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ORIGINAL RESEARCH

Family Communication of *BRCA1/2* Results and Family Uptake of *BRCA1/2* Testing in a Diverse Population of *BRCA1/2* Carriers

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Abstract Previous studies examining communication of *BRCA1/2* results with relatives and family uptake of *BRCA1/2* testing have sampled from predominantly white, high SES cohorts ascertained solely from tertiary care centers. No studies have focused on family communication and testing among relatives of diverse *BRCA1/2* carriers. We conducted structured interviews with 73 *BRCA1/2* carriers identified at a public hospital and a tertiary cancer center. We asked participants if each first- and second-degree relative was aware of their *BRCA1/2* results and whether or not each relative had tested. Generalized estimating equations identified rates and predictors of family communication and testing. Participants disclosed their test results to 73 % of 606 eligible relatives and 31 % of 514 eligible relatives tested. Communication and testing rates were similar for relatives of participants from the public hospital and the tertiary cancer center. Hospital site was not a significant predictor of either result disclosure or relative uptake of testing. African American and Asian/Pacific Islander participants were significantly less likely to disclose their results to their relatives; relatives of African American participants were significantly less likely to test. Addressing these disparities will require further research into the best ways to facilitate family communication and counsel at-risk relatives of racially and socioeconomically diverse *BRCA1/2* mutation carriers.

Keywords *BRCA1* · *BRCA2* · Hereditary breast and ovarian cancer · Family communication · Family testing · Disparities

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Introduction

BRCA1/2 testing has become standard of care for families at high risk of hereditary breast and ovarian cancer syndrome (HBOC) (Berliner and Fay 2007; Lu et al. 2009; NCCN 2011; Robson et al. 2010; USPSTF 2005). After a deleterious *BRCA1/2* mutation has been identified in a family, the index (first-identified) mutation carrier is primarily responsible for the next step of family communication. This involves disseminating his or her genetic test result to at-risk relatives and encouraging appropriate relatives to test (Offit et al. 2004). Additional relatives who subsequently test positive are also encouraged to disclose their results to other at-risk relatives.

If relatives decide to pursue *BRCA1/2* testing, several potential benefits emerge. Perhaps most importantly, testing allows relatives to clarify their personal risk of HBOC-associated cancers. Relatives who test positive for the family mutation can take advantage of screening, prevention, and risk-reduction interventions to decrease the risk of HBOC-associated cancers and overall mortality (Burke et al. 1997;

Domchek et al. 2010; Nathanson and Domchek 2011; Rebbeck et al. 2009). Relatives who test negative for the family mutation are at no higher risk of breast and ovarian cancer than the general population (Harvey et al. 2011; Kauff et al. 2005; Kurian et al. 2011). In the United States, testing for a known family mutation is also considerably less expensive than full sequencing of *BRCA1/2* (Plon et al. 2011).

Previous studies have found that the index (first-identified) carrier in a family shares their results with 84–96 % of first-degree relatives (Blandy et al. 2003; Finlay et al. 2008; Hughes et al. 2000; MacDonald et al. 2007; McGivern et al. 2004; Wagner-Costalas et al. 2003). In one study, 59 % of first-degree, second-degree relatives, and cousins were told about positive results (McGivern et al. 2004). *BRCA1/2* carriers are more likely to disclose results to female and first-degree relatives and less likely to disclose results to elderly relatives (Claes et al. 2003; MacDonald et al. 2007; McGivern et al. 2004; Patenaude et al. 2006; Wagner-Costalas et al. 2003). Barriers to communication of *BRCA1/2* results include lack of contact and emotionally distant relationships (Hughes et al. 2000; McGivern et al. 2004; Landsbergen et al. 2005).

Rates of *BRCA1/2* testing in at-risk relatives are fairly low; only 15–51 % of all first- and second-degree relatives test for known family mutations (Blandy et al. 2003; Finlay et al. 2008; Landsbergen et al. 2005; MacDonald et al. 2007; McGivern et al. 2004). In one study, 40 % of *BRCA1/2* carriers reported that none of their relatives had tested (Claes et al. 2003). Similar to family communication of results, female and first-degree relatives are more likely to uptake *BRCA1/2* testing (Blandy et al. 2003; McGivern et al. 2004). Members of cohesive families, as well as older individuals, are more likely to pursue *BRCA1/2* testing for a previously identified family mutation (Biesecker et al. 2000).

Few studies have examined predictors of family communication and *BRCA1/2* testing in diverse populations. Almost all studies on this topic have been done among predominantly white, high socioeconomic status cohorts ascertained from tertiary cancer centers which did not select for racially and socioeconomically diverse *BRCA1/2* mutation carriers (Blandy et al. 2003; Finlay et al. 2008; Hughes et al. 2000; MacDonald et al. 2007; McGivern et al. 2004; Wagner-Costalas et al. 2003).

One study reported that relatives of *BRCA1/2* carriers identified at public hospitals may be less likely to pursue family testing than relatives of *BRCA1/2* carriers from tertiary cancer centers, and that relatives of African American and Asian *BRCA1/2* carriers are also less likely to test (Cheung et al. 2010). This study, however, was not specifically designed to examine racial or hospital site predictors. It also did not examine pedigrees of *BRCA1/2* testers and was therefore unable to report the overall number of at-risk relatives or family communication and testing rates in these relatives (Cheung et al. 2010).

As *BRCA1/2* testing becomes more common in diverse populations, it is increasingly important to examine family communication and testing in diverse families. To our knowledge, this study is among the first specifically designed to examine family communication and testing in a diverse population that includes *BRCA1/2* testers at a public hospital and a tertiary cancer center. The specific aims of this study were to (1) calculate rates of *BRCA1/2* result disclosure and testing uptake among eligible relatives, (2) determine predictors of *BRCA1/2* result disclosure to relatives and *BRCA1/2* testing of at-risk relatives in a diverse sample of *BRCA1/2* carriers, and (3) to examine the independent predictive value of race/ethnicity on family communication and testing.

Materials and Methods

Study Population

We identified participants who had tested positive for a germline *BRCA1/2* mutation and had enrolled in the University of California San Francisco Cancer Risk Program's (CRP) IRB-approved follow-up protocol (Lee et al. 2005). The CRP provides genetic counseling and testing at two sites: San Francisco General Hospital (SFGH), a safety net, county hospital, and the Mt. Zion location of the Helen Diller Family Comprehensive Cancer Center (Mt. Zion), a tertiary referral center. Both sites use the same clinical staff and threshold for genetic testing. At SFGH, genetic counseling and testing are provided free of charge to patients if they are uninsured or if their insurance does not cover genetic testing. For relatives of known *BRCA1/2* carriers, both sites provide genetic counseling and single site family mutation testing regardless of a patient's ability to pay.

Participants were considered eligible if they underwent both counseling and testing with the CRP, had a life expectancy of at least 6 months at the time of the survey, had no significant history of mental illness, were currently living in the United States, and were conversant in English or Spanish. If more than one individual from a family had tested with the CRP, we attempted to contact the first family member who had tested. We did not limit participation to probands because we wanted to collect as many outcomes as possible in this understudied population. We surveyed one individual per family, however, so as not to double count outcomes for individuals in a family where more than one person had *BRCA1/2* tested with the CRP.

We applied this eligibility criteria to all *BRCA1/2* carriers who tested at SFGH, all non-white *BRCA1/2* carriers identified at Mt. Zion, and a random sample of white *BRCA1/2* carriers identified at Mt. Zion between January 2003 and August 2011. We did not include all white *BRCA1/2* carriers from Mt. Zion in our study population because family communication and family testing outcomes have been previously studied in

white women identified at tertiary cancer centers similar to Mt. Zion.

We identified the following numbers of BRCA positive families: 26 families from SFGH, 56 non-white families from Mt. Zion, and 246 white families from UCSF. Three families from SFGH and five non-white families from Mt. Zion did not meet the study eligibility criteria. We collected outcomes in 17 families from SFGH (3 African American, 3 Asian/Pacific Islander, 3 Hispanic, and 8 white) and 33 non-white families from Mt. Zion. Assuming a non-response rate of 30 %, we used a random number generator to identify 35 white families from Mt. Zion, and 24 of these were interviewed. Our overall survey response rate was 67 % (78 % from SFGH, 65 % from non-white families identified at Mt. Zion and 69 % among the sample of white families identified at Mt. Zion).

Procedures

We contacted all eligible participants by phone or e-mail from September 2011 to January 2012 and invited them to participate in a 15–20 min structured interview. Eligible participants with working emails received a brief electronic description of the study and were asked to respond if they were interested in participating. Email non-responders and eligible participants without working emails received phone calls. If we were unable to reach eligible participants after three phone attempts, we did not contact them further. Study participants from both sites were sent a grocery-card incentive (twenty-five dollars for SFGH participants and ten dollars for Mt. Zion participants).

Study participants completed the interview by phone, in person, or by e-mail, based on their preference. We contacted participants a minimum of 3 months after receiving positive *BRCA1/2* results. This allowed time to communicate results with relatives and to begin the family testing process.

During the interviews, we used each participant's pedigree to verify family structure and identify eligible relatives for sharing and testing. Our study instrument, the Family Communication Questionnaire (Kardashian et al. 2012), was pilot-tested in a sample of 19 *BRCA1/2* carriers from Mt. Zion in 2010. In order to sample a more diverse population, a professional translator translated the Family Communication Questionnaire into Spanish. We conducted interviews in both English and Spanish. All participants provided informed consent and this study was approved by our institution's IRB.

Measures

Participant Characteristics

For each participant, we recorded hospital testing site, self-reported race/ethnicity, Ashkenazi Jewish ancestry, whether or not the participant was born in the United States, education (categorized as less than high school graduate, high school graduate, college graduate, or completed a postgraduate degree), employment status (employed or not employed), medical insurance status (categorized as public insurance, private insurance, or uninsured), date of results, date of birth, and personal history of breast and/or ovarian cancer.

We queried participant's understanding of which parent they had inherited their mutation from with the text "often, a *BRCA1/2* mutation is passed down from either your mother's or your father's side of the family" followed by the questions: "Do you know what side of the family your mutation comes from? If so, how do you know?" This question was included in an attempt to only measure outcomes among relatives on the same side of the family the participant had inherited their mutation from and to adjust the denominator for eligible relatives accordingly. We also asked participants if they had tested for a *BRCA1/2* mutation previously identified in their family and if so, how they had found out about the family mutation, and how long it took them to test. For those relatives of study participants that tested within the CRP, we found that all participants had correctly reported their relative's test results.

Relative Characteristics

For each eligible first- and second-degree relative included on the participant's pedigree, we asked the participant to identify the relative's gender, relationship to participant, age, frequency of communication with participant (dichotomized as at least once a month or less than once a month), and whether or not the relative lives in the United States. Inclusion criteria for relatives in analyses of family communication and testing were based on eligibility criteria from consensus guidelines of the National Society of Genetic Counselors and the National Comprehensive Cancer Network (Berliner and Fay 2007; NCCN 2011).

Family Communication of BRCA1/2 Results

For each eligible first-and second-degree relative, we asked participants "To your knowledge, does he/she know about your *BRCA1/2* mutation?" Relatives eligible for sharing were at least 16 years old at the time of the survey and on the same side of the family the participant had inherited the mutation from (if known). If the participant did not know which side of the family they had inherited their mutation from, we asked about both maternal and paternal relatives. Our consent process did not allow us to directly contact relatives to verify participant reports of family communication or testing.

Family BRCA1/2 Testing

We asked participants if each of their eligible first- and second-degree relatives had undergone *BRCA1/2* testing

with the question, "To your knowledge, has this relative tested for a *BRCA1/2* mutation?" Relatives eligible for testing were at least 25 years old at the time of the survey and had at least a 25 % chance of carrying the mutation identified in the family (50 % if they were a first-degree relative and 25 % if they were a second-degree relative). This meant that some relatives were eligible for sharing, but not for testing, even if they were at least age 25 at the time of the survey. For example, if a participant's sister tested negative for the family mutation and had a 30-year old daughter, we considered this niece eligible for sharing, but not for testing. As the niece of the known carrier, but the daughter of a non-carrier, she cannot inherit the family mutation and is therefore not eligible for family *BRCA1/2* testing. We chose age 25 as the cut-off point for testing eligibility because that is the youngest age at which cancer screening is recommended if the relative tests positive (NCCN 2011). If relatives had tested, we asked whether they tested before or after the participant. If the relative tested after the participant, the study interview queried the amount of time that elapsed between knowing of the family mutation and testing.

Study data was entered at the time of interview and stored in a secure, password-protected RedCap database hosted at the University of California San Francisco (Harris et al. 2009).

Statistical Analysis

We first generated descriptive statistics to characterize both the participants and the relatives in our sample. Next, we used chi square tests to compare rates of family communication and testing among relatives. Finally, to account for family clusters, we used generalized estimating equations to identify bivariate and multivariate predictors of eligible relatives knowing about the participant's *BRCA1/2* mutation and uptake of *BRCA1/2* testing by eligible relatives. Because our primary outcomes were assessed in individual relatives, rather than study participants, our *n* for the bivariate and multivariate models was based on the number of eligible relatives for family communication and testing, respectively. Variables with $p < 0.2$ in bivariate models for testing were considered for inclusion in the final multivariate models of family communication and testing. The multivariate model controlled for relative gender, degree of relationship, whether the relative lives in the United States, frequency of communication with participant, hospital site, and participant race/ethnicity, education level (dichotomized as high school graduate or less or more than high school graduate), testing for a known family mutation, and participant history of breast and/or ovarian cancer. The model for testing also controlled for communication of results to the relative. All tests were two-tailed with $\alpha = 0.05$. Statistical analyses were conducted in SAS.

Results

Participant Characteristics

Participant demographic and clinical characteristics are shown in Table 1. Our study population was racially diverse (by design): 10 % African American, 19 % Asian/Pacific Islander, 23 % Hispanic, 44 % white, and 4 % mixed race. The mean age of participants at testing was 47.4 (SD 12.4) years. Participants received *BRCA1/2* results a mean of

Table 1 Baseline background and health history characteristics of study participants

	Total (N=73)
Background characteristics	
Testing site, n (%)	
San Francisco General Hospital	17 (23 %)
Mt. Zion	56 (77 %)
Race/Ethnicity, n (%)	
African American	7 (10 %)
Asian/Pacific Islander	14 (19 %)
Hispanic	17 (23 %)
White	32 (44 %)
Mixed	3 (4 %)
Ashkenazi Jewish, n (%)	15 (21 %)
Born outside the United States, n (%)	17 (23 %)
Education, n (%)	
Did not complete high school	6 (8 %)
Completed high school	16 (22 %)
Completed college	30 (41 %)
Completed postgraduate degree	21 (29 %)
Employment status, n (%)	
Employed	45 (62 %)
Not employed	28 (38 %)
Insurance, n (%)	
Public insurance	18 (24 %)
Private insurance	52 (70 %)
Uninsured	3 (4 %)
Number of first-degree relatives, mean (SD)[a]	3.6 (2.3)
Number of second-degree relatives, mean (SD)[a]	4.8 (5.1)
Health history	
Age at testing, years, mean (SD)	47.4 (12.4)
Time since testing, years, mean (SD)	2.8 (2.5)
History of breast/ovarian cancer, n (%)	
None	28 (38 %)
Breast cancer	36 (49 %)
Ovarian cancer	8 (11 %)
Both breast and ovarian cancer	1 (1 %)
Tested for known family mutation, n (%)	33 (46 %)

[a] Among relatives eligible for communication of *BRCA1/2* results

2.8 years prior to survey (range 0.2–8.6 years, SD 2.5 years). The majority of participants reported either breast or ovarian cancer: 49 % had a history of breast cancer, 11 % a history of ovarian cancer, and 1 participant (1 %) was affected by both. Of 73 participants, 81 % reported knowing whether they inherited the mutation from their maternal or paternal relatives, and 46 % had tested for a known family mutation.

Relative Characteristics

Overall, participants reported 606 relatives eligible for sharing and 514 relatives eligible for testing. Among relatives eligible for sharing, 263 were first-degree relatives, 305 were female, 497 lived in the United States, and 289 communicated with the participant at least once a month.

Family Communication and Testing Rates

Participants reported that 73 % of first- and second-degree relatives knew about their *BRCA1/2* mutation. As shown in Table 2, eligible relatives were more likely to know about the participant's *BRCA1/2* mutation if they were first-degree, female, living in the United States, and communicated with the participant at least once a month. Among relatives who knew about the participant's *BRCA1/2* mutation, most found out within a week (Fig. 1).

Only 31 % of all eligible relatives underwent *BRCA1/2* testing, however. Similar to family communication, first-degree relatives, female relatives, relatives living inside the United States and relatives who communicated with the participant at least once a month were significantly more likely to *BRCA1/2* test (Table 3). Of the 158 relatives who underwent *BRCA1/2* testing, 66 (42 %) had tested before the participant, and 92 tested after the participant. Among those who tested after the participant, most tested within 1 year (Fig. 2).

Predictors of Family Communication and Testing

After adjusting for relative and participant characteristics, only degree of relationship and frequency of communication with participant independently predicted whether or not the participant's mutation had been disclosed to the relative (Table 2). African American and Asian/Pacific Islander participants were less likely to disclose their mutation status to their relatives compared to white participants. No other participant characteristics were significantly associated with communication of *BRCA1/2* results to relatives. There were no significant interactions between relative gender, degree of relationship, whether the relative lives in the United States, frequency of communication with participant, hospital site, participant race/ethnicity, education level, testing for a known family mutation, or participant history of breast and/or ovarian cancer in the family communication model.

Relatives were more likely to undergo genetic testing if they were first-degree, female, or lived in the United States (Table 3). If the participant had not disclosed their mutation status to a relative, that relative was significantly less likely to *BRCA1/2* test. In the multivariate testing model, we identified significant interactions between the relative's degree of relationship to the participant and frequency of communication, so we stratified by degree of relationship for frequency of communication. In this stratified model, first-degree relatives who communicated with the participant at least once a month were significantly more likely to have undergone *BRCA1/2* testing. Relatives of African American participants were significantly less like to test than relatives of white participants.

Discussion

To our knowledge, this is the first study to examine family communication and family testing uptake among a racially and socioeconomically diverse population of *BRCA1/2* mutation carriers. This study found similar rates of family communication with relatives (73 % overall) compared to prior research. This is reassuring, given the demographic differences between our cohort and the majority white populations surveyed in other studies. *BRCA1/2* testing rates among eligible relatives in this study (31 %) were also similar to family testing rates in other studies (range 15–51 %). However, it is difficult to directly compare results from this study with prior research that queried testing among slightly different populations of relatives based on degree of relationship, gender, and age (Finlay et al. 2008; Hughes et al. 2000; MacDonald et al. 2007; Patenaude et al. 2006). Importantly, this study identifies several novel predictors of family communication and testing, particularly with respect to race. Because this study was specifically designed to include a racially diverse population, our findings can build upon prior work regarding *BRCA1/2* testing and family communication in diverse populations (Armstrong et al. 2003; Armstrong et al. 2005; Barlow-Stewart et al. 2006; Haffty et al. 2009; Hughes et al. 2003; Kurian et al. 2008; Lerman et al. 1999; Susswein et al. 2008; Thompson et al. 2003; Yoon et al. 2011).

In this study, African American participants were less likely to disclose their results to relatives, who were subsequently less likely to test. Rates of genetic counseling and testing uptake have historically been lower in African Americans compared to whites, although this may be attenuated in African American women with a recent diagnosis of breast cancer (Armstrong et al. 2003, 2005; Susswein et al. 2008). Qualitative interviews with African American women have identified genetic discrimination, abuses of genetic testing results, and medical mistrust as barriers to

Table 2 Rates and adjusted predictors of *BRCA1/2* result disclosure to eligible relatives (Relatives eligible for sharing were at least 16 years old at the time of the survey and on the same side of the family the participant had inherited the mutation from (if known)) based on relative and participant characteristics

	N (%)	Adjusted OR (95 % CI)[a]
Relative characteristics		
Degree of relationship		
Second-degree relative	198 (58 %)**	Ref
First-degree relative	243 (93 %)	4.1 (1.4 – 11.7)**
Relative gender		
Male	202 (67 %)*	Ref
Female	241 (79 %)	1.63 (0.84 – 3.2)
Frequency of communication with participant		
Less than once a month	151 (52 %)**	Ref
Once a month or more	269 (93 %)	7.3 (3.2 – 17.0)**
Where relative lives		
Outside United States	64 (59 %)**	Ref
Inside United States	379 (76 %)	1.2 (0.45 – 3.3)
Participant characteristics		
Where participant tested		
Mt. Zion	306 (80 %)	Ref
SFGH	137 (82 %)	1.8 (0.63 – 5.1)
Participant race/ethnicity		
White	135 (91 %)**	Ref
African American	53 (47 %)	0.15 (0.05 – 0.45)**
Asian/Pacific Islander	117 (70 %)	0.18 (0.07 – 0.49)**
Hispanic	123 (84 %)	1.1 (0.23 – 4.8)
Mixed	15 (80 %)	0.86 (0.10 – 7.5)
Participant education level		
High school graduate or more	379 (81 %)	Ref
Less than high school graduate	64 (77 %)	0.87 (0.27 – 2.8)
Personal cancer history		
None	178 (83 %)	Ref
Breast/ovarian cancer or both	265 (80 %)	0.66 (0.11 – 4.0)
Tested for known family mutation		
No	222 (78 %)	Ref
Yes	221 (84 %)	0.85 (0.14 – 5.4)

*$p<0.05$ **$p<0.01$

[a]Model controlled for relative's degree of relationship to participant, gender, frequency of communication with participant, if relative lives in the United States, as well as the participant's testing site, race/ethnicity, education level, personal cancer history, and whether or not they tested for a known family mutation

BRCA1/2 testing (Hughes et al. 2003; Thompson et al. 2003). Enhanced pre-testing education and counseling, however, have been associated with increased testing uptake among African American women (Lerman et al. 1999).

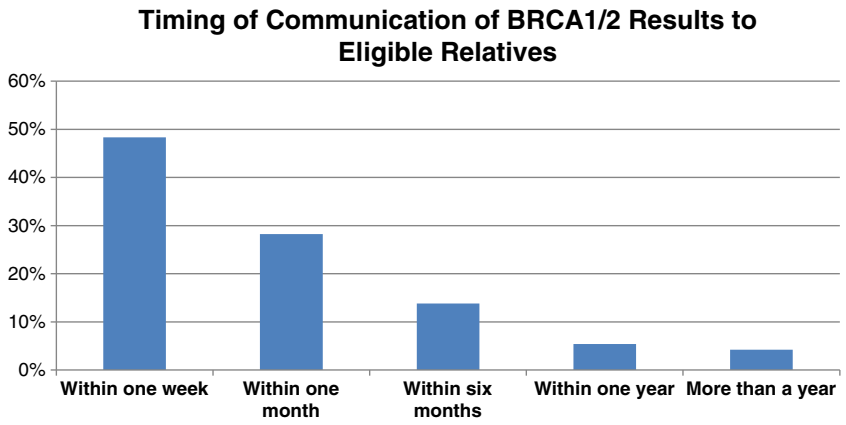

Fig. 1 Timing of Communication of *BRCA1/2* Results to Eligible Relatives. **a** Of 439 relatives to whom the participant's mutation was disclosed, participants did not remember when *BRCA1/2* results were communicated to 106 relatives. **b** Relatives were eligible for communication of *BRCA1/2* results if they were at least age 16 and had at least a 25 % chance of carrying the participant's *BRCA1/2* mutation

Table 3 Rates and adjusted predictors of *BRCA1/2* testing among eligible relatives (Relatives eligible for testing were at least 25 years old at the time of the survey and had at least a 25 % chance of carrying the mutation identified in the family) based on relative and participant characteristics

	N (%)	Adjusted OR (95 % CI)[a]
Relative characteristics		
Degree of relationship		
Second-degree relative	55 (20 %)**	Ref
First-degree relative	103 (43 %)	0.66 (0.25 – 1.8)
Relative gender		
Male	36 (14 %)**	Ref
Female	122 (47 %)	8.2 (4.8 – 13.8)**
Frequency of communication with participant		
Less than once a month	46 (19 %)**	Ref
Once a month or more	103 (40 %)	5.1 (1.1 – 22.9)[c]
Where relative lives		
Outside United States	10 (12 %)**	Ref
Inside United States	148 (35 %)	6.0 (1.6 – 22.8)**
BRCA1/2 result disclosed[b]		
Yes	–	Ref
No		0.16 (0.05 – 0.57)**
Participant characteristics		
Where participant tested		
Mt. Zion	121 (38 %)	Ref
SFGH	37 (32 %)	1.4 (0.63 – 3.2)
Participant race/ethnicity		
White	63 (44 %)*	Ref
African American	7 (6 %)	0.16 (0.06–0.40)**
Asian/Pacific Islander	36 (27 %)	0.68 (0.20 – 2.4)
Hispanic	40 (34 %)	1.9 (0.48 – 7.3)
Mixed	12 (68 %)	7.8 (1.8 – 34.0)
Participant education level		
High school graduate or more	147 (38 %)	Ref
Less than high school graduate	9 (17 %)	0.40 (0.15–1.1)
Personal cancer history		
None	84 (47 %)	Ref
Breast/ovarian cancer or both	74 (30 %)	0.55 (0.19 – 1.54)
Tested for known family mutation		
No	59 (25 %)	Ref
Yes	99 (50 %)	1.64 (0.57 – 7.5)

*$p<0.05$ **$p<0.01$

[a]Model controlled for relative's degree of relationship to participant, gender, frequency of communication with participant, if relative lives in the United States, as well as the participant's testing site, race/ethnicity, education level, personal cancer history, and whether or not they tested for a known family mutation

[b]Model stratified by degree of relationship. Odds ratio represents adjusted odds of testing among first-degree relatives who communicate with the participant at least once a month

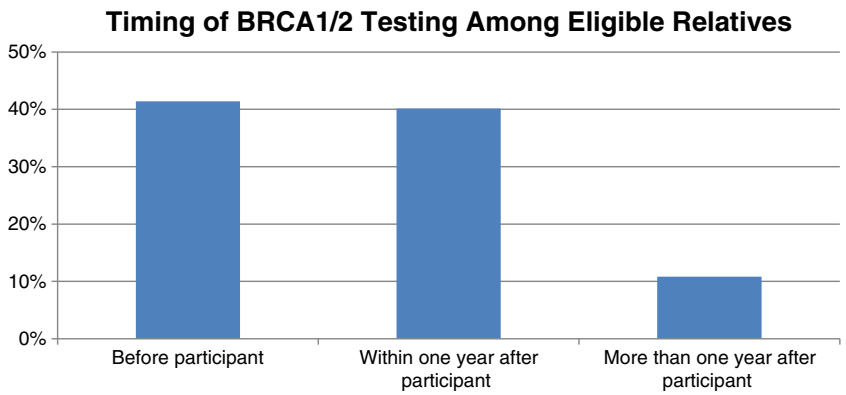

Fig. 2 Timing of *BRCA1/2* Testing Among Eligible Relatives. **a** Of the 158 eligible relatives tested, participants were unsure when 12 relatives underwent *BRCA1/2* testing. **b** Relatives were eligible for *BRCA1/2* testing if they were at least age 25 at the time of the survey and had at least a 25 % chance of inheriting the participant's *BRCA1/2* mutation

Relatives of Asian/Pacific Islander participants were also significantly less likely to disclose their *BRCA1/2* results in this study, although they were not significantly less likely to pursue *BRCA1/2* testing. This confirms the findings of Cheung and colleagues, who found that Asian *BRCA1/2* testers were less likely to communicate their results to their relatives and that their relatives were less likely to test (Cheung et al. 2010). Among Asian/Pacific Islanders at risk of HBOC, family histories and perceptions of hereditary cancer risk may be inaccurate and relatives may be reluctant to discuss cancer (Barlow-Stewart et al. 2006; Yoon et al. 2011). This may make *BRCA1/2* mutation prediction models that rely on family cancer history less accurate in Asian Americans (Kurian et al. 2008). Among women diagnosed with breast cancer before age 45, for example, Korean women are more likely to have no family history of cancer, and to test positive for a deleterious *BRCA1/2* mutation in the absence of a family history (Haffty et al. 2009).

Family communication of *BRCA1/2* results was equally likely among relatives who live in the United States compared to other countries, but relatives in the United States were significantly more likely to test. Although *BRCA1/2* testing is widely available in the United States, Canada, Europe, Israel, and Australia/New Zealand, testing done in many other countries is performed mainly for research purposes or is unaffordable for most of the population (De Leon Matsuda et al. 2002; Narod 2009; Yoon et al. 2011). Innovative approaches to increase *BRCA1/2* testing among relatives of *BRCA1/2* mutation carriers living outside countries where testing is widely available are urgently needed.

Practice Implications

Although rates of communication about positive *BRCA1/2* results were high, particularly for first-degree relatives, not all relatives learned of the family mutation. Educational materials provided during the results disclosure process could help facilitate this process (Kardashian et al. 2012; Ratnayake et al. 2011). At our institution, we provide newly identified *BRCA1/2* carriers with the Sharing Risk Information Tool (ShaRIT). ShaRIT includes a family letter, mutation report, risk-reduction and surveillance guidelines, and contact information for genetic counselors and therapists near where relatives live, and has been well-received by patients (Kardashian et al. 2012). Given our observation of lower odds of family communication among relatives of African American and Asian participants, culturally targeted counseling protocols and educational materials should be developed and evaluated to facilitate family communication and family uptake of *BRCA1/2* testing among relatives of patients from these backgrounds (Ratnayake et al. 2011).

Strengths of this study include the racial and socioeconomic diversity of participants, the long follow-up time after receiving *BRCA1/2* results (mean 2.8 years), and the fact that all participants were counseled and tested within the same genetic counseling program. Our survey response rate was acceptable (67 %), particularly in this diverse population, and we captured the majority of *BRCA1/2* carriers at both SFGH and Mt. Zion by offering the survey in both English and Spanish. Only three (3 %) eligible *BRCA1/2* carriers were excluded by limiting the survey to these two languages. While we only interviewed 73 *BRCA1/2* carriers, our study design allowed us to collect outcomes in over 600 relatives eligible for communication of *BRCA1/2* results and over 500 relatives eligible for *BRCA1/2* testing.

Study Limitations

Several limitations of this study are worth noting. We did not directly contact relatives to verify participant reports of family communication and testing, so true rates of family communication and testing may differ from those reported by participants. Most other studies that have examined family communication and testing outcomes among *BRCA1/2* carriers, however, have followed a similar approach and our consent process did not allow us to directly contact relatives. Because we could not directly contact relatives, we were unable to assess their recollections of how results were communicated, the implications of carrying a *BRCA1/2* mutation, or whether they themselves had undergone genetic counseling, but not testing (Sermijn et al. 2004; Vos et al. 2011). Future studies on this topic would benefit from interviewing relatives of diverse *BRCA1/2* carriers to confirm the disclosure of *BRCA1/2* results. Interviewing relatives directly would allow for an examination of relatives' decision-making process on whether or not to pursue *BRCA1/2* testing, and explore topics that probands would not necessarily be able to address, such as insurance status and the relative's concerns about the implications of testing.

Our eligibility criteria for result disclosure may underestimate family communication rates in our population. We considered relatives aged 16 and over to be eligible for *BRCA1/2* result disclosure. Other studies have considered children as young as 6 years (MacDonald et al. 2007) or 12 years (Claes et al. 2003) to be eligible for results disclosure, while other studies did not specify inclusion criteria based on age (Hughes et al. 2000; McGivern et al. 2004; Finlay et al. 2008). Including relatives 16–20 years of age may underestimate result disclosure rates. A majority of participants, however, had a history of breast or ovarian cancer, so we suspect that many children ages 16–20 would have been informed of the results given the history of cancer in the family. Furthermore, we considered children of family members who had tested negative to be eligible for sharing but not for testing. We chose to include these relatives

because we felt the benefits of knowing about the participant's mutation (and their parent's negative result) would be useful to evaluate their personal risk of BRCA-associated cancers. Including these relatives in the denominator for sharing may have decreased sharing rates, and our survey instrument did not query whether or not participants felt they needed to communicate their results to relatives not at risk of carrying a mutation.

We also acknowledge the potential for selection bias. The *BRCA1/2* carriers we contacted who completed the survey may have higher rates of sharing and testing compared to non-participants. Although we included participants from a safety-net hospital and a tertiary cancer center, both SFGH and Mt. Zion are affiliated with the University of California San Francisco's Cancer Risk Program. Future studies should compare family communication and family *BRCA1/2* testing between safety-net hospitals, unaffiliated tertiary cancer centers, and community-based settings.

Research Recommendations

Despite these limitations, this study identifies several important predictors of family communication and family member uptake of *BRCA1/2* testing. In this population, relatives of African American and Asian/Pacific Islander *BRCA1/2* mutation carriers were less likely to know about *BRCA1/2* test results. Furthermore, relatives of African American participants were less likely to test for the family mutation, as were relatives living outside the United States. Addressing these disparities will require novel approaches to educating individuals at high risk of HBOC who present for genetic counseling, making genetic testing available to their relatives, and research into the best ways to facilitate family communication and family testing among relatives of racially and socioeconomically diverse *BRCA1/2* mutation carriers.

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Conflict of interest The authors have no conflicts of interest to disclose. We have full control of all primary data and agree to allow the *Journal of Genetic Counseling* to review our data if requested.

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