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Authors

Beattie, Mary S
Copeland, Kelli
Fehniger, Julia
et al.

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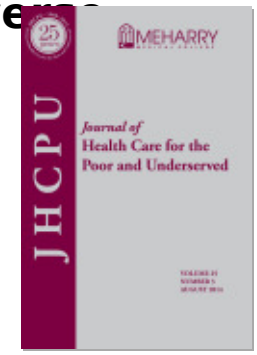

Mary S. Beattie, Kelli Copeland, Julia Fehniger, Eleanor Cheung, Galen Joseph, Robin Lee, Judith Luce

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Genetic Counseling, Cancer Screening, Breast Cancer Characteristics, and General Health among a Diverse Population of *BRCA* Genetic Testers

Mary S. Beattie MD, MAS
Kelli Copeland, BA
Julia Fehniger, BA
Eleanor Cheung, MD
Galen Joseph, PhD
Robin Lee, MS, CGC
Judith Luce, MD

Abstract: Outcomes after genetic testing for Hereditary Breast and Ovarian Cancer (HBOC) Syndrome have not been well studied in underserved populations. We surveyed 1,123 *BRCA* testers from a genetic counseling program serving an academic cancer center (n=1,045) and a public county hospital (n=78) a median of 3.7 years after testing for mutations in *BRCA1* and *BRCA2* (breast cancer susceptibility genes). We compared genetic counseling outcomes, cancer screening rates, and self-reported general health. We found no differences in genetic counseling outcomes between hospitals. Breast cancer screening rates were similarly high at both hospitals, which are warranted in this high-risk population. Screening rates for ovarian, colon, and skin cancer were significantly lower in participants from the public hospital. *BRCA* results were not a predictor of general health at either hospital. When creating a genetic counseling program that serves women in different hospital settings, providers should emphasize guidelines-based screening recommendations for all patients.

Key words: Genetic testing, hereditary breast and ovarian cancer syndrome, genetic counseling, health care disparities, cancer screening, *BRCA1/2*.

In the last 15 years, genetic testing for cancer predisposition has become clinically available, which has allowed for the identification of families at risk of Hereditary Breast and Ovarian Cancer (HBOC) Syndrome and other hereditary cancer syndromes. Prior literature has demonstrated disparities in the availability and uptake of genetic

*The authors are affiliated with the University of California San Francisco (UCSF) Cancer Risk Program **[MSB, JF, EC, RL]**, the UCSF Department of Internal Medicine **[MSB]**, the UC Department of Epidemiology and Biostatistics **[MSB]**, the UC School of Medicine **[KC]**, the UCSF Department of Anthropology, History, and Social Medicine **[GJ]**, and the UCSF Department of Internal Medicine, Division of Hematology-Oncology **[JL]**. Please address correspondence to Mary S. Beattie, 1635 Divisadero Suite 600, San Francisco, CA 94115; (415) 713-4191; mary.stanley.beattie@alumni.duke.edu.*

testing for HBOC in underserved and diverse families.[1,2,3,4] African American and Latina women are less likely than White women to undergo genetic testing for mutations in *BRCA1* and *BRCA2* (breast cancer susceptibility) genes,[2,3] and individuals with lower education levels are also less likely to test for *BRCA* mutations.[4] Mutations in the *BRCA1* and *BRCA2* genes cross many racial, ethnic, and socioeconomic boundaries,[5,6,7] but both genetic counseling and *BRCA* testing are typically less available and utilized in minority and low-income populations.[6]

Prior literature has examined outcomes after *BRCA* testing, including cancer screening and risk-reduction, emotional and psychological distress, general health, and family communication. These outcomes, however, have not been carefully studied in large, underserved populations. In predominantly White women at risk of HBOC, age and cancer history were associated with receiving cancer screening, risk-reducing mastectomy, and risk-reducing salpingo-oophorectomy (removal of the tubes and ovaries).[8,9] In individuals who test *BRCA* positive, prior literature has not shown increases in distress or anxiety.[10] Perceived general and emotional health may be reduced in women with cancer or who are the first-identified *BRCA* carriers in their family.[11] Communication of *BRCA* test results among family members in diverse populations was found to vary between ethnic and socio-economic groups.[12] None of these studies were specifically designed to examine disparities between populations of *BRCA* testers, although there is a growing need to study diverse families at risk of HBOC.

In recent years, *BRCA* testing has become more available to diverse populations through grants, charitable foundation gifts, expansion of coverage for some private insurers, and 26 state Medicaid programs.[13] Genetic counseling and testing programs across the US have developed methods to identify, screen and educate diverse and underserved women who are at high risk for hereditary cancer.[14–18] Although access to genetic counseling and testing for cancer risk may be increasing in these populations, the impact and long-term outcomes of these services is poorly understood. The ability to perform such studies has been limited by difficulties in recruiting large populations of diverse *BRCA* testers. Comparing separate *BRCA* testing programs presents another challenge, as programs targeted to diverse populations often have different protocols and recruitment strategies tailored to their patient population and practice environment. Furthermore, few studies have directly compared outcomes after *BRCA* testing among diverse and underserved populations in practice-based clinical settings.

To investigate the impact of *BRCA* testing on women at high risk of hereditary breast and ovarian cancer, particularly in diverse and underserved populations, we surveyed 1,123 women who were tested for *BRCA* mutations at two sites affiliated with the University of California San Francisco (UCSF) Cancer Risk Program (CRP). This program has served a racially diverse population since 1996, and has offered cost-free testing to eligible patients since 2002.[14] The two UCSF program sites, an academic cancer center and public county hospital, use the same clinical protocol and staff. The survey instruments and outcome assessments at both sites were identical. This infrastructure allows for a unique comparison of cancer screening behaviors, breast cancer diagnosis and treatment, genetic counseling outcomes, and self-reported general health between high-risk women in two different hospital settings.

Methods

Study protocol. We leveraged the clinical protocol of the UCSF CRP, which provides *BRCA* testing at two hospital sites: 1) an academic cancer center, the UCSF Helen Diller Family Comprehensive Cancer Center (Diller); and 2) a public county hospital, San Francisco General Hospital (SFGH). Both hospital sites use the same *BRCA* testing methods, genetic counselors, and threshold for *BRCA* testing.[14] The UCSF CRP has offered genetic counseling and testing at Diller since 1996. In 2002, with a gift from the Avon Foundation, the CRP opened a satellite clinic at the affiliate public county hospital, SFGH. Since that time, the SFGH clinic has served a diverse population of patients and offered genetic counseling and testing free of charge to uninsured or underinsured patients. Patients at SFGH have access to risk-reducing interventions and cancer screening, and those found to be at high risk of HBOC can receive appropriate screening and risk-reducing procedures.

Hospital sites and referral patterns. Diller is an academic cancer center within the 660-bed UCSF hospital system. The UCSF hospital system serves approximately 27,000 inpatients and 750,000 outpatients a year. The emergency department in this academic center receives 36,000 visits a year. Approximately 600 breast cancer patients are seen annually at Diller.

In contrast, SFGH is a public county hospital with 275 inpatient beds. San Francisco General Hospital serves approximately 16,000 inpatients and 489,000 outpatients a year. The emergency department at SFGH receives 53,000 visits a year. Approximately 60 breast cancer patients are seen annually at SFGH.

The referral patterns and volume of patients in the CRP at each hospital differ substantially. The UCSF CRP at Diller serves patients from throughout Northern California. Referrals to Diller come from oncologists, surgeons, and primary care providers across California and neighboring states. Additionally, approximately one-third of the referrals to the CRP at Diller come from a combination of family members, self-referrals, and genetic counselors outside UCSF. In 2008, the CRP at Diller received 1,182 referrals.

In contrast, SFGH serves as a safety-net hospital for the City and County of San Francisco only. Referrals to the CRP at SFGH are primarily received through public health screening and outreach programs, as well as from the hospital's oncology clinics and providers within San Francisco's community health network. One of the public health strategies used to identify high-risk patients in San Francisco is a family history questionnaire given to women prior to mammography.[14] These questionnaires are reviewed by a genetic counselor to assess heritable cancer risk. If the questionnaire responses indicate an increased risk of HBOC, the patient's primary care provider or the patient herself is contacted by the CRP and offered a free-of-charge genetic counseling visit. Unlike the Diller setting, very few patients at SFGH are self-referred or referred by family members for genetic counseling and *BRCA* testing. In 2008, the CRP at SFGH received 140 referrals.

Study participants. Participants for this study were recruited from both UCSF CRP hospital sites. All women who underwent *BRCA* testing at either hospital between January 1996 and March 2008 were considered eligible and were contacted in 2008 to

participate in an IRB-approved follow-up survey. Informed consent was obtained for all enrolled participants.

Measures. All study participants completed a comprehensive 22-page survey that used multiple choice and open-ended questions that queried demographic characteristics (including self-reported race and ethnicity), general medical history, cancer history, cancer screening and cancer prevention behaviors. Women who had been diagnosed with cancer completed an additional 6-page cancer module that included questions about cancer type, cancer detection and treatments. Chart review was used to confirm medical histories, including cancer history (verified by pathology reports) and *BRCA* genetic testing results. These genetic test results were categorized as positive, true negative, uninformative negative, or variant of undetermined significance. Positive *BRCA* results occurred when a woman tested positive for a known deleterious mutation that significantly increases the risk of breast, ovarian, and other *BRCA*-related cancers. True negative *BRCA* results occurred when a woman tested negative for a deleterious *BRCA* mutation that was identified in one of her relatives. Uninformative negative *BRCA* results occurred when a woman received a negative *BRCA* result, but there was no known deleterious *BRCA* mutation in her family. A variant of undetermined significance result means that a mutation in *BRCA1* or *BRCA2* was found that may or may not increase the risk of cancer.

Following pilot testing of the survey's language and structure in a diverse sample of *BRCA* testers, participants received the survey by mail, using reminder postcards and three mailings as necessary. In order to recruit women with low literacy and women for whom English is not their primary language, we employed language-concordant research assistants and interpreters in Spanish, Russian, Mandarin, and Cantonese to complete the survey verbally for 25 study participants at SFGH.

Demographic information and medical history. At enrollment, baseline census demographic data were collected. We collected self-reported race and ethnicity information by survey.

To assess socioeconomic status in all participants, we enlisted a third-party company, Nielsen Claritas, to determine income-producing assets (IPA) for each participant. Nielsen Claritas[19] was provided with anonymized census demographic data to estimate IPA per individual household using several variables, including income and home ownership.

Cancer screening behaviors. We queried breast cancer screening history with the following questions: "Have you ever had a mammogram for breast cancer screening?" "Have you ever had a breast MRI for breast cancer screening?" and "Have you ever had a clinical breast exam for breast cancer screening?" We queried ovarian cancer screening with the two questions "Have you ever had a transvaginal ultrasound for ovarian cancer screening?" and "Have you ever had a screening CA-125 blood test for ovarian (or primary peritoneal) cancer screening?" We considered participants to have undergone screening for ovarian cancer if they answered "yes" to either question.

To evaluate colon cancer screening, participants were asked, "Have you ever been screened for colon cancer with any of the following: colonoscopy, sigmoidoscopy, barium enema, stool blood test?" To evaluate skin cancer screening history, partici-

pants were asked, "Have you ever had a head to toe skin exam/mole check to screen for melanoma or skin cancer?"

To evaluate how closely participant cancer screening behaviors adhere to screening guidelines, we reviewed the most recent screening recommendations for four common cancers according to the United States Preventive Health Services Task Force (USPSTF), including whether or not routine screening is recommended for each cancer in the general population and if so, at what age and with what screening modalities.

Genetic counseling outcomes. Additional survey questions assessed women's ease of understanding their *BRCA* results, recollection of receiving screening and prevention recommendations, knowledge of screening and risk reduction recommendations, and satisfaction with the decision to *BRCA* test. To assess ease of understanding *BRCA* results, we asked participants, "When you received your genetic test results, how difficult were they to understand?" with the following four response choices: "easy to understand," "somewhat easy," "somewhat difficult," and "difficult." To assess participants' recollection of receiving screening and prevention recommendations, we asked the following two questions "Did you receive cancer screening recommendations from the Cancer Risk Program?" and "Did you discuss cancer prevention options with the Cancer Risk Program?" Answer choices to these questions were: yes, no, and I don't know.

To assess knowledge of screening and risk reduction, we asked eight true/false questions related to breast and ovarian cancer screening and prevention. To assess satisfaction with the decision to *BRCA* test, we used the validated six-point satisfaction with decision (SWD) scale,[20] modified specifically to query the decision to undergo *BRCA* testing for cancer risk. This scale includes the following components: feeling adequately informed about options, making a decision consistent with personal values, and having adequate input in the decision. All responses to the SWD scale used the same five-point Likert scale. The Cronbach's α for this measure in our population was 0.87.

General health. To assess self-reported general health, we asked participants, "In general, how would you describe your current overall health?" Response choices were: excellent, good, fair, or poor.

Statistical analysis. We described population characteristics, cancer screening behaviors, breast cancer diagnosis and treatment characteristics, genetic testing outcomes, and self-reported general health in both the Diller and SFGH populations. We compared the Diller and SFGH populations using Student's t-test for continuous variables and chi-squared tests for categorical variables. Fisher's exact test was used when cell sizes were < 5. Student's t-test and chi square tests were also used to compare method of detection, tumor characteristics and treatment among participants with a personal history of breast cancer. Multivariate regression was used to identify independent predictors of self-reported general health. All analysis was done in STATA 11 (Stata Corp).

Results

Of the 1,468 women eligible for the study, 1,123 completed the survey. The survey achieved a response rate of 80% overall (82% for patients from Diller and 70% for patients from SFGH). Age at survey, year of *BRCA* testing, *BRCA* test results, and cancer history

Table 1.

DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF 1123 *BRCA* TESTERS BY HOSPITAL SITE

Characteristic	Diller n=1045 (%)	SFGH n=78 (%)	p-value
Age at Survey			.52
Median	53 years	52.5 years	
Range	21–91	31–73	
Race[a]			<.001
White	904 (87)	40 (51)	
Asian	58 (6)	7 (9)	
Latina	32 (3)	14 (18)	
African American	15 (1)	7 (9)	
Mixed	19 (2)	7 (9)	
Other	16 (2)	3 (4)	
Income-Producing Assets (IPA)[b]			<.001
≤ $50,000	93 (8.9)	29 (37)	
$50,001-$100,000	72 (6.9)	13 (17)	
$100,001-$500,000	342 (33)	30 (38)	
$500,001-$1,000,000	147 (14)	4 (5.1)	
>$1,000,000	390 (37)	2 (2.6)	
Primary Language Spoken			<.001
English	1045 (100)	53 (68)	
Spanish	0	9 (12)	
Russian	0	13 (17)	
Cantonese	0	1 (1)	
Mandarin	0	2 (2)	
History of Cancer			
Breast	646 (62)	45 (58)	.47
Ovarian	71 (7)	10 (13)	.045
Self reported General Health			<.001
Excellent	414 (40)	12 (15)	
Good	530 (51)	30 (39)	
Fair	82 (7.8)	32 (41)	
Poor	19 (1.8)	4 (5.1)	

[a]One Diller participant did not report her race/ethnicity.
[b]Income-producing assets per household was estimated using income, home ownership, and other variables with methods from Nielsen Claritas via anonymized census demographic data

did not differ between non-responders and responders. Mean age at *BRCA* testing for all participants was 49 years and the mean age at the survey was 53 years. Median time since *BRCA* testing was 3.7 years. Overall, 14% of survey participants were non-White.

Table 1 describes and compares demographic and basic clinical characteristics of participants from Diller and SFGH. The majority of participants received their *BRCA*

testing at Diller (93%). Race, IPA, ovarian cancer prevalence and self-perceived general health differed between participants at the two hospital sites (p-value < .05). Participants at Diller were more likely to be White, have IPA greater than $500,000, and report good or excellent general health. In contrast, women at SFGH represented a broader racial, ethnic, and socioeconomic mixture; and these women were also more likely to report fair or poor general health. Breast cancer rates in the study population were similar between the two hospitals (62% at Diller and 58% at SFGH). The prevalence of ovarian cancer among SFGH participants was twice as high as in Diller participants (14% *versus* 7%).

As shown in Table 2, screening mammography rates (95% at Diller and 94% at SFGH) and screening clinical breast exam rates (93% at Diller and 92% at SFGH) were high at both hospital sites. Age at first mammogram was significantly different at the two hospitals: 35.9 years at Diller and 38.7 at SFGH. Self-reported rates of ovarian cancer screening, colon cancer screening, and skin cancer screening were significantly higher at Diller compared with SFGH ($p < 0.05$ for ovarian, colon, and skin cancer screening).

Overall, 691 women (62% of the survey population) reported a diagnosis of breast cancer. Table 3 describes the method of detection, estrogen receptor status, triple negative status, surgical interventions, and non-surgical treatments for these breast cancer survivors. The most common method of detection at both hospitals was self-reported lump. This detection method was significantly more frequent at SFGH (71% of diagnoses) compared with Diller (47% of diagnoses). Detection by screening mammography was more frequent at Diller (37% of diagnoses) compared with SFGH (16% of diagnoses). Breast cancer survivors from Diller were more likely to have estrogen receptor positive tumors (65% at Diller and 47% at SFGH), although 29% of breast cancer survivors from SFGH did not know their tumor's estrogen receptor status. Eighteen percent of breast cancer survivors at SFGH reported triple negative tumors (estrogen receptor negative, progestin receptor negative, HER2 negative) compared with 11% at Diller. Lumpectomy rates were similar at both hospitals, but bilateral mastectomy was more common at Diller and unilateral mastectomy was more common at SFGH. The type of surgical treatment for breast cancer was not statistically significantly different by hospital site. IV-chemotherapy was more common among SFGH participants (67% compared with 55% at Diller) and Tamoxifen was more commonly prescribed to Diller participants (47% compared with 24% at SFGH). Rates of radiation therapy and treatment with aromatase inhibitors were similar among participants from both Diller and SFGH.

Table 4 describes and compares *BRCA* results and genetic counseling outcomes between hospitals. More women at Diller were found to be *BRCA* positive or true negative, while women testing at SFGH were more likely to receive an uninformative negative or variant of unknown significance result. Women at Diller were more likely to recall receiving screening recommendations during genetic counseling compared with women at SFGH (51% *versus* 41%). Participant recall of discussing cancer prevention options with their genetic counselor was not significantly different between the two sites. Self-reported ease of understanding *BRCA* results was similar between Diller and SFGH participants. While women at Diller scored slightly higher in their knowledge of screening and prevention recommendations (4.6 of 8 answers correct at Diller *versus*

Table 2.

SELF-REPORTED CANCER SCREENING AMONG *BRCA* TESTERS AND SCREENING RECOMMENDATIONS FROM THE US PREVENTIVE SERVICES TASK FORCE FOR NORMAL-RISK POPULATIONS OF WOMEN

Characteristic	Diller n=1045 (%)	SFGH n=78 (%)	p-value	US Preventive Services Task Force Recommendation (Grade of Recommendation[a]
Screening mammography, ever	991 (95)	73 (94)	.6	All women should undergo biannual mammographic screening from ages 50–74 (B).[49]
Age at first mammogram, mean (±SD)	36 (±7)	39 (±8)	.001	Starting mammography in women under age 50 should be an individual decision. (C)
Ever received screening clinical breast exam	959 (93)	72 (92)	.9	Insufficient evidence to assess clinical breast exam beyond screening mammography in women ages 40 or older. (I)
Reported ever receiving screening breast MRI	437 (42)	6 (8)	<.001	Insufficient evidence to assess breast MRI instead of film mammography for breast cancer screening. (I)
Reported ever having any ovarian screening[b]	623 (60)	29 (37)	<.001	Recommends against routine screening. (D)
Reported ever having any colon cancer screening	638 (61)	37 (47)	.04	Recommended for all adults from ages 50–75 with fecal occult blood test, sigmoidoscopy, or colonoscopy. (A)
Reported ever having dermatologic screening for skin cancer	555 (53)	17 (22)	<.001	Insufficient evidence to assess the balance of benefits and harms in the adult general population. (I)

[a]Grades of US Preventative Services Task Force (USPSTF) screening recommendations are classified as follows:[50]

—Grades A and B indicate that the USPSTF recommends the service for the general population of women with either a high certainty of substantial (A) or moderate (B) net benefit.

—Grade C indicates that clinicians may provide this service based on individual circumstances, but for most asymptomatic individuals the service is likely to only have a small benefit.

—Grade D indicates that the service is not recommended

—Grade I indicates the current evidence is insufficient to assess the harms vs. benefits of the service.

[b]With screening transvaginal ultrasound or serum CA-125.

SD=Standard Deviation

Table 3.

BREAST CANCER CHARACTERISTICS OF 691 *BRCA* TESTERS DIAGNOSED WITH BREAST CANCER

Characteristic	Diller n=646 (%)	SFGH n=45 (%)	p-value
Method of detection			.01
Self-reported lump	302 (47)	32 (71)	
Clinical breast exam	58 (9)	2 (4)	
Screening mammogram	238 (37)	7 (16)	
Other/unknown	48 (7)	4 (9)	
Estrogen receptor status			.01
Estrogen receptor +	422 (65)	21 (47)	
Estrogen receptor –	131 (20)	11 (24)	
Not done or unsure of status	92 (15)	13 (29)	
"Triple negative"[a] breast cancer[a]	69 (11)	8 (18)	.10
Surgery type			.17
Lumpectomy	327 (51)	24 (53)	
Unilateral mastectomy	190 (29)	17 (38)	
Bilateral mastectomy	125 (19)	4 (9)	
Unknown	4 (0.6)	0 (0)	
Other treatments			
IV chemotherapy	353 (55)	31 (67)	.031
Radiation therapy	367 (57)	29 (62)	.168
Tamoxifen	303 (47)	12 (24)	.017
Aromatase inhibitor	206 (32)	15 (31)	.716

[a]Estrogen receptor negative, progestin receptor negative, HER2 negative breast cancer

4.2 of 8 answers correct at SFGH), these differences were not statistically significant (p = 0.06). Participant satisfaction with decision (SWD) to *BRCA* test was higher among Diller participants compared with SFGH participants (p = 0.006). Participants at both hospitals, however, reported fairly high SWD scores, and the absolute difference in mean SWD scores may not be clinically significant.

Table 5 reflects results of a multivariate analysis that examined predictors of self-reported general health. *BRCA* test results and satisfaction with the decision to undergo genetic testing were not independently associated with self-reported general health. Hospital site, race, IPA, cancer history, and knowledge of screening and prevention, however, were all associated with self-reported general health. Women most likely to report lower general health had received *BRCA* testing at SFGH, were non-White, had lower IPA, had histories of breast/ovarian cancer, and had less knowledge of cancer screening and prevention.

Table 4.

BRCA TESTING AND GENETIC COUNSELING OUTCOMES AMONG SURVEY PARTICIPANTS

Characteristic	Diller n=1045 (%)	SFGH n=78 (%)	p-value
BRCA Status			<.001
Positive	197 (19)	9 (12)	
True Negative	108 (10)	2 (2.6)	
Uninformative Negative	686 (66)	60 (77)	
VUS	54 (5.2)	7 (9)	
Understand *BRCA* test results, mean score ± SD	1.5 ± 0.7	1.5 ± 0.9	.61
Recall receiving screening recommendations	532 (51)	32 (41)	.02
Recall discussing cancer prevention options	472 (45)	28 (36)	.55
Knowledge of screening and prevention recommendations, mean ± SD	4.6 ± 1.7	4.2 ± 1.8	.06
Range of values	0–8	0–8	
Satisfaction with decision to test, mean ± SD	3.4 ± 0.6	3.2 ± 0.5	.006
Range of values	0–4	2.3–4	

Discussion

This study of 1,123 diverse *BRCA* testers provides an important comparison of genetic counseling and cancer screening outcomes between an academic cancer center and a public county hospital. Our population reflects one of the largest and most diverse long-term follow-up studies of *BRCA* testers to date. Because the CRP uses the same clinical protocol and staff at both hospital sites, our findings provide data on differences in screening and health outcomes that may not be attributable to clinical programs or health care providers.

The racial variation among our study participants is consistent with the diversity of the larger population at risk for BRCA mutations.[6] The demographic differences we report between *BRCA* testers at each hospital site are similar to prior published research.[14] Although both hospital sites are in the same city, the populations they serve are quite different, which may account for these demographic differences. Interestingly, the similar ages at *BRCA* testing, similar follow-up times, and similar rates of breast cancer at Diller and SFGH likely result from using the same CRP clinical protocol and staff at both sites.

It is intriguing that *BRCA* testers in the county hospital setting had higher rates of ovarian cancer than *BRCA* testers in the academic hospital setting in this study. This could reflect the outreach strategies employed there, or the systematic public health approach used by the gynecologic oncology clinic at SFGH for high-risk women. This clinic refers all women diagnosed with epithelial ovarian cancer, regardless of family

Table 5.

INDEPENDENT PREDICTORS OF SELF-REPORTED GENERAL HEALTH AFTER *BRCA* TESTING[a]

Variable	Odds Ratio[b]	95% Confidence Interval	p-value
Hospital Site			
Diller	1.0	—	Ref
SFGH	0.26	0.2–0.4	<.001
Race			
White	1.0	—	Ref
Non-white	0.53	0.4–0.7	<.001
Income-Producing Assets (by category)	1.2	1.1–1.4	<.001
Personal Cancer History			
Breast	0.62	0.5–0.8	.001
Ovarian	0.44	0.3–0.7	.001
BRCA Status			
Positive	1.0	—	Ref
True negative	0.97	0.6–1.6	.9
Uninformative negative	1.1	0.8–1.6	.4
Variant of unknown sig	1.6	0.9–2.8	.1
Knowledge of screening and prevention recommendations	1.2	1.01–1.5	.03
Satisfaction with decision to *BRCA* test	1.2	0.98–1.4	.09

[a]Of the 1123 survey respondents, 1102 had complete responses for all characteristics in the multivariate model predicting general health (hospital site, race, IPA, cancer history, *BRCA* test results, knowledge and satisfaction).
[b]Odds ratios less than 1.0 indicate variables independently associated with decreased self-reported general health.

history, for hereditary cancer risk assessment. This strategy is in agreement with National Comprehensive Cancer Center Network guidelines, which recommend all women with epithelial ovarian cancer consider *BRCA* testing, because their likelihood of testing positive is above 10%, a common testing threshold.[21] In contrast to a tertiary referral center, which sees many patients seeking second opinions, the public health approach to women with epithelial ovarian cancer may actually provide improved identification of *BRCA* carriers with ovarian cancer.

We found no significant differences in mammography rates or clinical breast exam rates between hospitals, which were all above 90%. Although previous studies have identified low breast cancer screening uptake in underserved women,[22,23] a population-based study of individuals with a family history of breast cancer found no significant racial/ethnic or income disparities in uptake of breast cancer screening.[24] It is possible that the strong family histories of breast cancer in our survey population made these women and their health care providers especially attentive to breast cancer screen-

ing. The earlier age at first mammogram at Diller compared with SFGH may reflect increased access to mammography in this high-risk population, particularly when the recommended age to begin mammography is younger than the recommended age to begin mammography in the general population.[25,26]

Screening rates for ovarian, colon, and skin cancer in this study were significantly lower at the public county hospital than at the academic cancer center. Screening recommendations for these cancers include a wide spectrum of utility, with evidence of harm from ovarian cancer screening to evidence of benefit from colon cancer screening.

Although ovarian cancer screening is not recommended in the general population[27,28] and is of questionable value even in high-risk populations,[29] a substantial number of women at both hospitals reported ever receiving ovarian cancer screening (60% at Diller and 37% at SFGH). As the USPSTF feels the harms of ovarian cancer screening outweigh the benefits, interestingly, women at SFGH may be more adherent to this recommendation than women at Diller.[27] For *BRCA* carriers, most guidelines focus on the benefits of risk-reducing salpingo-oophorectomy when childbearing is complete given the poor sensitivity and specificity of ovarian cancer screening.[30] The large number of women, particularly at Diller, who reported ovarian cancer screening may reflect unnecessary screening at their, or at their health care providers', urging. Consistent with this possible explanation, recent vignette-based physician survey found that physicians are more likely to order ovarian cancer screening tests if requested by patients, regardless of their ovarian cancer risk.[31]

The benefits of colon cancer screening and disparities in its uptake have been widely reported.[32,33,34] Our findings are consistent with previous studies documenting disparities in colonoscopy uptake between Whites and Asian Americans, African Americans, and Hispanics.[33,34] It is unclear whether *BRCA* carriers are also at higher risk of colon cancer,[35,36] so the recommended age to begin colonoscopy for most of this study population would be 50 years old. Even when we restricted our analysis to the 700 women who were 50 and older, we found that 85% of Diller participants reported having colon cancer screening *versus* 62% of SFGH participants ($p<.0001$). Because colon cancer screening in the general population has significant benefits (USPSTF grade A),[32] effective strategies to improve its uptake, particularly in underserved populations, are warranted. Prior research has demonstrated that a multipronged public health campaign targeted at providers and patients, as well as a patient navigator-based intervention, have shown promise in reducing these disparities.[37,38]

Routine skin cancer screening is not recommended by the USPSTF because of insufficient evidence to assess the balance of risks and benefits in the general population.[39] *BRCA2* mutation carriers are at higher risk of malignant melanoma than the general population,[36] and National Comprehensive Cancer Network guidelines state "a full body skin exam for melanoma screening should be considered for *BRCA1/2* carriers."[21[HBOC A2-2]] Although the evidence for skin cancer screening is minimal, even in high-risk populations such as ours, we observed disparities in reports of ever receiving a full body screening skin exam (53% at Diller *versus* 22% at SFGH). This may stem from lower levels of perceived skin cancer risk among SFGH participants, differences in access to primary care and dermatologic follow-up, or decreased skin cancer education by health care providers, compared with Diller participants.[40,41]

In addition to the disparities we observed in cancer screening practices, we also note differences between hospitals in breast cancer detection and treatment. Although lump palpation was the most frequent method of detection at both hospitals, mammographically detected breast cancer was more common at Diller compared with SFGH. Prior literature has shown racial, ethnic and socioeconomic differences in stage at breast cancer diagnosis,[42,43] and survival,[44,45] but few studies have focused on method of detection. The differences in detection methods that we identified could relate to differences in breast tumor biology, or differences in access to and uptake of first screening mammography. We also observed less tamoxifen use and more IV chemotherapy use for breast cancer treatment at SFGH. This could be related to differences in tumor types, as SFGH has less estrogen receptor positive (referred to as ER+) and more triple negative (negative estrogen, progesterone, and HER2 receptors) breast cancers compared with Diller.

The differences we observed in *BRCA* results, with more positives and true negatives at Diller, could result from differences in referral patterns between hospitals. As a tertiary cancer center, Diller's patients may have higher probabilities of testing *BRCA* positive. Diller also receives more referrals of relatives of *BRCA* carriers than SFGH; thus the higher rate of true negatives, which can only occur in families with a known *BRCA* mutation. Diller patients were more likely to recall receiving screening recommendations than SFGH patients, but both rates were slightly lower than those observed in prior literature.[46] Few studies have compared genetic counseling and testing outcomes between academic and public hospitals, and there is a need to engage in such comparisons in other diverse populations.

Self-reported general health in this study was significantly lower at SFGH compared with Diller. To explore potential reasons for these differences, we performed a multivariate logistic regression analysis to determine independent predictors of self-reported general health. The strongest independent predictor of this characteristic was hospital site, followed by race, then cancer status, then income-producing assets. Variables related to BRCA testing, including test results and SWD to test, were not independently associated with self-reported general health. Our results suggest that the *BRCA* testing process and actual test results have minimal effects on self-reported general health.

We recognize several limitations of this study. As with all surveys, participant responses are subject to recall bias, particularly for cancer screening. Women's recollections of receiving a mammogram in a given interval are not completely reliable: 12 months after *BRCA* testing, researchers found 88% concordance between self-reported and administrative data, with participants overestimating their uptake of mammogram in the previous year.[47] Recall of receiving a mammogram, however, is more sensitive than other cancer screening tests.[48]

Because our survey was predominantly self-administered, participants could have misinterpreted the intention of some questions. Although survey questions included clear and relevant examples of the differences between screening and diagnostic mammography, participants may still have confused mammograms done for screening versus diagnostic purposes. We attempted to minimize this possibility by developing the survey, which was written at an 8th grade reading level, with the contributions of survey experts. Our pilot testing of the survey carefully assessed both comprehension

and readability, but we did not include any assessment of a participant's overall or health-specific literacy level in either the pilot testing or the final survey. Participants at SFGH with limited English proficiency were administered the survey verbally by language-concordant research assistants and/or interpreters. Future research instruments would benefit from assessing participants' health and overall literacy to ensure that survey responses match the intention of survey questions and to look for associations with health literacy and health decisions such as cancer screening.

The number of *BRCA* testers surveyed at SFGH (n=78) was much smaller than the number of Diller testers surveyed (n=1,045). This was expected given the differences in hospital characteristics and referral patterns described in the methods section. The SFGH program began in 2002, compared with 1996 at Diller, which also contributes to the lower number of SFGH testers. Further research in this field is needed to examine the generalizability of our findings to larger populations of diverse *BRCA* testers.

Our survey instrument was primarily administered in English, with the exception of 25 SFGH participants. Approximately 30% of SFGH participants communicate in a language other than English, compared with less than 1% of Diller participants. We chose to include this understudied population at SFGH and enlisted language-concordant research assistants and translators at SFGH only. Although Diller participants were not given this option, we feel the preference at Diller for communicating medical information in English is true for 99% of the Diller population. This preference for English at Diller is likely similar to the proportion of English-speakers at most academic cancer centers in the United States.

In summary, this study, to our knowledge, represents the largest head-to-head comparison of *BRCA* testers between different types of hospitals (academic *vs*. public county). This unique comparison confirms disparities in demographic characteristics and cancer screening that has been observed in prior studies. However, this research also demonstrated that many important genetic counseling outcomes (e.g., understanding of *BRCA* results, knowledge of screening and prevention recommendation) did not differ significantly between the two study populations. It appears that genetic counseling programs operating with protocol-based referral, testing and counseling for high-risk patients can function well across diverse care-delivery sites.

This study also identifies novel disparities that should be further explored in larger populations. Examples include *BRCA* test results, cancer screening rates, methods for detecting breast cancer, and tumor treatments. Additionally, this research found that while the academic hospital had higher cancer screening rates, they were not always aligned with evidence-based recommendations. Long-term goals of future research should include providing appropriate, effective, and evidence-based cancer screening to families at risk of hereditary cancer, regardless of their hospital setting, race, or socioeconomic status.

Notes

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