



**Journal of Health Disparities Research and Practice**  
**Volume 12, Issue 3, Fall 2019, pp. 35-47**

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## **Understanding Medical Mistrust in Black Women at Risk of BRCA 1/2 Mutations**

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### **ABSTRACT:**

The benefits of genetic counseling and testing for hereditary breast and/or ovarian cancer (HBOC) are well documented; however, Black women are less likely to use these services compared to White women. Mistrust of the medical system has been associated with Black women's use of genetic counseling and testing (GCT). However, relatively little is known about the correlates of medical mistrust in Black women at increased risk of HBOC. In this study, we examined the prevalence and predictors of medical mistrust in 94 Black women at-risk of HBOC. Most women were married (48.7%) and had at least some collegiate education (57.1%). While no predisposing characteristics were significantly related to medical mistrust, bivariate analysis indicated significant relationships between mistrust and fatalism ( $p=0.04$ ), perceptions of discrimination in the healthcare setting ( $p=0.01$ ), and self-efficacy in obtaining GCT ( $p=0.01$ ). Multivariable analysis revealed that women who reported more discriminatory experiences and women with less confidence in obtaining GCT expressed greater medical mistrust. Multilevel approaches are needed to address psychosocial factors associated with feelings of mistrust. Future efforts must not solely focus on educating women on the importance of and need for GCT; addressing structural barriers, such as patient-provider interactions, that contribute to mistrust must become a priority.

Journal of Health Disparities Research and Practice Volume 12, Issue 3, Fall 2019

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**Keywords:** Genetic Counseling; Genetic Testing; Black Women; Medical Mistrust; Hereditary Breast/Ovarian Cancer

## INTRODUCTION

Pathogenic genetic mutations, most commonly related to *BRCA 1* and *BRCA2* are implicated in up to 10% of all breast cancers (American Cancer, 2016). For women at high risk for such mutations (e.g.  $\leq 50$  years of age at time of breast cancer diagnosis, family history of breast and/or ovarian cancer), National Comprehensive Cancer Network (NCCN) guidelines recommend referral to genetic counseling and testing (GCT) when appropriate. Access to GCT is an important part of cancer control, but in this fast-moving area of medicine many minority patients are being “left behind” (Hall & Olopade, 2006; Levy et al., 2011).

Despite NCCN guidelines, Black women significantly underutilize GCT compared to White women (Hall & Olopade, 2006; Levy et al., 2011). Even after adjusting for risk of carrying a mutation, Black women remain far less likely to receive GCT. The etiology of low participation in GCT for Black women may include several mutable (e.g. self-efficacy, low-awareness of GCT) and non-mutable (e.g. age) factors (Glenn, Chawla, & Bastani, 2012; Mays et al., 2012; Sheppard et al., 2014; Sherman, Miller, Shaw, Cavanagh, & Sheinfeld Gorin, 2014). Several studies have demonstrated lower interest in and awareness of GCT for *BRCA1/2* among Black women (Andrykowski, Munn, & Studts, 1996; Armstrong et al., 2000; Donovan & Tucker, 2000; Hughes et al., 1997; Kaplan et al., 2006; Machirori, Patch, & Metcalfe, 2019; Mai et al., 2014). However, GCT is especially important for Black women as they have the highest breast cancer recurrence and mortality rates (American Cancer, 2016). Additionally, genetic mutations are highly prevalent in women with triple negative breast cancer (TNBC). TNBC is an aggressive type of cancer that is negative for the three most common receptors (estrogen, progesterone, and HER-2) and is associated with poorer outcomes that occurs more frequently in Blacks (Greenup et al., 2013). Prior studies have identified contributing factors of GCT underutilization by Black women (e.g. low knowledge, lack of physician referrals, cost); however, we still know little about how these factors impact at-risk Black women and Black survivors’ decisions to utilize this resource (Cragun et al., 2017; Sherman et al., 2014).

Though underutilization of GCT by Black women can be attributed to numerous factors, medical mistrust deserves particular attention as Black women continue to report stronger feelings of medical mistrust than White women (Ford, Alford, Britton, McClary, & Gordon, 2007; Sheppard, Mays, LaVeist, & Tercyak, 2013; Suther & Kiros, 2009). Medical mistrust can be defined as a lack of trust in healthcare organizations and in medical personnel (Omodei & McLennan, 2000). Reasons that contribute to Black women’s mistrust include, but are not limited to, historical events, reports of discrimination in healthcare settings, and other healthcare factors (Gamble, 1997; Moore, Hamilton, Pierre-Louis, & Jennings, 2013; Smith & Blumenthal, 2012; Zimmerman et al., 2006). Additionally, medical mistrust contributes to underuse of healthcare services, medication and other life-saving treatment, including GCT (Bickell, Weidmann, Fei, Lin, & Leventhal, 2009; Ford et al., 2007; Forman & Hall, 2009; Sheppard et al., 2013). At-risk Black women who report greater mistrust in the medical establishment have been shown to have lower engagement in GCT (Sheppard et al., 2014). To our knowledge, there are no studies that examines

predictors of mistrust in at-risk Black women; therefore, it is important to identify and understand contributors of this group’s mistrust in the medical establishment to further efforts to engage these women in behaviors that contribute to positive health outcomes.

The aims of this study are to inform future interventions by (1) describing the prevalence of medical mistrust in Black women at increased risk of *BRCA 1/2* and (2) identifying factors that are significantly associated with medical mistrust in a sample of Black women. Given the impact of predisposing characteristics and psychosocial factors on medical mistrust found in aforementioned studies, we hypothesized that these factors would be associated with medical mistrust in this study. Findings from this study can help to identify subgroups within the Black community that may benefit from interventions to address medical mistrust, ultimately increasing GCT uptake.

The conceptual framework for this investigation was adapted from an expansion of the Andersen Healthcare Utilization Model. The original model observes the contributing role of individual-level factors - predisposing characteristics, enabling factors, and perceived need - in one’s ability to access healthcare services (Andersen, 1995). However, the expanded model recognizes the importance of psychosocial factors as determinants of health care utilization (Bradley et al., 2002). This model serves as an appropriate guide to identify individual-level characteristics (e.g. marital status, self-efficacy in obtaining GCT) and psychosocial factors (e.g. perceived difficulty of obtaining GCT) that may contribute feelings of mistrust in the medical establishment (Figure 1).

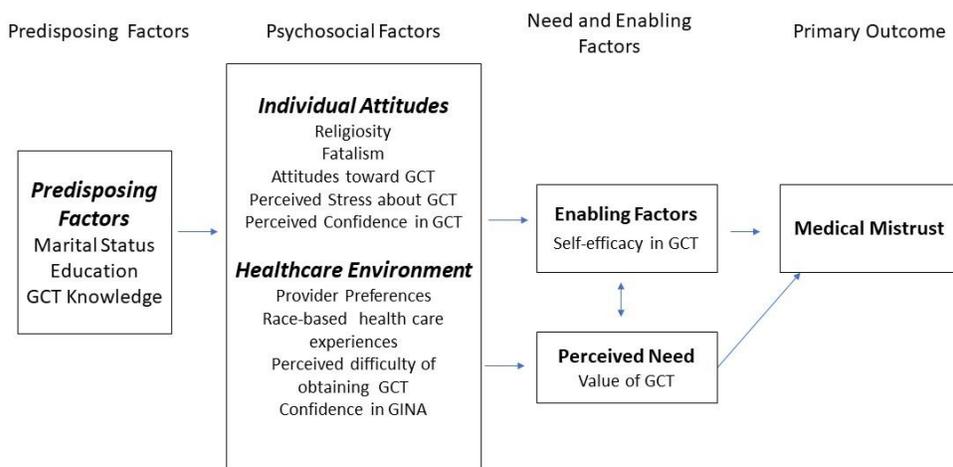


Figure 1. Conceptual Model of Medical Mistrust in Black Women at-risk for Hereditary Breast and Ovarian Cancer

## METHODS

### Settings and Population

This is a secondary analysis of data from a study of Black American women at increased risk of carrying a *BRCA 1/2* mutation. Details of the setting and procedures of this study have been reported elsewhere (Sheppard et al., 2014). This study was conducted in the mid-Atlantic region of the United States. Study procedures were approved by a local Institutional Review Board. This

study was nested in a larger project aimed to understand factors associated with Black women's GCT engagement.

Participants (n=100) were recruited via community-based settings and hospitals. This secondary analysis includes 94 women, as some participants were excluded due to missing data. Eligible participants were women who self-identified as African American or Black, were at least 21 years of age, able to read/understand English, and who were either breast or ovarian cancer survivors at risk for hereditary cancer or unaffected by breast or ovarian cancer. At-risk survivors included (1) women diagnosed with breast cancer when they were  $\leq 50$  years old (regardless of family history) or diagnosed at  $>50$  years old with at least one first-degree relative (e.g. mother) or two second-degree relatives (e.g. aunt) with breast and/or ovarian cancer. Eligible unaffected women reported having a least one first-degree relative affected by breast or ovarian cancer. A clinical research assistant contacted interested participants by phone, confirmed family and personal history information, consented eligible women, and administered the survey. Participants received a \$25 gift card for participating in the study.

#### Measures

*Outcome. Medical Mistrust.* This variable was measured using a 7-item Medical Mistrust Index (LaVeist, Isaac, & Williams, 2009). Participants were asked to consider their levels of mistrust in the American medical system using a 5-point Likert scale where response ranged from "Strongly Disagree" to "Strongly Agree" ( $\alpha = .76$ ). An overall score was created by calculating the mean of the seven items; higher numbers indicate greater mistrust (range 7-35).

*Predictors. Predisposing Characteristics.* Predisposing factors include marital status (single, married, living as married, divorced, separated, other), education (high school, some of any college, post-bachelors), and breast cancer genetics knowledge. To assess knowledge, participants responded to 13 true/false items (Erblich et al., 2005). The number of correct responses were added to create a score ranging from 0-13. High scores indicated higher breast cancer genetics knowledge. *Enabling Factor.* Self-efficacy in obtaining GCT was measured with a three-item 5-point Likert-type scale developed for this research ( $\alpha = .75$ ). (Sheppard et al., 2014) Participants were asked to rate their degree of agreement (ranging from strongly agree to strongly disagree) with three items related to participants' self-confidence in locating GCT services, knowing how to pay for those services, and knowing what to do with information obtained. Higher values indicated higher GCT self-efficacy. *Perceived Need.* Factors related to one's perceived need of obtaining healthcare services included value of GCT and pros/cons of obtaining GCT. We assessed how women valued GCT using three Likert scale items (e.g. the risk of discrimination from a positive genetic test result is not worth it). Higher scores denoted greater value in GCT. We measured participants' perceived pros/cons of GCT using Thompson's scale (H. S. Thompson et al., 2002). Eleven Likert-scale items question participants' feelings about learning outcomes of GCT. Higher scores indicated GCT as a perceived pro while lower scores indicated GCT as a perceived con. *Psychosocial Factors.* These factors included attitude toward genetic counseling, perceived difficulty of obtaining GCT, perceived confidence in GCT, perceived stress about GCT, religiosity, fatalism, race-based, or discriminatory, healthcare experiences, confidence in the Genetic Information Nondiscrimination Act (GINA), and provider preferences. Armstrong et al. 15-item scale was used to assess participants' *attitude toward GCT.* Scores range from 15-60 with higher scores indicating a more positive attitude toward GCT. Assessment of participants' *perceived difficulty* of obtaining GCT occurred via six 5-point Likert scale items. Participants

offered input on the importance of their families' opinions about GCT, distance to GCT facilities, and difficulty of having their blood drawn. Higher scores indicated greater perceived difficulty. We measured participants' confidence in obtaining CGT using Halbert et al. (Halbert et al., 2004), 6-item *perceived confidence* inventory. Items within this inventory assessed participants' confidence with communicating with their families about *BRCA 1/2* and confidence making decisions about cancer screening options. We measured *perceived cancer-related stress* with a 5-item Likert-type scale developed by Halbert and colleagues (2014) that assessed participants' levels of perceived cancer-related stress regarding: coping with the risk of cancer recurrence, making risk-reduction decisions, screening, communicating test results to relatives, and dealing with the impact of results on family members (Cronbach's  $\alpha = .80$ ). The four response choices ranged from "not at all stressful" to "very stressful." Higher scores indicated higher perceived cancer-related stress. We evaluated participants' *religiosity* using three 5-point Likert-scale items. Higher scores indicate higher religiosity. *Fatalism* inventory included three Likert-scale items that assessed participants' feelings regarding whether or not a cancer diagnosis is predestined for some people. Higher scores reflect fatalistic thinking regarding GCT. To measure participants' perceived discrimination in the context of interactions in the healthcare setting, we used Bird & Bogart's *Race-Based experiences* scale (Bird & Bogart, 2001). Participants were to consider their race or ethnicity to answer yes or no to seven items (e.g. have you had a doctor or nurse act as if he or she is better than you). Scores range from 7-14 with higher scores indicating more race-based experiences. The *confidence in GINA* scale included three Likert-scale items (e.g. having this law in place is important in my decision to test for *BRCA* mutation); higher scores indicated greater confidence in the GINA law. Lastly, we assessed *provider preferences* using two Likert-scale items ( $\alpha = 0.81$ ) - "it would be important for me to have a genetic counselor from my race/ethnic background" and "I would prefer to learn about genetic counseling and testing from a physician from my racial/ethnic background." Higher scores denoted a preference for a GCT provider of like racial/ethnic background.

#### Statistical Analyses

The descriptive statistics (e.g. mean, frequency) were summarized for each variable. T-test was used to assess mean differences for continuous variables and Wald chi-square test was used to assess relationship between medical mistrust total score and study variables (e.g. age, religiosity). Means and standard deviations are presented for continuous variables. The number and percentage of participants in each group of the categorical variables are presented. Linear regression model was applied and stepwise method was used for variable selection. All predictor variables represented in Table 1 were included in the multivariable model. All tests were assessed at a significance level of 0.05. Statistical analyses were conducted using SAS version 9.4.

## RESULTS

Participant characteristics and medical mistrust are displayed in Table 1.

Table 1: Participant Characteristics and Medical Mistrust

Variables	N (%)	Mean $\pm$ SD	p-value
<b>Sociodemographic Factors</b>			
Age			
$\leq$ 50years	62 (66.0)		0.86
> 50 years	32 (34.0)		
Age: Mean $\pm$ SD	94 (100.0)	44.9 $\pm$ 11.4	0.91
Marital status			
Married/Living as married	39 (50.6)		0.54
Single (Never Married)	38 (49.4)		
Education level			
Bachelor's and above	50 (53.2)		0.54
Some college or $\leq$ HS	44 (46.8)		
Employment status			
Full time employed	71 (75.5)		0.31
Not full time employed	23 (24.5)		
<b>Breast Cancer Genetics Knowledge</b>		8.3 $\pm$ 1.9	0.85
<b>Sociocultural Factors</b>			
Religiosity		9.2 $\pm$ 1.9	0.098
Fatalism		8.8 $\pm$ 2.0	0.04*
Perceived Discrimination		11.5 $\pm$ 2.4	0.01*
Confidence in GINA Law		10.7 $\pm$ 2.5	0.36
Provider Preferences		15.3 $\pm$ 2.8	0.35
<b>Psychosocial Factors</b>			
Attitude toward GCT		41.1 $\pm$ 4.0	0.34
Self-Efficacy in GCT		14.0 $\pm$ 2.0	0.01*
Perceived Difficulty of GCT		8.8 $\pm$ 4.8	0.06
Perceived Confidence in GCT		13.8 $\pm$ 2.2	0.66
Perceived Stress of GCT		9.8 $\pm$ 3.0	0.4
Value of Genetic Counseling and Testing		11.3 $\pm$ 1.9	0.07
Perceived Pros/Cons of <i>BRCA1/2</i>		40.2 $\pm$ 3.5	0.76

Note: N=Sample size; SD = Standard Deviation;

\* $p < 0.05$

The mean age of women in this study was 44.9 years. Most women had at least a bachelor's degree (53.2%) and were full-time employed (75.5). Less than half of women (48.9%) were affected with cancer. A majority of women in this study expressed moderate to high levels of medical mistrust, with total scores ranging from 16-35 (mean = 24.9; standard deviation = 3.9).

Bivariate analysis revealed significant relationships between enabling and psychosocial factors and medical mistrust. Among the psychosocial factors, fatalism ( $p=0.04$ ) and perceived discrimination ( $p=0.01$ ) were associated with medical mistrust. Self-efficacy, the enabling factor, was also significantly associated with medical mistrust ( $p=0.01$ ). No significant associations were observed between need and predisposing characteristic factors and medical mistrust.

Table 2 displays results of the multivariable model. Women with more perceived discrimination ( $B = 0.80$ ,  $CI: 0.51 - 1.0$ ;  $p < 0.0001$ ) and less confidence in GCT ( $B = -0.33$ ,  $CI: -0.64 - -0.016$ ;  $p = 0.0354$ ) reported greater medical mistrust. While significant in bivariate analysis, self-efficacy and fatalism were not selected to the final multivariable model.

Table 2. Multivariable Results for Medical Mistrust based on Stepwise Selection Method

Parameter	Estimate (95% CI)	p-value
Perceived Discrimination	0.80 (0.51, 1.10)	<0.0001*
Perceived Confidence	-0.33 (-0.64, -0.016)	0.0354*

Note: CI=Confidence Interval

\* $p < 0.05$

## DISCUSSION

Feelings of mistrust in the medical establishment were prevalent in this sample of women. Results suggest that there is a wide variation in levels of medical mistrust in African American women. Interestingly, a majority of women reported that they either agreed or strongly agreed with all items on the mistrust scale (Figure 2). This finding is consistent with those of similar studies, highlighting the need to identify and understand causal factors of mistrust (Armstrong, Weber, Ubel, Guerra, & Schwartz, 2002; Brenick, Romano, Kegler, & Eaton, 2017; Forman & Hall, 2009; H. S. Thompson et al., 2002). Results from this study offer further insight into contributors to Black women's mistrust in the medical establishment, specifically in regards to GCT.

Findings from this study highlight the important roles of providers when considering how feelings of mistrust manifest in Black women. Other studies have reported similar findings regarding Black women's feelings pertaining to GCT (Donovan & Tucker, 2000; Hull, Haas, & Simon, 2018; Sheppard et al., 2014; Hayley S. Thompson, Valdimarsdottir, Jandorf, & Redd, 2003). Although complex in nature, these factors, race and SES-based experiences, are mutable and offer opportunities to address mistrust felt by Black women. Provider education centered on cultural/racial competency and awareness is one example of an intervention that may began to reduce feelings of mistrust. Additionally, as Black women report a lack of communication regarding GCT from their providers, it is pertinent that providers are intentional about discussing

the purpose and importance of GCT to increase awareness, confidence, and uptake in this population (Cragun et al., 2017).

In this study, lack of confidence in GCT emerged as a significant predictor of one’s medical mistrust. Women with less confidence in their abilities to communicate with family members about their *BRCA1/2* test results and in their abilities to make good decisions about their cancer screening expressed greater mistrust. Effective strategies to build women’s confidence may require intentional patient-provider conversations that extend beyond the empirical cancer risk information; conversations must seek to increase confidence in GCT by delving into women’s needs, concerns, and uncertainties (Gaff et al., 2007; Hargraves, 2000; Peipins et al., 2018; Scherer et al., 2013).

Although not significant in the multivariable model, fatalism and self-efficacy were significantly related to medical mistrust. Addressing these factors in regard to education and intervention development may aid in moving the needle on mitigating feelings of medical mistrust. These factors must also be considered when seeking to motivate women to engage in CGT, as women who seek genetic counseling typically exhibit higher levels of self-efficacy and lower levels of fatalism (Lagos et al., 2008). Further, as empirical evidence shows a significant relationship between knowledge of GCT and GCT engagement, at-risk women may benefit from interventions focused on increasing knowledge and awareness of the importance and need for GCT (Hurtado-de-Mendoza, Jackson, Anderson, & Sheppard, 2017; Scherr, Bomboka, Nelson, Pal, & Vadaparampil, 2017).

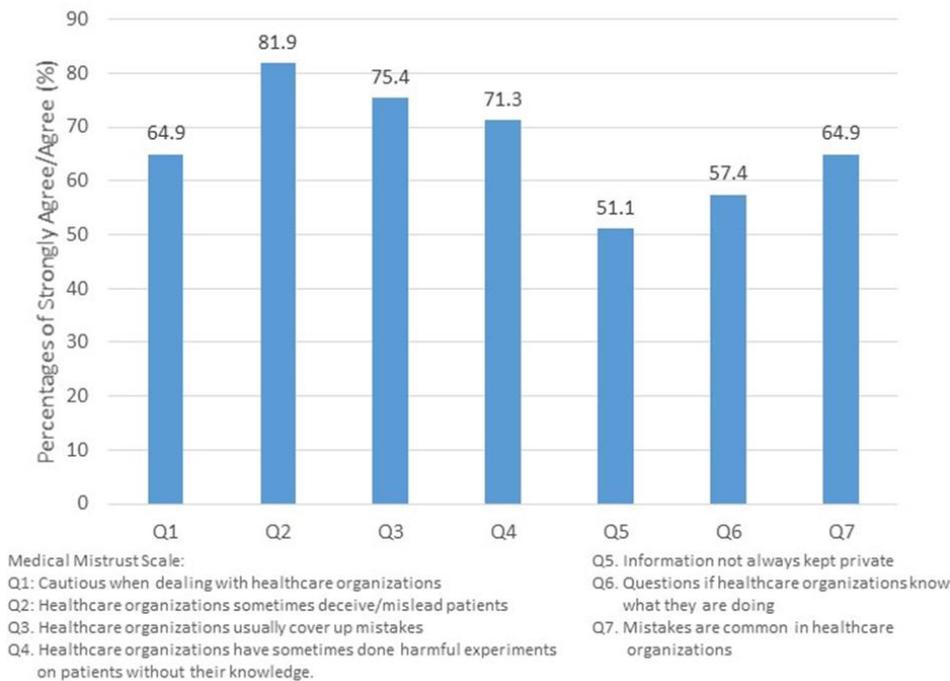


Figure 2. Distribution of Responses to Medical Mistrust Items

Strengths of this study include the inclusion of both affected and unaffected Black women at-risk for pathogenic *BRCA1/2* variants. To our knowledge, no studies involving GCT have

assessed and compared these groups of women. Additionally, recruiting women from various settings contributed to the generalizability of our findings. Even with several strengths, this study does have some weaknesses Breast/ovarian cancer status data (e.g. affected, unaffected) were collected via self-report rather than from medical/clinical histories. We also recognize that our sample size was relatively small. Lastly, most of our women were from urban settings; therefore, our findings may not be generalizable to women in non-urban and rural areas.

## CONCLUSION

Given the benefits of GCT in at-risk women, it is imperative to identify strategies and opportunities to diminish barriers to care and testing. Further, as Black women's breast cancer mortality rates exceed those of White women, efforts to understand factors related to underutilization of GCT must be explored. Medical mistrust remains a potentially modifiable factor that hinders Black women from seeking necessary care; however, causal factors are not solely due to sociodemographic or individual-level factors but institutional factors (provider interactions, discrimination, low referral rates) also play a significant role (Manriquez, Chapman, Mak, Blanco, & Chen, 2018). Future efforts must focus on causative influences (e.g. privacy concerns, race-based experiences) while engaging patients, at-risk individuals, and providers.

## ACKNOWLEDGEMENTS

We would like to thank the women who agreed to participate in this research study. We would also like to thank Mary Johnson for her assistance with manuscript preparation. This work was supported by the Jess and Mildred Fisher Center for Familial Cancer Research (2007-1), VCU Massey Cancer Center NIH-NCI Cancer Center Support Grant P30 CA016059, NCI 2T32 CA093423, the National Institute for Nursing Research R21NR016905, and NCI Center to Reduce Cancer Health Disparities, Award No. P30CA177558-05S3. This project was also supported by Georgetown-Howard Universities Center for Clinical and Translational Science (GHUCCTS) by Federal Funds; the National Center for Advancing Translational Sciences (NCATS); and the National Institutes of Health (NIH), through the Clinical and Translational Science Awards Program (CTSA) (KL2TR001432)

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