Published in final edited form as:

J Genet Couns. 2012 October ; 21(5): 676–683. doi:10.1007/s10897-012-9485-y.

Low Rates of African American Participation in Genetic Counseling and Testing for BRCA1/2 Mutations: Racial Disparities or Just a Difference?

Chanita Hughes Halbert¹, Lisa Kessler², Aliya Collier², Benita Weathers², Jill Stopfer³, Susan Domchek⁴, and Jasmine A. McDonald²

¹Center for Community-Based Research and Health Disparities, Department of Psychiatry and Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA

²Center for Community-Based Research and Health Disparities, Department of Psychiatry, University of Pennsylvania, Philadelphia, PA

³Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA

⁴Department of Medicine and Abramson Cancer Center, University of Pennsylvania, Philadelphia, PA

Abstract

Background—Low rates of genetic counseling among African American women have generated concerns about disparities; however, to the extent that women's decisions to accept or decline counseling are consistent with their values, then lower participation may reflect preferences and not disparities.

Purpose—We evaluated the extent to which women were satisfied with their decision about participating in genetic counseling for BRCA1/2 mutations and identified variables that were associated significantly with satisfaction.

Methods—Prospective study of decision satisfaction with 135 African American women who had a minimum 5% prior probability of having a BRCA1/2 mutation. Decision satisfaction was evaluated one month after women were offered participation in genetic counseling using a structured questionnaire.

Results—Women were satisfied with their participation decision; more than 80% reported that their decision was consistent with their family values. However, women who declined pre-test counseling had significantly lower satisfaction scores.

Conclusions—Our findings highlight the importance ensuring that racial differences that are due to preferences and values are not misclassified as disparities in order to identify and address the root causes of disparate treatment.

Keywords

African American; Participation; Genetic Counseling; BRCA1/2; Disparities

CORRESPONDING AUTHOR: Chanita Hughes Halbert, Ph.D., Center for Community-Based Research and Health Disparities, Department of Psychiatry, University of Pennsylvania, 3535 Market Street, Suite 4100, Philadelphia, PA 19104 Telephone: 215-746-7144, Fax: 215-746-7140, Chanita@mail.med.upenn.edu.

CONFLICT OF INTEREST

The authors do not have any conflict of interests.

INTRODUCTION

Since the availability of genetic testing for BRCA1/2 mutations, research has evaluated rates and predictors of test result acceptance (Lerman et al. 1996; Schwartz et al. 2000; Schwartz et al. 2005). Because of the greater rates of breast cancer morbidity and mortality among African American women (American Cancer Society 2009), and the potential for genetic risk information to enhance screening and surveillance among mutation carriers, characterizing acceptance of genetic counseling and testing among African American women has been a particular focus (Kinney et al. 2006). We found, for example, that while about 50% of African American women participate in genetic counseling (Halbert et al. 2005), a lower proportion undergo genetic testing and receive BRCA1/2 test results (Halbert et al. 2006). Similar trends have been reported in other studies (Armstrong et al. 2005; Thompson et al. 2002); these findings have generated concerns about racial disparities in genetic counseling and testing.

The Institute of Medicine defines racial disparities as differences in the quality of health care between groups that are not due to access, appropriateness of care, and patient preferences (Smedley et al. 2003). Thus, not all racial differences in health care should be categorized as disparities, especially if individuals choose to decline a service because it is inconsistent with their values. The distinction between racial differences and disparities becomes especially relevant in health care contexts for which the benefits may be equivocal. Genetic counseling and testing for BRCA1/2 mutations is one such context because test results may be uninformative, especially in African American women where as many as 40% may have sequence variants of uncertain significance (Nanda et al. 2005). Thus, genetic risk information and services may have limited clinical, and ultimately, personal value to these women. In these situations, it is important for individuals to make decisions that are consistent with their values.

Genetic testing for BRCA1/2 mutations is a multi-step process that begins with the identification and referral of women to counseling. A primary consideration of genetic counseling is that individuals make an informed decision about testing. Informed decisions are believed to occur when an individual understands the disease and the clinical service being offered, including its possible benefits and risks, and when individuals have made a choice that is consistent with their values (Briss et al. 2004). Satisfaction with the decision that was made is one outcome of making an informed choice (Briss et al. 2004; O'Connor and O'Brien-Pallas 1989). While informed decision making is a key outcome of genetic counseling, women make several decisions after being referred. These include decisions about participating in genetic counseling and deciding to accept or decline testing and/or test results.

We conducted a randomized trial to compare the effects of culturally tailored (CTGC) versus standard genetic counseling (SGC) for BRCA1/2 mutations on behavioral and psychological outcomes among African American women (Halbert et al. 2005; Halbert et al. 2006; Halbert et al. 2010). In designing this study, our goal was to move beyond the documentation and explanation of Black-White differences (Baquet et al. 2002; Long et al. 2004) in genetic counseling and testing that uses a racially comparative framework by developing an intervention to address the needs and preferences of African American women. For instance, based on previous research which found differences in referral patterns and knowledge between African American and white women (Hughes et al. 1997; Lerman et al. 1999), our recruitment procedures and study protocols were designed to mitigate a number of issues related to access to care (Penchansky and Thomas 1981). Specifically, we used community and clinic-based recruitment methods (Halbert et al. 2005) to increase awareness about the availability of genetic counseling and testing and enhance

the identification and referral of African American women at increased risk for hereditary disease. We also provided information about genetic counseling as part of our enrollment procedures. Further, the counseling protocols (Charles et al. 2006; Halbert et al. 2006) provided specific information about breast cancer in African American women and those who were randomized to CTGC received counseling that addressed beliefs and values that have been associated with participation in genetic counseling and acceptance of BRCA1/2 test results (Hughes et al. 2003). In addition, genetic counseling, and in some cases testing, was free of charge. Genetic counseling was also offered during weekend hours on a limited basis to accommodate women who could not otherwise participate.

Despite these features, participation in genetic counseling was modest, uptake of testing was limited, and there was no difference in test result acceptance between women who received CTGC and SGC (Halbert et al. 2005; Halbert et al. 2006). It is unknown, however, if these decisions are consistent with women's beliefs, values, and preferences. To the extent that women's decisions to accept or decline genetic counseling and testing are consistent with their values, then lower rates of participation among African American women (Armstrong et al. 2005), may reflect differences and not disparities. To clarify this issue, we evaluated African American women's satisfaction with their decision to participate in genetic counseling and receive BRCA1/2 test results. We focused specifically on African American women because these women have been under-represented in prior studies on genetic counseling and testing (Lerman et al. 1996; Schwartz et al. 2005).

MATERIALS AND METHODS

Study population

Subjects were African American women who were at increased risk for having a BRCA1/2 mutation. To be eligible for participation, women had to be at least age 18 and also have a minimum 5% prior probability of having a BRCA1/2 mutation based on their personal and family history of breast and/or ovarian cancer. The study was approved by the institutional review board at the University of Pennsylvania and was conducted from February 2003 to July 2008.

Procedures

The procedures for recruitment and study enrollment have been described in detail elsewhere (Halbert et al. 2005) and are summarized here. Women were referred for study participation from clinic and community settings; following referral, those who were interested in learning more about the study completed a referral form that collected information about race, date of birth, personal and family history of cancer, and contact information. Referral forms were reviewed by the study genetic counselor (LK) and eligible women were mailed an invitation letter. The informed consent form for genetic counseling was included with the invitation letter along with an opt-out option. This form provided information about BRCA1/2 mutations and genetic counseling. Women who did not decline participation at this point were contacted for study enrollment. Study enrollment consisted of completing a structured, 40-minute baseline telephone interview following provision of verbal consent. It should be noted that some women had provided a blood sample as part of a separate epidemiological study to identify genetic risk factors for breast cancer in African American women. However, genetic counseling and BRCA1/2 test results were not provided to these women prior to their enrollment. Also, in a small number of cases, multiple family members were enrolled in the study. The study enrollment rate was 62% (Halbert et al. 2005).

The counseling protocols and randomization procedures have been described in detail elsewhere (Charles et al. 2006; Halbert et al. 2006) and are summarized here. Following study enrollment and completion of the baseline, women were invited to participate in genetic counseling; those who accepted the invitation were randomized to SGC or CTGC. As part of both protocols, women received education about breast cancer in African American women, hereditary breast cancer and BRCA1/2 susceptibility genes, and information about the benefits, limitations, and risks of genetic testing. The CTGC protocol also provided an individualized discussion about cultural beliefs and values that have been shown to influence decisions about genetic testing (Hughes et al. 2003). Regardless of randomization to CTGC or SGC, women who were interested in genetic testing met individually with a medical oncologist and were given an opportunity to provide a blood sample for genetic testing. Women were notified when results became available and were invited to an individual test results disclosure session that was consistent with the pre-test counseling protocol. All genetic counseling and test result disclosure sessions were conducted by a single counselor, who was White. All women who enrolled in the study, including those who declined randomization, were contacted for 1-, 6-, and 12-month follow-up telephone interviews to assess psychological functioning and cancer screening behaviors. We evaluated satisfaction during the 1-month follow-up because this assessment was the most proximal to participation decisions. For participants in genetic counseling and testing, these interviews were completed based on their participation in genetic counseling and/or testing. Follow-up surveys were completed for non-participants and test result decliners based on the date they declined genetic counseling and/or results. The study enrollment date was used to complete follow-up surveys for women who declined randomization. The retention rate for the 1-month follow-up interview was 73% (Halbert et al. 2008). All women included in this report had made a decision about participating in genetic counseling and those who elected to receive results had completed the test results disclosure session.

Measures

Sociodemographics—Age, marital status, household income, education, and employment status were obtained during the baseline telephone interview.

Clinical factors—We calculated the total number of first-, second- and third-degree relatives affected with breast and/or ovarian cancer; women were categorized as having two or more relatives affected with cancer or less than two relatives affected with cancer. We estimated the probability of having a BRCA1/2 mutation based on women's personal and family history of breast and/or ovarian cancer using prior probability models and mutation prevalence tables (Domchek et al. 2003; Frank et al. 2002). Women were categorized as having a 5%–9% or 10% or higher prior probability of having a BRCA1/2 mutation.

Genetic counseling and testing—Participation status in genetic counseling and testing was obtained from study records using our previous methods (Halbert et al. 2005; Halbert et al. 2006). Women who completed pre-test counseling were categorized as participants and those who declined randomization and those who declined pre-test counseling after randomization were categorized as non-participants. Since declining genetic counseling was synonymous with declining testing and test results, we only asked women who received BRCA1/2 test results about their satisfaction with testing decisions to avoid redundancy.

Satisfaction with Decisions—We used the satisfaction with decisions scale to evaluate women's satisfaction with their participation decisions (Holmes-Rovner et al. 1996). We modified this instrument to facilitate telephone administration and to make it relevant to genetic counseling and testing decisions. Specifically, we asked women four questions to

determine if they were satisfied that: they were adequately informed about the issues that were important to their decision, the decision they made was the best for them personally, the decision was consistent with their personal values, and they were satisfied with the decision they made (1=strongly disagree to 5=strongly agree). These four items were summed to generate a satisfaction score; higher scores reflected greater satisfaction with participation decisions. Scores ranged from 10 to 20 and the instrument had excellent internal consistency (Cronbach's $\alpha=.90$). Since previous research has shown that concerns about the familial impact of genetic testing may be a barrier to genetic counseling in African American women (Hughes et al. 1997; Thompson et al. 2002), we also asked women if the decision they made was the best for their family and if they were satisfied that the decision they made was consistent with their family values. We also asked women if they were satisfied that participation in genetic counseling was their decision to make. Response options for these items were also 1=strongly disagree to 5=strongly agree. Similar items were used to evaluate satisfaction with decisions to receive BRCA1/2 test results.

Data Analysis

First, we generated descriptive statistics to characterize participants in terms of sociodemographics, clinical characteristics, and satisfaction. We then conducted bivariate analyses using non-parametric analysis of variance with the Kruskal-Wallis Chi Square Test. Next, we used multivariate regression analysis to identify factors having significant independent associations with satisfaction. This analysis used scores that were based on responses to the four questions from the satisfaction with decision scale. Variables that have a bivariate association of $p<0.10$ with satisfaction scores were included in the model. We also controlled for randomization to the genetic counseling protocols and sociodemographic and clinical variables that were associated with participation in genetic counseling (Halbert et al. 2005) in the regression analysis.

RESULTS

Table 1 shows the characteristics of the study sample. Overall, women were satisfied with their decisions to participate in genetic counseling for BRCA1/2 mutations. For instance, the highest possible satisfaction score was 20 and in our sample, the mean (SD) level of satisfaction was 17.4 (2.2). Not only had women made decisions about participating in genetic counseling that were consistent with their personal values and were the best for them personally, the majority of women reported that they were satisfied that whether or not to participate in genetic counseling was their decision to make (96% agree or strongly agree) and that they had made a decision that was consistent with their family values (88% agree or strongly agree). However, a lower proportion of women were satisfied that they had made a decision that was best for their family (84% agree or strongly agree). Similar results were obtained for satisfaction with decisions to have genetic testing among women who received BRCA1/2 test results ($n=44$) (see Figure 1).

The results of the bivariate analyses of satisfaction scores are shown in Table 2. None of the sociodemographic characteristics or clinical factors were associated significantly with satisfaction. However, genetic counseling participants reported significantly greater satisfaction with their decisions compared to non-participants. In the multivariate regression model, participation status for genetic counseling had a significant independent effect on satisfaction (Beta=1.27, $p=0.01$) while controlling for randomization to genetic counseling protocols, sociodemographic characteristics, and clinical factors.

DISCUSSION

To our knowledge, this is the first empirical study to evaluate satisfaction with decisions about participating in genetic counseling and testing for BRCA1/2 mutations among African American women. We focused specifically on African American women because this population has been under-represented in prior studies (Lerman et al. 1996; Schwartz et al. 2005) that measured genetic counseling outcomes, including those that evaluated satisfaction with the technical aspects of this service (DeMarco et al. 2004; Klemp et al. 2005). We recognize that racial group comparisons are important to identify and quantify differences in outcomes and are necessary to achieve objectives for equity in health care (National Cancer Institute 2006), and for this reason, future work should evaluate differences and similarities in satisfaction with participation decisions between African American and White women. But, this approach ignores the within group heterogeneity among African Americans that may be important to outcomes following genetic counseling and testing. Developing a better understanding of satisfaction with decisions specifically among African American women is important because it provides empirical data on the extent to which these choices are consistent with women's preferences. While our approach allows us to evaluate how the heterogeneity within African American women at increased risk for hereditary disease contributes to satisfaction with participation decisions and also presents a novel dimension of satisfaction with genetic counseling, our results should be considered within the context of a small sample and modest retention rate. Women who were lost to follow-up may have had lower satisfaction than those who were retained. Also, a small number of women were included in the analysis of satisfaction with testing decisions. In addition, we only enrolled women from clinics and community oncology resources located in the Philadelphia, PA metropolitan area and all sessions were conducted by a single genetic counselor. Because of these issues, the power to detect differences in satisfaction and the generalizability of our findings has limitations. Although satisfaction is an important outcome of informed decision making and our previous research has shown that women are satisfied with the counselor's technical skills (Charles et al., 2006), it is important for future studies to evaluate satisfaction along with other factors that are important to informed choices (e.g., knowledge about breast cancer genetics, genetic counseling and testing for BRCA1/2 mutations, and perceptions of the benefits, limitations, and risks of counseling and testing).

Despite these limitations, our findings shed new light on whether or not low rates of African American participation in genetic counseling (Armstrong et al. 2005; Halbert et al. 2005) is a disparity or are differences that are due to women's preferences and values. By offering genetic counseling as part of a program that addressed reduced access to this service, we were able to evaluate the extent to which participation decisions were consistent with women's preferences and values and not due to differential access to genetic counseling and testing. Overall, women reported that they were satisfied with the decisions that they made about participating in genetic counseling. Satisfaction did not differ among women with different sociodemographic or clinical backgrounds. But, women who declined to participate in genetic counseling reported lower levels of satisfaction compared to those who participated in counseling. It should be noted, however, that satisfaction levels were high among participants and non-participants. Previous research has focused on understanding uptake of genetic counseling (Armstrong et al., 2005; Halbert et al., 2006) and identifying factors that are predictive of BRCA1/2 test result acceptance in African American women (Halbert et al., 2006). Our findings suggest that it is important to understand why women decline participation in genetic counseling and develop strategies for ensuring that these issues are addressed. Thompson et al. (2005) found that women who declined BRCA1/2 counseling had less knowledge about breast cancer genetics and were more concerned about the emotional impact of testing and stigmatization. Further, women who participated in

genetic counseling and received BRCA1/2 test results had lower levels of familial guilt compared to decliners (Thompson et al., 2005). It could be that some women need more information about genetic counseling and testing to make an informed choice about participation. Another possibility is that women decline genetic counseling and/or testing to meet the needs and opinions of their family members. Nevertheless, our findings demonstrate that following referral and provision of information about genetic counseling and testing for BRCA1/2 mutations as part of the enrollment process, African American women are likely to make decisions about participating in genetic counseling that are consistent with their personal and family values. At a minimum, this information should be provided to women as part of the referral process to facilitate informed decisions about participating in counseling and reinforced during the pre-test counseling session, but other informational needs and concerns may need to be addressed, especially among women who initially decline. We were able to contact women who declined genetic counseling to complete the 1-month follow-up telephone interview as part of a research protocol; it may be important for genetic counselors to contact women who decline pre-test counseling to determine if they need additional information. This type of follow-up would have to be implemented with sensitivity to ensure that women who decline counseling do not feel coerced into participating.

An effective decision is one that is informed by one's evaluation of the medical evidence and is consistent with their beliefs and values (O'Connor and O'Brien-Pallas 1989); women reported that their participation decisions were consistent with both their personal and family values. Thus, lower rates in participation in genetic counseling among African American women compared to White women may in fact just be racial differences and not disparities. Clearly, however, there are several instances where racial differences are in fact disparities; these include lower rates of providing standard therapies to minorities even though they are indicated and appropriate, or not discussing treatment or prevention options with minority patients because of pre-existing assumptions about the likelihood of non-compliance (Schulman et al. 1999; Smedley et al. 2003; van Ryn and Burke 2000). Even if women are satisfied with their decisions about participating in genetic counseling and testing, this does not negate the potential for disparities to occur. Physicians play an important role in facilitating access to genetic counseling for BRCA1/2 mutations by identifying women who have a family history of breast cancer that is suggestive of hereditary disease and referring these women to counseling and testing services. Health care providers may not obtain family history information from non-White women at the same rates as White women (Murff et al. 2005). Lower rates of discussing family history of breast cancer with African American women may translate into reduced rates of referring these women to genetic counseling. These factors, combined with less exposure and knowledge about genetic testing (Hughes et al. 1997), may lead to low rates of uptake among African American women. Thus, disparities may exist in the identification and referral of African American women to genetic counseling and testing. But, when access and knowledge issues are addressed as we did in the present study, then the low rates observed among African American women may be due to their preferences and values and should not be categorized as disparities.

Our data underscore the importance of avoiding misclassification of racial differences that are due to preferences and values as disparities in order to identify and address the root causes of disparate treatment so that resources are used effectively to improve health outcomes in racial minorities. Empirical research has to move beyond descriptive studies that focus on comparing racial groups in terms of risk factors, behaviors, and outcomes in order to accurately distinguish between racial disparities and differences that are due to preferences and values. Research that evaluates within group variation among minorities in determinants and outcomes has been described (Doswell 2002; Kumanyika et al. 2007) and

used (Halbert et al. 2005; Halbert et al. 2006) as alternative paradigms for determining how members of these groups make decisions about health care and evaluating the outcomes of these decisions. Greater understanding of within group variation, and identification of factors that are protective as well as risk-promoting, and translation of these findings into programs and interventions, may lead to greater progress in achieving objectives for eliminating racial disparities in health care and outcomes.

Acknowledgments

This research was supported by Department of Defense grant #DAMD17-00-1-0262, National Human Genome Research Institute grant #P50HG004487, and National Cancer Institute grant #P30CA016520. Trial registration: www.clinicaltrials.gov (registration #NCT00419510). We would like to acknowledge Kiyona Brewster, MA for assistance with data collection and management and E. Paul Wileyto, Ph.D., for consultation on statistical analyses. We also thank the Penn Center for the Integration of Genetic Healthcare Technologies for assistance throughout the study. Costs for genetic testing were paid by institutional funds at the Abramson Cancer Center at the University of Pennsylvania. We thank all of the women who expressed an interest in this study and we are especially appreciative to those who participated in this research.

References

- American Cancer Society. Cancer Facts and Figures, 2009. Atlanta, GA: American Cancer Society; 2009.
- Armstrong K, Micco E, Carney A, Stopfer J, Putt M. Racial differences in the use of BRCA1/2 testing among women with a family history of breast or ovarian cancer. *Journal of the American Medical Association*. 2005; 293(14):1729–1736. [PubMed: 15827311]
- Baquet CR, Hammond C, Commiskey P, Brooks S, Mullins CD. Health disparities research—a model for conducting research on cancer disparities: characterization and reduction. *Journal of the Association for Academic Minority Physicians*. 2002; 13(2):33–40. [PubMed: 12362565]
- Briss P, Rimer B, Reilley B, Coates RC, Lee NC, Mullen P, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *American Journal of Preventive Medicine*. 2004; 26(1):67–80. [PubMed: 14700715]
- Charles S, Kessler L, Stopfer JE, Domchek S, Halbert CH. Satisfaction with genetic counseling for BRCA1 and BRCA2 mutations among African American women. *Patient Education and Counseling*. 2006; 63(1–2):196–204. [PubMed: 16533589]
- DeMarco TA, Peshkin BN, Mars BD, Tercyak KP. Patient satisfaction with cancer genetic counseling: a psychometric analysis of the Genetic Counseling Satisfaction Scale. *Journal of Genetic Counseling*. 2004; 13(4):293–304. [PubMed: 19736695]
- Domchek SM, Eisen A, Calzone K, Stopfer J, Blackwood A, Weber BL. Application of breast cancer risk prediction models in clinical practice. *Journal of Clinical Oncology*. 2003; 21(4):593–601. [PubMed: 12586794]
- Doswell W. Health disparities research: exploring different research pathways. *Research in Nursing and Health*. 2002; 25(2):87–88. [PubMed: 11933002]
- Frank TS, Deffenbaugh AM, Reid JE, Hulick M, Ward BE, Lingenfelter B, et al. Clinical characteristics of individuals with germline mutations in BRCA1 and BRCA2: analysis of 10,000 individuals. *Journal of Clinical Oncology*. 2002; 20(6):1480–1490. [PubMed: 11896095]
- Halbert C, Kessler L, Collier A, Paul Wileyto E, Brewster K, Weathers B. Psychological functioning in African American women at an increased risk of hereditary breast and ovarian cancer. *Clinical Genetics*. 2005; 68(3):222–227. [PubMed: 16098010]
- Halbert CH, Brewster K, Collier A, Smith C, Kessler L, Weathers B, et al. Recruiting African American women to participate in hereditary breast cancer research. *Journal of Clinical Oncology*. 2005; 23(31):7967–7973. [PubMed: 16258097]
- Halbert CH, Kessler L, Stopfer JE, Domchek S, Wileyto EP. Low rates of acceptance of BRCA1 and BRCA2 test results among African American women at increased risk for hereditary breast-ovarian cancer. *Genetics in Medicine*. 2006; 8(9):576–582. [PubMed: 16980814]

- Halbert CH, Kessler L, Troxel AB, Stopfer JE, Domchek S. Effect of genetic counseling and testing for BRCA1 and BRCA2 mutations in African American women: a randomized trial. *Public Health Genomics*. (In Press).
- Halbert CH, Love D, Mayes T, Collier A, Weathers B, Kessler L, et al. Retention of African American women in cancer genetics research. *American Journal of Medical Genetics Part A*. 2008; 146A(2): 166–173. [PubMed: 18076114]
- Holmes-Rovner M, Kroll J, Schmitt N, Rovner DR, Breer ML, Rothert ML, et al. Patient satisfaction with health care decisions: the satisfaction with decision scale. *Medical Decision Making*. 1996; 16(1):58–64. [PubMed: 8717600]
- Hughes C, Fasaye GA, LaSalle VH, Finch C. Sociocultural influences on participation in genetic risk assessment and testing among African American women. *Patient Education and Counseling*. 2003; 51(2):107–114. [PubMed: 14572939]
- Hughes C, Gomez-Caminero A, Benkendorf J, Kerner J, Isaacs C, Barter J, et al. Ethnic differences in knowledge and attitudes about BRCA1 testing in women at increased risk. *Patient Education and Counseling*. 1997; 32(1–2):51–62. [PubMed: 9355572]
- Kinney AY, Simonsen SE, Baty BJ, Mandal D, Neuhausen SL, Seggar K, et al. Acceptance of genetic testing for hereditary breast ovarian cancer among study enrollees from an African American kindred. *American Journal of Medical Genetics A*. 2006; 140(8):813–826.
- Klemp JR, O'Dea A, Chamberlain C, Fabian CJ. Patient satisfaction of BRCA1/2 genetic testing by women at high risk for breast cancer participating in a prevention trial. *Familial Cancer*. 2005; 4(4):279–284. [PubMed: 16341803]
- Kumanyika SK, Whitt-Glover MC, Gary TL, Prewitt TE, Odoms-Young AM, Banks-Wallace J, et al. Expanding the obesity research paradigm to reach African American communities. *Preventing Chronic Disease*. 2007; 4(4):A112. [PubMed: 17875256]
- Lerman C, Hughes C, Benkendorf JL, Biesecker B, Kerner J, Willison J, et al. Racial differences in testing motivation and psychological distress following pretest education for BRCA1 gene testing. *Cancer Epidemiology Biomarkers and Prevention*. 1999; 8(4 Pt 2):361–367.
- Lerman C, Narod S, Schulman K, Hughes C, Gomez-Caminero A, Bonney G, et al. BRCA1 testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes. *Journal of the American Medical Association*. 1996; 275(24):1885–1892. [PubMed: 8648868]
- Long JA, Chang VW, Ibrahim SA, Asch DA. Update on the health disparities literature. *Annals of Internal Medicine*. 2004; 141(10):805–812. [PubMed: 15545681]
- Murff HJ, Byrne D, Haas JS, Puopolo AL, Brennan TA. Race and family history assessment for breast cancer. *Journal of General Internal Medicine*. 2005; 20(1):75–80. [PubMed: 15693932]
- Nanda R, Schumm LP, Cummings S, Fackenthal JD, Sveen L, Ademuyiwa F, et al. Genetic testing in an ethnically diverse cohort of high-risk women: a comparative analysis of BRCA1 and BRCA2 mutations in American families of European and African ancestry. *Journal of the American Medical Association*. 2005; 294(15):1925–1933. [PubMed: 16234499]
- National Cancer Institute. Strategic Plan to Reduce and Ultimately Eliminate Health Disparities. 2006.
- O'Connor, A.; O'Brien-Pallas, LL. Decisional conflict. In: McFarland, GK.; McFarlane, EA., editors. *Nursing Diagnosis and Intervention*. Toronto, Ontario: Canada: C.V. Mosby; 1989. p. 573
- Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Medical Care*. 1981; 19(2):127–140. [PubMed: 7206846]
- Schulman KA, Berlin JA, Harless W, Kerner JF, Sistrunk S, Gersh BJ, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *New England Journal of Medicine*. 1999; 340(8):618–626. [PubMed: 10029647]
- Schwartz MD, Hughes C, Roth J, Main D, Peshkin BN, Isaacs C, et al. Spiritual faith and genetic testing decisions among high-risk breast cancer probands. *Cancer Epidemiology, Biomarkers and Prevention*. 2000; 9(4):381–385.
- Schwartz MD, Lerman C, Brogan B, Peshkin BN, Isaacs C, DeMarco T, et al. Utilization of BRCA1/BRCA2 mutation testing in newly diagnosed breast cancer patients. *Cancer Epidemiology, Biomarkers and Prevention*. 2005; 14(4):1003–1007.

- Smedley, BD.; Stith, AY.; Nelson, AR.; Care, IoMUSCoUaERaEDiH. Unequal treatment : confronting racial and ethnic disparities in health care. Washington, D.C: National Academy Press; 2003.
- Thompson HS, Valdimarsdottir HB, Duteau-Buck C, Guevarra J, Bovbjerg DH, Richmond-Avellaneda C, et al. Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiology, Biomarkers and Prevention*. 2002; 11(12):1579–1585.
- van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science and Medicine*. 2000; 50(6):813–828. [PubMed: 10695979]

Figure 1.

Satisfaction with Testing Decisions*

*n=44 women who received BRCA1/2 test results; Mean (SD) Satisfaction 18.6 (1.9)

Table 1

Sample Characteristics (n=135)

Variable	Level	n (%)
Age	50	82 (61%)
	> 50	52 (39%)
Marital status	Married	41 (30%)
	Not married	94 (70%)
Education level	Some college	94 (70%)
	High school	41 (30%)
Employment status	Employed	92 (68%)
	Not employed	43 (32%)
Income level	> \$35,000	65 (49%)
	\$35,000	68 (51%)
Cancer history	Affected	94 (70%)
	Unaffected	41 (30%)
Family history	2 or more	82 (61%)
	Less than 2	53 (39%)
BRCA1/2 prior probability	10%	76 (56%)
	5%–9%	59 (44%)
Randomization status [‡]	CTGC	55 (41%)
	SGC	62 (46%)
	NRC	18 (13%)
Participation in genetic counseling	Participant	79 (58%)
	Non-participant	56 (41%)

[‡]CTGC=Culturally Tailored Genetic Counseling; SCG=Standard Genetic Counseling; NRC=Non-Randomized Control Group

Table 2

Bivariate Analysis of Satisfaction (n=135)

Variable	Level	Satisfaction Mean (SD)	Kruskal Wallis Chi Square	P-Value
Sociodemographic Characteristics				
Age	50	17.5 (2.4)	0.07	0.79
	> 50	17.6 (2.2)		
Marital status	Married	18.0 (2.5)	3.16	0.08
	Not married	17.4 (2.2)		
Education level	Some college	17.7 (2.4)	2.19	0.14
	High school	17.2 (2.0)		
Employment status	Employed	17.5 (2.4)	0.005	0.94
	Not employed	17.6 (2.4)		
Income level	> \$35,000	17.8 (2.3)	2.26	0.13
	\$35,000	17.3 (2.2)		
Clinical Factors				
Cancer history	Affected	17.5 (2.2)	0.09	0.76
	Unaffected	17.6 (2.5)		
Family history	2 or more	17.6 (2.5)	0.67	0.41
	Less than 2	17.4 (1.9)		
BRCA1/2 prior probability	10%	17.7 (2.2)	1.26	0.26
	5%–9%	17.3 (2.3)		
Genetic Counseling Variables				
Randomization status [‡]	CTGC	17.5 (2.5)	0.54	0.76
	SGC	17.7 (2.1)		
	NRC	17.1 (2.2)		
Participation in genetic counseling	Participant	18.0 (2.0)	7.66	0.01
	Non-participant	16.9 (2.5)		

[‡]CTGC=Culturally Tailored Genetic Counseling; SGC=Standard Genetic Counseling; NRC=Non-Randomized Control (e.g., women who declined participation in genetic counseling at enrollment and were not randomized to CTGC or SGC)