

BARRIERS TO GENETIC TESTING FOR BREAST CANCER RISK AMONG ETHNIC MINORITY WOMEN: AN EXPLORATORY STUDY

Background/Aims: To assess awareness of genetic testing for breast cancer risk and identify influences on the decision-making process regarding counseling and testing among an ethnically-diverse sample of women.

Methods: Semi-structured interviews were conducted with 33 women who were breast or ovarian cancer survivors or first degree relatives of survivors. Interviews were audiotaped, translated, and transcribed. Analysis of transcripts identified relevant themes and quotes were extracted for illustration.

Results: Low levels of awareness were observed in minority women, including those with a significant family history of cancer. A number of potential influences on the decision-making process emerged including beliefs about risk factors for cancer and opinions about the options following testing. Distinct issues were identified within ethnic groups that may function as barriers such as concern about the misuse of genetic information (African Americans), unfamiliarity with Western preventive medicine (Asians), and women prioritizing family obligations over personal health needs (Latinas).

Conclusions: Results suggest there may be a need for interventions to raise awareness about genetic counseling and testing among minorities. Our findings contribute to the literature by using in-depth interviews to uncover potential barriers and facilitators to counseling and testing and by including Asians and Latinas, groups under-represented in previous research. (*Ethn Dis.* 2012;22(3): 267–273)

Key Words: Breast Cancer, Oncology, Ethnic Minorities, BRCA1/2, Barriers, Genetic Testing

From Fielding School of Public Health, and Jonsson Comprehensive Cancer Center, University of California, Los Angeles.

Address correspondence to Beth A. Glenn, PhD; Fielding School of Public Health, and Jonsson Comprehensive Cancer Center; 650 Charles Young Dr. South; Room A2-125, CHS; Los Angeles, CA 90095-6900; 310.206.9715; 310.206.3566 (fax); bgjenn@ucla.edu

Beth A. Glenn, PhD; Neetu Chawla, MPH, PhD; Roshan Bastani, PhD

INTRODUCTION

Breast cancer is the second most common cause of cancer-related death among women in the United States.¹ Approximately 5%–10% of all breast cancers can be attributed to mutations in the BRCA 1 or 2 genes.^{2,3} Although relatively rare, women affected by mutations in these two genes have a substantially elevated risk of developing breast (50%–85%) or ovarian (14%–40%) cancer in their lifetime.² Factors associated with an increased likelihood of BRCA mutations include the occurrence of both breast and ovarian cancer within a family, multiple cases of breast or ovarian cancer within a family, bilateral breast cancer, young age at diagnosis, and Ashkenazi Jewish heritage.^{4,5}

Prior to testing for BRCA 1/2, counseling is recommended in order to assess risk-level, explain the risks and benefits of testing, and provide psychosocial support and assistance with decision-making.⁶ Genetic counseling and testing has been shown to influence decisions regarding follow-up care including prophylactic surgery, chemoprevention, and screening (i.e. breast magnetic resonance imaging and mammography).^{7–9} Identification of the BRCA 1/2 mutation in one family member can inform other close family members about their own cancer risk and may encourage their use of services intended to reduce risk, such as increased surveillance or prophylactic surgery.^{8,10}

While availability and awareness of genetic counseling and testing services has grown over time, research has documented racial/ethnic disparities in utilization of genetic services.^{11,12} Most

studies examining the decision-making process regarding testing and counseling have been conducted with high risk populations, such as Ashkenazi Jewish women.¹³ Several studies have documented lower utilization of genetic testing and counseling services among ethnic minority women, particularly African Americans.^{14,15}

A study conducted by Armstrong et al found that African American women with a family history of breast or ovarian cancer were significantly less likely to undergo genetic counseling for breast cancer risk compared to White women, even after adjusting for the socioeconomic factors, probability of mutation, risk perception, and communication with primary care providers.¹¹ Underuse of counseling and testing services is problematic, since these services can help provide women access to cancer prevention research trials, medication to reduce the risk of cancer and cancer recurrence, information and referrals for prophylactic surgery, and increased surveillance to enhance early detection of breast cancer.^{9,16,17}

Limited research has examined uptake of counseling and testing among Latinas and Asian Americans or examined potential barriers and facilitators in ethnically-diverse samples.^{18,19} A recent review conducted by Forman and Hall specifically highlighted the lack of data focused on Asian American women and their potential barriers to genetic services.²⁰ Available data suggest that potential barriers to counseling and testing among minority women may include lack of awareness of the availability of testing, barriers to access and differences in some psychosocial factors.^{12,21,22} However, few studies have included

The primary purpose of this study was to use qualitative methods to explore potential barriers and facilitators to genetic testing in an ethnically diverse community-based sample of women who were either cancer survivors or first-degree relatives of breast or ovarian cancer cases.

Asian or Latina women or recruited multiethnic samples to allow for comparisons between ethnic groups.

The primary purpose of this study was to use qualitative methods to explore potential barriers and facilitators to genetic testing in an ethnically diverse community-based sample of women who were either cancer survivors or first-degree relatives of breast or ovarian cancer cases. The study assessed a range of topics, including beliefs about risk factors, awareness of testing services, cultural factors, perceived benefits and barriers to testing, and opinions about the options following testing. Given the lack of available data on minority women, we utilized qualitative methods in order to capture contributing factors that may not have been examined previously.

METHODS

Study Participants and Recruitment

Women were considered eligible for the study if they were a breast or ovarian cancer survivor or a first-degree relative of a breast or ovarian cancer case. Participants were identified through multiple community-based organiza-

tions and facilities offering cancer support services. A variety of methods were used to recruit participants. Flyers were posted at sites and the study was advertised through listservs targeting cancer patients. At some sites, staff assisted with recruitment by distributing flyers and providing information to potential participants. Some participants were also referred to the study through word of mouth. Recruitment sites included: The Wellness Community-West Los Angeles, Simms/Mann-UCLA Center for Integrative Oncology, Sisters' Network, Women of Color Breast Cancer Support Project, Chinese Herald Cancer Center, Asian Pacific Health Care Venture, Saath: South Asian Cancer Foundation, South Asian Network, and Filipino American Services Group, Inc. In addition, a few women were identified through their participation in a previous UCLA study.

Women were asked to participate in individual open-ended semi-structured interviews that were audiotaped for transcription and analyses. Interviews were conducted from March, 2004 to July, 2006. Although 36 women participated in individual interviews, two were excluded from the analysis sample due to inaudible audiotapes. One was excluded because she reported her racial/ethnic group as "other." The final sample included 33 women representing multiple Asian subgroups, African Americans, Latinas, and non-Latino Whites. The study maintained approval from the UCLA Institutional Review Board throughout its duration.

Study Interviewers

English interviews were conducted by the study's principal investigator. Bilingual research staff assisted with conducting, transcribing and translating interviews conducted with Spanish and Chinese speaking participants. Bilingual interviewers received training from the principal investigator regarding the purpose of the study, general information about genetic testing and counseling for

breast cancer risk, and the process of conducting qualitative interviews.

Data Collection and Analysis

A literature review was conducted to identify factors found to influence decision-making about genetic counseling and testing for breast cancer risk. The final interview guide utilized open-ended questions to assess the following domains: beliefs about risk factors for breast cancer; awareness and knowledge of genetic testing; interest in genetic testing; relevant cultural factors and beliefs; perceived barriers and benefits to testing; and opinions about options after a positive result.

Given that some women were learning about genetic testing for the first time, basic information was provided to all women regarding the options following testing (ie, prophylactic surgery to remove the breasts or ovaries, participation in a prevention research trial, or increased surveillance) based on information contained in the NCI brochure, *Genetic Testing for Breast and Ovarian Cancer Risk: It's Your Choice*.²³ This information was given to participants after awareness of counseling and testing was assessed.

On average, participant interviews were 60 to 90 minutes in duration. After English transcriptions were completed for all interviews, separate electronic documents were created by compiling participant responses for each domain. These files were analyzed to identify any emerging themes. Participant quotes were then extracted to illustrate these themes. Potential differences across racial and ethnic groups were also explored and highlighted in the analysis.

RESULTS

Participants' Characteristics

The characteristics of the participants are presented in Table 1. The median age of women interviewed was

Table 1. Participant characteristics (N=33)

Characteristics	% (n)	Characteristics	% (n)
Mean age		Marital status	
51.9 years	(n=32)	Married/living as	45.5 (15)
Ethnic background		Not married	45.5 (15)
Non-Latino White	9.1 (3)	DK/refused/missing	9.1 (3)
Asian	51.5 (17)	Education level	
Latino	15.2 (5)	<high school	9.1 (3)
African American	24.2 (8)	High school	45.5 (15)
Country of birth		College grad	18.2 (6)
United States	39.4 (13)	≥Grad school	21.2 (7)
Not United States	60.6 (20)	DK/refused/missing	6.1 (2)
Years lived in United States (among foreign-born)		Annual income	
≤9	20.0 (4/20)	<\$25,000	39.4 (13)
≥10	75.0 (15/20)	25,000–50,000	12.1 (4)
Missing	5.0 (1/20)	50,000–75,000	9.1 (3)
Health insurance		≥75000	24.2 (8)
Yes	87.9 (29)	DK/refused/missing	15.2 (5)
No	6.1 (2)	Cancer status	
DK/refused/missing	6.1 (2)	Survivor	69.7 (23)
Language of interview		Relative	30.3 (10)
English	75.8 (25)		
Spanish	12.1 (4)		
Chinese	12.1 (4)		

DK, don't know.

52 years. The ethnic distribution of the participants was: 17 Asians (52%; 7 South Asians, 6 Chinese, 2 Koreans, 2 Filipinos); 8 African Americans (24%); 5 Latinas (15%); and 3 non-Latino White women (9%). The study sample included 23 breast or ovarian cancer survivors (70%) and 10 first-degree relatives of breast or ovarian cancer cases (30%).

Qualitative Findings

Beliefs about Risk Factors

An open-ended question was used to assess personal beliefs about factors that increase a woman's risk for breast cancer. Women were encouraged to answer based on their own beliefs vs what they felt was the correct answer. Less than a third of participants mentioned genetics or family history when asked, "What in your opinion puts women at risk of getting breast or ovarian cancer?" Although a small group of participants included other known risk factors in

their response (ie, reproductive history), the most commonly cited risk factor was stress. Approximately half of the participants (16 of 33) cited stress as a risk factor and most of these women were either Asian or Latina.

Awareness of Genetic Testing

Out of the total sample, 11 women said they had heard of genetic counseling and testing for breast cancer risk prior to their involvement in the study. Although only a small number of non-Latino White women participated in the study (n=3), all had heard of genetic testing and at least one had participated in testing. The majority of ethnic minority participants had never heard about BRCA 1/2 testing. Only 3 out of 8 African American women, 5 out of 17 Asians, and none of the five Latina participants reported having heard of genetic testing. Among the participants who had heard of counseling and testing, some knew very little about

the process while others were quite informed, including a few participants who had undergone counseling or testing. In general, awareness about counseling and testing did not seem to differ between breast cancer survivors and first-degree relatives in the sample. Some of the women that were unaware of testing had significant family histories that would make them eligible for testing. For example, one African American participant who had never heard about testing prior to being referred to the study reported that her mother, several maternal aunts, and several first cousins had been diagnosed with breast cancer. There was a tendency for breast cancer survivors to confuse BRCA 1/2 testing with HER 2/Neu (human epidermal growth factor receptor 2) testing, which is recommended for women with invasive breast cancer to assess expression of the HER2/Neu gene in order to inform treatment decisions. In one case, a Latina breast cancer survivor reported that she had undergone "genetic testing." However, after further probing it was clear that she was referring to HER 2/Neu testing.

Interest in Genetic Counseling/Testing

After participants were provided with basic information about genetic assessment and testing, they were asked if they would be interested in pursuing genetic assessment services if they were determined to be eligible. Most women expressed interest with some ambivalence.

"I would have to think about it. Maybe. Sometimes I feel that I don't want to know if I have it [the gene] and sometimes I feel like I want to know." (Asian woman)

"If you are at least armed with the knowledge, you can make a decision. But when you don't know anything, you just feel like I'm going to have to sit here and wait for this to happen. Should I just wait and let a bomb be dropped on me or should I move? I think the best thing is to do something." (African American woman)

Cultural Factors Involved in Genetic Testing and Counseling

Women were asked if there was anything about being [African American, Latina or Asian] that would affect their opinion about genetic counseling and testing. Although some participants did not feel that culture or race would play a role, a number of potential influences on the decision-making process emerged for each ethnic group.

African Americans

Concerns about Misuse of Genetics and Distrust of Medicine and Research.

One of the themes that emerged in interviews with African American women was concern about the potential misuse of genetic information and general distrust of medicine and research. Women perceived this issue to be heightened for a health service such as genetic counseling and testing, which utilizes relatively new technology.

“One of my girlfriends who is so narrow-minded ... would say ‘I wouldn’t let those people experiment [referring to genetic testing] on me’ Some of my other friends, who are not as narrow-minded would think, ‘It’s best to find out all you can’... ‘Go for all the tests you can’ ”

“I think that for some women knowing that there might be some genetic predisposition for it [breast cancer] will get some antennae to go up.”

By referring to “antennae going up” this participant was suggesting that some African American women might be suspicious of genetic counseling and testing and of providers that wanted to engage women in the process of counseling and testing. She felt that some African American women would be concerned that documentation of genetic vulnerability could be used to denigrate African Americans as has happened in the past.

Lack of Awareness of Family History Due to Poor Family Communication.

Several African American women mentioned that they would have difficulty tracing their family history of cancer as

would be necessary to fully benefit from genetic counseling and testing.

“...We [African Americans] are not always sure [about disease diagnoses] ‘cause we have never gone to the hospital to follow up, to keep our history. We don’t have much [health information].

“I think that because ... our history goes down verbal...some women will [feel] alarm [if they learn about genetic testing] because there is no family connection to harvest the information [about family history]. But for those who have family connections, it would probably be an easier process.”

Asians

Unfamiliarity or Discomfort with Western Preventive Medicine.

A number of Asian women suggested that the mismatch between traditional medicine practiced in their countries of origin and genetic counseling and testing may prevent Asian women from pursuing testing.

“Nobody knows it [genetic testing]. They are so far away [from Western medicine]. The mammogram is coming out but this is the first time I heard about the gene test.”

“This concept is too advanced for [people from my country]. They are not familiar with this concept [of prevention through medical tests]. They are not so accepting of preventive medicine [Western medicine].”

Concerns about Stigma of Having

“Bad Genes.” “I think that in Asian families it is a big deal that you have a bad gene in the family. ... I think people were afraid before they had the [genetic] information and would make a big deal about family history [medical history]... when it comes to marriage. The parents would ask those questions what kinds of diseases were in your family before their children would get married.”

This participant described that family history of disease is sometimes taken into account by Asian families when

determining suitability of a potential son- or daughter-in-law. She expressed concern that Asian women might decline genetic testing because they would not want this information to affect their ability to marry in the future.

Feeling it is not Beneficial to Know about Negative Events in One’s Future.

Several participants suggested that Asian women may be less interested in testing because they do not want to learn about negative future events.

“I think that [women from my country] may be less accepting of this procedure than women of other ethnicities. We are pessimistic. They don’t want to know they are going to get something. It is a matter of fate to them.”

“Some people may not want to do it. They don’t want to know. They are afraid...[people from my country] are afraid of knowing.”

Latinas

Women Prioritizing Family Responsibilities over Personal Health Needs and Lack of Awareness about Medicine and Advanced Technologies.

Several Latina participants mentioned that traditional female roles may lead Latinas to prioritize their family’s needs over their own and make them less aware and accepting of preventive health services such as genetic counseling and testing.

“I think we [Latinas] tend to be more concerned about... family loyalty [vs personal health care needs]...we become martyrs and we will take the pain and suffering...Culturally this is what women do, it is something that is ingrained in your culture in your upbringing...You [women] don’t burden the family unnecessary”

“Now people know what cancer is and before they knew nothing. The people are still embarrassed...to do the regular check-ups like pap and mammogram ... They are lacking in information. ”

“Well, even when I was living in [my home country] I never had a conversation in regards to cancer. I

was very diligent in keeping up with my health. Yet there is the lack of information that is available out there.”

Perceived Benefits of Testing

Women who expressed interest in pursuing counseling and testing were asked to provide reasons. Three basic themes emerged: to provide information for their families; to inform their own health, which was particularly important for survivors; and for the benefit of society and scientific research. Below are illustrative quotes within each theme.

To Provide Information for Their Families. “Well, for one, for my granddaughter I think it is really important to know and my daughter too. To know if I have the gene...and they will be tested and if it comes out positive they can make an honest choice about it.” (African American woman)

To Inform Their Own Health. “So I know what the chances are that I will get cancer again. Or, if it is clear, it will make me happy. More relaxed. Especially because I had it twice.” (Asian woman).

“...for prevention and to know what to do in case it would happen to me or... to any of my relatives or future generations.” (Latina woman).

To Contribute to Science and Society through Participation in Research. “I would also like to do it to help other people because it is still experimental. I would do it for the good of others because it is research.” (Asian woman)

Perceived Barriers to Testing

All women were asked about what they saw as potential barriers to counseling and testing. Major perceived barriers were cost, concerns about the potential effect on family members, and potential insurance discrimination.

Cost. “Since I only rely on Medi-Cal...I would not know what to do if the test would not be covered.” (Latina woman).

“If I had to pay for it I wouldn’t do it.” (Asian woman)

Potential Insurance Discrimination.

“I am already worried about it. I can’t get insurance...I have tried to get insurance...I have been looking for ten years...It’s already a concern...and yeah! You are discriminated [against]. The people [who] need it the most can’t get it.” (Latina woman)

“They [insurance company] try not to pay or don’t want to give insurance. They did not want to give me insurance for diabetes and high blood pressure.” (Latina woman)

Concern about the Effects on Family Members. “When you find out about your diagnosis I think I would get worried that I’m a carrier and worried that my children may be carriers as well. I felt it more after seeing my friends die from breast cancer.” (Latina woman)

“I would be worried about my family knowing the results....They have seen me going around bald headed. They do know how horrible chemo is...I think it would make them more depressed because they know what I went through.” (African American woman)

Opinions about Options Following Testing

Participants were then asked their opinions about the some of the options to reduce future cancer risk that may be available to women who receive a positive test result: prophylactic surgery to remove the breasts or ovaries; participation in a research study testing risk reduction strategies; or increased surveillance (eg, more frequent mammograms, magnetic resonance imaging of the breast). Opinions about prophylactic surgery and involvement in a prevention trial were mixed. However, women held uniformly positive attitudes towards increased surveillance for women with a positive test result.

Prophylactic Surgery. Women held a range of opinions about prophylactic

surgery. Most Asian and Latina participants felt that this option was too extreme, whereas the African American and non-Latino White women were more open to the idea. Breast cancer survivors were generally more open to prophylactic surgery than were first-degree relatives in the sample.

“I think it depends how much it’s in her family. And I think it depends on her stability... See somebody like me it’s a different story when you got no support system and you’re home by yourself. I mean when there are people there to help you...It makes it different.” (non-Latino White woman).

“Among healthy women... I don’t agree with that. I think it is too extreme..... among otherwise healthy survivors....a little different. It would be more acceptable.” (Asian woman).

Joining a Research Study or Clinical Trial to Evaluate Risk Reduction Strategies. Women generally had favorable opinions about participation in research that evaluated the effect of a change in lifestyle like a special diet, physical activity program or a vitamin. However, most participants, particularly first-degree relatives, expressed concern about participating in trials that involved medications due to concerns about side effects.

“I would love nothing else but for my daughter to get into a study. I would volunteer her name, so someone could call her and ask her if she just wants to start now to be tracked and be in a study. (non-Latino White woman)

“My whole thing is side effects. With side effects I could get a whole different kind of cancer even though it can’t be detrimental...just the fact that knowing that I could get it...I wouldn’t begin to take the medication.” (African American woman)

DISCUSSION

This was one of the first studies to qualitatively examine potential barriers

and facilitators to genetic counseling and testing for breast cancer risk in an ethnically diverse sample of women including Asians and Latinas. Most minority women in our sample were not aware of the availability of genetic counseling and testing for breast cancer risk. This included a number of women with significant family histories of breast cancer, such as women with multiple premenopausal diagnoses on the same side of the family. Low levels of awareness among ethnic minority women about genetic services has been observed in prior population-based studies, particularly among immigrants.^{20,24,25} Perhaps more importantly, our results revealed a number of potential influences on the decision-making process including beliefs about risk factors for cancer, opinions about the options following receipt of a positive test result and cultural factors.

Causal attributions related to the development of cancer may conceivably predict interest in cancer genetic services. Although participants were specifically recruited for a genetic study most did not mention genetics or family history when asked about risk factors. In contrast, many women, particularly Latinas and Asians in our sample, cited stress as the most important risk factor. These beliefs may underlie, in part, lower utilization of genetic services for some women.

Although many participants were hearing about genetic counseling and testing for the first time, most were interested in learning more about the process. The most commonly perceived benefits of counseling and testing were providing information to family members, informing one's own health and making a contribution to science and society through research.

Women also voiced a number of concerns about genetic testing, which may function as barriers, including cost, concern about effect on the family, and concerns about potential insurance discrimination as consistent with prior

research.²⁰ Interest also appeared to be related to acceptability of options following testing. As might be expected, we found that women viewed less invasive measures more favorably such as enrolling in a prevention trial evaluating a behavioral strategy or increased surveillance as compared to taking a medication to reduce risk or prophylactic surgery. Immigrant women in our sample voiced strong objections to the option of prophylactic surgery.

Finally, a number of cultural factors emerged as potential influences on the decision-making process within each ethnic group. African American women cited a lack of awareness of familial cancer diagnoses due to poor communication between family members and concerns about misuse of genetic information as has been observed in prior studies.²¹ Asian participants expressed discomfort with Western medicine, concern about the stigma associated with "bad" genes, and expressed resistance to learning about negative future events, especially those out of one's control. Resistance to learning about negative future events may be similar to prior research that documented Asian and Latina women to be more likely than non-Latina Whites to perceive counseling and testing as interfering with the natural order of life or fate.²⁶ Themes emerging from interviews with Latinas revealed a lack of familiarity with and use of medical care and the tendency for Latinas women to not prioritize their own health needs, observations consistent with prior research.²⁷

Several limitations of this study should be acknowledged. The sample size is small, particularly for some ethnic groups, although we feel that thematic saturation was reached across most domains. In addition, some participants would not be eligible for genetic testing based on their personal and familial cancer histories but many would be eligible for counseling. Due to the challenging nature of identifying high

Most minority women in our sample were not aware of the availability of genetic counseling and testing for breast cancer risk.

risk women in community settings, we used multiple methods for recruitment, allowed both cancer survivors and first-degree relatives to participate, and did not restrict our sample to women eligible for genetic testing, which may have affected the generalizability of our results.

While there were some limitations to the study, there were also a number of strengths. Our results revealed potential influences on decision-making related to genetic counseling and testing among Asian and Latina women – two ethnic groups that are under-represented in the existing literature. This study also utilized a qualitative approach which helped illustrate several themes, particularly in the areas of cultural factors, perceived barriers to testing and opinions about follow-up care that have not been well-documented in the quantitative literature. In addition, these findings are useful in generating hypotheses and suggest avenues for future research. Large-scale studies within ethnically-diverse samples of high risk women are needed to assess the relative importance of factors in influencing the decision-making process as well as to assess predictors of receipt of risk-appropriate cancer genetics services.

ACKNOWLEDGMENTS

We would like to thank the community-based organizations and Dr. Kimlin Ashing-Giwa (City of Hope, Duarte, CA) for their assistance with participant recruitment. Funding sources: Department of Defense, Breast Cancer Research Program, Concept Award #BC995003; Jonsson Cancer Center

Foundation Postdoctoral Fellowship; California Breast Cancer Research Program, Postdoctoral Fellowship #9FB-0093.

REFERENCES

- American Cancer Society. *Cancer Facts and Figures, 2009–2010*. 2011;www.cancer.org, May 20, 2011.
- Thompson D, Easton DF. Cancer Incidence in BRCA1 mutation carriers. *J Natl Cancer Inst*. 2002;94(18):1358–1365.
- Chen S, Parmigiani G. Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol*. 2007;25(11):1329–1333.
- Antoniou AC, Pharoah PD, McMullan, et al. A comprehensive model for familial breast cancer incorporating BRCA1, BRCA2 and other genes. *Br J Cancer*. 2002;86(1):76–83.
- Hartge P, Struewing JP, Wacholder S, Brody LC, Tucker MA. The prevalence of common BRCA1 and BRCA2 mutations among Ashkenazi Jews. *Am J Hum Genet*. 1999;64(4):963–970.
- Nelson HD, Huffman LH, Fu R, Harris EL, US Preventive Services Task Force. Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: systematic evidence review for the U.S. Preventive Services Task Force. *Ann Intern Med*. 2005;143(5):362–379.
- Schwartz MD, Peshkin BN, Tercyak KP, Taylor KL, Valdimarsdottir H. Decision making and decision support for hereditary breast-ovarian cancer susceptibility. *Health Psychol*. 2005;24(4 Suppl):S78–S84.
- Brekelmans CT, Seynaeve C, Bartels CC, et al. Effectiveness of breast cancer surveillance in BRCA1/2 gene mutation carriers and women with high familial risk. *J Clin Oncol*. 2001;19(4):924–930.
- Grann VR, Jacobson JS, Thomason D, et al. Effect of prevention strategies on survival and quality-adjusted survival of women with BRCA1/2 mutations: an updated decision analysis. *J Clin Oncol*. 2002;20(10):2520–2529.
- Bradbury AR, Dignam JJ, Ibe CN, et al. How often do BRCA mutation carriers tell their young children of the family's risk for cancer? A study of parental disclosure of BRCA mutations to minors and young adults. *J Clin Oncol*. 2007;25(24):3705–3711.
- Armstrong K, Micco E, Carney A, Stopfer, Putt M. Racial differences in the use of BRCA1/2 testing among women with a family history of breast or ovarian cancer. *JAMA*. 2005;293(14):1729–1736.
- Pagan JA, Su D, Li L, Armstrong K, Asch DA. Racial and ethnic disparities in awareness of genetic testing for cancer risk. *Am J Prev Med*. 2009;37(6):524–530.
- Lehmann LS, Weeks JC, Klar N, Garber JE. A population-based study of Ashkenazi Jewish women's attitudes toward genetic discrimination and BRCA1/2 testing. *Genet Med*. 2002;4(5):346–352.
- Halbert CH, Kessler LJ, Mitchell E. Genetic testing for inherited breast cancer risk in African Americans. *Cancer Invest*. 2005;23(4):285–295.
- Thompson HS, Valdimarsdottir HD, Duteau-Buck C, et al. Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiol Biomarkers Prev*. 2002;11(12):1579–1585.
- Kriege M, Brekelmans CT, Boetes C, et al. Efficacy of MRI and mammography for breast-cancer screening in women with a familial or genetic predisposition. *N Engl J Med*. 2004;351(5):427–437.
- Hamm RM, Lawler F, Scheid D. Prophylactic mastectomy in women with a high risk of breast cancer. *N Engl J Med*. 1999;340(23):1837–1838.
- Huo D, Senie RT, Daly M, et al. Prediction of BRCA Mutations Using the BRCAPRO Model in Clinic-Based African American, Hispanic, and Other Minority Families in the United States. *J Clin Oncol*. 2009;27(8):1184–1190.
- Hall MJ, Reid JE, Brubridge LA, et al. BRCA1 and BRCA2 mutations in women of different ethnicities undergoing testing for hereditary breast-ovarian cancer. *Cancer*. 2009;115(10):2222–2233.
- Forman AD, Hall MJ. Influence of race/ethnicity on genetic counseling and testing for hereditary breast and ovarian cancer. *Breast J*. 2009;15 Suppl 1:S56–S62.
- Peters N, Rose A, Armstrong K. The association between race and attitudes about predictive genetic testing. *Cancer Epidemiol Biomarkers Prev*. 2004;13(3):361–365.
- Sussner KM, Thompson HS, Jandorf, et al. The influence of acculturation and breast cancer-specific distress on perceived barriers to genetic testing for breast cancer among women of African descent. *Psychooncology*. 2009;18(9):945–955.
- National Cancer Institute. *Genetic Testing for Breast and Ovarian Cancer Risk: It's Your Choice*. www.cancer.gov/cancertopics/genetic-testing-for-breast-and-ovarian-cancer-risk. December 17, 2009.
- Wideroff L, Vadaparampil ST, Breen N, Croyle RT, Freedman AN. Awareness of genetic testing for increased cancer risk in the year 2000 National Health Interview Survey. *Community Genet*. 2003;6(3):147–156.
- Honda K, Neugut AI. Associations between perceived cancer risk and established risk factors in a national community sample. *Cancer Detect Prev*. 2004;28(1):1–7.
- Thompson HS, Valdimarsdottir HB, Jandorf L, Redd W. Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: differences across African American, Latina and Caucasian women. *Patient Educ Couns*. 2003;51(3):217–227.
- Elder JP, Ayala GX, Parra-Medina D, Talavera GA. Health communication in the Latino community: issues and approaches. *Annu Rev Public Health*. 2009;30:227–251.

AUTHOR CONTRIBUTIONS

Design and concept of study: Glenn, Chawla, Bastani

Acquisition of data: Glenn, Bastani

Data analysis and interpretation: Glenn, Chawla, Bastani

Manuscript draft: Glenn, Chawla

Statistical expertise: Glenn

Acquisition of funding: Glenn, Bastani

Administrative: Glenn, Bastani