Attitudes and Interest in Genetic Testing for Breast and Ovarian Cancer Susceptibility in Diverse Groups of Women in Western Washington[1]

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Abstract

Objectives. This paper examines the knowledge, opinions, and predictors of interest in genetic testing for breast cancer risk in a demographically diverse group of women in western Washington who participated in a randomized controlled trial (RCT) of breast cancer risk counseling methods.

Materials and Methods. Four groups of women were surveyed, all with some family history of breast cancer: (*a*) 307 white women; (*b*) 36 African-American women; (*c*) 87 lesbian/bisexual women; and (*d*) 113 Ashkenazi Jewish women. As part of the baseline questionnaire for the RCT, participants were asked about their familiarity with genetic testing for breast cancer risk, their interest in such testing and opinions of it, and actions they anticipated based on test results.

Results. Women in all four groups favored ready access to testing, believed the decision to be tested should be a personal choice, believed that genetic test results should stay confidential, and were not greatly concerned that this might not be possible. Women anticipated using such genetic test results to increase the frequency of various breast cancer screening methods (in all four groups, >69% would increase mammogram frequency, >85% would increase clinician exam, and >92% would increase breast self exam). Women overwhelmingly rejected prophylactic surgery as a preventive measure (in all >80% probably or definitely would not consider it). Significant predictors of interest in genetic testing for cancer risk included perceived risk, cancer worry, and beliefs about access to testing.

Conclusions. These data will be of interest to health care providers, payers, public health professionals, legislators, and others as they consider issues associated with population testing for susceptibility to common diseases such as breast cancer.

Introduction

Medical genetics and genetic counseling are moving rapidly into the area of preventive health care through the increasing ability to test for genetic susceptibility to common diseases such as cancer, cardiovascular disease, and diabetes. Genetic testing for inherited susceptibility to breast and ovarian cancer has been proposed to be the first example in which large-scale genetic testing for susceptibility to a common disease condition might be applied (1).

If more widespread testing for genetic susceptibility to common diseases ultimately occurs, it will be extremely important to devise methods to communicate complicated information about such genetic tests and to provide support to individuals from diverse cultures, ethnicities, and socioeconomic groups. To do this, it will be critical to understand how diverse groups of potential counseling and/or testing recipients view such testing. Current understanding of general knowledge, attitudes, and interest in testing for breast and ovarian cancer risk, limited as it is, has been derived from populations that are predominantly Caucasian and often at increased risk for breast cancer (2–5), and for many studies, *e.g.,* Chaliki *et al.* (6), limited or no demographic data are provided. One group has reported on interest of participants in an Ashkenazi Jewish pilot screening project (7), and a second reports on African-American women's attitudes and interest in *BRCA1* testing and the informed consent process (8). To date, efforts to develop models to predict utilization of *BRCA1* testing have been limited to one study (9).

This study examined the knowledge and opinions about genetic testing for breast cancer risk in a demographically diverse group of Western Washington State women who were recruited for a RCT[3] of breast cancer risk counseling methods. Predictors of interest in genetic testing were also examined. Four groups of women were surveyed: (*a*) white women with a family history of breast cancer, called "Main study"; (*b*) African-American women with and without a family history of breast cancer; (*c*) lesbian/bisexual women with and without a family history of breast cancer; and (*d*) Ashkenazi Jewish women with and without a family history of breast cancer. The data presented in this report are from the subset of women who reported a family history of breast cancer. All of these groups are of interest because members of these groups have been suggested to have a higher incidence of breast cancer (Ashkenazi Jewish and lesbian/bisexual women) or a higher mortality rate from breast cancer (African American women) and as such might be considered to be reasonable target groups for genetic testing for inherited susceptibilities (10–12). In addition, it is possible that women who belong to one of these groups may demonstrate a heightened sense of worry regarding their risk for breast cancer and a high level of interest in genetic testing for

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[3] The abbreviation used is: RCT, randomized controlled trial.

cancer risk. Data on the interest and knowledge of women in these groups are of interest to health care providers, payers, public health professionals, legislators, and others as they design, implement, and/or fund various cancer risk counseling and genetic testing programs.

Materials and Methods

Recruitment

In late 1993, we began a RCT of different counseling methods for women with a family history of breast cancer. Between 1994 and 1996, women from four diverse groups were recruited: (*a*) white women with a family history of breast cancer (Main study); (*b*) lesbian/bisexual women; (*c*) African-American women; and (*d*) Ashkenazi Jewish women. The latter three groups included women both with and without a family history of breast cancer; however, for this report, data are presented only for those women with a family history of breast cancer. The knowledge and interest in genetic testing of women in these groups may be heightened because of their membership in these groups and is of general interest in developing targeted education and counseling programs for breast cancer risk. The recruitment methods for each of the four groups were similar in concept but targeted to the characteristics of the group being recruited. Women forming the Main study group were recruited from the greater Seattle area using a variety of methods, described in detail elsewhere.[4] For this report, data are presented from women in that group who were recruited through mass media advertisement, including announcements on radio and television, and study descriptions in major employer newsletters, assorted daily and weekly newspapers, and one of the two major Seattle daily newspapers. Lesbian and bisexual women were recruited through advertisements in lesbian and gay employees' E-mail networks and in community newspapers, and distribution of brochures at community events. African-American women were recruited through placement of notices with religious organizations and in local African-American newspapers and through personal contact with community church and newspaper representatives, who then informed their constituencies about the study (13). A strategy similar to that used to recruit lesbian/bisexual and African-American women was used to recruit Ashkenazi Jewish women. Study announcements were placed in various newspapers and posted in many locations, announcements were made at organization gatherings, and brochures were distributed at community events.

Study Overview

Eligibility for the RCT was determined using a brief telephone screen that also assessed cancer worry and breast cancer risk perception. Women were eligible to participate if they were between 18 and 74 years of age, lived within 60 miles of the research center, and agreed to participate in counseling and complete questionnaires. The Main study group had at least one relative (any degree) affected by breast cancer. In all four groups, women were ineligible if they had more than two first-degree relatives with breast cancer; these women were offered the opportunity for genetic counseling.

After initial screening, all eligible women completed a baseline questionnaire and were randomized to various counseling options. This study reports data from the telephone screen and initial baseline questionnaire only for the subset of women with a family history of breast cancer; results from the larger study will be reported elsewhere.

Measures

Background Variables. The following sociodemographic factors were assessed in the telephone survey and/or in the baseline questionnaire: age, ethnicity, sexual orientation, current religion, marital status, annual income, education, and health insurance status.

Predictor Variables. (*a*) Sociodemographic factors: Ethnicity and sexual orientation were assessed in the telephone survey and baseline questionnaire. (*b*) Breast cancer risk: Number of relatives affected with breast cancer and the degree of biological relationship to the affected relative was measured by self-report as part of the baseline questionnaire. Self-report has been shown to be a reliable measure of family history of breast cancer (14). Questions included in the baseline questionnaire assessed number of previous breast biopsies, age at menarche, and age at first live birth. Together with family history information and current age, these data were used to calculate cumulative breast cancer risk estimates from current age to age 80 for each study participant using the method of Gail *et al.* (15). The baseline questionnaire also asked study participants to estimate their personal perceived risk of breast cancer, using a scale of 0 to 100, where 0 is no chance of getting breast cancer and 100 means you will definitely get it (13). The Cancer Worry Scale was used during the telephone screen to measure cancer-specific worry (16). (*c*) Beliefs about genetic testing: Specific beliefs about breast cancer genetic testing were measured using three scales. All items for these scales consisted of belief statements with 4-point response scales from strongly disagree to strongly agree. We adapted a 3-item scale measuring the fear of stigma associated with genetic testing for cystic fibrosis (17) to stigma potentially associated with breast cancer. Items included: (*a*) If I were found to have a gene that increased my risk for breast cancer in the future, I would feel less healthy than other people; (*b*) If I were found to have a gene that increased my risk to develop breast cancer in the future, I would feel singled out; (*c*) If I had genetic testing for breast cancer risk, I would worry that the results might not stay confidential. We then drafted and included items measuring beliefs about unrestricted access to genetic testing ($n = 5$) and about unrestricted flow of information about test results among family members and physicians ($n = 3$). Items measuring access included: (*a*) Physicians have an obligation to offer genetic testing for breast cancer risk to all of their patients; and (*b*) Anyone who wants genetic testing for breast cancer risk should be able to get it, regardless of whether or not they can pay for it. Items measuring information flow included: (*a*) No one should feel obligated to have genetic testing; (*b*) Physicians have an obligation to inform their patients' relatives of the results of genetic testing; and (*c*) People who have genetic testing for breast cancer risk have an obligation to inform their relatives of their test results. We performed a factor analysis of principal components on these scales, and the resultant scale items, access ($n = 2$) and information flow ($n = 3$), were averaged. For each of the three scales, higher values of the scale score mean higher fear of stigma, more unrestricted access to genetic testing, and more restrictions on information flow about test results. Alpha coefficients for each of these scales were reasonably high ($\alpha = 0.83$, 0.78, and 0.82, respectively), indicating good internal consistency.

[4] D. Bowen, W. Burke, A. McTiernan, D. Powers, J. Gralow, K. Malone, and S. Durfy. Interest in breast cancer risk counseling among women with a family history, submitted for publication.

Table 1 Characteristics of western Washington participants in a RCT of counseling for breast cancer risk

	Main study $n = 309$	Lesbian/Bisexual $n = 76$	African American $n = 36$	Ashkenazi Jewish $n = 116$
Ethnicity (%)[a]				
White not Hispanic	92.9	96.1	0	98.3
White, Hispanic	1.3	2.6	2.8	0.9
African American	1.6	0	91.7	0
Asian or Pacific Islander	1.9	0	0	0
Native American	1.3	0	0	0
Bi/multiracial	1.0	1.3	2.8	0.9
Mean age in years (SD)[a]	42.7 (11.0)	40.0 (8.51)	42.9 (11.58)	46.8 (10.5)
Education (%)				
Less than high school	0.6	0	0	0
High school degree	4.2	0	2.8	2.6
Post high school training	26.5	18.4	41.7	10.3
College degree	44.3	26.3	22.2	25.0
Graduate/Professional	24.3	55.3	33.3	62.1
Current religion (%)[a]				
Catholic	11.0	6.6	11.1	5.2
Protestant	34.3	14.5	63.9	0
Jewish	4.9	11.8	0	87.9
Other	2.9	5.3	8.3	0.9
None	38.8	50.0	8.3	5.2
Marital status (%)[a]				
Single	18.1	38.2	36.1	16.4
Married/Partnered	65.4	52.6	44.4	76.8
Widowed/Separated/Divorced	16.5	9.2	19.5	6.9
Sexual orientation (%)[a]				
Heterosexual	94.2	0	97.2	93.1
Homosexual	1.3	88.2	2.8	4.3
Bisexual	2.6	10.5	0	2.6
Annual income (%)[a]				
<$15,000	6.1	6.6	2.9	1.7
$15–$30,000	14.9	26.3	11.8	10.4
$30–$50,000	24.9	31.6	35.3	17.4
$50–$70,000	23.3	11.8	29.4	20.9
>$70,000	28.2	23.7	20.6	49.6

[a] Significantly different across the four study groups, $P < 0.01$.

Outcome Variables. The baseline questionnaire included questions regarding testing for inherited susceptibility to breast cancer. We asked two questions as outcome measures: interest in obtaining genetic testing and judgment of being a good candidate for genetic testing, both with 4-point scales, where one was "definitely not" and four was "definitely yes."

Specifically the questions were: "Would you be an appropriate candidate for this genetic testing, given your family history?" and "Would you be interested in taking such a test?" We adopted questions from the cystic fibrosis literature (17) to assess a participant's estimates of changes in behavior she would make if she received positive test results, with similar response scales.

Analyses

For between-group comparison purpose in Tables 2–5, women who reported characteristics of more than one group (*i.e.*, African-American, Lesbian, Jewish) were removed from analysis to make the groups more homogeneous. For example, women from the African-American sample who reported they were lesbian or bisexual were removed from the African-American and lesbian/bisexual sample. Descriptive statistics were used to determine participants' demographic characteristics and to describe the cancer risks associated with each of the four groups. Significant differences among the four groups were determined using one-way analyses of variance or χ^2, as appropriate. Descriptive statistics were also calculated to assess participants' knowledge, interest, and attitudes toward genetic testing for breast cancer risk. Logistic regression was used to identify predictors of interest in and judgments of candidacy for cancer genetic testing. All predictor variables were entered simultaneously into the equation to control for each other. Variables entered included study (Main study = 0, each of the other three studies = 1), Gail score, age, perceived risk, cancer worry, and the three sets of beliefs about genetic testing (stigma, access, and information flow).

Results

Participant Demographic Information. Demographic data for the present study are reported in Table 1. All groups contained some individuals who reported characteristics used to distinguish another group. For example, 6.5% of the African-American group reported they were lesbian, gay, or bisexual; about 11% of the lesbian/bisexual group reported they had Jewish ancestors. Table 1 shows demographic data after the elimination of women who reported characteristics typical of a group other than that for which they were recruited. With the exception of the African-American group, the other three groups recruited for this study were overwhelmingly white (92.8–98.3%). The mean age range of participants in all sam-

Table 2 Breast cancer risk variables and breast cancer worry in participants in a RCT of counseling for breast cancer risk

	Main study $n = 278$	Lesbian/ Bisexual $n = 67$	African American $n = 35$	Ashkenazi Jewish $n = 108$
No. of affected relatives (%)[a]				
One	54.1	59.5	67.7	55.9
Two	45.9	40.5	32.3	44.1
Mean perceived risk[b]	51.0	42.9	44.7	41.9
(SD)	(25.2)	(24.7)	(28.9)	(24.9)
Mean actual risk[b,c]	12.8	12.3	9.7	9.6
(SD)	(4.6)	(4.9)	(3.6)	(3.7)
Mean cancer worry	6.1	6.0	6.4	6.2
(SD)	(1.7)	(1.8)	(2.1)	(2.1)

[a] Significantly different across the four study groups, $P < 0.05$.
[b] Significantly different across the four study groups, $P < 0.01$.
[c] Actual risk: Gail estimates of cumulative risk (%) of developing breast cancer between current age and age 80.

ples is 40–47 years. Participants in all groups show high educational levels. Over half of the lesbian/bisexual and Ashkenazi Jewish groups report graduate and/or professional education. Highest annual income is reported by the Ashkenazi Jewish group.

Cancer Risk and Worry. Table 2 shows the mean actual lifetime risk for breast cancer for each of the study groups, calculated using the method of Gail *et al.* (15). The mean actual risk is highest for the Main study group, as expected given the high number of women with first-degree relatives affected with breast cancer in that group. It is notable that in all groups, the mean perceived risk of study participants is considerably higher than the mean actual risk. The highest mean perceived risk is seen in the Main study group, but for all groups, the mean perceived risk ranges from 3.7 to 4.5-fold higher than the mean actual risk for that group. Mean cancer worry scores were similar for all four groups (6.1–6.2).

Attitudes and Interest in Genetic Testing. Table 3 shows study participants' interest and attitudes toward genetic testing for risk of breast cancer. From these data, it can be seen that the vast majority of women from each group had read or heard almost nothing or relatively little about genetic testing for breast cancer risk. African-American women were the least likely to have heard about such genetic testing. Despite this self-reported lack of knowledge of genetic testing for risk of breast cancer, a large proportion of women from all study groups responded they would be "appropriate candidates for this genetic testing given their family history" (between 86 and 70% in all four groups).

Interest in taking a test for breast cancer risk is uniformly high. Although interest in all study groups drops when women are asked about their interest if they had to pay for the test themselves, in all cases a majority remains interested in testing. Drop in interest when self-paying is greatest for African-American women. When further probed on how much they would be willing to pay for a genetic test for cancer risk, almost all women would be willing to pay up to $200, but very few would be willing to pay $500 or more. The majority of African-American women would be willing to pay <$100 for a genetic test.

Women anticipate using genetic test information in a number of ways, as shown in Table 3. Most women in all study groups expect that, if tested and found to carry a gene mutation, they would examine their breasts more frequently, have a physician examine their breasts more frequently, and obtain more frequent mammograms. In all groups, the vast majority of women would definitely or probably not consider prophylactic surgery as a method of risk reduction, and did not anticipate that the results of this genetic testing would affect their decisions regarding having children. Overall, most women (approximately 79–94% across all four groups) would want to know if they had a gene mutation that increased their risk for breast cancer in the future, "even if this knowledge would not change your options for detection or treatment." Belief scale values differed across study groups for two of the three belief scales. African-American women and lesbians reported beliefs in more unrestricted access to data on genetic testing ($P < 0.01$ in post-hoc comparisons with Main study participants and Jewish participants). African-American women also reported significantly higher beliefs in more information flow ($P < 0.01$ in post-hoc comparisons with the other three study groups).

Predictors of Interest in Genetic Testing. Tables 4 and 5 present predictors of interest in, and beliefs about, candidacy for genetic testing for breast cancer risk. In Table 4, women in the lesbian/bisexual, African-American, or Jewish groups were significantly less likely, by a factor of 3–5 times, to believe that they were candidates for genetic testing, compared with the Main study group, even after adjustment for potential confounders such as breast cancer risk factors (using the Gail model) and perceived risk. Estimated lifetime risk was associated with a 15% increase in a woman considering herself a candidate for testing, for every 1% increase in the Gail score ($P < 0.001$). Similarly, each 1% increase in lifetime perceived risk was associated with a 3% increase in likelihood of a woman considering herself a testing candidate. Increasing the access score by one point was associated with a 48% increase in likelihood of a woman believing she is a candidate for testing. Cancer worries and beliefs about stigma and information flow were not associated with the chance of a woman believing she is a testing candidate.

Factors affecting a woman's interest in getting tested were not necessarily the same as those affecting her belief that she is an appropriate candidate for testing (Table 5). Lesbian/bisexual, African-American, and Jewish women were slightly, but not significantly, less likely to be interested in genetic testing compared with women in the Main study. Perceived risk of developing breast cancer was significantly associated with increasing likelihood for interest in genetic testing; each 1% increase in perceived lifetime risk was associated with a 2% increase in chance of wanting testing ($P < 0.01$). Cancer worry was also significantly associated with testing interest; each 1-point increase in cancer worry scale was associated with a 23% increased chance of wanting testing ($P = 0.04$). Stigma and access were significant negative and positive predictors, respectively, of testing interest. Each one point increase in the stigma score was associated with a 48% reduction in likelihood of interest in genetic testing. Neither estimated lifetime risk nor age was associated with likelihood of wanting genetic testing.

Discussion

Data presented in this report provide insights into the perceptions, knowledge, and opinions about genetic testing for breast cancer risk in a demographically diverse group of Western Washington State women who were recruited for a RCT of breast cancer risk counseling methods. It should be noted, however, that the groups included in this study were not specifically designed to be representative of any particular population. Women were eligible for the RCT only if they were willing to participate in counseling sessions, either group or

Table 3 Knowledge and interest in genetic testing for breast cancer risk in western Washington women participating in a RCT of counseling for breast cancer risk

	Main study $n = 307$	Lesbian/Bisexual $n = 87$	African American $n = 31$	Ashkenazi Jewish $n = 113$
Read/heard about genetic testing for cancer risk (%)[a] (almost nothing/relatively little)	70.4	75.0	90.3	72.7
Candidacy for testing (%)[a] (probably/definitely yes)	86.0	77.4	83.9	70.1
Interest in testing (%)[a] (probably/definitely yes)	89.9	88.1	87.1	82.9
Interest if self pay (%)[a] (probably/definitely yes)	72.0	64.3	51.6	68.4
Amount would pay (%)[a]				
≤$100	33.1	41.0	54.9	21.3
$100–$200	50.3	43.4	32.2	52.1
$500	9.5	8.4	3.2	7.1
≥$1,000	2.9	2.4	0	7.7
Anticipated actions if positive				
Increase breast self-exam? (% probably/definitely yes)	95.8	92.7	100.0	97.5
Increase clinician exam? (% probably/definitely yes)	86.3	85.6	100.0	86.4
Increase mammogram frequency? (probably/definitely yes)	72.9	79.5	93.6	69.5
Consider prophylactic surgery? (% probably/definitely NOT)	88.6	89.1	93.6	82.0
Affect childbearing decisions? (% probably/definitely NOT)	88.1	85.4	77.4	86.9
Want test results even if options don't change? (% probably/definitely yes)	81.1	84.4	93.5	78.7
Beliefs about genetic testing (mean, SD)				
Fear of stigma	3.0 (1.1)	3.0 (1.1)	2.5 (1.0)	3.0 (1.1)
Information access[a]	4.0 (1.3)	4.7 (1.2)	5.1 (1.0)	4.1 (1.2)
Information flow[a]	2.1 (0.9)	2.0 (0.9)	2.6 (1.2)	2.0 (1.0)

[a] Significantly different across the four study groups, $P < 0.01$.

Table 4 Predicting candidate for genetic testing (probably/definitely "Yes" *versus* probably/definitely "No") for breast cancer risk in western Washington women participating in a RCT of counseling for breast cancer risk

Predictor variable[a]	β estimate	SE	P	Odds ratio	Confidence interval
Study					
Lesbian/Bisexual	1.54	0.25	0.07	0.22	1–0.8
African American	0.81	0.33	0.67	1.26	0.4–3.8
Ashkenazi Jewish	1.07	0.44	0.05	0.34	0.2–0.9
Background					
Gail score	0.14	0.03	<0.001	1.15	1.1–1.2
Age	0.02	0.01	0.05	1.00	1.01–1.1
Classic screening predictors					
Perceived risk	0.02	0.00	0.011	1.03	
Cancer worry	−0.21	0.00	0.00	1.05	1.0–1.2
Beliefs about genetic testing					
Stigma	1.06	0.11	0.55	1.02	0.8–1.3
Access	0.39	0.09	<0.001	1.48	1.2–1.8
Information flow	0.13	0.11	0.30	1.14	0.9–1.2

[a] All variables were entered simultaneously into a logistic regression model.

Table 5 Predicting interest in genetic testing for breast cancer risk in western Washington women participating in a RCT of counseling for breast cancer risk

Predictor variable[a]	β estimate	SE	P	Odds ratio	Confidence interval
Population					
Lesbian/Bisexual	−0.38	0.43	0.32	0.68	0.1–1.4
African American	−0.73	0.64	0.25	0.42	0.1–1.2
Ashkenazi Jewish	−0.37	0.35	0.28	0.68	0.2–1.1
Background					
Gail score	0.01	0.04	0.69	1.01	0.9–1.1
Age	−0.01	0.01	0.35	0.98	0.9–1.0
Classic screening predictors					
Perceived risk	0.02	0.00	0.01	1.02	1.0–1.1
Cancer worry	0.22	0.10	0.04	1.23	1.0–1.5
Beliefs about genetic testing					
Stigma	−1.64	0.13	<0.001	0.52	0.4–0.2
Access	0.32	0.11	<0.001	1.36	1.1–1.7
Information flow	0.08	0.15	0.58	1.09	0.8–1.5

[a] All variables were entered simultaneously into a logistic regression model.

individual. This eligibility requirement may target women who are particularly comfortable with counseling settings and/or have characteristic learning styles. In addition, recruitment methods may have targeted women with a particular interest in breast cancer. This is most certainly the case for the Main study group, in which ~70% of women report a first-degree relative with breast cancer. Women with a particular interest in breast cancer may be more worried about their cancer risk, may have more knowledge of the topic of genetic testing for cancer risk, and may be more interested in the possibility of genetic testing than a similar group of women recruited without reference to the topic of breast cancer. Finally, these women were relatively highly educated and were from high income groups. Nevertheless, the study has several strengths. It permits comparison between culturally, experientially and/or ethnically diverse

groups of women who comprise substantial proportions of the general population, for whom questions of breast health services or genetic testing related to breast cancer risk have been raised, and who are interested in obtaining information about their risk for breast cancer. This is a significant contribution to the literature in this area, which is largely concerned with women who are members of families with strong family histories of breast cancer and for whom the worries, experiences, and perceptions of genetic risk may be different from women such as our participants.

Data from this study emphasize the discrepancy between women's actual risk for breast cancer and women's perceived risk. In all groups studied, mean perceived risk of breast cancer is significantly higher than the mean actual risk as calculated using the model of Gail *et al.* (15), with mean perceived risk highest for women from the Main study, most of whom have a first-degree relative with breast cancer. Women's tendency to overestimate their risk of breast cancer has been reported previously (18, 19). Both very low and very high levels of perceived risk have been associated with lower levels of breast screening behaviors (20, 21). Other analyses have not supported this relationship (22). This discrepancy might be explained by differences in sampling or due to chance findings. In any case, the relation between perceived risk and interest in genetic testing has not previously been fully explored.

This study also explores women's cancer worry and its relation to interest in obtaining genetic testing for breast cancer risk. Women from all groups expressed cancer worry levels that have been labeled as high in other research (16). The highest levels of cancer worry were observed in the Main study group. However, it is notable that the mean cancer worry in the other three groups can also be labeled as high. In a separate report on the African-American group, even women considered underestimators of their risk for breast cancer report high breast cancer worries (13). It is possible that recruiting methods emphasizing breast cancer risk as a focus of the study may have led to a selection of participants unusually worried about their breast cancer risk. Regardless of the reason, the high (and inaccurate) perceived risk combined with high levels of cancer worry observed in these groups underscores the importance of developing resources that will aid women in understanding their risk for breast cancer and in coping with their breast cancer worries.

Several studies have demonstrated that interest in genetic testing for breast cancer risk is high (2–4, 6), and these data support those results. In this study, interest in testing was high, despite a self-reported lack of knowledge about such testing, and remained high even among those who did not perceive themselves as appropriate candidates for testing. Interest in knowing mutation status was still high under the scenario that breast screening or treatment options would not be affected by that knowledge. In addition, in all groups, women's perception that they were appropriate candidates for genetic testing was higher than the numbers of women currently considered potential candidates for testing and much higher than current population estimates of the frequency of mutations in *BRCA1* and *BRCA2* (23).

A high degree of interest has been observed with the availability of predictive testing for other genetic conditions, such as Huntington's disease (24–26), but has not resulted in high numbers of tested individuals (26–28). Initial data indicate that for testing for inherited susceptibility to breast and ovarian cancer, utilization may be less than initial expressed interest in testing (9, 29). However, these data reveal key issues that must be addressed both in public education about *BRCA1* and *BRCA2* testing and in programs that help women understand their breast cancer risk.

Despite the high degree of interest in testing for inherited susceptibility to breast and ovarian cancer, many questions remain to be addressed prior to establishing population testing programs. The predictive value of a positive test in various populations has yet to be determined, as the penetrance of these mutations has been tested only in families with inherited predispositions to breast and ovarian cancer. Currently, risks and benefits associated with such testing remain unclear. Presumed benefits include positive psychological effects, relief from uncertainty, and increased ability to manage one's medical care, although there are no data as yet to clarify the medical benefits of testing (30), and only initial results concerning psychological effects of testing are available (9, 31). Presumed risks include psychological effects of testing on individuals and their families and societal stigmatization and discrimination, including insurance discrimination, although the nature and extent of these potential risks is unknown. Uncertainty exists about the impact of testing on individual cancer screening decisions and behavior and the best methods for providing education and support to those considering testing and to their physicians (32). Current models for provision of genetic services may be inadequate when used for genetic testing for inherited susceptibility to breast and ovarian cancer.

These data are of interest to health care providers, payers, public health professionals, legislators, and others as they consider issues associated with genetic counseling and population testing for susceptibility to breast and ovarian cancer. Several findings of this study underscore the need for some form of counseling associated with breast cancer risk testing, including the discrepancy between actual and perceived risk for breast cancer and high levels of cancer worry in all groups. If testing for inherited susceptibility to breast and ovarian cancer becomes more widespread, all of these professional groups will be concerned with developing approaches to testing and counseling that are efficient and that meet the needs of women and their families for information and support. Data on the interest and perceptions of diverse groups of women such as that provided by this study will be useful in this process.

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