 2002; Lipkus, et al., 1999; Kinney et al., 2001) have reported similar findings. Lipkus and colleagues (1999), for example, found that despite their low perception of risk African-American women with a family history of breast cancer were concerned about their personal risk of breast cancer. Interestingly, these concerns translated into higher levels of interest in genetic testing.

A second possible explanation for the underuse observed offered by Hall and Olopade (2005) was poor knowledge of health screening and comprehensive cancer services. They cited the significantly lower rates of regular prenatal and routine health screening visits in African-American women as evidence. They also suggested that this low participation contributed to their poorer scores on health status indices as well as decreased awareness of advanced primary preventive services (e.g. genetic counseling and testing) that may be available. Focus group results from another study (Matthews, et al., 2000) cited by Hall and Olopade (2005) found that among African-American women with a strong family history of cancer nearly half (48%) reported rarely discussing cancer-related issues with family members and none had knowledge of breast cancer genetics, genetic counseling, or the *BRCA* genes.

*Knowledge about BRCA Mutations among African-American Women (AAW)*

Other studies have evaluated knowledge of genetics and knowledge of genetic testing for hereditary breast and ovarian cancer in the general population and among women identified at high-risk for breast cancer comparing responses of African-American to Caucasian participants (Tambor, et al., 2002; Peters, et al., 2004; Kinney, et al., 2001; Peters, et al., 2004; Donovan, et al., 2000; Armstrong, et al., 2002; Lipkus, et al., 1999; Hughes, et al., 1997; Durfy et al., 1999; Tambor, et al., 1997). Evidence suggests that knowledge about breast cancer genetics and exposure to information about genetic counseling and testing is limited among African-American women (Culver, et al., 2001; Hughes, et al., 1997; Kinney, et al., 2001; Halbert, et al., 2005a; Halbert, 2005b). For example, in a survey of 407 Maryland residents, African-American women were one half as likely to have ever heard of the mapping of the human genome; and in a survey of 430 adults waiting for jury duty assignment in Philadelphia, African-American women were less aware of the availability of predictive genetic testing (25% of African-American vs. 35% of Caucasian respondents having heard of *BRCA* testing) (Peters, et al., 2004).

Lipkus and colleagues (1999) conducted a survey of 266 African-American women with and without a family history of breast cancer and found poor knowledge regarding breast cancer factors. In another survey of 95 adult members of a large African-American kindred with a known *BRCA 1* mutation, overall knowledge regarding hereditary breast and ovarian cancer was limited (Kinney et al., 2001). Moreover, among women ascertained from mammography and OB/GYN clinics, African-American women reported significantly lower levels of knowledge about breast cancer genetics than Caucasian women, even though educational levels were comparable (Culver, Burke, Yasui, et al., 2001). Similar results were reported by Hughes and colleagues (1997) who evaluated knowledge in 97 African-American and 310 Caucasian women who had a first-degree relative affected with breast and/or ovarian cancer as part of a randomized trial comparing models of providing pretest education about hereditary breast cancer and genetic testing. Compared with Caucasian women, African-American women reported significantly lower levels of knowledge about inherited disease and exposure to information about genetic testing even after controlling for socio-demographic factors.

Low levels of knowledge about breast cancer genetics may be due to less exposure to information about genetic testing for inherited cancer risk. For example, 31% of African-American women reported having heard or read almost nothing about the availability of genetic testing for inherited cancer compared to 14% of Caucasian women in the study conducted by Hughes and colleagues (1997). In another study that also included first-degree relatives of breast cancer patients, African-American women were less likely to be aware of the availability of genetic testing for inherited breast cancer risk (Durfy, Bowen, McTiermen, Sporleder, Burke, 1999). Only 10% of African-American women were aware of the availability of genetic testing compared to 30% of Caucasian and 27% of Ashkenazi Jewish women. Similar findings have been reported in studies of women who were unselected for family history of the disease. For example, in a cross-sectional study that included African-American and Caucasian women recruited from a primary care clinic, 53% of all participants were aware of genetic testing for breast cancer, and awareness of testing was

inversely associated with African-American ethnic background (Armstrong, et al., 2002). Only one reported survey of 473 low-risk female HMO members age 50 and older in the Raleigh Durham Chapel Hill area showed no differences in awareness of the discovery of the *BRCA 1* gene by race (Tambor et al., 1997). The results of these studies suggest that knowledge of genetics and awareness of genetic testing for hereditary breast and ovarian cancer is lower among African-American women compared to their white counterparts across different segments of the population. Their low knowledge and awareness, however, has not adequately explained the observed underuse.

*African-American Women's Attitudes about Genetic Counseling/Testing*

Consistent with findings reported for Caucasian women who have a family history of breast or ovarian cancer, several studies have shown that African-American women also report high interest and favorable attitudes about genetic testing (Lerman, et al., 1994, 1995; Hughes et al., 2003; Hughes et al., 2004). For example, more than 80% of African-American women reported that preventing cancer, reduced uncertainty and knowledge about the need for increased cancer screening would be important in their decisions to have genetic testing (Hughes, et al., 1997). This study also found that expectations about the benefits of genetic testing were significantly greater among African-American women than among Caucasian women. In another study, the majority of African-American participants endorsed benefits of genetic testing such as increasing screening behaviors and considering prophylactic surgery if test results were positive (Durfy, et al., 1999). Similar findings have been reported in high-risk African-American women; at least 90% of participants reported that genetic testing would help with decision making regarding testing for family members, determining the frequency of mammograms, and increase their motivation to perform breast self-examinations more frequently (Kinney, et al., 2001).

It should be noted that despite these reports about high perceptions regarding the benefits of genetic testing in African-American women, concerns about some of the limitations and risks were greater in this population. For example, Hughes and colleagues (1997) found that concerns about the



emotional and familial impact of testing were greater among African-American women than in Caucasian women. Donovan and Tucker (2000) reported similar differences; in this study, one third of African-American participants had concerns about their ability to handle the emotional impact of testing, whereas only 12% of the Caucasian participants cited this as a concern. In addition, concern about the confidentiality of test results was a salient issue for 72% of African-American participants compared to only 45% of Caucasian participants in another study (Culver, et al., 2001).

Moreover, in an annual general interest survey among 852 adults in the Louisville, KY metropolitan area, African-American women were more likely than Caucasian women to believe that genetics was harmful for society. Specific negative reactions included the idea that genetic researchers were “playing God” or there was a general mistrust in science (Tambor, et al., 2002). Among jury duty candidates, African-American respondents were more likely to feel that genetic testing would be used by the government to label groups inferior and they were less likely to endorse the potential health benefits of genetic testing (Peters, et al., 2004). Despite conflicting reports about African-American women’s attitudes towards genetic research and genetic testing, those studies that reported more favorable attitudes towards genetic testing did not report that these attitudes necessarily translated into actual participation. The evidence seems to overwhelmingly suggest that the negative attitudes of African-American women and their concerns about the potential risks associated with uptake of genetic services seems to adversely affect their participation. However, a small body of evidence has suggested factors that could be important in estimating African-American women’s uptake of these services.

#### *Factors Associated with Use of Genetic Counseling/Testing in African-American Women*

A few investigators have evaluated factors predictive of the use of genetics services among high-risk African-American women (Armstrong, et al., 2005; Kinney et al., 2001; Thompson, et al., 2002). In the study by Kinney and colleagues (2001), women without a personal history of breast cancer had a low rate of adherence to breast cancer screening recommendations. However, despite

this, 67% of respondents were interested in discussing risk factors for breast cancer and 82% reported that they would have genetic testing for hereditary breast and ovarian cancer if available. Intention to undergo genetic testing was associated with having at least one relative with breast and/or ovarian cancer, a 50% perceived risk of being a gene carrier and a lack of knowledge regarding the risk of being a gene carrier. Cost and availability of the test were cited as barriers.

Another investigation evaluated predictors of acceptance of genetic counseling and testing for hereditary breast and ovarian cancer among 76 high-risk African-American women in Harlem who were offered both genetic counseling and testing (Thompson et al., 2002). Women who rejected both genetic counseling and genetic testing had significantly less prior knowledge about the genetics of breast cancer than women who accepted both. Women who rejected genetic counseling reported greater levels of concerns about stigmatization and they had higher anticipated levels of negative emotional reactions to positive test results than women who had both. Women who had neither genetic counseling nor genetic testing demonstrated strong anticipation of guilt among family members. Perceived benefits of genetic counseling and testing among women who tested positive included increased motivation for breast self examination and increased motivation to help female relatives decide about genetic testing.

Barriers to genetic counseling included worry about passing the gene to offspring and anxiety about other family members. Armstrong et al. (2005) conducted a case control study at the cancer risk evaluation program of the University of Pennsylvania on racial differences in uptake of genetic testing and factors related to referral for genetic testing. In this study, African-American women with a family history of breast or ovarian cancer were significantly less likely to undergo genetic counseling than Caucasian women. These differences were not explained by the predicted probability of carrying a *BRCA 1* or *BRCA 2* mutation, socio-economic status, cancer risk perception and worry, attitudes about the risks and benefits of *BRCA 1* and *BRCA 2* testing or primary care physician discussion.

Overall, the body of evidence suggests that there is a racial divide in the use of genetic services. It is clear that African-American women have low knowledge and awareness regarding genetic services and the utility of these services in helping to identify their personal risk. Additionally, while some studies report high interest and favorable attitudes, the overwhelming majority of studies suggest that African-American women may have more negative attitudes towards genetic services. Moreover, although factors such as affected status and family history, for example, have been suggested as being important in estimating use of these services the evidence overall is equivocal. There is still a need to understand the disparity in genetic services uptake within African-American women and few studies investigate this phenomenon within the context of a theoretical framework. As such, it is important to understand underuse of genetic services within a theoretical context; however, there is utility in first understanding the constructs within the theory. Therefore, it is possible that a construct such as perceived behavioral control (PBC) may help explain some of the underuse.

### *Theoretical Framework*

The guiding theoretical framework for this study was the Theory of Planned Behavior (TPB), an extension of the Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1985; Ajzen, 1991, 2002). This theory postulates that an individual's behavioral intention is the most proximal determinant of their behavior. Constructs of **attitudes** (positive or negative evaluation of genetic testing and counseling), **subjective norms** (perceived social pressures regarding genetic counseling/testing), and **perceived behavioral control** (confidence and control over getting genetic counseling/testing) are postulated to independently influence behavioral intention (See Table 3 for explanation of constructs).

**Table 3. Theory of Planned Behavior Constructs**

<b>Concept</b>	<b>Definition</b>	<b>Measurement Approach</b>
<ul style="list-style-type: none"> <li>• Behavioral Intention</li> <li>• Attitude</li> <li>• Subjective Norm</li> <li>• Perceived Behavioral Control</li> </ul>	<ul style="list-style-type: none"> <li>• Perceived likelihood of performing behavior</li> <li>• Personal evaluation of the behavior</li> <li>• Beliefs about whether key people approve/disapprove of the behavior</li> <li>• Belief that one has and can exercise control over performing the behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Are you likely or unlikely to get GC/T?</li> <li>• Do you see (GC/T) as good, bad, neutral?</li> <li>• Do you agree/disagree that most people approve of/disapprove of getting GC/T</li> <li>• Do you believe getting GC/T is up to you/not up to you?</li> </ul>

This framework was selected because it has demonstrated robust performance when predicting health-related behavioral intention than the TRA (Ajzen, 1988). The TPB has improved the predictability of intention when examining health behaviors such as: (1) condom use (e.g., Sheeran & Taylor, 1999); (2) leisure (e.g., Ajzen & Driver, 1992); (3) exercise (e.g., Blanchard, et al., 2007); (4) alcohol use and risky sexual activity (e.g. Norman, et al., 2007; Ravis, et al., 2006); (5) consuming soy products (Rah, 2004); (6) reducing screening delay (Gullatte, 2006) and (7) diet (e.g., Gardner, et al., 2005). Evidence to date, however, has shown that there is a paucity of literature using the TPB to examine the health behaviors of African-American women and even fewer that examine genetic counseling and testing uptake.

*Theory of Planned Behavior, African-American Women and GC/T*

An extensive review of the literature yielded only three studies that were tangentially related to uptake of genetic counseling and testing and African-American women. The first was conducted by Hughes-Halbert and colleagues (2006). In this study, 128 self-referred African-American smokers participated in a structured telephone interview to evaluate their intentions to participate in research on genetic risk factors for smoking. Socio-demographic characteristics, attitudes about genetic testing and intentions to participate in genetic research were evaluated. Over half (58%) of the study participants indicated that they would be very likely to participate in research to identify genetic risk factors for smoking. Greater beliefs about the benefits of participating in medical research (OR 3.17;

95% CI, 1.45-6.94;  $p=0.004$ ) and fewer perceptions of the limitations and risks of genetic testing (OR 0.90; 95% CI, 0.82-0.98;  $p=0.01$ ) had significant independent associations with reporting a high likelihood of participating in genetic research. The theoretical framework guiding this study was the theory of reasoned action (TRA) and therefore did not include the construct of perceived behavioral control. In another study by Satia and colleagues (2006), 658 African-Americans selected through North Carolina's Department of Motor Vehicles completed an at home survey designed to assess attitudes and correlates of intention to take a genetic test for colon cancer. Respondents expressed favorable attitudes and high intention regarding genetic testing for colon cancer; where 87% would definitely/probably take a genetic test although only 42% had read/heard a lot or some about genetic testing. This study did not use the TPB as a framework but used the construct of "intention" to participate in genetic counseling and testing.

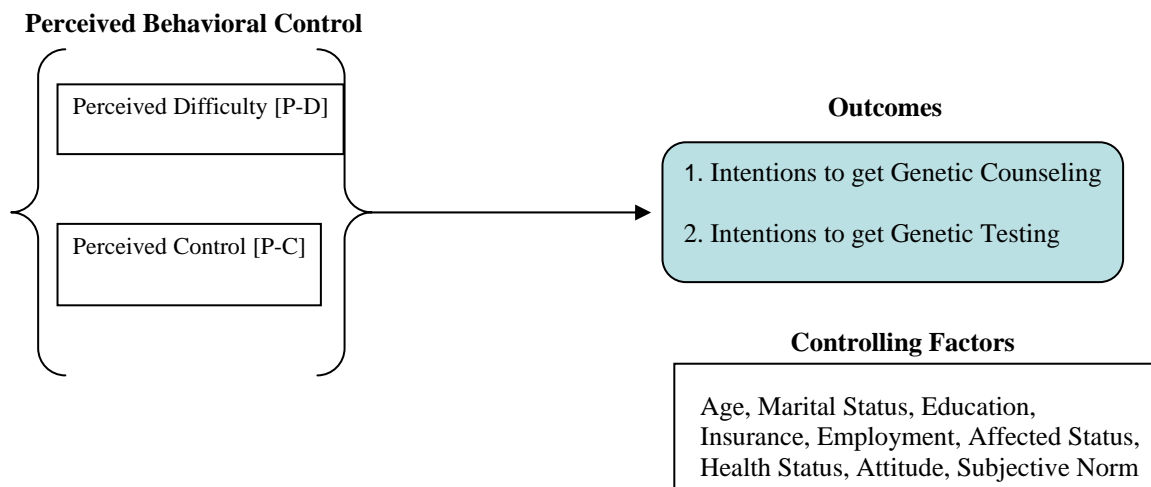
The third study by Gullatte (2006) examined the utility of applying the theory of reasoned action and planned behavior (TRA/TPB) as a theoretical framework for determining cultural relevance of spirituality and religiosity to breast cancer screening delays among African-American women. This author conducted a meta-analysis with 24 studies involving beliefs and barriers to breast cancer screening delays in African-American women. Meta analytic findings suggested that spirituality was an important component in the lives of many African-American women and it has been associated with health seeking behaviors but has often been cited as a barrier to seeking healthcare for serious conditions, such as cancer in this group.

#### *The Theory of Planned Behavior (TPB) and the Current Study*

With the exception of the study by Gullatte (2006) and to the best knowledge of the principal investigator, the TPB has not been used as a guide to examine African-American women's uptake of genetic counseling and testing. Moreover, the construct of "attitude" has been the only construct in the TPB used to examine genetic counseling and testing uptake in African-American women. Although mixed, the overwhelming evidence suggests that women's attitudes are mostly negative.

While the construct of “attitudes” has been shown to be a good predictor of intention (Terry & O’Leary, 1995; Armitage & Conner, 1999; Trafimow, et al., 2002) this construct alone has not explained the underutilization observed. Studies have not often used the construct of “subjective norms” to explain intentions or behaviors because this construct is a poor predictor of intentions and behavior (Trafimow, et al., 2002). Therefore it is most often used as a controlling variable.

The construct of perceived behavioral control, like “attitudes”, has been shown to be a good predictor of both intentions and behaviors within the TPB. However, this construct has not been used to examine genetic counseling and testing uptake in African-American women. Therefore, the current study proposed to use this construct to explore the underuse of genetic counseling and testing services in this population. While perceived behavioral control has been conceptualized as the belief that one has and can exercise control over performing a given behavior, there is evidence to suggest that this construct may be an amalgamation of multiple dimensions (e.g. perceived difficulty and perceived control; Trafimow et al., 2002; see Figure 2). It is possible that either of these dimensions may help explain the observed underuse. For example, if perceived difficulty was found to be associated with genetic counseling and testing uptake then interventions would need to target these specific barriers (e.g. having blood drawn, distance to testing facility or cost).

**Figure 2. Adapted Theory of Planned Behavior**

*Perceived Behavioral Control: Support for its Dimensionality*

Meta-analyses suggest that the prediction of behavior is enhanced when perceived behavioral control is added to the theory of reasoned action as an additional predictor variable (Ajzen, 1988, 1991; Armitage & Conner, 1999b; Godin & Kok, 1996; Sheeran & Orbell, 1999; Sheeran & Taylor, 1999). Despite the increase in predictive power produced by augmenting the theory of reasoned action with perceived behavioral control, researchers have suggested that perceived behavioral control is not well understood (Trafimow, Sheeran, Conner, Finlay, 2002). For example, although the theoretical justification for including this variable in the theory of reasoned action is to account for behaviors that might not be under the person's control, Ajzen (1991; Ajzen & Madden, 1986) has also described it as 'the person's belief as to how easy/difficult performance of the behavior is likely to be' (Ajzen & Madden, 1986). However, perceptions of 'under my control/not under my control' and 'easy/difficult' are not necessarily the same concepts (Trafimow, et al., 2002).

Several other studies have also drawn a distinction between 'control' vs. 'difficulty' as components of perceived behavioral control (e.g. Armitage & Conner, 1999a, 1999b; Armitage, et al., 1999; Povey, et al., 1999; Povey, et al., 2000; Sparks, et al., 1997; Terry & O'Leary, 1995; Trafimow & Trafimow, 1998; White, et al., 1994). Evidence to support the

distinction are as follows: first, despite the fact that perceived behavioral control has, at times, been measured reliably with what is believed to be both 'control' and 'difficulty' items (e.g. Ajzen & Madden, 1986); there have also been failures to get a reliable measure (Beale & Manstead, 1991; Chan & Fishbein, 1993; Sparks, 1994).

These failures suggest the possibility that perceived behavioral control is really an amalgamation of two variables. Occasionally, the two variables are highly correlated resulting in large Cronbach alphas, while other occasions suggest they are not. Second, a variety of factor analytic techniques (e.g. confirmatory factor analysis, principal components analysis) have indicated that 'under my control/outside my control' and 'up to me/not up to me' items load on one factor, whereas items such as 'easy/difficult' and 'confident/unconfident' load on a second factor (Manstead & van Eekelen, 1998; Sparks, et al., 1997; Terry, 1993; Terry & O'Leary, 1995; White, et al., 1994). Finally, correlations between 'control', 'difficulty' and other variables appear to support the distinction.

Although there is little evidence that control beliefs about 'internal' factors (e.g., skill) and control beliefs about 'external' factors (e.g., opportunity) have different associations with control vs. difficulty (e.g., Armitage, et al., 1999; Povey, et al., 2000), studies have shown that control and difficulty both predict intentions independently (Trafimow & Trafimow, 1998). This is also true of behavior (Povey, et al., 2000) and sometimes control and difficulty have different associations with intentions and behavior (e.g. Manstead & van Eekelen, 1998; Sparks et al., 1997; Terry & O'Leary, 1995). Presumably, control and difficulty items would be unlikely to have either additive effects on criterion variables or differential associations with them if control and difficulty were really the same concept. Therefore, although the evidence is correlational, there are some grounds to suspect they are two constructs rather than one.

One cause contributing to the confusion is that the names of relevant variables have not been used in a consistent manner. For example, 'perceived behavioral control' has been used to refer to the



extent to which the behavior is under voluntary control, the ease or difficulty of performing the behavior, and Terry and O’Leary (1995) have even used the term to refer to external constraints on the behavior. Terry and O’Leary have also used the term ‘self-efficacy’ to refer to internal constraints, which is a more specific use of the term than Bandura (e.g. 1997a,b), who used the term to also include external factors and contends that ‘there is a marked difference between possessing sub-skills and being able to use them well under diverse circumstances’ (Bandura, 1997b, p. 391). Consequently, in this project, ‘perceived control’ is used to refer to the extent to which the behavior is perceived to be under a person’s voluntary control and ‘perceived difficulty’ to refer to the extent to which the behavior is perceived to be easy or difficult for the person to perform (see Sparks et al., 1997; Trafimow, et al., 2002).

If perceived control and perceived difficulty are two different constructs that may or may not be correlated then by amalgamating them into one construct (perceived behavioral control), social psychologists have obscured the causes of behavioral intentions and behaviors. That is, perceived control and perceived difficulty may be separate causes of behavioral intentions or behaviors; however, correlational data fail to provide a convincing argument in either direction. The fact that perceived behavioral control often accounts for unique variance in behavioral intentions or behaviors does not provide a convincing argument against the proposed distinction. It is possible that measuring them separately would result in a better prediction of behavioral intentions or behaviors.

One could always argue that measures of the two constructs are actually different measures of the same construct (perceived behavioral control), but two measures are better than one, and thus provide a far better prediction of behavioral intentions or behaviors (Trafimow, et al., 2002). Even the factor analytic evidence cited fails, by itself, to provide a compelling case. Such evidence merely demonstrates that items containing words such as ‘easy/difficult’ in them are more highly correlated with each other than with items containing words such as ‘under my control/not under my control’ (Trafimow, et al., 2002). The fact that participants can tell that some words are more synonymous

with each other than with other words, does not imply they distinguish between perceived difficulty and perceived control when they form behavioral intentions or perform behaviors. It should be noted that the aforementioned observation does not render previously cited research as uninformative but suggests that the various types of correlational evidence provide important contributions. For example, the evidence suggests that more variance in intentions can be accounted for by considering perceived control and perceived difficulty separately than by considering either variable alone but more empirical evidence is needed to support these ideas.

#### *Dimensionality of Perceived Behavioral Control and African-American Women*

All of the psychological literature associated with the dimensionality of the PBC construct examined for this project have been conducted using specific populations such as (1) undergraduate students (e.g. Armitage & Conner, 1999; Terry & O'Leary, 1995; Armitage, et al., 1999; Kraft, et al., 2005; Trafimow, et al., 2002); (2) adolescents (e.g. Tavousi, et al., 2009; Manstead & van Eekelen, 1998); (3) hospital employees (e.g. Armitage & Conner, 1999; ) or (4) patients with chronic diseases such as osteoarthritis (Liu, Doucette, Farris, 2007). Behaviors examined ranged from eating a low fat diet (e.g. Armitage & Conner, 1999), participating in regular exercise activities (Terry & O'Leary, 1995), assessing legal and illicit drug use intentions (e.g. Armitage, et al., 1999), substance abuse prevention (Tavousi, et al., 2009) to drug seeking behavior in osteoarthritis patients (Liu, et al., 2007).

Only one study was found which addressed the dimension of perceived difficulty specifically in African-American women (Crosby, et al., 2005). In the Crosby and colleagues study (2005), 143 face-to-face interviews were conducted with African-American women attending an urgent care clinic. Results indicated that women perceiving an inability to cope with positive results were more likely to report high disclosure difficulty ( $p=0.01$ ) and women perceiving an inadequate support system and those believing that HIV would substantially complicate their lives were more likely to

anticipate high disclosure difficulty ( $p=0.006$  and  $p=0.03$ , respectively). Disclosure difficulty, however, was not associated with intent for HIV testing.

An exhaustive review for studies examining the controllability dimension in African-American women did not yield any results. Studies examining the dimensionality of the PBC construct have used dimensions including perceived difficulty, self-efficacy, perceived controllability, confidence and locus of control. However, it has been suggested that the most reliable way to predict behavioral intention and actual behavior is to use the dimension of perceived difficulty and controllability or self-efficacy and controllability (Liu, et al., 2007; Trafimow, et al., 2002; Kraft, et al., 2005; Armitage & Conner, 1999; Tavousi, et al., 2009).

#### *Summary of Literature Review*

More widespread use of genetic counseling and testing for hereditary breast and ovarian cancer among high-risk African-American women has the potential to increase early detection, introduce the option of preventive measures and lower cancer mortality rates; however, there is a serious lack in uptake of these services within this community. Underuse of genetic services in African-American women may be in part due to limited lower perceived risk, poor knowledge of genetics and the associated services and negative attitudes. Thus far, differences in uptake have not been explained by the predicted probability of carrying the mutation, socioeconomic status, risk perception, attitudes about the risks and benefits or knowledge. It is possible that constructs such as perceived behavioral control in the Theory of Planned Behavior may help explain African-American women's low uptake of genetic counseling and testing by examining their intentions using two dimensions (perceived difficulty and controllability).

## Chapter 3

### *Methods*

#### *Introduction*

This study was conducted in two phases. The first phase employed a qualitative methodology and in the second phase, a quantitative methodology was used. The principal investigator sought to draw on the strengths of both methods to attempt to provide a comprehensive view of the phenomena. The aims of this study were as follows: **first**, to conduct two focus groups with moderate to high-risk African-American women to explore their expressed levels of perceived behavioral control and general motivations regarding genetic counseling and testing; **second**, to explore relationships among the perceived difficulty [P-D] and perceived control [P-C] scales and participant demographic (socio and psychosocial) characteristics.; **third**, To determine if there is a difference in the mean scores of perceived difficulty [P-D] and perceived control [P-C] based on affected status in moderate to high-risk African-American women; **fourth**, To use factor analysis to determine whether the two dimensions of perceived behavioral control, that is, perceived difficulty [P-D] and perceived control [P-C], are distinct factors; **fifth**, to determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic counseling** while controlling for relevant demographic factors; **sixth**, to determine which of the two scales is a better predictor of participants' intentions to get **genetic counseling**; **seventh**, to determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic testing** while controlling for relevant demographic factors and eighth, to determine which of the two scales is a better predictor of participants' intentions to get **genetic testing**.

#### *Phase I: Qualitative Methods*

The purpose of the qualitative phase of this study was to use focus groups to explore African-American women's expressed levels of perceived behavioral control and general motivations

regarding genetic counseling and testing. The findings from these focus groups were later used to refine a pre-existing survey. Approval from Institutional Review Boards at Georgetown University and Virginia Tech was received prior to data collection. Two focus groups were conducted with a total of 21 participants. Participants in Focus Group One (n=13) had been affected with either breast or ovarian cancer while participants from Focus Group Two (n=8) were not affected with breast or ovarian cancer but had a family history of breast or ovarian cancer.

#### *Research Team*

Both focus groups were facilitated by the principal investigator. The principal investigator has had several years of experience with focus groups through the following activities: (1) strategic planning and organizing, (2) collecting and analyzing the data and (3) independently facilitating several focus groups. These activities occurred under the tutelage of Dr. Joann Richardson from Virginia Commonwealth University in Richmond, Virginia and Dr. Vanessa Sheppard from Georgetown University in Washington, DC. Drs. Richardson and Sheppard are both well respected faculty members in their respective departments and are well versed in mixed methods research and cancer health disparities in African-American women. As such, the principal investigator has been well trained and possesses the requisite skills to elicit rich responses from participants and adequately explore the phenomenon under study. Dr. Sheppard was the primary faculty member involved on the research team for this study. Additionally, two research assistants sponsored by Dr. Sheppard actively participated in both note taking and portions of data analysis (e.g. coding, transcript revision). The research assistants were not involved in focus groups discussions. Their primary activities involved sitting in strategic locations around the table to note facial expressions, body language, and verbal intonations and attempted to identify incongruities or conflicting statements from participants.

### *Reflexivity*

The principal investigator does not have a personal experience or a known family history of cancer. However, as a result of involvement in this project and probing into family history, the principal investigator became aware of sporadic cancer episodes in two cousins who were 68 and 70 at time of diagnosis, respectively. The principal investigator is not aware of any overt bias with respect to the topic under study. However, because the principal investigator is a member of the African-American community the following assumptions are held: (1) the principal investigator can understand why many African-American woman may be leery of genetic research; (2) why participation may not be a top priority for many African-American women; (3) why African-American women may have negative attitudes towards genetic research; and (4) why cost may be a significant deterrent for many African-American women when seeking preventive services. The principal investigator's personal passion is educating African-American women about the utility in using preventive services but most importantly to help them become empowered through health education in order to become aware of healthcare options that may not have otherwise been apparent.

### *Research Design*

#### *Qualitative Methodology*

In order to begin to explore the phenomenon of interest, a methodology robust enough to capture its complexities would be required. Therefore, a qualitative methodology was adapted from Stemler (2001), Creswell (2003), Weber (1990) and Krippendorff (2004) which used content analysis. Qualitative research emphasizes an interpretive and holistic strategy to address the "meaning" behind the beliefs, ideas and attitudes that could emerge within this phenomenon. As such, data gathered using this method results in rich, dense, detailed accounts of the phenomenon. Data collection is not constrained by predetermined categories of analysis, allowing for a level of depth and detail that quantitative strategies, for example, cannot provide. In order to analyze the resulting data, content analysis a type of systematic, replicable qualitative technique was used to compress the words of text

into fewer content categories based on explicit rules of coding (Stemler, 2001). The design for this phase of the study utilized the principal investigator and other members of the research team as the instruments of data collection and the participants were the sources of data.

### *Participant Selection*

Participants were selected using purposive sampling from the Greater DC metropolitan area and were recruited through various venues: fliers, word of mouth and phone calls. **Fliers** containing information about the study, eligibility requirements and contact information were disseminated at community activities such as community picnics and health fairs. These activities were sponsored by the following organizations: (1) Capital Breast Care Center (CBCC; a center in the Washington, DC metro area that provides culturally appropriate breast cancer screening services and health promotion regardless of ability to pay); (2) Black Public Health Network (local DC chapter; established to develop African-American leaders in the Washington, DC public health community); (3) Area Cancer Ministries (local cancer support group) and (4) Sisters Informing Sisters (SIS<sup>SM</sup>; culturally appropriate program developed by Dr. Sheppard to help African-American women make informed breast cancer treatment decisions.). **Word-of-Mouth**--Flier recipients were encouraged to share the information about the focus groups with family and friends. **Phone Calls**--Participants from the Sisters Informing Sisters program who had indicated interest in future research projects were recruited for the focus groups through phone calls. Participants were also informed about the eligibility criteria and given a thorough description of the study once contact was made. Each participant was contacted at least twice and messages were left when appropriate. None of the participants approached with fliers or from the Sisters Informing Sisters program refused to participate when asked.

### *Setting and Eligibility Criteria*

Both focus groups were conducted at the Martin Luther King Library in the District of Columbia. This site was chosen primarily because it is a well known land mark; it is easily accessible

by metro and has ample parking. In addition to the principal investigator, two research assistants were present to take notes. Participants for both focus groups were invited to participate if they met the following criteria based on established risk factors for hereditary breast and ovarian cancer (See Table1) and the American Society of Clinical Oncology's (ASCO) recommendations for genetic testing (See page10): (1) at least one first-degree or second-degree relative affected with breast or ovarian cancer (e.g., mother, sister, daughter, cousin); (2) diagnosed at age  $\leq 50$  years regardless of family history or (3) diagnosed  $> 50$  years with at least one first degree relative or two second degree (aunt, grandmother) relatives with breast or ovarian cancer. Additional eligibility criteria included that participants be  $\geq 21$  years of age, able to read/understand English, and have sufficient cognitive ability to provide informed consent.

It should be noted that although the majority of the studies reviewed for this project used high-risk African-American women with the exception of Matthews and colleagues (2000), this project recruited women at moderate to high-risk. This was done because recruiting African-American women based on a strict criteria (e.g. at least one 1<sup>st</sup> degree affected relatives or diagnosed at age  $\leq 50$  years) made it difficult to recruit women within the designated time line. Therefore, the criteria were expanded to include second-degree relatives as well as a diagnosis  $> 50$  years with at least one first degree relative or two second degree (aunt, grandmother) relatives with breast or ovarian cancer. One focus group was conducted on Sunday, November 2<sup>nd</sup>, 2008 and the other on Sunday, November 9<sup>th</sup>, 2008. Both occurred in the late afternoon. Additionally, focus groups were divided such that participants in focus group one had been affected with breast or ovarian cancer (n=13) and participants in focus group two had not been affected with breast or ovarian cancer (n=8). Both groups had a family history of breast or ovarian cancer.

### *Study Procedures*

**Procedure 1:** Two focus groups (FG 1: affected participants; FG 2: unaffected participants) were convened to explore women's expressed levels of perceived behavioral control and general



motivations regarding genetic counseling and genetic testing. Both focus groups were audio taped, convened for one session and lasted 1 ½ hours. During the introduction, the principal investigator shared the following with participants: (1) she was a doctoral student working with Dr. Sheppard, a cancer researcher from Georgetown University's Lombardi Comprehensive Cancer Center and (2) the purpose of the focus groups were to elicit women's thoughts and feelings about genetic testing and counseling for breast and ovarian cancer. Participants were also told of the principal investigator's interest in cancer disparities research in African-American woman and were made aware that their responses would also be used for the principal investigator's doctoral project. Participants were then given the opportunity to provide consent and filled out a brief demographic survey. They were also provided with definitions of genetic counseling and testing so that each participant would have the same basic knowledge.

A semi-structured format, which allows for the interview to be guided by a list of questions where questions may be asked or answered out of order, was used. Additionally, questions were designed as open-ended questions (Appendix C for the Interview Guide). It should be noted that the interview guide was pilot tested using two African-American breast cancer survivors and two African-American women who had not been affected with breast or ovarian cancer but had a family history. These women were associated with the SIS<sup>SM</sup> program but were neither official study team members nor study participants. These women provided general feedback about the appropriate nature and phrasing of questions. During the focus groups, participants were encouraged to freely share their thoughts and feelings about the phenomenon. Any questions or concepts discussed in the groups that were not understood by participants were discussed until an understanding was reached.

**Procedure 2:** The resulting data from both focus groups were analyzed following content analytic procedures. For example, transcripts were reviewed for errors; excerpts related to the phenomenon were coded and placed into their respective categories. Themes emerging from women's coded responses in both focus groups led to the refinement of items on the previously

created survey. The survey was entitled *Understanding Barriers and Motivators to African-American Women's Participation in Genetic Counseling and Testing*. This survey which was part of a larger parent study was funded by the Jess and Mildred Fisher Center for Familial Cancer Research at Georgetown University. The authors included Georgetown faculty and members of the Jess and Mildred Fisher Center--Dr. Vanessa Sheppard, Dr. Kristi Graves and Mrs. Beth Peshkin; the principal investigator and Toni Michelle Harrison, one of the research assistants. The survey was designed to identify barriers and facilitators to BRCA 1/2 genetic counseling and testing among moderate to high-risk African-American women in order to assess potential messages that may be used to help inform them about the benefits of genetic counseling and testing.

The survey had a total of 152 items that were designed to capture information such as breast and ovarian cancer diagnosis and treatment history, clinical risk perception, genetic counseling and testing breast/ovarian cancer knowledge and attitudes, cancer fatalism, medical mistrust, genetic counseling and testing intentions, and perceptions of stress related to getting genetic counseling and testing. Survey items were measured on 5-point Likert scales (e.g. strongly agree/strongly disagree) or using yes/no responses. Selected survey items refined based on the focus group findings were as follows: (1) perceived difficulty in getting genetic counseling and testing for breast and ovarian cancer; (2) the influence of spirituality on genetic counseling and testing decisions; (3) types of lifestyle adaptation if found to carry the BRCA 1/2 gene; (4) privacy and discrimination concerns; (5) the value of genetic counseling and testing and (6) general knowledge and confidence in passage of the GINA law (Genetic Information Nondiscrimination Act; law passed by Congress in 2008 which makes it illegal for any health insurance company or employer to discriminate against anyone with a genetic mutation). All other survey items were adapted from reliable measures found in the literature and were used to assess constructs such as attitudes towards genetic counseling and testing, genetic knowledge, perceptions of stress, medical mistrust, and clinical risk perception. Items used in the quantitative phase of this study were as follows: (1) items assessing perceived difficulty in getting

genetic counseling and testing—derived from focus group data; (2) items assessing perceived control—adapted from Hendy, Lyons and Breakwell (2006) and (3) items assessing genetic counseling and testing intentions—adapted from Green, Peterson, Baker, Harper, Friedman, Rubinstein and Mauger (2004).

**Procedure 3:** Once all questions were established and compiled, the final survey was piloted using the four SIS<sup>SM</sup> program associates who also provided feedback on the interview guide. They served to help establish the length of time to administer the survey, offered feedback on question phrasing and placement of survey items within the survey. The survey was administered as a telephone-based survey and was conducted with 100 participants. These African-American women were a different group of women from the two focus groups; however, they were recruited using the same criteria (See *Setting and Eligibility Criteria* section). Data were collected such that 50 women had been affected with breast or ovarian cancer and 50 were not affected but had a family history of breast or ovarian cancer. Data from both groups were analyzed in aggregate such that women represented a moderate to high-risk group for the BRCA 1/2 mutation. Affected status was only used as a controlling factor in this study.

#### *Data Collection*

The research assistants took notes on legal size pads noting participants' gestures, facial expressions and mannerisms. The principal investigator also took notes (using participants' salient phrases or terms relevant to the phenomenon) on a large writing pad mounted on an easel. The pad served as a visual record for participants of items discussed and as a reference when questions about previous statements made were posed. Using open-ended questions, the principal investigator elicited thoughts, feelings, attitudes and perceptions from participants about the phenomenon. Transcripts from each focus group session were created based on responses; however, due to conflicts in both the facilitator and participants' schedules it was not possible to return transcripts to participants for

comments or further meetings. Participants were each compensated with a \$25 American Express gift cheque.

### *Data Management*

Participant responses were transcribed verbatim by the principal investigator and one of the research assistants, using Microsoft Word for Windows 2003 (Microsoft, 1998-2003). The resulting transcripts were password protected. Demographic data were entered into SPSS statistical package version 17.0 (SPSS, 2008). All transcripts and demographic data were de-identified.

### *Validity*

Validity was ensured based on suggestions by Stemler (2001), Weber (1990) and Krippendorff (2004). Two strategies to ensure internal validity are triangulation which uses either multiple methods, investigators or data sources to confirm the emerging findings and assessing researcher bias. The principal investigator used two focus groups and an adapted survey as multiple forms of data collection. Additionally, transcripts were analyzed by multiple investigators (e.g. research team) including one outside faculty consultant versed in mixed methods to validate the inferences made from the data. Researcher bias was acknowledged at the beginning of the study. The principal investigator's review of the literature helped in acquiring a better understanding of some of the factors associated with African-American women's low participation in genetic research. Additionally, the literature review helped the principal investigator to focus on perceived behavioral control as a possible explanation for the disparity in participation.

### *Reliability*

Weber (1990) noted that in "order to make valid inferences from the data, it is important that the classification procedure be reliable in the sense of being consistent: different people should code the data in the same way (p. 12). Reliability can be discussed using the following terms: stability or intra-rater reliability (can the same coder get the same results try after try) and reproducibility or inter-rater reliability (do coding schemes lead to the same text being coded in the same category by

different people). Reliability for this study was assessed using inter-rater reliability and Cohen's kappa statistic which measures the percent of agreement between raters.

### *Data Analysis*

The principal investigator used a systematic coding approach. Generally, coding is described as a systematic use of some short hand designation to various aspects of the data so that specific pieces of the data can be readily retrieved as needed. Stemler (2001) described two types of coding: (1) emergent coding: categories are established following some preliminary examination of the data and (2) a priori coding: categories are established prior to the analysis based on some theory. The principal investigator employed a whole text analysis and the emergent coding process to analyze the data. According to Stemler (2001) the general steps are as follows: **first**, two people independently review the material and come up with a set of features that forms a checklist; **second**, the researchers compare notes and reconcile any differences that show up on their checklist; **third**, the researchers use a consolidated checklist to independently apply coding and **fourth**, the researchers check the reliability of the coding (95% agreement is suggested; .8 for Cohen's kappa).

Following Stemler's (2001) explanation, the recorded focus groups were transcribed paying particular attention to participants' tones of voice. Transcripts were transcribed verbatim. Focus group one was transcribed by the principal investigator and focus group two was transcribed by one of the research assistants. Transcripts were then exchanged for review and correction using the respective audiotapes. As such, the transcript from focus group one was given to the research assistant and the transcript from focus group two was given to the principal investigator.

Once corrections were made, both transcripts and the respective audio-tapes were given to Dr. Sheppard for final review. Finalized transcripts were each read through to its entirety twice to be certain that participants' responses were understood and checklists of categories were independently developed by the principal investigator, one research assistant and Dr. Sheppard. These categories were compared and differences in categories were reconciled through consensus and notes from the

focus groups. The consolidated checklist became the team's "codebook" and was used by each member to independently code the data.

During the coding process, excerpts from different portions of the transcripts that either addressed the phenomenon directly or provided context for understanding the phenomenon were extracted. Each excerpt was at least one full sentence, but on most occasions an excerpt was multiple sentences. Once the excerpts were identified, each was analyzed and coded for its particular meaning. Once each excerpt had been coded, the codes were printed on individual strips of paper and were organized into categories based on the consolidated codebook. Codes were then meaningful grouped and tentative labels were assigned to each group or category. The categories were revisited after one day and category labels were altered to better fit each category representation.

The resulting categories were then analyzed to see if any subcategories needed to be created. After a thorough review of the codes in each category, it was determined that no subcategories were necessary. Inter-rater reliability was assessed at (.85). Six categories of codes were identified from the data analysis and represent the primary themes that emerged. The six categories were (1) high versus low levels of perceived behavioral control; (2) desired information about genetic counseling and testing for *BRCA 1/2*; (3) women's attitudes towards genetic counseling and testing for *BRCA 1/2*; (4) facilitators and barriers to genetic counseling and testing for *BRCA 1/2*; (5) role of spirituality in genetic counseling and testing for *BRCA 1/2*; and (6) knowledge about genetic counseling and testing for *BRCA 1/2*. A comprehensive discussion of the results from the analysis can be found in chapter 4.

### *Phase II: Quantitative Methods*

The purpose of the quantitative phase of the study was to use measures refined during the qualitative phase of the study to assess how well the theorized dimensions of perceived behavioral

control predicted intention to get genetic counseling and testing for breast and ovarian cancer in moderate to high-risk African-American women.

### *Research Design*

The design utilized was a cross-sectional survey design. This design was used because it provided a quick and simple way to assess a representative cohort of African-American women for which genetic counseling and testing services for breast and ovarian cancer would be applicable. Telephone interviewing was the type of survey administration chosen because it is an inexpensive method for data collection that draws on the benefits of a controlled interview with the probability of high response rates.

### *Sample and Study Criteria*

A total of 100 African-American women participated in this phase of the study. There were 50 participants that were unaffected by breast or ovarian cancer and 50 who were affected by breast or ovarian cancer. Participants were invited to participate in this study if they met the following criteria which are based on the established risk factors for hereditary breast and ovarian cancer (See Table 1) and the American Society of Clinical Oncology's (ASCO) recommendations for genetic testing (See page 10): (1) at least one first-degree or second-degree relative affected with breast or ovarian cancer (e.g., mother, sister, daughter, cousin) and (2) diagnosed at age  $\leq 50$  years regardless of family history or (3) diagnosed  $> 50$  years with at least one first degree relative or two second degree (aunt, grandmother) relatives with breast or ovarian cancer.

Additional eligibility criteria included that participants be  $\geq 21$  years of age, able to read/understand English, and have sufficient cognitive ability to provide informed consent. It should be noted that although the majority of the studies reviewed for this project used high-risk African-American women with the exception of Matthews and colleagues (2000), this project recruited women at moderate to high-risk. This was done because recruiting African-American women based a strict criteria (e.g. at least one 1<sup>st</sup> degree affected relatives or diagnosed at age  $\leq 50$  years) made it

difficult to recruit women within the designated time line. Therefore, the criteria were expanded to include second-degree relatives as well a diagnosis > 50 years with at least one first degree relative or two second degree (aunt, grandmother) relative with breast or ovarian cancer.

### *Participant Recruitment*

Participants were recruited from the following venues: (1) Capital Breast Care Center (CBCC); (2) the Betty Lou Ourisman Breast Health Center at Georgetown University; (3) Sisters Informing Sisters Program (SIS<sup>SM</sup>); (4) the NBC Health and Fitness Expo held in the district; (5) Area Cancer Ministries; (6) Black Public Health Network-DC Chapter; (7) Craig's List and (8) African-American breast cancer support groups from across the country (i.e. Sisters Network-- Dallas, Texas, Ohio, Florida, North Carolina, and Richmond, Virginia). Participants were informed about the study through the use of **fliers** using mass distribution at a health fair (i.e. NBC Health and Fitness expo), Area Cancer Ministries bi-monthly support meetings and two Black Public Health network community outreach events.

Participants were also notified using fliers by clinic staff at Georgetown, CBCC, and the Sisters Informing Sisters program. **E-mails** with study details and eligibility criteria were sent to the respective directors for each breast cancer support group to be posted on message boards so that potential participants could feel free to contact the research team if they were interested. E-mails were also sent to anyone who contacted the principal investigator or one of the research assistants directly to inquire about the study. Internet postings on **Craig's List** were also used as a recruitment method. Fliers and e-mails given to potential participants included a brief description of the study, eligibility requirements, survey length (30-35 minutes) and the amount they would be compensated (\$25 AMEX gift cheque).

### *Procedures*

Interested participants who e-mailed the principal investigator directly or consented for their contact information to be sent by clinic staff, were contacted for the telephone interview. Verbal



consent was obtained prior to each interview. Interviews were conducted by both the principal investigator and one of the research assistants. In an attempt to be cognizant of participants' time, interviews were usually scheduled in advance; however, most interviews were conducted at first contact. Once the survey ended, participants were asked if they would like to be contacted for future studies and for their mailing address so that the research team could send out consent forms and gift cheques. Participants received a thank you letter with detailed instructions on returning consent forms which were mailed in duplicate (one white copy and one blue copy) along with a self addressed stamped envelope and the gift cheque. Participants were instructed to retain the white copy of the consent form for their records and sign and date all highlighted portions of the blue copy of the consent form and return it by mail using the self-addressed stamped envelopes. They were also given information on how to activate the gift cheque.

### *Study Measures*

Measures were drawn from the survey administered as part of the larger parent study (See Procedure 2 in the Qualitative Section for a description of the parent study). The following constructs were assessed in the present quantitative study:

#### *Outcome Measures*

The two outcome measures were (1) intention to get genetic counseling and (2) intention to get genetic testing. Both variables were measured using continuous scales and were adapted from Green and colleagues (2004) which had good reliability ( $\alpha = .78$ ). The original scale consisted of 6 items used to assess only genetic testing intentions. The only response excluded from the adapted scale was "I have not thought about it" [getting genetic testing]. This response was excluded because only responses associated with what participants intended to do were desired.

Additionally, instead of asking only about genetic testing intentions, an additional scale assessing genetic counseling intentions was added. This adaptation was made because according to ASCO recommendations, genetic counseling is an important requisite to getting genetic testing

(American Society of Clinical Oncology, 1996). Participants were asked two separate questions; one to assess their intentions to get genetic counseling and one to assess their intentions to get genetic testing. As such, they were instructed to indicate “which of the following statements best described their thoughts about having genetic **counseling** and/or genetic **testing** for breast and ovarian cancer risk”.

Five response options were provided and used to assess participants’ intentions to get **genetic counseling**: (1) I definitely will not get genetic counseling; (2) I probably will not get genetic counseling; (3) I probably will get genetic counseling; (4) I definitely will get genetic counseling; (5) I already had genetic counseling. Participants who already had genetic counseling would be excluded from the analysis. Additionally, five responses were provided and used to assess participants’ intentions to get **genetic testing**: (1) I definitely will not get genetic testing; (2) I probably will not get genetic testing; (3) I probably will get genetic testing; (4) I definitely will get genetic testing; (5) I already had genetic testing. Participants who already had genetic testing would be excluded from the analysis.

#### *Predictor Variables*

Predictor or independent variables of interest were the Perceived Difficulty [P-D] and Perceived Control [P-C] items. The items on the Perceived Difficulty [P-D] scale were developed based on results from the principal investigator’s formative work that emerged in the qualitative phase of the study. This variable has been operationally defined as the ease or difficulty for an individual in performing a given behavior; in this case, the types of barriers participants perceived that would make it difficult if they wanted to get genetic counseling and/or testing for breast and ovarian cancer.

The P-D scale contained six items and a range from 6-30; items were reversed scored so that higher scores reflect greater perceived difficulty. On the survey, participants were asked to describe how much they agreed/disagreed with statements related to factors that would prevent them from

getting genetic counseling and/or testing for breast and ovarian cancer. Items used to assess participants' perceived difficulty were as follows: 1) Having to have blood drawn; 2) Distance to the genetic counselor; 3) Distance to the genetic testing facility; 4) The opinion of a family member; 5) The opinion of a close friend; 6) I would not pursue BRCA testing, because I feel genetic testing is experimenting on people. Participants responded to the P-D items using a 5-Point Likert continuous scale ranging from strongly agree-1 to strongly disagree-5.

The Perceived Control [P-C] variable was measured using a continuous 5-Point Likert scale ranging from completely disagree—1 to completely agree—5. The Perceived Control [P-C] scale has three items and a range from 3-15. These items were adapted from Hendy, Lyons and Breakwell (2006) which had good internal consistency ( $\alpha = .77$ ). The scale was adapted to include the term genetic counseling in addition to genetic testing on each item. It was also adapted conceptually to be used as a measure of perceived control. The authors used this scale as a measure of self-efficacy; however, this construct was vaguely defined as a person's perceptions of control.

Work by Trafimow, et al. (2002), Kraft, et al., (2005), Armitage and Conner (1999) and Tavousi, et al. (2009) suggest this definition is more closely related to the construct of perceived control or controllability. As such, this scale was used to measure perceived control and was operationally defined as the belief about the extent to which performing a given behavior is up to the individual or under a person's voluntary control. In this case, participants' belief about the extent to which getting genetic counseling and/or testing for breast and ovarian cancer is up to the participant or under her control. On the survey, participants were asked to describe how strongly they agreed/disagreed with the following statements: 1) I have complete control over the decision to undergo genetic counseling and testing for breast and ovarian cancer; 2) It is my choice whether or not I receive genetic counseling and testing for breast and ovarian cancer; 3) It is entirely my decision whether or not to undertake genetic counseling and testing for breast and ovarian cancer.

### *Controlling Variables*

Socio-demographic variables used in the study were as follows: **Age** was measured as a continuous variable and was computed using participants' birth date. **Marital status** was measured as a categorical variable and options included married, single, divorced, separated and widowed. **Education** was measured as a continuous variable and options included first through 11<sup>th</sup> grade, 12<sup>th</sup> grade, no diploma, high school graduate, some college but no degree, diploma or certificate from a vocational/business school, associates degree, bachelors, masters, doctorate, and professional school (i.e. MD, JD) degree. **Insurance** was measured as a categorical variable and was assessed by asking participants whether or not they were covered. Insurance type was also collected (i.e. Medicare, Medicaid/Charter Health, Kaiser, Blue Cross/Blue Shield, Americare, Alliance, Other, specify). **Employment** was measured as a categorical variable and was assessed by asking participants if they worked full time, part time, full/part-time student, never worked, retired or unemployed.

Socio-cultural variables used were as follows: **Subjective Norms** was measured as a continuous variable and was assessed by asking participants to choose the one person closest to her whose opinion would matter most. Options included friends, spouse, parents, siblings, children or other (specify). **Attitudes** were measured as a continuous variable using a 4-Point Likert scale (1-Very Important to 4-Not at All Important). The "attitude towards genetic counseling and testing scale" was taken from Armstrong and colleagues (2000). The scale contained 15 items and had a range from 15-60; items were reversed scored so that higher scores reflected greater importance. Participants were asked to rate how important each factor read to them would be in their decision to get genetic counseling and testing.

Items used were as follows: (1) learning about my breast cancer risk; (2) learning about my ovarian cancer risk; (3) providing information for my family members; (4) help deciding about removing one or both breasts to prevent cancer; (5) help deciding about removing the ovaries to prevent cancer; (6) help deciding about estrogen replacement; (7) desire to be reassured is the test

was negative; (8) desire to be reassured if the test was positive; (9) concern about my anxiety if the test was positive; (10) fear of health insurance discrimination; (11) fear of job discrimination; (12) cost of the test; (13) my doctor's recommendation; (14) my family's recommendation; (15) desire to help advance research.

Clinical demographic variables used were as follows: **Affected status** was measured as a continuous variable (dummy-coded) and was assessed by asking whether or not participants had ever been diagnosed with breast or ovarian cancer. **Health Status** was measured as a continuous variable by asking participants whether they would rate their general health as excellent, very good, good, fair or poor. This scale was reversed coded such that "excellent health" was reflected by a higher score and "poor" health by a lower score.

#### *Data Management*

Data were entered into SPSS Statistical package version 17.0 (SPSS, 2008) and used to run basic descriptive statistics, factor analysis, hierarchical and multiple regression. Data were de-identified and password protected. Data quality checks were conducted using double data entry by the principal investigator and a research assistant. Additionally, frequencies were also run to double check for missing and incorrectly entered data.

#### *Data Analysis*

The distributions of all continuous variables were examined and any needed transformations were conducted to achieve normal distribution or to select analytic approaches for non-normally distributed data. Reliability using Cronbach's alpha was assessed for all relevant scales (i.e. perceived difficulty, perceived control). Appropriate descriptive statistics were calculated for each variable type. Frequencies were calculated to examine categorical demographic variables (marital status, insurance, employment) and means and standard deviations were calculated for all continuous demographic variables (age, education, affected status, and health status). Data analysis occurred in several steps and is described below based on each aim and/or hypothesis.

*Aims and Corresponding Analyses*

**Aim I:** To explore relationships among the perceived difficulty [P-D] and perceived control [P-C] scales and participant demographic (socio and psychosocial) characteristics.

**Analysis:** A correlation matrix will be run to see if demographic variables correlate with the P-D and P-C scales. Categorical variables will be turned into 2 groups and dummy coded for correlational analysis.

**Aim II:** To determine if there is a difference in the mean scores of perceived difficulty [P-D] and perceived control [P-C] based on affected status in moderate to high-risk African-American women.

**H<sub>1</sub>:** Women who were unaffected with cancer will have a higher score on the perceived difficulty [P-D] scale.

**H<sub>2</sub>:** Women who have been affected by cancer will have a higher score on the perceived control scale [P-C].

**Analysis:** Two t-tests, one for the P-D scale and one for the P-C scale, will be conducted to determine if there are statistically significant mean differences between the group that has been affected by cancer and the group that has not been affected by cancer on the scales.

**Aim III:** To use factor analysis to determine whether the two dimensions of perceived behavioral control, that is, perceived difficulty [P-D] and perceived control [P-C], are distinct factors.

**H<sub>3</sub>:** The six items of the P-D scale will load into one factor and the three items of the P-C scale will load into another factor, showing that they are distinct constructs.

**Analysis:** In the factor analysis, principle components analysis will be used to examine all nine items from both scales. Those factors with Eigen values greater than one will be used for the item loading to ascertain if the items load into separate factors as predicted.

**Aim IV:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic counseling** while controlling for relevant demographic factors.

**Analysis:** Bivariate correlations will be run, then hierarchical regression will be used with the outcome variable being the likelihood of participants' intentions to get genetic counseling. If neither the P-D nor the P-C scales are correlated with counseling intention, then the hierarchical regression will become unnecessary. Only those demographic variables that are correlated with genetic counseling intention will be entered into the first step of the hierarchical regression with the PBC scales entered at the second step.

**Aim V:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic counseling**.

**H<sub>4</sub>:** The perceived difficulty scale will be a better predictor of **genetic counseling** intentions in moderate to high-risk African-American women than the perceived control scale.

**Analysis:** Multiple regression with the enter method will be used to determine which of the two scales will enter into the model first and have the higher beta weight, thus being the better predictor. Studies suggest that perceived difficulty is a better predictor of intentions than perceived control (Trafimow & Trafimow, 1998; Manstead & van Eeklen, 1998; Sparks, et al., 1997, Terry & O'Leary, 1995, Armitage & Conner, 1999; Trafimow, et al., 2002). Therefore, it is expected that the same will hold true in this study.

**Aim VI:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic testing** while controlling for relevant demographic factors.

**Analysis:** Bivariate correlations will be run, then hierarchical regression will be used with the outcome variable being the likelihood of participants' intentions to get genetic testing. If neither the P-D nor the P-C scales are correlated with testing intentions, then the hierarchical regression will

become unnecessary. Only those demographic variables that are correlated with genetic testing intentions will be entered into the first step of the hierarchical regression with the PBC scales entered at the second step.

**Aim VII:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic testing**.

**H<sub>5</sub>:** The perceived difficulty dimension will be a better predictor of **genetic testing** intentions in moderate to high-risk African-American women than the perceived control dimension.

**Analysis:** Multiple regression with the enter method will be used to determine which of the two scales will enter into the model first and have the higher beta weight, thus being the better predictor. Studies suggest that perceived difficulty is a better predictor of intentions than perceived control (Trafimow & Trafimow, 1998; Manstead & van Eeklen, 1998; Sparks, et al., 1997, Terry & O'Leary, 1995, Armitage & Conner, 1999; Trafimow, et al., 2002). Therefore, it is expected that the same will hold true in this study.

### *Reliability*

Reliability for each scale (P-D, P-C and counseling/testing intentions) will be assessed using Cronbach's alpha. The reliability of the items measuring perceived control will be compared with the Hendy, et al. (2006) scale originally used to measure self-efficacy (.77). Reliability for both the genetic counseling intention scale and the genetic testing intention scale will be compared with the Green, et al. (2004) (.78) scale.

### *Validity*

Both the Hendy, et al. (P-C scale; 2006) and the Green, et al., (counseling/testing intentions scales; 2004) scales were established scales and have been previously validated. Validity for the perceived difficulty items was established during the focus group process (i.e. triangulation; See *Validity* subheading in the Qualitative section).



*Ethical Considerations*

Every effort was taken to ensure participation in both phases of the study was entirely voluntary and no identifying information would be collected or revealed at any time throughout the study. Participants were also informed that they could refuse to answer any question and withdraw from the focus groups and the survey at any time. All data collected became the property of the principal investigator, Georgetown University and Virginia Tech. No transcripts were produced that would connect participants to their comments (i.e., no identifying information was recorded). Additionally, survey data were de-identified saved on a dedicated survey and password protected. The principal investigator received permission from both Georgetown University and the Virginia Polytechnic and State University Institutional Review Board for Research to conduct research on human subjects.

## Chapter 4

### *Results*

#### *Phase I: Qualitative Results*

The purpose of the qualitative phase of this study was to use focus groups to explore African-American women's expressed levels of perceived behavioral control and general motivations regarding genetic counseling and testing for *BRCA 1* and *BRCA 2* (*BRCA1/2*). The following findings from the two focus groups were used to refine a pre-existing survey which was used in the quantitative phase of this study. The principal investigator conducted two focus groups and employed a whole text analysis and the emergent coding process to analyze the data. A total of 21 participants consented to participate; 13 in focus group 1 (the affected group) and 8 in focus group 2 (the unaffected focus group). Most participants were US born (90%), employed full time (57%), were single (71%), reported having insurance (95%) and were between 56-65 years of age (38%). See Table 4 for demographic characteristics of participants.

**Table 4. Demographic Characteristics of Focus Group Study Participants (N=21)**

<b>Demographic Characteristics</b>	<b>N</b>	<b>(%)</b>
<b>Age</b>		
21-35	4	(19)
36-45	3	(14)
46-55	3	(14)
56-65	8	(38)
65 and older	3	(14)
<b>Currently Insured</b>	20	(95)
<b>Private</b> (e.g. Blue Cross Blue Shield)	15	(71)
<b>Public</b> (e.g. Medicare)	5	(24)
<b>Income</b>		
≤\$35K	2	(9)
\$35,001-\$85K	14	(67)
\$85,001- >\$100K	5	(24)
<b>Marital Status</b>		
Married/Partnered	6	(28)
Divorced	6	(28)
Separated	2	(9)
Widowed	2	(9)
Single/Never Married	5	(23)
<b>Education</b>		
Completed High School	3	(14)
Some College	4	(19)
Vocational School	2	(9)
College Educated	12	(57)
<b>Currently Employed</b>	41	(82)

Six categories of codes emerged from the data and were organized into the following domains: (1) high versus low levels of perceived behavioral control; (2) desired information about genetic counseling and testing for *BRCA 1/2*; (3) women's attitudes towards genetic counseling and testing for *BRCA 1/2*; (4) facilitators and barriers to genetic counseling and testing for *BRCA 1/2*; (5) role of spirituality in genetic counseling and testing for *BRCA 1/2*; and (6) knowledge about genetic counseling and testing for *BRCA 1/2*. The results that follow present a synthesis of how women responded to questions asked from the interview guide. The domains characterize the perceptions and thoughts of African-American women at moderate to high-risk for breast cancer in relation to their perceived levels of behavioral control and general motivations to get genetic counseling and testing for *BRCA 1/2*. See Table 5 which displays the coded categories and respective exemplar quotes.

**Table 5. Major Focus Group Themes and Exemplar Quotes****High vs. Low Levels of Perceived Behavioral Control**

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*High Levels of Control*

- *“I feel very confident in my ability to get tested...I mean, I am in the process right now to find out what I need to do.”*
- *“I feel very confident about going to get it [genetic counseling and testing]; if I make up my mind to get tested I would definitely get it because I don’t worry about insurance.”*
- *“I am very confident that I could get tested...there is breast cancer on both sides of my family...I think my insurance would pay; I mean it is good insurance...but if they didn’t cover it I would definitely find a way...there must be so me place I could go to get help.”*

*Low Levels of Control*

- *“I think it [genetic counseling and testing] is important but I am on the lower side of being confident; I see a midwife for my well woman care and I am not certain what her resources would be to give me a referral or about the cost but either way...no, I am not really confident in getting testing.”*
- *“I am somewhat confident...I mean I do think testing is important but I don’t know if my insurance allows it [getting genetic counseling and testing]...I don’t know what my insurance will allow me to do so I am not going to try right now to get tested.”*
- *“I am worried about cost...I mean I might want to get it [genetic counseling and testing] but I don’t think I can afford it without coverage and I don’t have insurance so I am not very confident at all.”*

**Desired Information about GC/T for BRCA 1/2**

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- *“I want to know about the test’s accuracy...I mean how accurate is the test and is it going to help me know about getting cancer.”*
- *“I wanna know if testing is a one shot deal and if it will be painful...but mostly, am I gonna get sick after getting tested?”*
- *“If I get tested, I want what my oncologist gives me now...I wanna know how to read the report and tell me what a positive result means...I wanna see the report don’t just give me numbers and know what my options are...”*

**Women’s Attitudes Towards GC/T for BRCA 1/2**

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- *“I found the information that they gave me very informative and useful...there was lots of literature and they were able to tell me what the possibilities of what side of the family the cancer came from and what the possibility that my nieces or great nieces would be subjected because I have multiple cancers.”*
  - *“I think that getting it [genetic counseling and testing] could help. It’s a good idea especially if it helps tell family members like your nieces and daughters about their risk.”*
  - *“If I could get it [genetic counseling and testing]...I’d take it. At this point in my life if I could get it I would take it and I wouldn’t even worry about it [cost]. I would just do it because I see it as important.”*
-

**Table 5. Major Focus Group Themes and Exemplar Quotes (Cont'd)****Facilitators and Barriers to GC/T for BRCA 1/2**

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*Facilitators*

- *“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...they were my motivation..”*
- *“If a close, close relative had breast cancer then I would be curious to see if I’m carrying that gene or maybe if I was expecting a child...I would want to know if I was gonna pass it [on to the child].”*
- *“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 [genetic counseling and testing] locally at a reasonable cost would motivate me.”*

*Barriers*

- *“If the medical recommendation is not to pay for [genetic counseling and testing] if you don’t have any family history then you have to make the decision, ‘ok well how am I going to pay for this’ then you see the real cost...then you need to figure out how you are going to get that money so I think that would probably be the biggest barrier that if [I] knew [my] insurance company was not going to help pay for what I assume is a very expensive test.”*
- *“...me personally...it’s about having the preventive mastectomy...because if you do find out you have the gene then you are now forced to make those types of decisions...I would never want that [for myself] ...I don’t want to have to think about that.”*
- *“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.”*

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**Role of Spirituality in GC/T for BRCA 1/2**

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- *“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].”*
- *“My spiritual beliefs play a big part of my decisions for myself including my health...so whatever the outcome of a genetic test I think God would help me...”*
- *“I don’t think it’s playing God...if anything it [getting tested] could be a positive thing but some African-American women might and that view might stop them.”*

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**Women’s Knowledge about GC/T for BRCA 1/2**

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- *“I heard about it [genetic counseling and testing] when I was diagnosed but I didn’t know what it was all about...I just didn’t know.”*
  - *“I had a co-worker who had cancer...it runs in her family...her mother and sister had cancer but before that I didn’t know anything about it [genetic counseling and testing] ...I really didn’t know anything at all not even about this new thing...B-R-C-A.”*
  - *“Before now I didn’t know anything about it [genetic counseling and testing] but I remember seeing something on TV about BRCA and testing because of that celebrity that was on Oprah...I think her name is Christina Applegate.”*
-

*High versus Low Levels of Perceived Behavioral Control*

*High Levels of Perceived Behavioral Control*

At both focus groups, women were asked individually to extrapolate (close ended question) on their responses regarding their sense of the level of confidence they had in getting genetic testing and counseling for *BRCA 1/2* if they chose. The majority of women (66.6%) reported high levels of perceived behavioral control and overwhelmingly stated that they felt either “*highly*” or “*very*” confident in their ability to seek out these services if necessary. These women voiced that they felt genetic counseling and testing for *BRCA 1/2* could be important as a preventive tool and would be eager “*to explore every avenue necessary in order to get it regardless of cost or insurance.*”

According to one woman, “*I am the type of person that wants to get tested for everything under the sun...I think it [genetic counseling and testing] is important and if I had to get tested I would go so far as to ask my family for the money.*” Another woman who was in the process of actively seeking genetic counseling and testing for *BRCA 1/2* commented, “*I feel very confident in my ability to get tested...I mean, I am in the process right now to find out what I need to do.*”

These participants not only voiced their high levels of confidence in their ability to get genetic counseling and testing for *BRCA 1/2* but were willing to “actively” seek out means in order to get it in spite of possible obstacles. One woman who had not been affected by breast or ovarian cancer but had experienced her maternal aunt’s breast cancer stated:

*“I don’t think I have a strong family history but I know we have cancer in the family...I am not sure about insurance because they may not want to cover the cost without a strong family history but I will do whatever it takes because I need to know...I mean...I might even have to find some kind of creative way to find out but I think I need to know so I am confident that I can find a way to get it [genetic testing].”* Another woman with a strong family history of breast cancer commented: “*I am very confident that I could get tested...there is breast cancer on both sides of my family...I think my*

*insurance would pay; I mean it is good insurance...but if they didn't cover it I would definitely find a way...there must be some place I could go to get help."*

Additionally, when asked if it was important to think of themselves as people who had control over whether they could go and get genetic counseling and testing for *BRCA 1/2* these women unanimously agreed. No one wanted to be forced to have to make the decision to get genetic counseling and testing for *BRCA 1/2* but it was important to each woman that they perceived that they had the control over their ability to make the decision. According to one woman who felt like the nurse of her oncology team was dissuading her from getting tested:

*"If I make up my mind to get it [genetic testing] I would definitely get it because I don't worry about insurance or other people...a nurse even said to me, 'well you know, sometimes its best not to know these things [about genetic testing results]' and I thought, 'who is she to tell me this and she is supposed to be on my oncology team' ...so I stayed away from her because she was negative and trying to tell me what I could or couldn't do...so I researched it [genetic testing] myself and had my questions to ask the doctor."* Moreover, another woman commented, *"anytime your freedom is threatened you would be concerned...you should be free to make decisions about anything concerning your own life...no one should be able to stop you from doing that."*

#### *Low Levels of Perceived Behavioral Control*

Women who responded that they felt "somewhat" or were on the "lower side of being confident" were all group into the low category of perceived behavioral control (33.3%). Although these women also voiced that they felt genetic counseling and testing for *BRCA 1/2* was important; they were more concerned about the barriers that would prevent them from getting genetic testing and counseling if they wanted to receive it. According to one woman, *"I think it [genetic counseling and testing] is important but I am on the lower side of being confident; I see a midwife for my well woman care and I am not certain what her resources would be to give me a referral or about the cost but either way...no, I am not really confident in getting testing."* Another woman who was concerned



about insurance coverage commented, *“I am somewhat confident...I mean I do think testing is important but I don’t know if my insurance allows it [getting genetic counseling and testing]...I don’t know what my insurance will allow me to do so I am not going to try right now to get tested.”*

Despite the fact that women in the lower perceived behavioral control group may have viewed genetic counseling and testing for *BRCA 1/2* as an important screening tool, barriers such as cost, lack of a strong family history and insurance overshadowed their confidence making them more “passive” and hesitant to act on their feelings of confidence in their ability to get genetic counseling and testing for *BRCA 1/2*. One woman voiced that she was *“interested in getting testing”* but thought that the process for getting genetic counseling and testing may be *“cost prohibitive”* and thus shied away from actively seeking it out. Another woman voiced that she *“didn’t try to get genetic testing because [she] feared that [she] would not be seen as a priority without a strong family history.”*

According to another woman who had received genetic testing while pregnant:

*“I know genetic testing is available because I got tested after my second child due to my advanced maternal age...so at least through that experience I know it is possible for me to get referred to a genetic counselor because of family history but I don’t think we can afford the test...I don’t know what insurance will cover so I probably won’t try to get it right now.”*

Interestingly, these women also reported that it was important for them to think of themselves as people who had control over whether they could go and get genetic counseling and testing for *BRCA 1/2*. Women in the lower perceived behavioral control group also voiced that they would not want *“to feel forced”* to have to make the decision to get genetic counseling and testing for *BRCA 1/2* but it was important to each woman that they perceived that they had the control over their ability to make the decision. According to one woman, *“ultimately it [getting tested] lies with me...my choice is very important even if I can’t afford to get tested...I wouldn’t want someone to make me feel like I had to go get tested...it has to be my choice.”*

*Desired Information about Genetic Counseling/Testing for BRCA 1/2*

Apart from two women in the focus groups (one who had been affected by cancer and had received genetic testing and one who had testing while pregnant), most women did not have any experience or knowledge about genetic counseling and testing for *BRCA 1/2*. Most women commented, *“outside of the information I got in this focus group, I never knew about genetic counseling and testing for BRCA 1/2.”* Women, however, shared that they were interested in getting information about the test’s accuracy in predicting cancer risk. According to one woman, *“I want to know about the test’s accuracy...I mean how accurate is the test and is it going to help me know about getting cancer.”* Another woman added, *“I would want to know exactly what’s my probability...am I 65% [at risk to get cancer] by the age of sixty...am I 25% [at risk to get cancer] by the age of forty...how accurate is the test, really?”*

Additionally, women were interested in knowing more about the logistics involved with genetic counseling and testing for *BRCA 1/2*, including the number of visits, the length of time it would take to receive test results, if testing was painful, was blood or saliva required, the potential risks involved by participating in genetic testing and whether getting tested would make them sick. According to one woman who was very concerned about the potential harm getting testing could bring, *“I would be really curious to know if years down the road am I gonna be denied life insurance because someone got a hold of my results from this test and now they see me as a huge risk.* Another woman added, *“I wanna know if testing is a one shot deal and if it will be painful...but mostly, am I gonna get sick after getting tested?”*

Moreover, women expressed concern about whether they would have to make decisions regarding prophylactic mastectomy following genetic counseling and testing for *BRCA 1/2*. One woman who was especially concerned voiced, *“I am into my boobs and even though I have a aunt who had cancer I think we see her as an anomaly so I just am interested to know if I would have to get a mastectomy because my breast are very important to me.”* Additionally, participants were

interested in information concerning test interpretation and knowing what to do with their results.

One woman stated, *“I want to know what specific test is available for me and when I get the results what to do...I mean what does a positive result mean for me and my family or even a negative one?”*

Women were also interested in knowing specifically how *“participating in genetic counseling and testing actually cures or prevents cancer.”* Furthermore, women were interested in learning about the implications of testing, particularly the various options following receipt of a positive test result and any other potential consequences associated with their participation in genetic counseling and testing. According to one woman:

*“I need the doctor to explain things to me in 7/11 language...meaning that anybody off the street could understand...I wanna see my report...if my report is normal what does that mean...if I am positive then what do I do, what comes next for me...and does a positive result mean that everybody in my family has to get tested or think about a mastectomy?”* See Table 6 for information about genetic counseling and testing that was desired by women.

**Table 6. Summary of Desired Information about Genetic Counseling/Testing for *BRCA 1/2***

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**Information****Testing**

- How accurate is the test

**Test Procedure**

- Is it Painful
- Does it require multiple visits
- What's involved
- How long to wait for results
- Where will test be given and will it fit into my schedule
- Is there a specific test for women who had cancer to determine next steps

**Testing Implications**

- Will I get sick, loose my hair, have to loose my breast
- Are there risks involved of having test done
- Are there side effects from testing
- Will it tell me my odds of developing cancer
- Who can and won't be tested
- How does counseling and testing help cure cancer and/or prevent it
- What do I do with the results
- How do I read results to know what is normal

**Discrimination Risk**

- Will testing lead to future insurance denial
  - How will the information be used against me
-

*Women's Attitudes towards Genetic Counseling/Testing for BRCA 1/2*

Overall, most women had positive attitudes towards genetic counseling and testing for *BRCA 1/2*. Women saw it as “*necessary and useful*” if it would help facilitate cancer risk reduction. One woman who had already had genetic counseling and testing for *BRCA 1/2* shared: “*I found the information that they gave me very informative and useful...there was lots of literature and they were able to tell me what the possibilities of what side of the family the cancer came from and what the possibility that my nieces or great nieces would be subjected because I have multiple cancers.*”

Women voiced their desire to participate in genetic counseling and testing for *BRCA 1/2* but also voiced concern that participation would not be possible without insurance or their own personal ability to cover the cost of the test. One woman offered, “*I mean if I could get it [get counseling and testing] I would but realistically it doesn't matter how much you want it or how positive you think getting it [genetic counseling and testing] is if you don't have insurance or some way to pay you just aren't gonna get it.* Another woman retorted, “*If I could get it [genetic counseling and testing]...I'd take it. At this point in my life if I could get it I would take it and I wouldn't even worry about it [cost]. I would just do it because I see it as important.*”

*Facilitators and Barriers to Genetic Counseling/Testing for BRCA 1/2*

*Facilitators*

Participants shared that having a “*family history*” of breast and/or ovarian cancer or having “*a family member at risk for developing the disease*” would greatly motivate them to seek out genetic counseling and testing for *BRCA 1/2*. One woman affected by cancer 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.*” Another participant offered, “*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 I would want to know if I was passing...or likely to pass it [to my child].*” One woman was

concerned about the implications of cancer in the African-American community at large and one 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 studies]."

Interestingly, male relatives (i.e. brother) were mentioned as being a strong motivator for one woman. She highlighted the fact that most usually do not consider males as being at risk for breast cancer, however, she stated that "*their risk should also be considered because they could potentially suffer similar results as African-American women.*" She added, "*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 find it; prayerfully everyone here had it and they found it [breast cancer] but they [the men] get it and they die.*"

Additionally, women reported that being symptomatic and having genetic counseling and testing for *BRCA1/2* more accessible were also be primary motivators for their willingness to participate. One woman who actively participated in breast self exams stated, "*I think I would be very motivated if when I was doing an exam I felt something around my breast area or maybe if I was feeling sick.*" Another woman added, "*Yes, I think having symptoms would definitely motivate me to seek out getting tested.*" Other women reported that they would be motivated to seek out genetic counseling and testing for *BRCA 1/2* if they received a referral from their primary care physician and could get the test locally without the hassle of too much paperwork. One woman commented, "*What would motivate me is if my primary care physician recommended it and gave me a referral or if it was part of my annual exam and if I could get the test locally without too much red tape.*"

Additionally, one woman shared that she would be motivated to get genetic counseling and testing for *BRCA 1/2* "*if there was easy access to the testing facility.*"

### *Barriers*

Barriers to getting genetic counseling and testing for *BRCA 1/2* cited by women included money or the cost of the test, whether they had insurance coverage and fear. Although women were interested in genetic counseling and testing one woman commented “*cost is a big factor for me...you would have to come up with a way to pay for it [genetic counseling and testing]...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.*” Another woman shared that she was “*turned down*” by her insurance company because she didn’t have a family history of cancer. One woman shared that she found the cost of the test “*prohibitive*” and that without insurance she “*did not see the possibility of receiving genetic counseling and testing without adequate coverage because the test was very expensive.*”

Women were also very preoccupied with fear of the unknown, employment discrimination and risk management as it related to genetic counseling and testing for *BRCA 1/2*. When asked what would stop them from getting genetic counseling and testing for *BRCA 1/2* in addition to cost and insurance one woman blurted out, “*definitely fear of the unknown...you just never know how even knowing is going to affect you and your family...I mean is getting tested going to come back and haunt you?*” Additionally, women associated participation in genetic counseling and testing for *BRCA 1/2* with possible “*stigma*”. According to one 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.*” Fear of decisions about risk management also emerged as a barrier for women. Many commented that they did not want to have to think about having to make risk management decisions especially if their genetic testing results for *BRCA 1/2* came back positive. One 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’.*”

*Role of Spirituality in Genetic Counseling/Testing for BRCA 1/2*

Women generally agreed that spirituality would “*play an important role in their decision to get genetic counseling and testing for BRCA 1/2.*” For women who had been affected by cancer, their belief in God and their understanding of spiritual teachings helped them to make sense of their cancer diagnosis thus these women reasoned that God would help them make sense of their test results.

According to one affected woman, “*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].*” Overall, woman viewed their reliance on God and belief in spiritual teachings as a means to buffer the effects of unfavorable test results. One woman who was unaffected by cancer but was interested in testing commented, “*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’.*”

Women also saw spirituality as a venue to facilitate social support. All women when asked responded that they knew of someone in their church whom they could contact if they received an unfavorable test result and needed support. One woman who had been affected by cancer commented that, “*I have nine spiritual sisters in cue [available to provide support] who helped me through my illness [cancer] and I know I can lean on them to uplift me if I had a positive test result.*” Woman also viewed the idea of a spiritual social support venue as an excellent way to share with others who may be at risk for breast and ovarian cancer about genetic counseling and testing. According to her, “*if I got tested, regardless of the results...I could get support but also it would give me the chance to share with other people and encourage them to get tested as well.*” None of the women saw their belief in God conflicting with a decision to get genetic counseling and testing for *BRCA 1/2* but voiced that it was possible that it may hinder some African-American women. One woman shared, “*I don’t think it’s playing God...if anything it [getting tested] could be a positive thing but some African-American women might and that view might stop them.*”



### *Women's Knowledge about Genetic Counseling/Testing for BRCA 1/2*

Overall, women did not have much knowledge about genetic counseling and testing for *BRCA 1/2*. For example they were unaware of the process, where to get testing, that counseling should precede testing or general recommendations for testing. However, two women who had been affected with breast cancer responded that although they didn't have much knowledge they were aware of testing through their physician mentioning it as a result of their own diagnosis or hearing about it on television, respectively. One woman commented, *"I heard about it [genetic counseling and testing] when I was diagnosed but I didn't know what it was all about...I just didn't know."* Another woman added, *"before now I didn't know anything about it [genetic counseling and testing] but I remember seeing something on TV about BRCA and testing because of that celebrity that was on Oprah...I think her name is Christina Applegate."* Women who were unaffected with breast or ovarian cancer shared that they had no knowledge of genetic counseling or testing for *BRCA1/2* before participating in the focus group.

### *Qualitative Results Summary*

Overall, > 60% of the women who participated in the focus groups reported feeling high levels of perceived behavioral control and was very confident in their ability to get genetic counseling and testing if they chose. Alternatively, despite similar views on the importance of genetic counseling and testing, women with lower levels of perceived behavioral control were less confident about getting genetic counseling and testing due to perceived barriers such as cost of the test and insurance coverage. Women generally had very low knowledge of genetic counseling and testing despite their favorable attitudes towards these services.

Additionally, women reported that they would be motivated to pursue these services for reasons such as: a family history, experiencing symptoms, had a doctor's referral or if the services were easily accessible. Cost, insurance coverage and fear of the unknown and possible employment discrimination were reported as barriers to seeking genetic counseling and testing services. Women

unanimously voiced that spirituality would not deter them from seeking genetic counseling and testing services but would give meaning and context to interpret unfavorable results and provides a venue to facilitate social support.

### *Phase II: Quantitative Results*

The purpose of the quantitative phase of the study was to use measures refined during the qualitative phase to assess how well the theorized dimensions of perceived behavioral control predicted intention to get genetic counseling and testing for *BRCA 1/2* for breast and ovarian cancer in moderate to high-risk African-American women. Moderate to high-risk women were those participants who either were affected by cancer at an early age and/or had at least one primary or secondary relative affected with breast and/or ovarian cancer (See page 10 for specific ASCO recommendations). A cross-sectional telephone survey design was employed. A total of 100 African-American women participated in this phase of the study. Fifty women were unaffected by breast or ovarian cancer and 50 were affected by breast or ovarian cancer.

Of the women who were affected with cancer, most reported having breast cancer (98%) and only 1 (2%) had been affected by ovarian cancer (affected women's data not shown). Women reported that they had received a combination of treatments for their breast cancer. Treatments included chemotherapy (66%), radiation therapy (54%), and hormonal therapy (20%). Additionally, participants reported receiving other treatments for their breast cancer such as lumpectomies (16%) and mastectomies (26%). Stage I and stage II were the more often reported breast cancer stages at which women were diagnosed; 18% and 38%, respectively. The participant who reported being affected with ovarian cancer was diagnosed at stage III and underwent a radical hysterectomy for treatment.

On average, survey respondents were 44.0 years of age (SD 11.46). The majority of women were educated beyond a Bachelors degree (53%) and employed (84%) with some type of insurance

(93%). Most women described their health as very good or good (36% and 44%, respectively). See Table 7 for more demographic information.

**Table 7. Demographic Characteristics of Survey Respondents (N=100)**

<b>Demographic Characteristics</b>	<b>N</b>	<b>(%)</b>
<b>Age</b>		
23-33	22	(22)
34-44	28	(28)
45-55	33	(33)
≥56	17	(17)
<b>Health Status</b>		
Excellent	9	(9)
Very Good	36	(36)
Good	44	(44)
Fair	10	(10)
Poor	1	(1)
<b>Education</b>		
≤ High School Graduate	18	(18)
Some College but no Degree	18	(18)
Certificate Program/Associate Degree	11	(11)
≥ Bachelors Degree	53	(53)
<b>Marital Status</b>		
Married	41	(41)
Single	59	(59)
<b>Employment</b>		
Full-time	73	(73)
Part-time	11	(11)
Retired	5	(5)
Unemployed/Looking for work	11	(11)
<b>Insurance Coverage</b>		
Yes	92	(92)
No	8	(8)
<b>Type</b>		
Medicare	9	(9)
Medicaid	6	(6)
Private (e.g. Cigna, BCBS, Aetna)	85	(85)

There were no missing data. The distributions of all continuous variables apart from the two scales were within range of normality and therefore no transformations were necessary to achieve normal distribution. However, both the P-D and P-C scales were slightly skewed; the P-C scale towards more control and the P-D scale towards less difficulty. There were no significant differences observed for affected status and any of the demographic variables apart from age ( $p=.000$ ). The average score for the P-D scale was 23.15 (SD 3.611) with a range of 17; minimum = 13 and maximum = 30. The average score for the P-C scale was 13.96 (SD 2.247) with a range of 12; minimum = 3 and maximum = 15.

It should be noted that most respondents (71%) had perfect scores on the P-C scale, which could result in insufficient variability for this scale. When only those cases that didn't have a perfect score were selected, the data were distorted and the sample size was severely lowered ( $n=29$ ). Therefore, the scale remained unchanged. See Table 8 for scale item frequencies. Reliability using Cronbach's alpha was assessed for each scale. Both scales had good internal consistency; the perceived difficulty scale [P-D] = 0.779 and the perceived control scale [P-C] = 0.861.

**Table 8. P-D and P-C Scale Item Frequencies (N=100)**

Items	Response Options N (%)				
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
<b>P-D Scale Items</b>					
1. Having to have blood drawn	2 (2)	3(3)	--	70(70)	25(25)
2. Distance to genetic counselor	1(1)	13(13)	6(6)	65(65)	15(15)
3. Distance to genetic testing facility	1(1)	17(17)	3(3)	64(64)	15(15)
4. The opinion of a family member	3(3)	14(14)	8(8)	61(61)	14(14)
5. The opinion of a close friend	2(2)	15(15)	8(8)	62(62)	13(13)
6. I would not pursue BRCA testing because I feel testing is experimenting on people	--	5(5)	5(5)	66(66)	24(24)
<b>P-C Scale Items</b>	<b>Completely Agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Completely Disagree</b>
7. I have complete control of the decision to undergo genetic counseling and testing	77(77)	14(14)	2(2)	4(4)	3(3)
8. It is my choice whether or not I receive genetic counseling and testing	79(79)	16(16)	1(1)	1(1)	3(3)
9. It is entirely my decision whether or not to undergo genetic counseling and testing	81(81)	15(15)	1(1)	--	3(3)

With respect to the outcome variables, the mean score for the genetic counseling scale was 3.25 (SD 1.095); the genetic testing scale had a mean score of 3.38 (SD 1.144). Both scales had a range of 4 and minimum of 1 and maximum of 5. Most participants reported that they would probably get genetic counseling and testing; 35% and 37%, respectively. Interestingly, twenty-three percent of the respondents reported already having been tested for BRCA 1/2 and 17% reported receiving genetic counseling for BRCA 1/2. These respondents were not, however, included in the analysis. See Table 9 for frequency distribution of item responses.

**Table 9. Frequency Distributions of Item Responses for Outcome Variables (N=100)**

Items	Response Options N (%)				
	Definitely won't get counseling	Probably won't get counseling	Probably will get counseling	Definitely will get counseling	Already had counseling
<b>1. Intent to get genetic counseling</b>	3(3)	24(24)	35(35)	21(21)	17(17)
	Definitely won't get testing	Probably won't get testing	Probably will get testing	Definitely will get testing	Already had testing
<b>2. Intent to get genetic testing</b>	4(4)	18(18)	37(37)	18(18)	23(23)



The mean score for the Attitude scale was 22.9 (SD 7.04) with a range of 34.00; minimum = 15 and maximum = 49. This scale had good internal consistency 0.832. Women had favorable attitudes towards genetic counseling and testing for BRCA 1/2. Moreover, the majority of participants (>70%) felt that genetic counseling and testing for BRCA 1/2 would help them learn more about their breast and ovarian cancer risk; useful in providing breast and ovarian cancer risk information to their families; and useful when deciding about treatment options (e.g. mastectomy or oophorectomy). See Table 10 for attitude scale response frequencies. With respect to the subjective norm—important others whose opinion would matter most as to whether a woman decided to get genetic counseling/testing for BRCA 1/2—the majority (27%) of women reported that their spouses' opinions would matter most followed by the opinion of their children (20%) and parents (18%). Seven percent of the women reported that only their own opinion would matter when making decisions about genetic counseling and testing for BRCA 1/2. Interestingly, only two women reported that their physician's opinion would matter most.

**Table 10. Frequency Distributions for Attitude Scale Items (N=100)**

Items	Response Options N (%)			
	Very Important	Moderately Important	A Little Important	Not At All Important
1. Learning about my breast cancer risk	95(95)	3(3)	1(1)	1(1)
2. Learning about my ovarian cancer risk	90(90)	4(4)	5(5)	1(1)
3. Providing information for family members	90(90)	6(6)	3(3)	1(1)
4. Help deciding about removing one or both breasts to prevent cancer	79(79)	15(15)	5(5)	1(1)
5. Help deciding about removing the ovaries to prevent cancer	83(83)	11(11)	3(3)	3(3)
6. Help deciding about estrogen replacement	49(49)	33(33)	6(6)	12(12)
7. Desire to be reassured if test was negative	66(66)	24(24)	6(6)	4(4)
8. Concern about my anxiety if test was positive	71(71)	17(17)	7(7)	5(5)
9. Fear of health insurance discrimination	62(62)	17(17)	3(3)	18(18)
10. Fear of life insurance discrimination	62(62)	18(18)	6(6)	14(14)
11. Fear of job discrimination	51(51)	15(15)	6(6)	28(28)
12. Cost of the test	51(51)	26(26)	7(7)	16(16)
13. My doctor's recommendation	67(67)	29(29)	3(3)	1(1)
14. My family's recommendation	49(49)	31(31)	10(10)	10(10)
15. Desire to help advance research	56(56)	34(34)	7(7)	3(3)

### *Aims and Corresponding Results*

**Aim I:** To explore relationships among the perceived difficulty [P-D] and perceived control [P-C] scales and participant demographic (socio and psychosocial) characteristics.

*Results:* A Spearman Rho correlation matrix was run to see if demographic variables correlated with the P-D and P-C scales. Categorical variables were turned into 2 groups and dummy coded for correlational analysis. A few weak correlations were observed between the demographic variables. For example, there was a weak positive correlation between affected status and health status ( $r = .23, p = .021$ ). A weak positive correlation was observed between health status and education ( $r = .25, p = .011$ ). Additionally, there was a moderately strong positive correlation between age and affected status ( $r = .55, p = .000$ ).

There was a weak negative correlation observed between the P-C scale and marital status (dummy coded; 1=married and 0=single) ( $r = -.22, p = .030$ ). As such, participants who had higher scores on the perceived control scale tended to be single. A weak but positive correlation was observed between the P-D scale and level of education ( $r = .25, p = .014$ ). Additionally, there was a weak positive correlation between the P-D scale and health status ( $r = .21, p = .041$ ). There was a moderately weak positive correlation of the P-D scale with the P-C scale ( $r = .32, p = .001$ ). There were no other significant correlations observed between either of the scales [P-D or P-C] and any other demographic variables (affected status, employment, insurance, age). See Table 11 for correlations.

**Table 11. P-D and P-C Scales and Demographic Variables Correlations (N=100)**

	Affected Marital		Health					PD_Total	PC_Total
	Status	Status	Education	Status	Employment	Insurance	Age		
Affected Status	1.000	.020	-.053	.231*	-.014	-.074	.550**	-.021	-.031
Marital Status	.020	1.000	.163	.131	-.079	-.021	.187	.057	-.218*
Education	-.053	.163	1.000	.254*	-.069	-.010	-.046	.245*	.121
Health Status	.231*	.131	.254*	1.000	-.107	-.060	-.170	.205*	.157
Employment	-.014	-.079	-.069	-.107	1.000	-.094	-.026	-.062	.180
Insurance	-.074	-.021	-.010	-.060	-.094	1.000	-.142	.001	-.055
Age	.550**	.187	-.046	-.170	-.026	-.142	1.000	.026	-.007
PD_Total	-.021	.057	.245*	.205*	-.062	.001	.026	1.000	.319**
PC_Total	-.031	-.218*	.121	.157	.180	-.055	-.007	.319**	1.000

\* Correlation is significant at the 0.05 level (2-tailed); \*\*Correlation is significant at the 0.01 level (2-tailed)

**Aim II:** To determine if there is a significant difference in the mean scores of perceived difficulty [P-D] and perceived control [P-C] based on affected status in moderate to high-risk African-American women.

**H<sub>1</sub>:** Women who were unaffected with cancer will have a higher score on the perceived difficulty [P-D] scale.

**H<sub>2</sub>:** Women who have been affected by cancer will have a higher score on the perceived control scale [P-C].

*Results:* Two t-tests, one for the P-D scale and one for the P-C scale, were conducted to determine if there were statistically significant mean differences between the group that has been affected by cancer and the group that had not been affected by cancer on the scales. Both hypotheses were disconfirmed. There was no significant difference between the two groups on either the P-D scores ( $p = .847$ ) or the P-C scores ( $p = .860$ ).

**Aim III:** To use factor analysis to determine whether the two dimensions of perceived behavioral control, that is, perceived difficulty [P-D] and perceived control [P-C], are distinct factors.

**H<sub>3</sub>:** The six items of the P-D scale will load into one factor and the three items of the P-C scale will load into another factor, showing that they are distinct constructs.

*Result:* In the factor analysis, principle components analysis was used to examine all nine items from both the P-D and P-C scales. Those factors with Eigen values greater than one were used for the item loading to ascertain if the items load into separate factors as predicted (See Table 12). As shown in Table 13, 37.85% of the variance is accounted for in component 1. The first five items load high except for the item addressing “whether BRCA testing is experimenting on people”. In this component, it would seem that eight of the nine items are measuring essentially the same construct, which could be viewed as the overall construct of perceived behavioral control (PBC).

However, in the second component--which accounts for 20.64% of the variance--all of the items associated with the P-D scale load positive and relatively small, while the items associated with

the P-C scale load negative and relatively high. As such, the data indicate that these scales can indeed be understood as separate dimensions.

**Table 12. Principle Component Analysis (N=100)**

Items	Component		
	1	2	3
• Having to have blood	.578	.289	-.151
• Distance to genetic counselor	.657	.335	-.586
• Distance to genetic testing facility	.667	.377	-.565
• The opinion of a family member	.620	.372	.586
• The opinion of a close friend	.736	.265	.504
• I would not pursue BRCA testing because I feel genetic testing is experimenting on people	.324	.331	.337
• I have complete control over the decision to undergo genetic counseling and testing	.654	-.579	-.078
• It is my choice whether or not I receive genetic counseling and testing	.593	-.711	.008
• It is entirely my decision whether or not to undertake genetic counseling and testing	.620	-.599	.082

**Table 13. Eigenvalues (N=100)**

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.406	37.848	37.848	3.406	37.848	37.848
2	1.858	20.640	58.488	1.858	20.640	58.488
3	1.411	15.675	74.163	1.411	15.675	74.163



**Aim IV:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic counseling** while controlling for relevant demographic factors.

*Result:* Spearman Rho bivariate correlations showed that neither the P-D scale ( $r = .08, p = .454$ ) nor the P-C scale ( $r = .15, p = .183$ ) was correlated with the outcome variable of intention to get genetic counseling. There was a moderately weak but positive correlation of the P-D scale with the P-C scale ( $r = .32, p = .003$ ). As for the demographic variables, there was a weak negative correlation between marital status (dummy coded; 1=married and 0=single) and intention to get genetic counseling ( $r = -.25, p = .022$ ). As such, participants who were not married were more likely to intend to get genetic counseling. However, there were no other significant correlations between the outcome variable (i.e. genetic counseling intent) and the following demographic variables: affected status, education, health status, employment, insurance and age. Given that neither scale was correlated with the genetic counseling intention outcome, the hierarchical regression was unwarranted. See Table 14 for correlations.

**Table 14. Correlations between Demographics, Scales and Genetic Counseling Intent**

N=83	Affected Marital		Health				Genetic Counseling			
	Status	Status	Education	Status	Employment	Insurance	Age	PD_Total	PC_Total	Intent
Affected Status	1.000	.034	-.043	.235*	-.003	-.039	.589**	-.018	-.031	.086
Marital Status	.034	1.000	.145	.139	-.145	-.015	.181	.016	-.206	-.252*
Education	-.043	.145	1.000	.263*	-.089	-.012	-.089	.238*	.103	-.074
Health Status	.235*	.139	.263*	1.000	-.198	-.083	-.189	.209	.126	.021
Employment	-.003	-.145	-.089	-.198	1.000	-.112	-.030	-.207	.071	-.035
Insurance	-.039	-.015	-.012	-.083	-.112	1.000	-.151	.005	-.067	.142
Age	.589**	.181	-.089	-.189	-.030	-.151	1.000	-.047	.016	.181
PD_Total	-.018	.016	.238*	.209	-.207	.005	-.047	1.000	.323**	.083
PC_Total	-.031	-.206	.103	.126	.071	-.067	.016	.323**	1.000	.148
Genetic Counseling Intent	.086	-.252*	-.074	.021	-.035	.142	.181	.083	.148	1.000

\* Correlation is significant at the 0.05 level (2-tailed); \*\*Correlation is significant at the 0.01 level (2-tailed).

**Aim V:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic counseling**.

**H<sub>4</sub>:** The perceived difficulty scale will be a better predictor of **genetic counseling** intentions in moderate to high-risk African-American women than the perceived control scale.

*Results:* Given that neither the P-D scale ( $r = .08, p = .454$ ) nor the P-C scale ( $r = .15, p = .183$ ) was significantly correlated with the genetic counseling outcome (See Table 14), multiple regression was unwarranted and the hypothesis was disconfirmed.

**Aim VI:** To determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicts participants' intentions to get **genetic testing** while controlling for relevant demographic factors.

*Result:* Spearman Rho bivariate correlations were run and there was a moderately weak but positive correlation between the P-C scale and the outcome variable of intention to get genetic testing ( $r = .25, p = .027$ ). There was a moderately weak positive correlation of the P-D scale with the P-C scale ( $r = .39, p = .001$ ). There was no significant correlation between the P-D scale and intention to get genetic testing ( $r = .07, p = .563$ ). Additionally, there were no significant correlations between the demographic variables (affected status, marital status, education, health status, employment, insurance and age) and the outcome variable being intention to get genetic testing, therefore, a hierarchical regression was unnecessary. See Table 15 for the correlations.

**Table 15. Correlations between Demographics, Scales and Genetic Testing Intent**

N=77	Affected Marital		Health				Genetic		Testing	Intent
	Status	Status	Education	Status	Employment	Insurance	Age	PD_Total		
Affected Status	1.000	.039	-.055	.254*	-.021	-.001	.608**	-.075	-.115	.097
Marital Status	.039	1.000	.095	.150	-.186	-.010	.188	-.015	-.171	-.199
Education	-.055	.095	1.000	.206	-.129	-.004	-.093	.230*	.119	-.087
Health Status	.254*	.150	.206	1.000	-.216	-.070	-.150	.186	.178	.075
Employment	-.021	-.186	-.129	-.216	1.000	-.111	-.079	-.182	.125	-.026
Insurance	-.001	-.010	-.004	-.070	-.111	1.000	-.141	.025	-.049	.067
Age	.608**	.188	-.093	-.150	-.079	-.141	1.000	-.080	-.065	.148
PD_Total	-.075	-.015	.230*	.186	-.182	.025	-.080	1.000	.386**	.067
PC_Total	-.115	-.171	.119	.178	.125	-.049	-.065	.386**	1.000	.252*
Genetic Testing Intent	.097	-.199	-.087	.075	-.026	.067	.148	.067	.252*	1.000

\*Correlation is significant at the 0.05 level (2-tailed); \*\*Correlation is significant at the 0.01 level (2-tailed)

**Aim VII:** To determine which of the two scales is a better predictor of participants' intentions to get **genetic testing**.

**H<sub>5</sub>:** The perceived difficulty dimension will be a better predictor of **genetic testing** intentions in moderate to high-risk African-American women than the perceived control dimension.

*Result:* Given that only the P-C scale was significantly correlated with the genetic testing outcome ( $r = .25, p = .027$ ) while the P-D scale was not ( $r = .07, p = .563$ ), multiple regression was unwarranted as the results indicate that the P-C scale would be the better predictor. Therefore, the hypothesis was disconfirmed. See Table 15.

#### *Quantitative Results Summary*

Over half the women (53%) were educated beyond a Bachelors degree and the majority was employed (84%) with some form of insurance (98%). Of the women who were affected by cancer, the majority (98%) reported having breast cancer. Women tended to be diagnosed at either stage I (18%) or stage II (38%) and treatment included chemotherapy (66%), radiation therapy (54%) and hormonal therapy (20%).

There were no significant differences observed for affected status and any of the demographic variables apart from age ( $p = .000$ ). With respect to the scales, both the P-D (.78) and P-C (.86) scales had good internal consistency. The mean score for the genetic counseling outcome scale was 3.25 (SD 1.095); the genetic testing outcome scale had a mean score of 3.38 (SD 1.144). Both scales had a range of 4; minimum of 1 and maximum of 5. Most participants reported that they would probably get genetic counseling and testing; 35% and 37%, respectively.

The mean score for the attitude scale was 22.9 (SD 7.04) and had good internal consistency 0.832. Women reported favorable attitudes towards genetic counseling and testing for BRCA 1/2 and reported that it would be useful in helping them learn about their breast and ovarian cancer risk; useful for informing their families about risk and useful in helping them make treatment decisions (e.g. getting mastectomies or oophorectomies). With respect to important others whose opinions

would matter most when women were deciding about getting genetic counseling and testing for BRCA 1/2, the opinions of spouses (27%), children (20%) and parents (18%) were mostly cited as being important.

Data from the principal components analysis indicated that the P-D and P-C scales can be seen as distinct. Correlations between the P-D and P-C scales and demographic variables yielded a few weak but significant correlations. For example, there was a weak negative correlation observed between the P-C scale and marital status (dummy coded; 1=married and 0=single) ( $r = -.22, p = .030$ ). As such, participants who had higher scores on the perceived control scale tended to be single. A weak but positive correlation was observed between the P-D scale and level of education ( $r = .25, p = .014$ ). Additionally, there was a weak positive correlation between the P-D scale and health status ( $r = .21, p = .041$ ). There was a moderately weak positive correlation of the P-D scale with the P-C scale ( $r = .32, p = .001$ ). There were no other significant correlations observed between either of the scales [P-D or P-C] and any other demographic variables (employment, insurance, age and affected status).

There were no significant differences observed between the mean of the P-D scores ( $p = .847$ ) and the P-C scores ( $p = .860$ ) based on affected status. Bivariate correlations showed that neither the P-D scale ( $r = .08, p = .454$ ) nor the P-C scale ( $r = .15, p = .183$ ) was correlated with the outcome variable of intention to get genetic counseling. As for the demographic variables, there was a weak negative correlation between marital status (dummy coded; 1=married and 0=single) and intention to get genetic counseling ( $r = -.25, p = .022$ ). As such, participants who were not married were more likely to intend to get genetic counseling. However, there were no other significant correlations between the outcome variable (i.e. genetic counseling intent) and the following demographic variables: affected status, education, health status, employment, insurance and age.

With respect to the outcome variable 'intention to get genetic testing', only the P-C scale was significantly correlated with this outcome ( $r = .27, p = .027$ ). No other significant correlations were

observed between the outcome of 'intent to get genetic testing' and the P-D scale ( $r = .07, p = .563$ ) or the demographic variables of interest (i.e. affected status, marital status, education, health status, employment, insurance and age). Evidence from bivariate correlations disconfirmed hypotheses rendering hierarchical and multiple regressions unnecessary. However, it did suggest that the P-C scale would be a better predictor of genetic testing intentions only.

## Chapter 5

### *Discussion and Recommendations*

This purpose of this mixed-methods study was twofold: first, to conduct two focus groups with moderate to high-risk African-American women to explore their expressed levels of perceived behavioral control and general motivations regarding genetic counseling and testing (GC/T); and second, to use measures refined during the qualitative phase of the study to assess how well the theorized dimensions of perceived behavioral control (PBC) predict intention to get genetic counseling and testing for BRCA 1/2 for breast and ovarian cancer in moderate to high-risk African-American women.

### *Key Findings*

Results from both phases of the study showed that women overwhelmingly had high levels of perceived behavioral control. Additionally, qualitative results indicated that even women who reported low levels of control felt that it was important to think of themselves as people who had control over seeking out genetic counseling and testing services for BRCA 1/2. Women reported positive attitudes towards the benefits of genetic counseling and testing for BRCA 1/2 in both phases of the study although qualitative results showed low knowledge. Family, family history, accessibility of testing facilities and physician referrals were reported as general motivators to seeking out BRCA 1/2 counseling and testing services.

Quantitative data support these findings suggesting that the opinions of referent others such as spouses, children, and parents were important in influencing decisions for testing uptake. Barriers reported in the focus group included money, cost of the test, insurance coverage, and fear. However, when survey respondents were asked if distance to the testing facility/genetic counselor, opinions of family members or drawing blood would act as barriers to counseling and testing, results indicated that these barriers were not important but that perceptions of control were important. This was only



true for testing and not counseling. Data from principal components analysis indicated that the two scales [P-D and P-C] can be thought of as distinct constructs. Quantitative data supported only three of the seven aims of this study.

*Knowledge and Attitudes towards Genetic Counseling/Testing*

Similar to other findings (Halbert, et al., 2005; Hughes et al., 1997; Kessler, et al., 2007), focus group data suggested that women's knowledge about genetic counseling and testing for BRCA 1/2 was low. Studies suggest that African-American women's low levels of knowledge may be due to low exposure to information and low numbers of physician referrals for these services (Hughes et al., 1997, 2003). This low knowledge, however, should not suggest lack of interest as some findings have demonstrated that African-American women reported high levels of endorsement of the benefits of genetic testing (Durfy et al., 1999; Hughes et al., 1997; Halbert et al., 2005; Kinney et al., 2001).

Despite high interest and positive attitudes, observed low participation underscores the importance of addressing the barriers to seeking out genetic counseling and testing services for BRCA 1/2 in African-American women. One obvious way to address low knowledge in this group would be to develop educational efforts to improve knowledge about medical genetics which highlight test procedure and implications, risk management, genetics terminology and the state of the science. Providers would be a logical choice to implement educational programs; however, previous research has shown that healthcare providers may not be comfortable addressing genetic issues with patients (Fry, Campbell, Gudmundsdottir, 1999; Kessler, et al., 2007; Watson, Austoker, Lucassen, 2001). An even more important issue may be that it is not logistically feasible to address educational needs related to medical genetics services during the limited time frame for medical care visits. Therefore, referrals to genetic counselors for more intensive education about genetics services may be one way to improve knowledge about genetics among African-American women without impacting the amount of time that patients have with physicians. However, there are limited numbers of genetics professionals available to provide education; thus alternative methods will be needed.

One study by Green and colleagues (2004) showed that computer-based educational programs may be effective for providing education about genetic factors involved in specific diseases. This approach may also be useful for enhancing knowledge about genetics among African-American women thus demystifying the science and in turn facilitate participation.

#### *Motivators and Barriers*

Women were generally motivated to seek out genetic counseling and testing services for BRCA 1/2 if they had a family history of breast or ovarian cancer. These findings are similar to those reported in the literature (Kinney et al., 2006, 2001; Susswein et al., 2008; Thompson et al, 2002). Focus group data indicated that daughters, nieces and the potential of passing the risk on to unborn children were high motivators for women. Interestingly, although male breast cancer is extremely rare, concern over their male relative's breast cancer risk was also a strong motivator for women.

Other motivators included accessibility of testing facilities, being symptomatic and physician referrals for genetic counseling and testing. Two observations regarding being symptomatic and physicians' referrals are warranted. First, it should be noted that genetic counseling and testing for BRCA 1/2 are preventive services that help to communicate a woman's breast cancer risk and unlike mammograms is not an on-going surveillance procedure. Moreover, one's genetic risk is not a mutable factor as are lifestyle factors (e.g. diet and exercise). As such, African-American women at moderate to high-risk for BRCA 1/2 mutations should be educated to facilitate an understanding of personal breast cancer risk and familial risk transmission; the utility of genetic counseling and the clinical efficacy of testing.

Second, evidence suggest that physician referrals have been shown to be predictive of women's pursuit of genetic counseling, testing and uptake of test results (Metcalf, McLaughlin, Risch, Rosen, Murphy, 2009; Pal, Vadaparampil, Betts, Miree, Li, Narod, 2008; Schwartz, Lerman, Brogan, Peshkin, Isaacs, DeMarco, 2005). However, notwithstanding African-American women's low participation, disparities in referrals exist. Determinants of physician referrals usually include

family history, receipt of genetic testing information within the past year and patient inquiries about getting genetic testing (Hughes-Halbert et al., 2005) but low levels of knowledge and exposure to breast cancer genetics may reduce the likelihood that African-American women would self-refer or communicate interest in these services.

One study (Harrison, Graves, Peshkin, Stephen, Sheppard, 2010) found that physicians tended to refer African-American women to genetic services based on ASCO recommendations and if they presented with “triple negative” disease which is more prevalent in this group. Triple negative disease refers to breast cancers that do not involve the hormones estrogen, progesterone, or the Her-2 protein resulting in fewer treatment options and high morbidity and mortality (Hurvitz & Finn, 2009). It should be noted that referrals for BRCA 1/2 genetic counseling and testing based on triple negative status is not part of ASCO recommendations. However, it was clear from the findings by Harrison and colleagues (2010) that the process of informing African-American women about genetics services for BRCA 1/2 occurred over time but providers did not follow-up to see if uptake of services occurred.

As such, because it may not be feasible for providers in subspecialties such as oncology to consistently fill the referral gap, future research can examine the best ways to educate non-specialist physicians on how to take a family history so that high-risk women can be referred to genetic counselors for more in-depth education about the benefits and limitations of BRCA1/2 genetic testing. With accumulating evidence related to the use of patient navigation services in underserved cancer survivor populations, (Davis, Darby, Likes, Bell, 2009; Ell, Vourlekis, Xie, Nedjat-Haiem, Lee, Muderspach, 2009; Sheppard, Williams, Harrison, Jennings, Lucas, Stephen, 2009) incorporating genetics services into the array of patient education and supportive service options available may be one way to address the apparent gap in referrals to services and uptake of counseling and testing.

Barriers to getting genetic counseling and testing for BRCA 1/2 included money or the cost of the test and insurance coverage. Almost all of the participants had insurance but the major concern

was whether insurance would actually pay. In the focus groups, motivated women suggested the use of agencies to defray some of the cost for genetics services. While there may be such entities that can offer financial assistance provider awareness of these agencies is low (Harrison et al., 2010).

Genetics counselors appear to be familiar with the process of helping women through these procedures but the process appears quite arduous and coverage by government funded insurance (e.g. Medicaid) varies by state. Despite these challenges, the utility of the resources that genetic counselors can potentially provide underscores the important role they can play in facilitating uptake of genetics services in African-American women.

Another barrier often cited was fear. Women were preoccupied with fear of the unknown; the implications of a positive test result which was often equated with a decision for prophylactic mastectomy and the potential for employment discrimination due to stigma associated with being a mutation carrier. These findings are consistent with those of Simon and Petrucelli (2009). The current study along with findings from Durfy and colleagues (1999) suggest that African-American women do not favor prophylactic surgery as a preventive measure. It should be noted, however, that prophylactic surgery may not be appropriate for all BRCA 1/2 mutation carrier; therefore, women need to be educated about appropriate candidates and other prophylactic options available.

The fear of stigma has also been reported elsewhere as a barrier to breast cancer preventive services (Thompson et al., 2002). This evidence suggests that within the African-American community, shame and secrecy about breast cancer influence preventive services (i.e. screening mammography). As such, the fear reported may go beyond employment discrimination. Other research has shown that African-American women are more likely to endorse the belief that males respond unfavorably to breast cancer and that relationships with men would be affected by such information (Lannin et al., 1998). Anticipated negative effects on interactions with male partners and significant others may also contribute to stigma and shame related to breast cancer. It is plausible that these stigma-related beliefs may extend beyond breast cancer diagnosis and be applicable as barriers

to BRCA 1/2 counseling and testing because the confirmation of mutation status may increase a woman's perceived (and actual) likelihood of eventually being diagnosed with breast cancer. Therefore, potential interventions will need to focus on barriers associated with stigmatization, shame and secrecy.

*Genetic Counseling and Testing: Desired Information and the Role of Spirituality*

Despite potential challenges that could preclude some of the women in this study from uptake of genetics services (e.g. money, insurance, fear), participants were interested in acquiring information about genetic counseling and testing for BRCA 1/2. Women were generally curious about getting information related to the test's accuracy in predicting cancer risk. Additionally, women were interested in knowing more about the logistics involved with genetic counseling and testing for BRCA 1/2 including the number of visits; the length of time it would take to receive test results; if testing was painful; if blood or saliva was required; the potential risks involved by participating in genetic testing and whether getting tested would make them sick. This general interest coincides with findings in the literature (Andrews, Case, Allard, Kelly, 2005; Hughes-Halbert, 2005; Somers, Michael, Klein, Baum, 2009). However, to date, there is paucity in the genetics information seeking literature addressing the specific information seeking needs of African-American women. As such, additional research will be needed to add to the current findings.

Dissemination of cancer genetics information to African-American women may be best facilitated through general healthcare services. Genetic counseling protocols that address breast cancer concerns in women could be used as a tool to develop informational programs (Burke, Culver, Bowen, Lowry, Durfy, McTiernan, Andersen, 2000). Such information could be provided directly by healthcare providers, through printed educational materials or through computer-based interactive programs (Burke & Emery, 2002; Green et al, 2004; Watson, Shickle, Qureshi, Emery, Austoker, 1999). Future research will have to evaluate the effectiveness of distributing cancer genetics

information through these means and whether or not such methods meet the needs of African-American women.

With respect to spirituality, some studies suggest that it does play an important role in the lives of African-American women when having to make decisions about preventive services including genetic testing (Gullatte, 2006; Hughes, et al., 2003; Schwartz et al., 2000). Women in the current study voiced that while spirituality did play an important role in their decision to get genetic counseling and testing for BRCA 1/2 it did not stop them from seeking these services. As such, spirituality for these women may function as a coping mechanism and a way to make sense of potentially unfavorable test results if they sought testing. For example, for women who had been affected by cancer, their belief in God and their understanding of spiritual teachings helped them to make sense of their cancer diagnosis thus these women reasoned that God would help them make sense of their test results.

Additionally, women may view “working with God” as a strategy to facilitate decision making regarding whether or not to seek out genetic risk assessment and testing for BRCA 1/2. Overall, woman viewed their reliance on God and belief in spiritual teachings as a means to buffer the effects of unfavorable test results. These findings are contrary to some literature which suggests that religious beliefs may act as a barrier to participation in genetic counseling and testing for BRCA 1/2 for African-American women (Lannin, Matthews, Mitchell, Swanson, Edwards, 1998; Phillips & Smith, 2001). Women also saw spirituality as a venue to facilitate social support. It was also seen as an opportunity to communicate to other women potentially at risk for breast and ovarian cancer the importance of genetics services and as a way to encourage genetics information seeking behavior. None of the women saw their belief in God conflicting with a decision to get genetic counseling and testing for BRCA 1/2. Women who see “working with God” as a means to facilitate healthier cancer preventive practices may be good candidates to participate in navigator-driven breast cancer prevention/education programs.

### *Findings in Relation to the Theory of Planned Behavior*

Within the context of this study, the Theory of Planned Behavior (TPB) postulates that constructs of attitudes (attitude towards GC/T), subjective norms (influence of important others regarding GC/T), and perceived behavioral control (factors affecting how “doable” GC/T seems) independently influence behavioral intention to get genetic counseling and testing for BRCA 1/2 (Fishbein & Ajzen, 1985; 1991, 2002). Both qualitative and quantitative data suggest that women had positive attitudes towards genetic counseling and testing. In both focus groups, women voiced that they felt genetic counseling and testing for BRCA 1/2 was both “necessary and useful” if it would help facilitate cancer risk reduction. Additionally, women had high scores on the attitudes scale suggesting that they viewed these preventive services as useful within the context of helping to ascertain risk and make decisions about prophylactic treatments. These findings are similar to those found in the literature (Hughes et al. 1997; Hughes-Halbert, 2006; Kessler et al., 2007).

With respect to the opinions of important referent others (subjective norms) regarding a woman’s intention to get genetic counseling or testing for BRCA 1/2, data from both phases of the study suggested that the opinions of family members such as spouses and children would matter most. Interestingly, when asked if the opinions of their family members would stop them from getting genetic counseling and testing, the majority of survey respondents answered “no”. It may be that some type of decisional balance could be influencing the degree to which familial opinions would matter to these women. Future research would need to explore under which conditions the opinions of others actually influence women’s intentions to pursue genetic counseling and testing services for BRCA 1/2.

### *Women’s Levels of Perceived Behavioral Control*

Findings from the qualitative inquiry suggested that the majority (>60%) of women had high levels of perceived behavioral control (PBC). Moreover, in the quantitative phase, most respondents had nearly perfect scores >70% on the P-C scale. It is clear that perceptions of control over the

decision to undergo genetic counseling and testing for BRCA 1/2 were important to respondents as the same was true for women reporting lower levels of control. Despite the influence of barriers, these women maintained that it was important to think of themselves as being in control over the decision to undertake counseling and testing for BRCA 1/2.

These findings are somewhat surprising because it was assumed that women reporting lower levels of control would be more concerned with barriers to seeking out counseling and testing services for BRCA 1/2. Therefore, perceptions of control over a decision for seeking out these preventive services would either not be in the forefront of their minds or a moot point because the barriers/perceived difficulties would seem insurmountable. Findings in the literature support the idea that African-American women tend to have low confidence when seeking out breast cancer preventive services (e.g. mammograms) (Black, Stein, Loveland-Cherry, 2001; Jennings-Sanders, 2009; Russell, Monahan, Wagle, Champion, 2007). However, the current findings contradict this assumption. It is possible that other factors may be driving women's control beliefs thus influencing their confidence and health seeking behavior. One way this confidence could translate into actual genetic counseling and testing uptake would be to provide intensive training and educational interventions in counseling and testing for BRCA 1/2 to sustain this level of confidence. Findings by Adderley-Kelly and Green (1997) support this idea.

*Perceived Behavioral Control: Support for Dimensionality and other Findings*

Results from the principle components analysis supported the hypothesis that both the P-D and P-C scales were indeed distinct. Results indicated that >35% of the variance was accounted for in component 1 which was labeled the P-D scale. The first five of the six items of this scale loaded high except for the item addressing "whether BRCA testing was experimenting on people". Despite the fact that the question was framed negatively and used strong language such as "experimentation" to describe participation in BRCA 1/2 testing, most participants (>60%) disagreed that it would act as a barrier. It is unclear, however, whether participants were responding to the fact that they felt that



testing for BRCA 1/2 was experimenting on people or whether they actually felt that it would act as a barrier to BRCA 1/2 testing.

It is possible that this question may be tapping into another domain associated more with attitudes towards genetic counseling and testing for BRCA 1/2 instead of barriers. As such, the question could have been removed but keeping it in the analysis did not significantly increase the variance in the other factors. Future studies using the P-D scale can omit this item and more psychometric testing can be used to determine appropriate domains and factors more closely related to this item.

Overall, in this first component, it would seem that eight of the nine items are measuring essentially the same construct, which could be viewed as the overall construct of perceived behavioral control (PBC). As such, this would explain any weak to moderate correlations observed if the first six components and the last three are taken separately (as two scales) and correlated. The resulting scales should not yield high correlations as this would indicate that they are not separate components. In the second component--which accounted for 20% of the variance--all of the items associated with the P-D scale loaded positive and relatively small, while the items associated with the P-C scale loaded negative and relatively high. This second component was labeled as the P-C scale. These findings are similar to findings by Trafimow and colleagues (2002) who conducted four studies that used a variety of paradigms to show that people distinguish between beliefs that are presumed to underlie perceived control and perceived difficulty.

The fact that the P-D and P-C scales can be seen as distinct suggests some theoretical implications. One implication concerns the proximal determinants of behavioral intentions and behaviors. For example, in addition to the attitude and subjective norm constructs suggested by the Theory of Planned Behavior, perceived control and perceived difficulty (instead of Ajzen's perceived behavioral control construct) should be added as proximal determinants of behavioral intentions/behaviors. Several advantages to making this change exist in addition to having a theory

that is more in accordance with these and other findings (Kraft et al., 2005; Trafimow et al., 2002). First, distinguishing between perceived control and perceived difficulty has heuristic value as the distinction suggests a large number of testable predictions. It is suspected that the present study would have added more credence, in addition to the correlational findings, to this assertion if the hierarchical regression was done.

Second, it is expected that making the distinction would increase the reliability of measurement instead of measuring perceived behavioral control in an unreliable way (Sparks et al., 1997). Third, if future research includes both perceived control and perceived difficulty constructs they might be able to better determine exactly what is controlling the intentions/behaviors of concern. Findings from this study suggest that this would hold true for African-American women seeking out preventive BRCA 1/2 services making it easier for researchers to decipher between the influences of difficulty and control beliefs on intentions. That is, for some aspects of preventive genetics services perceived control might be very relevant and perceived difficulty may not at all be relevant; or the reverse might be true for other behaviors associated with seeking out preventive services for genetic counseling and testing for BRCA 1/2.

With respect to aim one which sought to explore relationships among the P-C and P-D scales and participant demographic characteristics, two significant correlations were found: one negative correlation between the P-C scale and marital status and one between the P-D scale and health status. The negative correlation suggests that respondents who were single tended to score higher on the perceived control [P-C] scale. It is possible that married respondents tended to respond lower on this scale because the decision for them to participate in genetics services is multi-factorial. For example, they have to consider the impact such a decision would have on their spouses, shared resources and the marriage relationship. Alternatively, for single respondents without the constraints of the opinions of a spouse control may be a more salient and important factor.

Data also suggested that the hypothesis associated with aim 6 were partly supported. However, the hypothesis for aim 7 was not supported. The goals of aim 6 were to determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicted participants' intentions to get genetic testing while controlling for relevant demographic factors. It was hypothesized in aim 7 that the P-D scale would be the better predictor. Data indicated that perceived difficulty was not correlated with testing intentions; however, a significant correlation was found between perceived control and testing intent. By default, the P-C scale was the better predictor. Instead of barriers being more important, data suggested that women tended to think that the perception of control was more important. When considering this finding in relation to the underuse of genetics services by African-American women it is possible that while women want to be in control of their decision making process they may not be ready currently to follow through with the behavior and undertake testing. This assumption could have been tested if women were followed to examine the factors predictive of actual behaviors.

The items on the P-D scale also may not have been good predictors of testing intent because the items may not have been sensitive enough despite the scale's high reliability. In addition to removing the item related to thinking that BRCA testing was experimenting on people, more psychometric testing would be needed to see which terms would be reliably salient and identified as real barriers to counseling and testing in this group. Trafimow and colleagues (2002) found that perceived difficulty was a better predictor of most behavioral intentions than perceived control. As such, difficulty beliefs presumed to underlie perceived difficulty should be more important than the underlying beliefs presumed to underlie perceived control. Data from both the qualitative and quantitative phases of this study, however, suggested that the underlying beliefs of perceived control are more important.

During the initial refinement of the P-D scale, women candidly discussed issues such as "distance to the testing facility", "having to have blood drawn" and "distance to the genetic

counselor” as potential obstacles to seeking out these preventive services. Therefore, the addition of these items seemed pertinent to constructing the P-D scale using salient items associated with potentially difficult scenarios for African-American women at moderate to high-risk for breast and ovarian cancer when attempting to seek preventive genetics services. In light of the cancer disparities observed between African-American women and their white counterparts, it seemed logical to conclude that difficulty beliefs would be a more prominent part of their existence thus influencing how they would go about seeking out genetic counseling and testing services for BRCA 1/2. It is clear that difficulty and control beliefs may be operating differently in this sample.

Data did not support the hypothesis for aim two which suggested that there would be a significant difference in the mean scores of perceived difficulty [P-D] and perceived control [P-C] scales based on affected status. It was also hypothesized that unaffected women would score higher on P-D items while affected women would score higher on P-C items. Although genetics services are underused by African-American woman, studies have found that for women affected and unaffected by cancer, a personal and family history of risk have been associated with increase testing uptake (Kinney et al., 2006; Susswein et al., 2008). One study by Thompson and colleagues (2002), however, found that unaffected women were more likely to decline counseling and testing due to perceived barriers. As such, it was assumed that the same would be true in the current study; women unaffected by cancer would be significantly different from affected women due to more perceived difficulty/barriers.

It was assumed that the opposite would be true for women affected with cancer and that they would be more concerned with perceptions of control than barriers due to their personal experiences with the disease and its associated treatments. Data did not support this assumption. The means of the two groups were too close to detect a significant difference. Although data from the focus groups helped to refine the P-D scale, it is possible that items in this scale may not have had enough face

validity for survey respondents. Perhaps if items specifically used terms such as cost and insurance as potential barriers women probably would have responded differently.

Lastly, the data did not support the goals of aims four and five. The goal of aim four was to determine how strongly each PBC scale (perceived difficulty [P-D] and perceived control [P-C]) predicted participants' intentions to get genetic counseling while controlling for relevant demographic factors. The goal of aim five was to determine which of the two scales would be a better predictor of counseling intent. First, neither scale correlated with counseling intentions; however, marital status was shown to be negatively correlated with counseling intent. As such, participants who were not married were more likely to intend to get genetic counseling. Being married has been traditionally associated with use of preventive services such as mammography and pap smear screenings in minority women (Calle, Flanders, Thun, Martin, 1993; Farmer, Reddick, D'Agostino, Jackson, 2007; Garbers, Chiasson, 2006; Lukwago, Kreuter, Holt, Steger-May, Bucholtz, Skinner, 2003; Zambrana, Breen, Fox, Gutierrez-Mohamed, 1999). Additionally, data from Hughes and colleagues (2005a) suggested that being married was positively correlated with testing intent for colon cancer. However, findings from the current study suggested that being single was associated with intention to seek preventive genetic counseling services for BRCA 1/2. Similarly, results from a study by Zhu and colleagues (2000), found that single women at times seek out preventive services (e.g. mammography) because they were just as interested in breast health. On the other hand, it is possible that married respondents were less likely to intend to get genetic counseling because doing so may mean having to deal with the implications of breast cancer and stressors on their spouse if they had to consider a prophylactic mastectomy.

It was hypothesized that the perceived difficulty scale would be a better predictor of genetic counseling intentions in moderate to high-risk African-American women than the perceived control scale. However, no significant correlation was observed between both scales and counseling intent. Trafimow and colleagues (2002) found that perceived difficulty was a better predictor of most

behavioral intentions than perceived control. In their reported studies, participants' intentions were measured using perceived control and perceived difficulty items associated with running a 10K race and completing a weekend reading assignment.

Perceived difficulty items were measured on a 4-point Likert type scale ranging from "not at all easy" to "extremely easy" and perceived control items were measured on a 4-point Likert type scale ranging from "not at all under my control" to "extremely under my control". Notwithstanding the terms used to describe both scale choices, it seemed logical to conclude, that similar to the findings of Trafimow and colleagues (2002), difficulty beliefs presumed to underlie perceived difficulty would be more important than the underlying beliefs presumed to underlie perceived control. Neither scale was associated with counseling intent suggesting that women may not view counseling to be as important as they claim. Moreover, it is possible that women may not truly understand the utility of genetic counseling; therefore, educational efforts highlighting the benefits of genetic counseling are needed.

### *Limitations, Conclusions and Future Research*

#### *Limitations*

The following limitations should be considered when interpreting these results. First, while most African-American women do have a high school diploma the sample for this study was highly educated (e.g. beyond a bachelors degree) and had some form of insurance. Thus, findings based on these responses may not be representative of African-American women who did not complete high school and are uninsured. Second, this study was a cross-sectional study; therefore, responses represent variables at a single point in time. Women's thoughts and feelings about genetics services may change at future points in time. Additionally, any event that can affect the dimension of PBC (i.e. P-D and P-C scales) as they relate to genetic counseling and testing intentions can alter the relationships between variables examined in this study. Third, the P-D and P-C scales were slightly skewed which affected the variability of both scales. Fourth, bivariate analyses were the primary

statistics conducted so inferences could not be made based on multivariate analyses that would have allowed for the control of other factors. Lastly, participants were primarily from an urban setting as such their views about seeking genetic services for BRCA 1/2 may not reflect those of women from a rural setting.

#### *Conclusion and Recommendations for Future Research*

To the best of the principal investigator's knowledge, this study was the first to explore the dimensionality of the construct perceived behavioral control from the Theory of Planned Behavior to begin to understand genetic counseling and testing for BRCA 1/2 underuse in African-American women at moderate to high risk for breast and ovarian cancer. Based on the current findings it is noteworthy to mention the following. First, although women in both phases of the study were given the definition of genetic counseling and testing some of the responses from the focus groups suggest that women may have used the terms interchangeably. It was also noted that at times women made reference only to testing. Additionally, data from Table 11 indicated that more women reported actually having received BRCA 1/2 testing than they did counseling for BRCA 1/2 (23% vs. 17%). Therefore, African-American women at moderate to high-risk for BRCA 1/2 mutations need to be educated on the meaning of both genetic terms and the importance of genetic counseling and its implications.

The fact that fear of employment discrimination, stigma and spirituality were important to women it would be important for educational efforts to include information about the GINA LAW (Genetic Information Non-Discrimination Act) and its implications for privacy and the prevention of discrimination based on genetic information. Additionally, intervention efforts should be culturally tailored to address issues associated with stigma and include a platform for the inclusion of spirituality. A study by Hughes and colleagues (2003) found evidence to suggest that religious coping could be used as a basis for providing culturally sensitive genetic counseling to African-American women. Culturally sensitive educational materials have been shown to increase

comprehension of complex medical topics among members of minority groups (Michielutte, Bahson, Dignan, Schroeder, 1992). As such, outreach efforts in the African-American community should seek to reinforce the belief that cancer can be combated through collaborative relationship with God that involves a combination of spiritual faith and personal proactive health behaviors including seeking out genetics services (i.e. counseling and testing) for individuals with a personal and family history of cancer.

Findings from the current study underscore the need for implementing educational programs focused on the benefits of genetics counseling in addition to genetics testing so that African-American women at moderate to high-risk for BRCA 1/2 mutations can understand their risk, the genetics process and demystify the science. Theoretical implications for future research would include the addition of the constructs spirituality and knowledge in addition to measuring perceived behavioral control as separate constructs (i.e. P-D and P-C) in hopes that this would help explain the observed underuse.



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## **Appendix A**

## **Genetic Counseling and Testing Process**

### *The Genetics Team*

Comprehensive cancer genetic services typically involve a multidisciplinary staff specializing in the fields of genetics and medical oncology. Additionally, depending on the specific malignancy, the expertise of other medical and surgical subspecialties may be sought. If possible, an interdisciplinary cancer genetics service may employ individuals with expertise in the fields of mental health and diet/nutrition (DeMarco, Smith, Nusbaum, Peshkin, Schwartz, Isaacs, 2007).

The genetic service should include a genetic counselor and a medical or surgical oncologist (or a medical geneticist with experience in the field of cancer genetics). Genetic counselors and medical geneticists are skilled in getting medical and family history, providing pedigree and risk assessment, and discussing genetic testing. Medical and surgical oncologists provide expertise in the discussion of diagnosis, cancer screening and prevention, and treatment options (DeMarco, et al., 2007). At times, cancer genetics services may employ the expertise of surgical and radiation oncologists, other specialists in the field of oncology (such as breast surgeons and gynecologic oncologists), and oncology nurses.

### *The Genetic Counseling and Testing Process*

Comprehensive genetic counseling services can be provided using various models which have been described elsewhere (Demarco et al., 2007). A common model discussed in the literature is the Two-Visit model as described by Roche, Lucas and Hughes (2001). The two-visit model provides genetic services using a genetic counselor, an oncologist, and a mental health professional. In this model, the genetic counselor gets the medical and family history, constructs a family pedigree, provides a risk assessment, and begins to assess the patient's risk and discuss screening and prevention options. The medical oncologist then joins the genetic counselor and expands the discussion of medical management options and also possibly performs a physical examination. While the counselor and oncologist will have begun a psychological assessment, a mental health

professional can be asked to further evaluate the patient's anxiety if necessary and to provide strategies for coping.

Comprehensive genetic counseling and testing sessions for breast cancer genetic risk assessment includes multiple components as shown in Table 2. As such, only the major components will be discussed: contracting and informed consent, medical and family history, psych-social assessment, cancer risk assessment, sample collection, testing, interpretation of test results, result disclosure and post test genetic counseling.

**Table 2. Review of Genetic Counseling Sessions (Two-Visit Model): Pre- and Post-test Pre-visit**

- Call triaged
- Intake completed
- Genetic Counselor (GC) calls patient to schedule appointment
- Patient is sent appropriate forms (i.e., appointment letter, brochure, medical release forms—if necessary, billing and insurance information)
- Patient returns medical release form
- Medical records reviewed
- Genetics chart assembled and forms filed
- GC calculates cancer risk using statistical model if available
- Discuss case at conference if available
- Contact lab/send patient pre-authorization for insurance if necessary

**Visit 1**

- Patient meets with GC to review and/or discuss the following:
  1. contracting/review of consents (if applicable)
  2. review of medical/family history
  3. genes/inheritance
  4. cancer susceptibility genes
  5. appropriateness of testing (especially if proband unaffected)
  6. review of medical management screening and prevention options
  7. prophylactic surgery
  8. risk of genetic discrimination/review of HIPAA and state laws
  9. pros and cons of genetic testing
  10. family communication issues
  11. logistics of blood draw and availability of results –turnaround time
- Patient meets with physician:
  1. history and physical
  2. review of history
  3. more in-depth medical management discussion
- Blood drawn and sent for testing if appropriate
- If blood drawn provide option to schedule visit 2
- Review adjunct research options that may be available to patient

**Between visit 1 and 2**

- GC writes clinic note and/or patient letter
- Results received, copied, and filed
- Patient scheduled for visit 2 if not done so already

**Visit 2 (if genetic testing is undertaken)**

- Patient meets with GC and physician to discuss/review the following:
  1. results
  2. cancer risks
  3. surveillance and prevention options
  4. risks and disclosure to relatives
  5. testing of at-risk family members
  6. referrals—physicians and/or psychologists
  7. adjunct services provided and/or scheduled

**After visit 2**

- Second chart note and/or patient letter written per patient's permission/HIPAA compliant—results and/ or letter sent to referring physicians and/or appropriate providers
- Patient chart updated with information
- Follow-up phone call 2–3 weeks after results provided if possible

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*Contracting and Informed Consent*

Contracting occurs at the beginning of the genetic counseling session and is important in guiding the content of the session. The genetic counselor outlines what will be reviewed and provides patients with the opportunity to discuss their expectations and motivation for seeking counseling then an agenda is set for the session. Informed consent is necessary when providing genetic testing through a commercial or research laboratory. Informed consent requires the genetic counselor to disclose information needed for a patient to make an informed, voluntary decision about genetic testing, including all risks, benefits and limitations (Brown, Moglia, Grumet, 2007).

The rationale for informed consent is to protect patients' autonomy during decision making, allowing their values, beliefs and medical objectives to guide their decision. Pre-test genetic counseling includes the following elements required for the patient to provide informed consent (Brown et al., 2007): (1) General description of the test; (2) Statement of the purpose of the test; (3) General information about genetics (e.g. genes, mutations, etc.); (4) Explanation of the possible test results, including their impact on the patient's cancer risk and implications for family members; (5)

Statement of the likelihood of testing positive; (6) Information about the genetic test and the laboratory, including the test method, accuracy, turn around time, and the laboratory's policy on disclosure of test results, DNA storage and reuse; (7) Description of the cost of the test and options for payment; (8) Discussion of the potential risk for "genetic discrimination"; (9) Discussion of the psychosocial aspects of testing, including anticipating reactions to test results and family issues; (10) Review of policy on disclosure of genetic test results and/or family history information; (11) Review of the options for screening and prevention, including the benefits and imitations; and (12) Explanation of the alternatives to genetic testing (Brown, et al., 2006-2007). Patients able to provide informed consent include competent individuals over the age of 18. If a breast cancer syndrome increases the risk for cancer before the age of 18 a legal guardian may provide consent to test a minor (Brown et al., 2006-2007). More commonly, parents may request genetic testing for their older adolescents at risk for a known familial *BRCA* mutation. They should be advised of the disadvantages and risks compared to the limited benefits of testing a minor.

Genetic testing of incompetent or incapacitated adults requires the consent of a surrogate decision maker. The previously stated wishes of the patient and the law will determine who should serve in this role. Although one person may have the legal authority to consent to genetic testing, the family, especially those who will be affected by the test results, should be included in the genetic counseling and decision making process (Brown et al., 2007).

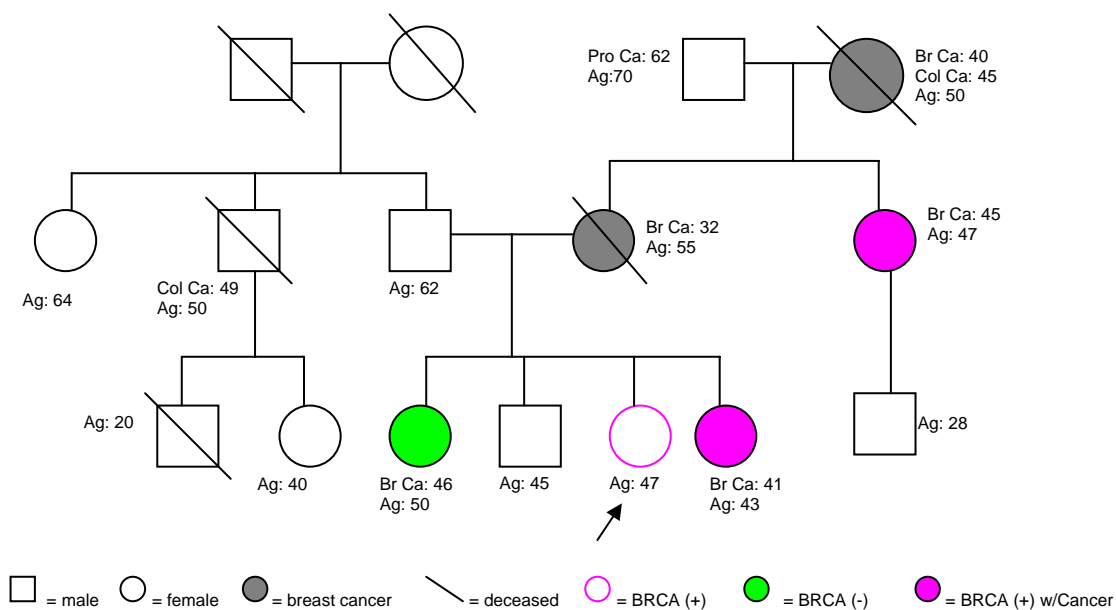
#### *Medical and Family History*

Medical history questions asked of each patient include the following: (1) General Medical History [e.g. major illnesses, chronic conditions, benign or precancerous conditions and current medications]; (2) Cancer History and Treatment [e.g. metastatic disease sites, age at diagnosis and cancer treatment]; (3) Gynecologic History [e.g. age at menarche, age at first live birth and number of pregnancies] and (4) Cancer Screening History [e.g. frequency of self-breast examinations, frequency and type of breast imaging and ovarian cancer screening]. See Brown et al., 2006-2007 for

a more detailed list of medical history questions. A thorough history is important for counseling patients regarding cancer risk as well as options for screening and prevention.

For a family history, the pedigree is a cornerstone of cancer risk assessment (See Figure 3). Figure 3 depicts a proband (person being tested), Deidre age 47 (AAW) as positive for the *BRCA* mutation but does not have cancer. Her two sisters were tested resulting in one (age 50) having cancer but negative for the *BRCA* mutation and the other positive for the *BRCA* mutation with cancer. Her aunt (age 47) who was also tested had the *BRCA* mutation and cancer at age 45. Ideally, a pedigree should include three to four generations using standardized pedigree nomenclature (Brown, et al., 2007). Both the maternal and paternal family history should be detailed even if the history of cancer or familial gene mutation is known to be on one side of the family. A thorough family history may uncover other cancer syndromes or hereditary conditions.

**Figure 3. Pedigree Example**



For each family member, the following information may be written on the pedigree: (1) Current age/age at death; (2) Cancer diagnosis [age at diagnosis, primary site of cancer, treatment, pathology]; (3) Cause of death; (4) Chronic diseases; (5) Benign or precancerous conditions; (6)

Major surgeries and (7) Environmental exposures (Brown et al., 2006-2007). In addition, the ancestry of each branch of the family should be documented since certain cancer predisposition gene mutations are more common in select populations due to founder effects. If the reliability of the cancer history is questionable, it may be helpful to document the source of the information and ask about cancer symptoms and treatment.

When possible, it is best to verify the cancer diagnoses by getting pathology reports, death certificates or hospital notes or by checking a cancer registry. Emotional distress can result from gathering medical information from family members. Problems may include difficulty in contacting estranged relatives, resistance to discussing cancer diagnoses, focusing attention on unpleasant memories and the discovery of previously unknown medical history (Demarco et al., 2007). The patient may discover that certain family members are opposed to getting genetic information.

#### *Psychosocial Assessment*

The psychosocial assessment is a unique component of a genetic counseling session. Important components of the assessment include (1) Motivation for seeking counseling and possibly testing; (2) Cancer risk perception; (3) cultural and religious background; (4) Socioeconomic status; (5) Beliefs and attitudes regarding cancer and genetic testing; (6) Attitudes towards cancer and screening and prevention; (7) Past health behaviors; and (8) Family member relationships (Brown, et al., 2006-2007). The adequacy of patients' coping strategies has implications for the amount of support that may be required during the genetic counseling session and in post-test counseling as such the patient may need to be referred to a mental health professional.

#### *Cancer Risk Assessment*

One of the primary functions of a cancer risk assessment is to identify patients and families with hereditary cancer syndromes. This complex process aims to assess both the likelihood that an individual has an identifiable genetic mutation that predisposes to cancer and the likelihood that an individual will develop cancer (Demarco et al., 2007). The risk-assessment process involves



collecting information about personal and family medical history and cancer risk factors, and review of medical records. Once this historical information has been gathered, several resources are available that review the clinical features associated with hereditary cancer syndromes and can help the genetics team to determine if the personal and family history collected is suggestive of a known genetic predisposition (Lindor, Greene, 1998; Schneider & Garber, 2001).

Once this determination is made, risk assessment can then be further refined and quantified through the use of models and, if the patient chooses, through genetic testing. Empiric models can be used to further quantify risk in families not suggestive of specific hereditary cancer syndromes. For example, the Gail Model uses current age, race, age at first live birth, age at menarche, number of first-degree relatives with breast cancer, and number of prior breast biopsies to provide an age-specific estimate of breast cancer risk (Demarco et al., 2007). For patients whose pedigree suggests a Mendelian pattern of autosomal dominant inheritance consistent with a hereditary cancer syndrome, the risk that an individual harbors a genetic mutation can be estimated based on his/her position in the family tree (Roche, et al., 2001).

Sophisticated computer-based statistical models have been developed to assist with risk assessment by estimating the likelihood that an individual carries a genetic mutation associated with an inherited syndrome (e.g., Cancer-Gene). Limited validation data, however, exist for any of the currently available models assessing cancer risk, and each has a different set of strengths and weaknesses (Olufunmilayo, et al., 2000; Trepanier, Ahrens, McKinnon, Peters, Stopfer, Grumet, Manley, Culver, Acton, Larsen-Haidle, Correia, Bennett, Pettersen, Ferlita, Costalas, Hunt, Donlon, Skrzynia, Farrell, Callif-Daley, Vockley, 2004).

During the genetic counseling risk assessment session, patients may be presented with two different risk estimates: the risk to develop a particular type of cancer (“cancer risk”) and the risk to have a detectable mutation discovered through genetic testing (“mutation risk”). Cancer risk is usually conveyed as an absolute risk. This can be presented as a cumulative lifetime risk and as

interval risks, which are lifetime risks divided into age intervals (van Sprundel, Schmidt, Rookus, Brohet, Van Asperen, Rutgers, Van't Veer, Tollenaar, 2005). Risk estimates are usually presented to the patient as a percentage or fraction and a comparison of risk to that of the general population helps facilitate a better patient perspective.

#### *Sample Collection*

Sample collection can be done either immediately following the genetic counseling session or at a later date. During this time, patients are informed of cost and turn around time and are advised of the option to have the test cancelled or the disclosure of the results delayed. Prior to sample collection the patient is given the opportunity to read the consent form and ask questions before signing. An appointment for results disclosure is arranged and the patient is given the option to bring a support person (Trepanier, et al., 2004).

#### *Genetic Testing*

Offering genetic testing following comprehensive genetic counseling is a key element of risk assessment. The results of genetic testing can refine risk assessment and guide medical management recommendations (Demarco et al., 2007). Genetic testing should be considered in cases in which informed consent has been obtained, the personal and/or family history is consistent with a possible hereditary cancer syndrome (noting the potential limitations such as small family size and a paucity of relatives), and in which the test results will be interpretable and may potentially impact the patient's management (Trepanier, et al., 2004).

According to Demarco and colleagues (2007) it is most informative to initiate testing in affected individuals, especially those diagnosed at young ages (e.g., ovarian cancer in a breast and ovarian cancer family or colorectal cancer less than age 50 in a hereditary colon cancer family). The range of possible test results (true positive, true negative, uninformative negative, and variant of uncertain significance) are usually reviewed prior to testing. Studies have suggested that genetic testing results can at times be inconclusive and therefore patients should be informed that the absence

of a positive test result does not always obviate the need for consideration of intensive screening and/or prevention options (Trepanier, et al., 2004; Roche, et al., 2001; Peshkin, DeMarco, Brogan, Lerman, Isaacs, 2001).

Genetic testing may be offered through a clinical or research laboratory. Clinical laboratories offering genetic testing must meet certain standards to insure the quality and accuracy of the test. For example, the United States Congress passed the Clinical Laboratory Improvement Amendments (CLIA) in 1988 establishing quality standards for all laboratory testing to ensure the accuracy, reliability and timeliness of patient test results regardless of where the test is performed (Brown, et al., 2007). Genetic test results must be provided by or confirmed in a CLIA-approved laboratory before they are disclosed to a patient in the United States (FDA/CDRH, 2005).

#### *Interpretation of Genetic Test Results*

Accurate interpretation of results is essential; therefore, patients are counseled prior to testing on the possible outcomes and how each result will affect cancer risk and medical management for themselves and at-risk family members. Generally, there are three classes of test results: true positive, true negative, and uninformative negative or variant of uncertain significance (Peshkin, et al., 2001). There are two types of definitive results that may be obtained from testing. A *positive* result means that the patient was found to have a deleterious mutation in a cancer susceptibility gene. The risk for cancers associated with this gene mutation should be explained to the patient. In syndromes transmitted in an autosomal dominant fashion, the first-degree relatives of the patient each have a 50% chance to also have the mutation. Second-degree relatives have a 25% chance and third degree relatives have a 12.5% chance.

A *true negative* result occurs when a familial mutation is ruled out in the tested individual. Unaffected patients are typically advised that their risks to develop the cancers seen in the syndrome are similar to those of the general population; however, they still need to be counseled about the potential effect of other risk factors (e.g., family history on the side not segregating the mutation,

modifier genes or environmental factors). An *uninformative* or *variant of uncertain significance* result indicates that a mutation was not detected in the tested cancer susceptibility gene and needs to be interpreted in the context of the family history. A negative result in the setting of a strong personal and/or family history of cancer does not eliminate the possibility of a hereditary predisposition.

Current technology may not detect all mutations in a cancer susceptibility gene. In addition, a mutation may exist in a different gene (e.g., one that is rare or not yet identified). It is also possible that an affected person developed sporadic cancer, or represents a phenocopy within a hereditary breast cancer family (DeMarco, 2007). On the other hand, a negative result in the context of a personal and/or family history that is not consistent with a cancer predisposition syndrome may suggest the occurrence of sporadic cancer in the patient or family (DeMarco, 2007). Another type of indeterminate result arises when a variant in gene sequence is identified. Gene sequencing can reveal changes in the DNA sequence that are polymorphisms and do not affect gene function. Other changes represent deleterious mutations that disrupt function and result in an increased risk to develop cancer.

In some cases it is difficult to determine if a variant is a polymorphism or a deleterious mutation, leading to a genetic test result of an indeterminate variant. As of December 2005, unpublished data from Myriad Genetic Laboratories show the overall frequency of variant results among individuals undergoing *BRCA1* and *BRCA2* testing to be 7.0%. The frequency of variants may vary from one population to another. In the African American population, *BRCA1* and/or *BRCA2* variants were observed 21% of the time (Brown, et al., 2006-2007). These numbers are subject to change as more is learned about the clinical significance of some of these variants.

#### *Result Disclosure and Post Genetic Test Counseling*

Given the complexity and copious amounts of information and the emotional response that may occur, disclosure of genetic test results is usually done face-to-face. The results are disclosed once the patient's questions have been answered. Test results, whether positive or negative, tend to

elicit an emotional response which can range from relief, disbelief, anger, guilt, to fear and sadness. The face-to-face venue gives the genetic counselor an opportunity to assess the patient's verbal and non-verbal cues and provide support as needed.

The specificity and sensitivity of the test is explained along with any other limitations of the test. The patient's cancer risk and cancer screening and prevention guidelines are then reviewed as generally accounts for the new information provided by the genetic test results. The genetic counselor will opt to make referrals to medical professionals who can provide additional information as appropriate. Additionally, potential implications of test results for family members and how to inform them are also discussed. For patients who test positive, written documentation in the form of a consultation note or a letter addressed to family members containing the test results and pedigree can be copied by the patient and given to at-risk family members. Information on how to identify a genetic counseling service may also be included. The patient has the option of removing his or her name from these documents for confidentiality.

## **Appendix B**

### Definition of Terms

1. **Ashkenazi Jew:** Jews from Western and Central Europe.
2. **BRCA 1 & BRCA 2:** Acronym for BReast CAncer 1 and BReast CAncer 2; Class of human genes associated with increased breast and ovarian cancer risk.
3. **BRCAPRO Model:** A Bayesian model developed by Parmigiani and colleagues in 1998 that incorporates published *BRCA1* and *BRCA2* mutation frequencies, cancer penetrance in mutation carriers, cancer status (affected, unaffected, or unknown), and age of the proband's first- and second-degree relatives and it provides estimates for the likelihood of finding either a *BRCA1* or *BRCA2* mutation in a family.
4. **Bilateral Disease:** Breast cancer occurring in both breasts.
5. **Clinical Breast Exam:** Manual breast exam performed by a physician or health professional.
6. **Deleterious Mutation:** A mutation that is documented to be associated with risk of disease.
7. **First Degree Relative:** A parent, sibling, or child.
8. **Founder Mutations:** Mutations identified in a group of individuals suggestive of a common ancestor.
9. **Genetic Counseling:** Process of informing patients and relatives at risk for an inherited disorder about the nature of their disorder, the probability of developing and transmitting it to their offspring.
10. **Genetic Diversity:** Variation among and within species that is attributable to differences in hereditary material.
11. **Genetic Testing:** Analyses of a person's genetic material to ascertain risk.
12. **Germline Mutations:** Mutation occurring in the reproductive or sex cells thus the mutation is passed from parent to offspring.
13. **Hereditary Breast and Ovarian Cancer Syndrome (HBOC):** Inherited tendency to develop breast, ovarian and other cancers that is passed down from a blood relative; mutations occur in every cell in body.
14. **Kindred:** An extended family; group of related individuals.
15. **Mastectomy:** Removal of one or both breast.
16. **Mutations:** Alterations or changes in a person's DNA; DNA errors copied during replication can cause excessive cell growth resulting in tumors.
17. **Oophorectomy:** Removal of the ovaries.

18. **p53 Mutation:** Most frequently mutated tumor suppressor gene in human cancers; germ-line *p53* mutations cause a familial predisposition for cancer.
19. **Pedigree:** A diagram mapping the genetic history of a particular family.
20. **Penetrance:** The likelihood a given gene will result in disease. For example, if half (50%) of the individuals in a given family with the *BRCA 1* gene have breast cancer, the penetrance of the *BRCA 1* gene is 0.5.
21. **Polymorphism:** Term to describe a non-disease causing mutation.
22. **Proband:** Term used to describe the specific subject being studied or reported on; the first affected person in a pedigree that seeks medical attention for a genetic disorder.
23. **Protein Truncating Mutations:** Mutations that change or shorten the structure of a protein (amino bases) thus render the protein unstable and incapable of performing its intended function.
24. **Second Degree Relative:** An aunt or uncle, nephew or niece, half-sibling, grandparent, or grandchildren.
25. **Sporadic Cancer:** Cancer occurrence does not appear to have a familial/inherited link; mutation occurs in a specific cell.
26. **Tamoxifen:** Drug used to treat breast cancer by blocking the effects of estrogen in the breast.
27. **Ubiquitination:** Process of tagging specific proteins for destruction.



## **Appendix C**

## Interview Guide

### A. Introductory Comments and Consent

**Introduction:** Thank you for coming today. We greatly appreciate your time with us. I am \_\_\_\_\_ and my colleague(s) \_\_\_\_\_ are from the Lombardi Comprehensive Cancer Center at Georgetown University.

**Purpose:** The purpose of this discussion today which is also called a focus group is to understand what women think about genetic counseling and testing for breast cancer. We hope that you will candidly share your thoughts, feelings, or concerns with us. Please know that all information you share is confidential. We will not use any names of individuals in any of the material. Information will be summarized for the overall group.

**Process:** I will serve as the facilitator. I will ask questions and allow members of the group to provide answers. The session will be recorded and there will be a person taking notes. (Identify person who will take notes)

**There are simple rules for our discussion today.**

- 1) Please keep in mind, there are no right or wrong answers. We simply want you to speak from your own experiences and thoughts.
- 2) There is no need to raise your hand to speak, however since your answers are important to us and your responses are being recorded, we ask that only one person speak at a time.
- 3) This is not a place to disagree or evaluate another person's answers. We will accept all answers given.
- 4) If you do not understand the question, it is perfectly acceptable to ask for clarification.
- 5) We encourage everyone to participate.

**Introductions:** As I already told you my name is \_\_\_\_\_. Let's take a minute to go around the room and give everyone the opportunity to state their name. Before we begin our discussion, please complete the brief biographical form and the consent form that are being distributed to you. (Facilitator will read the directions for providing the information.)

**Consent:** (Ensure that everyone has completed the consent form. If not, read through the consent form and collect.) Does anyone have a problem with the tape recorder? Ok, let's begin.

**As I mentioned before, tonight's discussion will be about genetic counseling and testing so before we start with our questions for the evening, I would like to take the opportunity to provide you with the definition of genetic counseling and testing.**

#### **Definitions:**

**Genetic counseling--** Genetic counseling is a process in which a genetic counselor educates families or individuals about their risk of passing on a genetic predisposition (tendency to develop a certain disease) for certain disorders or of having inherited a disorder themselves (retrieved on October 1, 2008 from [www.dnadirect.com/patients/tests/breast\\_cancer/more\\_about/glossary.jsp](http://www.dnadirect.com/patients/tests/breast_cancer/more_about/glossary.jsp))

**Genetic Testing--** Tests performed to determine if a person has certain gene changes (mutations) or chromosome changes which are known to increase cancer risk. The test looks at a person's genetic

code, by using a sample of blood or other body fluids/tissues (retrieved from [www.hhs.gov/myhealthcare/glossary/glossary.html](http://www.hhs.gov/myhealthcare/glossary/glossary.html) and [www.lpch.org/DiseaseHealthInfo/HealthLibrary/oncology/glossary.html](http://www.lpch.org/DiseaseHealthInfo/HealthLibrary/oncology/glossary.html) on October 1, 2008.

## B. Focus Group Questions:

### Knowledge and Awareness about Genetic Counseling and 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?

**Probes:** For those of you who have heard about GC/T for breast and ovarian cancer and BRCA 1/2, I'd like to hear more about all that you have heard (**How did you hear about it; From whom did you hear this information**—friends, family, doctor—rank the order of information sources)?

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.

**Probes:** What was it like? Did the race/ethnicity of the counselor matter?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

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.

**Probe:** AAW are more likely to receive uninformative test results has anyone had that experience?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

4. If you had a choice, where would you prefer to receive genetic counseling and testing for BRCA 1/2?

**Probe:** (Examples of sites: home, Dr. Office, lab etc.). From whom would you want to receive the results (Examples: GC, Physician, Nurse etc.)?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

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

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

6. What kinds of things would motivate you to get genetic testing for breast and ovarian cancer/BRCA 1/2?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

7. What kinds of things would prevent you from getting genetic counseling for breast and ovarian cancer/BRCA 1/2?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
8. What kinds of things would prevent you from getting genetic testing for breast and ovarian cancer/BRCA 1/2?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
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?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.

**Usefulness of Results, Cultural Beliefs and Perceived Behavioral Control 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?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
11. What would you do if the results were positive? Do you understand what that means?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
12. What would you do if the results were negative? Do you understand what that means?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
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**)?  
**Probes:** Who would be the first person you would tell? Why would this person be the most important? Do you feel confident in your ability to understand and share your test results?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
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?  
**Note:** Make note of all comments and pose the question, “anything else”  
**Note:** Ask participants to provide more detail about their responses.
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?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

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?

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

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.

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

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.

**Note:** Make note of all comments and pose the question, “anything else”

**Note:** Ask participants to provide more detail about their responses.

**Closing:** Thank you very much for taking time to talk with us. Is there anything else anyone would like to discuss? Please see \_\_\_\_\_ to receive your gift cheque on your way out. We really appreciated your time.