Research Article

Cancer Epidemiology, Biomarkers & Prevention

Communication of *BRCA* Results and Family Testing in 1,103 High-Risk Women

Eleanor L. Cheung[1,2], Ashley D. Olson[2], Tina M. Yu[2], Pamela Z. Han[2], and Mary S. Beattie[2,3,4]

Abstract

Background: Genetic testing for hereditary cancer risk has implications for individuals and families. This study of women at risk of hereditary breast and ovarian cancer examines communication of *BRCA* results and subsequent genetic testing in the family.

Methods: We surveyed 1,103 female *BRCA* testers at two hospitals, querying for communication of results and testing in relatives.

Results: Ninety-seven percent of participants communicated *BRCA* results with at least one relative. Communication was negatively associated with older age [odds ratio (OR), 0.66 per decade; 95% confidence interval, (95% CI), 0.4–0.9], Asian race (OR, 0.18; 95% CI, 0.06–0.5), and testing at the public hospital versus the cancer center (OR, 0.19; 95% CI, 0.07–0.5). Communication was positively associated with increased knowledge of hereditary breast and ovarian cancer screening and risk reduction recommendations (OR, 1.9; 95% CI, 1.1–3.4) and increased satisfaction with the decision to *BRCA* test (OR, 2.6; 95% CI, 1.6–4.0). Seventy-five percent of *BRCA*-positive participants reported that at least one relative pursued genetic testing. Family testing was negatively associated with Asian race (OR, 0.15; 95% CI, 0.02–0.8) and positively associated with increased socioeconomic status (OR, 1.4; 95% CI, 1.1–1.7) and increased satisfaction with decision (OR, 2.1; 95% CI, 1.1–4.1).

Conclusion: Despite high overall rates of communicating *BRCA* results, underserved and some minority women seem less likely to inform relatives of their *BRCA* status or have relatives test for a known family mutation. Satisfaction with the decision to *BRCA* test is positively associated with both outcomes.

Impact: This study identified several novel predictors of family communication and family genetic testing in a large population of high-risk women. This work can inform clinicians interested in improving family communication regarding cancer predisposition testing. *Cancer Epidemiol Biomarkers Prev; 19(9); 2211–9. ©2010 AACR.*

Introduction

Genetic medicine often bears consequences beyond the patient who carries a deleterious mutation because medical implications extend to his or her entire family. In *BRCA* testing, family implications are particularly strong, given the autosomal dominant inheritance and high cancer penetrance of the gene. Because privacy laws often preclude the direct involvement of health-care professionals (1), communication within the family is a necessary precursor to testing for a known deleterious mutation ("family testing").

Authors' Affiliations: [1]Robert Wood Johnson Medical School, Piscataway, New Jersey; [2]Cancer Risk Program and Departments of [3]Medicine and [4]Epidemiology and Biostatistics, University of California, San Francisco, San Francisco, California

Corresponding Author: Eleanor Cheung, University of California, San Francisco, Suite 600, 1635 Divisadero Street, San Francisco, CA 94115. Phone: 908-601-5815; Fax: 415-353-2494. E-mail: cheungel@umdnj.edu

doi: 10.1158/1055-9965.EPI-10-0325

Several studies have begun to characterize communication of *BRCA* results within families. Observed rates of communication are consistently high, with 91% to 100% of participants reporting communication with at least one blood relative (2-6). In contrast, testing for a known deleterious mutation may occur at rates as low as 30% to 60% of relatives, even in the setting of cost-free testing (6-8).

Previous literature has identified some predictors of these outcomes. For example, *BRCA* testers are more likely to communicate genetic test results to female relatives (2, 9), and relatives from older generations seem more likely to pursue testing for a known family mutation than relatives from younger generations (6). Genetic medicine is not immune to racial and ethnic disparities (10, 11), with evidence that non-white race is associated with decreased use of *BRCA* genetic services (12). The specific outcomes of communication of genetic results and family testing have not been carefully studied in non-white populations. Socioeconomic status independent of race has also not been extensively studied with respect to these outcomes.

Family communication of genetic test results, and subsequent genetic testing in relatives, are complex processes.

One way to study these outcomes is to begin with the "index patient," the first person in a family to pursue *BRCA* testing. Many factors could influence her communication of *BRCA* results with relatives, including demographic characteristics and medical history, as well as knowledge, cancer worry, risk perception, and satisfaction with her decision to *BRCA* test. After she informs family members of her *BRCA* results, additional genetic testing in relatives could be influenced by these same variables. By identifying variables associated with family communication and family genetic testing, particularly those variables that are modifiable, we may be able to guide clinical care toward improving these outcomes.

Prior literature suggests that increased knowledge of hereditary breast and ovarian cancer is associated with a more positive attitude toward *BRCA* testing (13). After genetic counseling, most women report decreases in cancer worry and improvements in the accuracy of their risk perception (14-16). In some studies, information booklets have been associated with decreased decisional conflict and increased rates of genetic testing (17). Although these variables have been examined during *BRCA* testing for index patients, they have yet to be carefully studied with respect to the subsequent outcomes of family communication and genetic testing in relatives.

This study is among the first to estimate rates of family communication and genetic testing in relatives, as well as their predictors, in a large and diverse population of *BRCA* testers. We aim to examine potential associations between several key variables (demographics, cancer history, hospital type, and psychometric measures) and two main outcomes: family communication and genetic testing in relatives. We hypothesize that two novel predictors—knowledge of screening and risk reduction recommendations, as well as satisfaction with the decision to *BRCA* test—will be positively associated with both outcomes. This study is based on newly collected data from the University of California, San Francisco (UCSF), Cancer Risk Program, which has served a racially diverse population for more than a decade, and has offered cost-free genetic testing to eligible patients for 7 years (18).

Materials and Methods

Study participants

We recruited participants from the UCSF Cancer Risk Program, which provides *BRCA* testing at two locations: the Helen Diller Family Comprehensive Cancer Center (Diller), a tertiary referral cancer center, and San Francisco General Hospital (SFGH), a public county hospital. UCSF uses the same *BRCA* testing protocol, genetic counselors, and threshold for *BRCA* testing at both locations (18). In addition, both locations offer free or subsidized single-site testing to underserved relatives of *BRCA*-positive patients.

All women who received genetic counseling and *BRCA* testing between January 1996 and March 2008 at either UCSF location were eligible for this study. Women who enrolled in the Institutional Review Board–approved UCSF Cancer Risk Program follow-up protocol (18) were contacted in late 2008. Participants who had moved outside the United States were excluded. Informed consent was obtained for all participants.

Measures

All study participants received a comprehensive 22-page survey that used multiple choice and open-ended questions to query the following domains: race and ethnicity, cancer screening and prevention behaviors, general medical history, and cancer history if applicable. This survey also included the following scales, detailed below: knowledge of screening and risk reduction recommendations, cancer worry, risk perception, and satisfaction with the decision to *BRCA* test. Measurement of the two main outcomes of this study, communication of *BRCA* results with relatives and family testing for known deleterious *BRCA* mutations, is also described below. Following a pilot test, most participants received the survey by mail, using reminder postcards and three mailings as necessary. To include a more diverse population, we surveyed non-English speakers from both locations with in-person interviews in Spanish, Russian, or Chinese (n = 25).

Demographic information and medical history

At enrollment, baseline census demographic data were collected. Self-reported race and ethnicity information was collected by survey.

To assess socioeconomic status, we enlisted a third-party company, Nielsen Claritas, to determine income-producing assets (IPA) for each participant. Nielsen Claritas was provided with anonymized census demographic data to estimate IPA per individual household using several variables, including income and home ownership. This measure indicates the liquid financial assets of a household but does not take into account financial liabilities (19).

Chart review was used to confirm medical histories, including cancer history verified by pathology reports and *BRCA* results. *BRCA* results were categorized as positive, uninformative, or true negative. True negative results occurred when the *BRCA* tester did not carry a known deleterious mutation that had previously been identified in her family.

Knowledge of screening and risk reduction recommendations

Our knowledge construct consisted of eight true/false questions on breast and ovarian cancer screening and risk-reducing interventions. At the time of this survey, prior knowledge measurement scales did not focus on screening and prevention in women at risk of hereditary breast and ovarian cancer. Therefore, we developed and tested this construct in collaboration with content and measurement experts. All items in this construct are routinely discussed during *BRCA* genetic counseling.

Cancer worry

Cancer worry was assessed in women unaffected with cancer using Lerman's cancer worry scale (20). This three-item scale queried how often women thought about developing cancer within the past month, as well as if these thoughts affected their mood and ability to perform daily activities. All responses used a four-point Likert scale. The Cronbach's α for this measure in our population was 0.73.

Risk perception

In women without a history of cancer, we queried their absolute and relative risk perceptions of developing breast, ovarian, or any cancer. For absolute risk of any cancer, participants answered the single question "How likely do you think it is that you will develop cancer of any type at some time in your life?" using a five-point Likert scale. For relative risk of any cancer, participants answered the single question "Compared to other women your age, do you think your chances of developing cancer of any type at some time in your life are:" using a five-point Likert scale with responses ranging from "much lower" to "much higher."

Satisfaction with the decision to *BRCA* test

We used the six-point satisfaction with decision (SWD) scale (21) and queried the decision to undergo genetic testing for cancer risk. The components of this scale included assessments of the following: feeling adequately informed about options, making a decision consistent with personal values, and having adequate input in the decision. All responses used the same five-point Likert scale. The Cronbach's α for this measure in our population was 0.87.

Family communication of *BRCA* results and family genetic testing

The two main outcomes of this study were measured as survey responses regarding the communication of *BRCA* results and family genetic testing. We queried the communication of results with the following question: "Have you told other family members about your genetic test results for cancer risk?" If participants answered yes, they were asked to identify family members with whom they communicated from a list of first-, second-, and third-degree relatives. Write-in space was available to list other relatives. Family testing was queried with the following question: "As far as you know, have any of your relatives received genetic testing for cancer risk?" If participants answered yes, they were asked to identify relatives who underwent *BRCA* testing from a list of first-degree relatives. Write-in space was available for other family members.

Data analysis

Descriptive and comparative analyses were done to characterize participants in terms of demographics, IPA, and health measures. We examined potential differences between populations at each UCSF location using *t* tests and χ^2 tests, where applicable.

For descriptive analyses regarding the communication of *BRCA* results, we classified responses into male or female relatives, as well as first-, second-, or third-degree relatives. We then compared communication rates among these classifications, as well as among differing *BRCA* test results. We followed a similar protocol for analyses of family testing, but restricted the sample to index patients with positive *BRCA* results to focus on families where further genetic testing is indicated.

The primary outcomes of this study, communication of *BRCA* results and family genetic testing for a known *BRCA* mutation, were based on self-reported survey responses and in-person interviews. We performed multivariate logistic regression analyses to determine variables independently associated with these outcomes. For the multivariate analysis of family testing, we excluded *BRCA*-positive participants who were tested for a known family mutation, as these women were not index patients and by definition had to report at least one other family member who underwent *BRCA* testing.

Both logistic regression analyses considered the following variables: *BRCA* test result, cancer history, race and ethnicity, hospital type (cancer center versus public hospital), socioeconomic status represented by IPA, perceived importance of estimating cancer risk, cancer worry, risk perception, attitudes toward screening, knowledge of screening and risk reduction recommendations, and satisfaction with the decision to *BRCA* test. We first used univariate logistic regression to determine significant variables associated with the primary outcomes. To build the multivariate logistic regression models, we included both clinically and statistically significant predictors ($P < 0.10$ on univariate analysis), testing each model for potential confounding factors and interactions. Predictors were removed from the multivariate model in a stepwise approach if they were not statistically significant ($P < 0.05$) and if they did not confound relationships between other variables in the model [defined as a change in the odds ratio (OR) of at least 10%]. Based on preliminary data and clinical experience, we examined two a priori hypotheses for potential interactions between hospital type (cancer center versus public hospital) and either race or IPA. STATA 10.0 statistical software was used (STAT Corp.) for analysis.

Results

Description of the study population

One thousand four hundred sixty-eight women met the inclusion criteria for this study. Of these, 48 women declined participation. Of the remaining eligible women, we achieved an 80% response rate (1,135/1,420). Of survey responders, 1,103 answered all questions required for complete statistical analysis. There was no pattern of omitted questions. Nonresponders and responders who could not be included in the final analysis did not differ significantly from the 1,103 included participants in age, year of testing, *BRCA* results, or cancer status. Two of

these women were from the same family. The median follow-up time for all women was 3.4 years. The mean follow-up time at Diller was 3.5 years (range 6 months–12 years), and at SFGH was 2.8 years (range, 6 months–6 years; $P = 0.04$).

Ninety-three percent of participants (1,026/1,103) received *BRCA* testing at Diller. As shown in Table 1, participants at both locations had statistically similar median ages, overall cancer rates, and *BRCA*-positive rates. The ovarian cancer rate was lower at Diller than at SFGH. Diller and SFGH also differed in the proportion of true negative and uninformative test results (Table 1), with more true negative results at Diller and more uninformative results at SFGH.

We combined race and ethnicity variables because all Ashkenazi Jewish women self-identified as Caucasian. The proportion of Ashkenazi Jews was similar at both locations. Diller was less diverse than SFGH, with lower proportions of Asians, Latinas, and African Americans, and a much higher proportion of Caucasians (Table 1).

IPA, a measure of socioeconomic status, had different distributions at each UCSF location (Table 1). The average IPA at Diller was in the $250,000 to $500,000 range, with 37% of Diller participants in the top IPA bracket (greater than $1 million). The average IPA at SFGH was in the $50,000 to $75,000 range, with 3% of SFGH participants in the top bracket.

Participants at both locations reported similar satisfaction with the decision to *BRCA* test (SWD), with an average satisfaction score of 4.1 at Diller and 4.0 at SFGH on a scale of 1 to 5 ($P = 0.1$). However, Diller had a statistically higher average knowledge score (3.3 versus 3.1 at SFGH on a scale of 1–4; $P = 0.01$).

Communication of *BRCA* results

Of the study participants, 97.5% (1,075/1,103) reported communicating *BRCA* results to at least one blood relative (98% at Diller and 88% at SFGH, $P < 0.001$). Of those 1,075 participants, 94% described communication with more than one relative, and 48% described communication with five or more relatives. Participants reported communicating *BRCA* test results to female relatives more often than male relatives ($P < 0.001$; Fig. 1). Participants most often reported communicating with members of the same generation compared with older or younger generations ($P < 0.001$).

Table 1. Description of the study population of 1,103 female *BRCA* testers at both hospital sites within the UCSF Cancer Risk Program

Characteristic	Diller, *n* = 1,026 (%)	SFGH, *n* = 77 (%)	*P*
Age at testing			
Median	48 y	49 y	0.9
Range	19–87	29–68	
Race			
White non-Jewish	641 (62)	23 (30)	<0.001
White/Ashkenazi Jewish	265 (26)	19 (25)	0.8
Asian	58 (6)	8 (10)	0.09
Latina	44 (4)	17 (22)	<0.001
African American	18 (2)	10 (13)	<0.001
IPA			
<$50,000	93 (9)	28 (36)	<0.001
$50,001–$100,000	71 (7)	13 (17)	0.001
$100,001–$500,000	335 (33)	30 (39)	0.3
$500,001–$1,000,000	146 (14)	4 (5)	0.03
>$1,000,000	381 (37)	2 (3)	<0.001
BRCA status			
Positive	194 (19)	9 (12)	0.1
True negative	104 (10)	2 (3)	0.03
Uninformative	728 (71)	66 (86)	0.005
Cancer diagnosis*			
Any cancer	721 (70)	55 (71)	0.8
Breast cancer	631 (62)	44 (57)	0.4
Ovarian cancer	72 (7)	10 (13)	0.05
No cancer	305 (30)	22 (29)	0.8

*Percentages do not total 100% because some participants had more than one type of cancer.

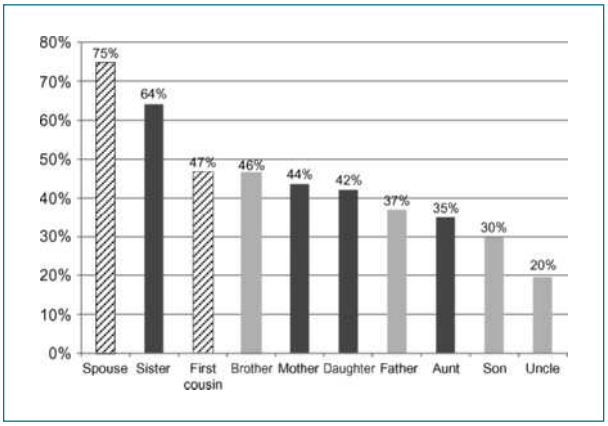

Figure 1. Percentage of participants reporting communication with each type of relative.

On multivariate analysis, several characteristics were independently associated with the likelihood of communicating results (Table 2). Although the proportion of participants who did not communicate their results was small, we found the following variables to be independently associated with decreased likelihood of communication: older age by decade [OR, 0.66; 95% confidence interval (95% CI), 0.4–0.9], Asian race (OR, 0.18; 95% CI, 0.06–0.5), and testing at the public hospital (SFGH; OR, 0.19; 95% CI, 0.07–0.5).

Variables independently associated with increased communication were increased satisfaction with the decision to *BRCA* test (OR, 2.6; 95% CI, 1.6–4.0) and increased knowledge of screening and risk reduction recommendations (OR, 1.9; 95% CI, 1.1–3.4).

BRCA test results were not statistically associated with family communication: 99.5% of *BRCA*-positive participants, 99.0% of true negative participants, and 96.7% of participants with an uninformative result reported communicating their *BRCA* results with family (P = 0.1). We found no statistical association between the likelihood of communication and socioeconomic status as measured by IPA. We did not identify any statistically significant interactions in the final multivariate model.

Family testing in *BRCA*-positive participants

Of the 203 *BRCA*-positive participants, 52 tested for a known family mutation and therefore were not the first in the family to *BRCA* test. We included only the 151 women who were the first in their family to test positive to better examine dissemination of family testing. Of these 151 index patients, 113 (75%) reported at least one blood relative who pursued genetic testing (77% of participants at Diller and 29% at SFGH, P = 0.004). Participants more often reported that female relatives pursued genetic testing than male relatives (P < 0.001; Fig. 2).

In multivariate regression analysis, several participant characteristics were independently associated with family testing for the known *BRCA* mutation (Table 3). Asian race was associated with decreased family testing (OR, 0.15; 95% CI, 0.02–0.8). Decreased family testing was also seen in all other racial groups compared with Caucasians, but these results were not statistically significant (Table 3).

Participant characteristics independently associated with an increased likelihood of family testing included increased satisfaction with the decision to *BRCA* test (OR, 2.1; 95% CI, 1.1–4.1) and increased socioeconomic status as measured by IPA (OR, 1.4; 95% CI, 1.1–1.7). We did not detect any statistically significant interactions in the final model.

Table 2. Variables associated with family communication of *BRCA* results in the study population of 1,103 female *BRCA* testers

Variable	OR (95% CI)	*P*
Age (by decade)	0.66 (0.4–0.9)	0.03
Race		
White	1 (—)	—
Asian	0.18 (0.06–0.5)	0.001
Latina	0.63 (0.1–2)	0.5
African American	2.6 (0.3–25)	0.4
Income-producing assets (by category)	1.1 (0.9–1.2)	0.4
Location		
Diller	1 (—)	—
SFGH	0.19 (0.07–0.5)	0.001
Decisional satisfaction	2.6 (1.6–4.0)	<0.001
Knowledge of high-risk screening and risk reduction recommendations	1.9 (1.1–3.4)	0.02

NOTE: The multivariate logistic regression model included all variables in this table, with no other variables.

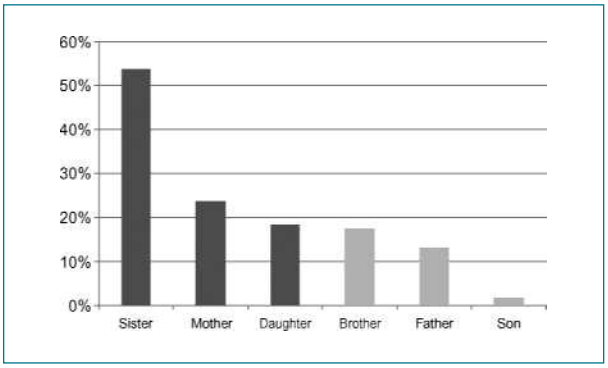

Figure 2. Percentage of *BRCA*-positive participants reporting follow-up genetic testing of each type of relative.

Discussion

In hereditary cancer syndromes, one of the most clinically important and cost-effective ways to potentially decrease cancer incidence is to target genetic testing toward families with known deleterious mutations. Our work examines two important steps in this process: family communication of genetic test results and subsequent genetic testing for known family mutations. We have identified rates of communication and family testing in a large group of *BRCA* testers, as well as important predictors of these outcomes.

The high rates of communication we observed are consistent with prior studies (2-6). Some patterns of testing relatives for a known family mutation are also in line with prior literature, including increased testing in female relatives (2, 6). New findings shown by this study include patterns of communication and family testing in underserved and non-white populations, as well as careful examination of potential predictors of these outcomes, including socioeconomic, knowledge, and satisfaction measures.

The rate of family testing in this study seems higher than in prior literature (5-7, 22), which could have occurred for several reasons. This study benefited from a long follow-up period, up to 12 years for some participants, which might have allowed for more time to test family members. Our methods of measuring outcomes could also result in observed higher rates of family genetic testing. Whereas some previous studies examined the proportion of relatives who tested, we researched the percentage of participants who reported that a relative received genetic testing. In addition, our survey was administered in late 2008, by which time the recently passed Genetic Information Nondiscrimination Act could have encouraged increased genetic testing in relatives.

Satisfaction with the decision to *BRCA* test (SWD) was strongly associated with both family communication and family testing. This study is the first, to our knowledge, that has examined the relationship between the index patient's SWD and family communication or family genetic testing. We hypothesized that SWD would have an independent association with both outcomes, but the magnitude of this association was larger than expected. It is important to recognize that this population has already made the decision to *BRCA* test, so values for SWD could be mistakenly high in an attempt to resolve cognitive dissonance. However, this concept would apply to the entire survey population; thus, the associations between higher SWD and increased communication with relatives as well as increased family genetic testing seem valid. If our findings are replicated in other populations, further exploration of ways to improve SWD in index patients may be warranted.

Knowledge of screening and risk reduction recommendations was also independently associated with family communication, but not with family genetic testing. This relationship implies that patients with greater knowledge may feel more comfortable communicating their *BRCA* results with relatives. However, in subsequent testing for known family mutations, other factors such as socioeconomic status and SWD may play a larger role. Interestingly, cancer worry and risk perception were not independently associated with either outcome. This lack of association may be because these measurements were only possible in unaffected women. Also, the cancer worry scale was developed to examine worry that interferes with mood and function; thus, this measurement may not be particularly sensitive to milder anxiety.

Our framework for examining psychometric predictors of family communication and family genetic testing highlights the key role of the index patient. When *BRCA* testing became clinically available in the

Table 3. Variables associated with testing of relatives for a family mutation in 151 *BRCA*-positive participants

Variable	OR (95% CI)	*P*
Age (by decade)	0.89 (0.6–1.4)	0.6
Race		
White	1 (—)	—
Asian	0.15 (0.02–0.8)	0.03
Latina	0.95 (0.2–4)	0.9
African American	0.29 (0.04–3)	0.3
IPA (by category)	1.4 (1.1–1.7)	0.003
Location		
Diller	1 (—)	—
SFGH	0.52 (0.08–3.4)	0.5
Breast/ovarian cancer	0.29 (0.08–1.1)	0.06
Decisional satisfaction	2.1 (1.1–4.1)	0.02

NOTE: Multivariate logistic regression model included all variables in this table, with no other variables.

mid-1990s, most *BRCA* testers were women affected by cancer. Today, however, many genetic counseling programs test unaffected relatives of index patients as frequently as they identify index patients. Although index patients typically receive genetic counseling in medical settings, relatives are often informed of the implications of *BRCA* testing by the index patient herself. With this shift in focus, it is increasingly important to study ways to educate and support the index patient as she informs her relatives of a deleterious family mutation. We anticipate a growing need for health-care providers to facilitate communication in families with known *BRCA* mutations.

In the U.S. health-care system, particularly in low-income and multicultural settings, this can be a challenge. Our study is strengthened by its unique ability to compare differences in outcomes between two different hospital types that use the same genetic testing thresholds and protocols (18). Participants at Diller, the tertiary referral cancer center, reported higher rates of communication of test results and family testing compared with participants at SFGH, the public county hospital. We identified a larger proportion of true negative results at Diller than at SFGH, which has several potential explanations. This finding could reflect the higher communication and family genetic testing rates at Diller identified by our data because true negatives by definition have participated in family communication. It is also possible that women with a known family mutation are more often referred to Diller than to SFGH for subsequent genetic testing.

To our knowledge, this is the first study to examine different hospital types and their relationship to family communication and family genetic testing. Hospital type was independently associated with family communication, with lower reported communication rates at the public hospital. The public hospital was also associated with lower family genetic testing rates, but this was not statistically significant. We did not find evidence of interactions between hospital type and race or IPA, suggesting that differences in race or socioeconomic status cannot completely explain differences in outcomes. Nonmeasured population differences likely exist between Diller and SFGH. For instance, approximately one third of *BRCA* testers at SFGH are recent immigrants (18), and these geographically separated and often fractured families may encounter more barriers to family genetic testing than their counterparts at Diller. The lower family testing rate at SFGH could also arise from the comparatively short lifetime of its *BRCA* testing program, established in 2002 versus 1996 for Diller. This difference is reflected in the statistically significant difference in follow-up time between the two locations. Further study is warranted to examine these outcomes of *BRCA* testing in underserved populations.

Because of its large and fairly diverse population, this study was also able to compare family communication and family genetic testing outcomes among different racial groups. Asian race, in particular, was associated with decreases in both of these outcomes in multivariate models. Several prior studies have reported lower uptake of screening mammography (23) and *BRCA* genetic testing (24) in Asians, as well as potential cultural beliefs that could affect breast cancer screening and genetic testing in Asians (25, 26). Until further studies replicate our findings, however, we recommend interpreting our data regarding race with caution. The absolute number of non-white women in our study who reported no family communication or testing was relatively small, and the confidence intervals for these estimates were fairly wide. These data could encourage further investigation, including examination of the effects of racial concordance between genetic counselors and patients.

We examined the influence of economic factors on both study outcomes, using IPA as a proxy for socioeconomic status. Although this measure may not fully denote all aspects of socioeconomic status, it may be valid in our population. In the San Francisco Bay area, self-reported income often does not reflect the significant impact of other forms of wealth such as inherited assets, property holdings, and family income. These other forms of wealth can potentially be captured with the measurement of IPA. IPA was not associated with communication of *BRCA* test results, but it was associated with increased testing of relatives for a known family mutation, independent of hospital type and race. This association exists despite the availability of subsidized testing at both locations, indicating that cost-free testing is not sufficient to remove economic barriers to genetic testing. Future studies of economics and genetic testing should additionally examine socioeconomic status of individual relatives.

Our study is strengthened by a large and representative proportion of responders to an in-depth survey, with follow-up data available for more than 1,000 *BRCA* testers and more than 200 *BRCA* mutation–positive participants. This population also included significant numbers of ethnic minority and underserved women. The comprehensive survey included several validated measures of potential predictors in the complex outcomes of communication among families and genetic testing in relatives.

We recognize several limitations of our study, which we have carefully considered in our interpretation of results. We did not link data on individual family structure to these survey results; thus, we caution that some descriptive results from this study cannot be directly compared with prior research. Instead, we used aggregate survey data to provide information on the patterns of family communication as described by *BRCA* testers. Despite differences in methodology, our work agrees with prior research indicating that more female than male relatives are informed of *BRCA* results (2, 9), and that more females subsequently pursue family genetic testing (6).

We also relied on self-report for family genetic testing and were unable to verify outcomes with the family members themselves. Although our overall population is large, only 3% reported no communication with relatives; thus, we have identified predictors of a fairly rare outcome. Similarly, despite the relatively large number of minority participants in our population, this group made up only 14% of the overall population. Future studies in larger or combined populations could potentially provide more precise estimates of the effects of some of these predictors on family communication and family genetic testing.

In conclusion, this study showed high overall rates of communication of genetic results and identified important populations that are less likely to pursue family testing for known genetic mutations. As genetic testing for cancer predisposition becomes more accepted and available in diverse and underserved populations, it is essential to study their communication of genetic testing results and subsequent family genetic testing. The disparities we have identified can inform medical providers of populations that deserve special consideration. The positive associations that we observed, particularly those of knowledge and satisfaction with the decision to *BRCA* test, could potentially inform clinical practice. Specifically, clinicians and genetic counselors could focus efforts on providing tailored education and improving satisfaction with the decision to *BRCA* test. Future studies examining the most effective ways to provide these services to underserved and ethnic minority populations are fundamental to realizing the potential of genetic testing for cancer predisposition.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Acknowledgments

We thank Robin Lee, Kate Lamvik, Nicola Stewart, Julie Mak, and Beth Crawford for their generous contributions to data interpretation and patient care, and Carolina Wilcox and Maya Metrikin for their assistance. We also value the data management assistance of David Crawford, the survey design and implementation assistance of Kelli Copeland, the cultural perspectives of Dr. Galen Joseph, and interpretation of psychometric measures from Dr. Sara Knight. We are extremely grateful to Dr. Judith Luce for her wonderful perspectives as a breast oncologist from San Francisco General Hospital.

Grant Support

Doris Duke Charitable Foundation, Avon Foundation, UCSF Clinical and Translational Science Institute, NIH Roadmap KL2 program, and a Program Project Grant from the National Cancer Institute (1P01CA130818), the Center for Translational and Policy Research in Personalized Medicine (TRANSPERS).

The costs of publication of this article were defrayed in part by the payment of page charges. This article must therefore be hereby marked *advertisement* in accordance with 18 U.S.C. Section 1734 solely to indicate this fact.

Received 04/01/2010; revised 06/11/2010; accepted 06/25/2010; published OnlineFirst 08/10/2010.

References

1. Offit K, Groeger E, Turner S, Wadsworth EA, Weiser MA. The "duty to warn" a patient's family members about hereditary disease risks. JAMA 2004;292:1469–73.
2. Patenaude AF, Dorval M, DiGianni LS, Schneider KA, Chittenden A, Garber JE. Sharing BRCA1/2 test results with first-degree relatives: factors predicting who women tell. J Clin Oncol 2006;24:700–6.
3. MacDonald DJ, Sarna L, van Servellen G, Bastani R, Giger JN, Weitzel JN. Selection of family members for communication of cancer risk and barriers to this communication before and after genetic cancer risk assessment. Genet Med 2007;9:275–82.
4. McGivern B, Everett J, Yager GG, Baumiller RC, Hafertepen A, Saal HM. Family communication about positive BRCA1 and BRCA2 genetic test results. Genet Med 2004;6:503–9.
5. Claes E, Evers-Kiebooms G, Boogaerts A, Decruyenaere M, Denayer L, Legius E. Communication with close and distant relatives in the context of genetic testing for hereditary breast and ovarian cancer in cancer patients. Am J Med Genet A 2003;116A:11–9.
6. Finlay E, Stopfer JE, Burlingame E, et al. Factors determining dissemination of results and uptake of genetic testing in families with known BRCA1/2 mutations. Genet Test 2008;12:81–91.
7. Landsbergen K, Verhaak C, Kraaimaat F, Hoogerbrugge N. Genetic uptake in BRCA-mutation families is related to emotional and behavioral communication characteristics of index patients. Fam Cancer 2005;4:115–9.
8. Ropka ME, Wenzel J, Phillips EK, Siadaty M, Philbrick JT. Uptake rates for breast cancer genetic testing: a systematic review. Cancer Epidemiol Biomarkers Prev 2006;15:840–55.
9. Wagner Costalas J, Itzen M, Malick J, et al. Communication of BRCA1 and BRCA2 results to at-risk relatives: a cancer risk assessment program's experience. Am J Med Genet C Semin Med Genet 2003;119C:11–8.
10. 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:S56–62.
11. Hall MJ, Olopade OI. Disparities in genetic testing: thinking outside the BRCA box. J Clin Oncol 2006;24:2197–203.
12. Armstrong K, Weber B, Stopfer J, et al. Early use of clinical BRCA1/2 testing: associations with race and breast cancer risk. Am J Med Genet A 2003;117A:154–60.
13. Rose A, Peters N, Shea JA, Armstrong K. The association between knowledge and attitudes about genetic testing for cancer risk in the United States. J Health Commun 2005;10:309–21.
14. Nelson HD, Huffman LH, Fu R, Harris EL. 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;143:362–79.
15. Bowen DJ, Burke W, McTiernan A, Yasui Y, Andersen MR. Breast cancer risk counseling improves women's functioning. Patient Educ Couns 2004;53:79–86.
16. Green MJ, Peterson SK, Baker MW, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. JAMA 2004;292:442–52.
17. Mancini J, Noguès C, Adenis C, et al. Impact of an information booklet on satisfaction and decision-making about BRCA genetic testing. Eur J Cancer 2006;42:871–81.
18. Lee R, Beattie M, Crawford B, et al. Recruitment, genetic counseling, and BRCA testing for underserved women at a public hospital. Genet Test 2005;9:306–12.
19. Claritas [Internet]. New York: The Nielsen Company; c2007-2008 [updated 2008; cited 2010 May 19]. Income producing assets and net worth profiles: assessing wealth by segment targeting. Available

from: https://ishare.nielsen.com/sln/Claritas/Products/Lists/Data%20%20Segmentation%20List/Attachments/293/IPA%20NetWorth%20102808.ppt.

20. Lerman C, Trock B, Rimer BK, Jepson C, Brody D, Boyce A. Psychological side effects of breast cancer screening. Health Psychol 1991; 10:259–67.
21. Holmes-Rovner M, Kroll J, Schmitt N, et al. Patient satisfaction with health care decisions: the satisfaction with decision scale. Med Decis Making 1996;16:58–64.
22. Lerman C, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. J Clin Oncol 1994; 12:843–50.
23. Smith-Bindman R, Miglioretti DL, Lurie N, et al. Does utilization of screening mammography explain racial and ethnic differences in breast cancer? Ann Intern Med 2006;144:541–53.
24. Huo D, Olopade OI. Genetic testing in diverse populations: are researchers doing enough to get out the correct message? JAMA 2007;298:2910–1.
25. Suh EE. The sociocultural context of breast cancer screening among Korean immigrant women. Cancer Nurs 2008;31:E1–10.
26. Barlow-Stewart K, Yeo SS, Meiser B, Goldstein D, Tucker K, Eisenbruch M. Toward cultural competence in cancer genetic counseling and genetics education: lessons learned from Chinese-Australians. Genet Med 2006;8:24–32.