



Christine Zalewski. *White Parrot Tulip I*. Photograph.

Genetic counseling can increase knowledge and affect the decision to undergo genetic testing in those at high risk for having a hereditary mutation predisposing to breast-ovarian cancer.

Cancer Genetics Knowledge and Beliefs and Receipt of Results in Ashkenazi Jewish Individuals Receiving Counseling for *BRCA1/2* Mutations

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Background: Genetic counseling for *BRCA1* and *BRCA2* mutations (mutations associated with increased risk of breast-ovarian cancer) endeavors to communicate information that will help individuals make informed decisions regarding genetic testing.

Methods: This repeated-measures study examined cancer genetics knowledge and beliefs before and after counseling and their relationship to receipt of results for *BRCA1/2* mutations in 120 highly educated Ashkenazi Jewish individuals.

Results: A repeated-measures analysis examined change in knowledge and beliefs regarding personal behavior, mechanisms of cancer inheritance, meaning of a positive result, practitioner knowledge, frequency of inherited cancer, and meaning of a negative result from pre- to post-counseling with the between subjects variables of education (with/without graduate training) and personal history of breast or ovarian cancer (yes/no), and risk of having a mutation entered as a covariate. Mechanisms of cancer inheritance, meaning of a positive result, and practitioner knowledge increased from pre- to post-counseling. Those with graduate training had higher ratings of mechanisms of cancer inheritance ratings and lower ratings of frequency of inherited cancers than those without. Mann-Whitney *U* tests found those testing had higher ratings in mechanisms of cancer inheritance, specifically in the association of multiple primary cancers with hereditary cancer, than those not testing.

Conclusions: Genetic counseling is helpful in improving overall knowledge of cancer genetics even for highly educated individuals. Particular areas of knowledge improvement should be explored in relation to receipt of results, especially to further elucidate the relationship of knowledge of the association of multiple primary cancers with hereditary cancer to receipt of test results.

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Introduction

Genetic counseling for hereditary breast-ovarian cancer associated with *BRCA1/2* mutations represents a specific area for the communication of complex cancer genetic information to assist individuals in making informed decisions about genetic testing. Our study focused on knowledge of and beliefs about breast-ovarian cancer genetics from before to after counseling on specific topics: personal behavior, mechanisms of cancer inheritance, meaning of a positive result, practitioner knowledge, frequency of inherited cancer, and meaning of a negative result. These topic areas have been identified as key to genetic counseling for hereditary breast-ovarian cancer. We located no studies that reported changes in knowledge in key topic areas from before to after counseling and the receipt of results in the Ashkenazi Jewish population at increased risk for having a mutation. Therefore, the goals of this paper are to examine the knowledge of and beliefs about cancer genetics both before and after counseling and the relationship of knowledge and beliefs to receipt of results in the Ashkenazi Jewish population at increased risk for carrying *BRCA1/2* mutations.

Risks Associated With *BRCA1/2* Mutations

Women carrying mutations in *BRCA1/2* have up to an 85% risk of breast cancer and up to a 60% risk of ovarian cancer by age 70.^{1,2} For men with the *BRCA2* gene mutation, the risk of breast cancer is also increased above population rates.³ In the Ashkenazi Jewish population, the frequency of three *BRCA1* and *BRCA2* mutations (the Ashkenazi Jewish panel) is approximately 2.6%,⁴ while the general population frequency is approximately 0.1%.⁵ The presence of risk factors, such as a personal and/or family history of breast or ovarian cancer and multiple generations affected, increases the risk of having a mutation.^{2,6} Hence, these mutations occur at a higher frequency in the Ashkenazi Jewish population than in the general population and represent a significant health threat due to their association with cancer.

Cancer Genetic Knowledge and Interest in Testing

A MEDLINE search of “*BRCA1*” and “knowledge” as well as “*BRCA1*” and “beliefs” was conducted to identify studies examining cancer genetic knowledge and receipt of results. Eight⁷⁻¹⁴ of the 15 studies identified used the National Institutes of Health National Center for Human Genome Research Cancer Genetics Consortium knowledge scale,⁷ an 11-item scale with a true/false response format. Topics included mechanisms of cancer inheritance,

frequency of hereditary cancer, meaning of a positive result, and efficacy of cancer screening. We identified no studies that included beliefs about the ability of healthcare practitioners to predict cancer or the role of personal health behaviors in the development of cancer.

Overall, increases in knowledge after genetic counseling are evident in studies of changes in knowledge.^{11,12,14} Three studies found that higher knowledge before counseling and increases in knowledge were associated with levels of education beyond high school.^{11,14,15} Those with graduate education were not examined separately for their level of knowledge, and it is possible that those with graduate education may benefit more from genetic counseling as some concepts may be difficult to comprehend. Two studies included a cancer genetics knowledge assessment of Ashkenazi Jewish individuals in their sample.^{12,16} Knowledge was higher in the Ashkenazi Jewish group than in other populations, and knowledge increased as a result of receiving general cancer and genetic testing materials. This finding of greater knowledge and greater ability to gain new knowledge is consistent with the cultural emphasis on education and learning among Ashkenazi Jews.¹⁷ However, knowledge levels were variable before and after intervention (eg, education sessions, genetic counseling, print materials), even in the Ashkenazi Jewish sample. The scales used to assess knowledge in these studies included items that were critical for understanding cancer genetics and for decision-making. For example, if an individual does not understand that a father can pass down an altered *BRCA1* gene to his daughter, this could result in the incorrect perception that heredity is irrelevant and thus result in a decision not to test and also in low perceived need for cancer screening.

Two studies found that the actual receipt of test results was approximately 50%.^{11,18} Knowledge of the availability of testing was not related to interest in genetic testing.¹⁹ The relationship between education levels and interest in testing is inconsistent. Two studies reported no relationship,^{10,20} one a positive relationship (ie, greater interest in testing for those with higher levels of education),²¹ and one a negative relationship (ie, those with higher levels of education were less likely to be interested in testing).¹⁶

Genetic Testing in Ashkenazi Jewish Individuals

Genetic testing is more feasible in the Ashkenazi Jewish population because the number of shared genes in this population is greater than in the population at large.²² Further, DNA for genetic research from Ashkenazi Jewish individuals has been available as a result of routine carrier screening for such conditions as Tay Sachs.²³ Some within the Ashkenazi Jewish community have expressed concern that stigmatization will occur due to the use of DNA sam-

ples to find mutations associated with hereditary diseases such as cancer,²⁴ and studies have been conducted to examine receptivity to genetic testing in the Ashkenazi Jewish population. One study found individuals were concerned about the *BRCA1/2* focus on Ashkenazi Jewish individuals (14%). Respondents felt that genetic information could be used to single out an ethnic group (15%) and that being tested would not improve the health of the Jewish community (25%),²⁵ but these were not majority views. However, one study found no relationship between being Ashkenazi Jewish and interest in genetic testing.²⁰ It is important to note that these are Ashkenazi Jewish individuals in the general population and not at increased risk due to personal or family history; Ashkenazi Jewish individuals with a personal or family history of cancer may be more interested in testing.

Rather than conceptualize knowledge in a true/false format, we endeavored to provide respondents with increased response options and give our study less of the appearance of a test in order to better understand beliefs and the strength of these beliefs related to key concepts in genetic counseling. Also, rather than consider an entire

scale for change in knowledge and its relationship to receipt of results, we considered our items in terms of subscales that were used to assess key concepts from genetic counseling. Further, we wished to explore how these key concepts were related to whether an individual received test results.

Consistent with prior studies, we hypothesized that all areas of knowledge of cancer genetics would change in the direction of improvement from before to after counseling. However, we predicted an interaction such that those with graduate education would show greater improvements in genetic counseling due to the difficult concepts discussed in genetic counseling. In addition, we hypothesized that individuals with a personal history of breast or ovarian cancer will have greater knowledge of topics in cancer genetics than those without as they have prior experience with cancer. Although one study found that being Ashkenazi Jewish was not associated with interest in genetic testing, we believed our sample of Ashkenazi Jewish individuals with a personal or family history of the disease would have higher rates of testing than prior reports of non-Ashkenazi Jewish individuals in the general population. Finally, we hypothesized individuals proceeding with testing would have greater knowledge gains and more education than those not testing.

Table 1. — Demographics of the Sample (N = 120)

	% Reporting
Cancer History:	
Personal breast or ovarian	50.0
Family only	50.0
Gene Status:	
Not testing	14.2
Testing	85.8
Gender:	
Male	10.8
Female	89.2
Education Level:	
Less than high school graduate	0.0
High school graduate	6.0
College	43.1
Graduate school and above	50.9
Age:	
Less than 30	4.3
30–39	15.7
40–49	33.9
50–59	22.6
60–69	17.4
70 and above	6.1
Annual Family Income:	
Less than \$25,000	4.4
\$25,000–49,999	12.4
\$50,000–99,999	37.2
\$100,000–249,999	38.1
\$250,000 and above	8.0
Country of Familial Origins:*	
Poland	39.6
Germany	13.6
Russia	68.1

* These were not mutually exclusive categories.

Methods

Participants

Participants were recruited for the study through newspaper articles, letters to local oncologists and gynecologists, and presentations at relevant community groups (Jewish organizations and breast cancer interest groups). Eligibility for the study was determined by a board-certified or board-eligible genetic counselor. Participants were 18 years of age or older, were of Ashkenazi Jewish descent, and had a personal or family history indicating risk for a *BRCA1/2* mutation (eg, early-onset breast cancer, male breast cancer, ovarian cancer). Individuals without a personal history of cancer were encouraged to test after a family member with a personal history of cancer had tested. Of 142 individuals meeting these eligibility criteria, 120 individuals from approximately 70 families presented for genetic counseling and completed questionnaires before and after counseling. The demographics of the sample are included in Table 1.

Design and Procedure

The study design was repeated-measures with observations at two key time points — before counseling (T1) and 1 to 2 days after counseling (T2) — and conducted under full Institutional Review Board (IRB) approval.

Once an individual was determined to be eligible, a questionnaire packet that included a consent form and the T1 questionnaire was mailed to that person. The consent form asked for their participation in counseling, tape recording of counseling sessions, and a series of four interviews. Participants received free genetic counseling and genetic testing in return for their participation. Participation did not require tape recording of counseling sessions. However, if individuals did not wish to participate in the T1 and T2 interviews, they were asked to pay the standard genetic counseling (\$150) and genetic testing (\$250) fees. The T1 questionnaire contained questions for a larger study investigating the response to counseling and testing for *BRCA1/2* mutations. We report here the data on knowledge of cancer genetics collected as part of this study. After completing the T1 questionnaire, participants were instructed to contact the genetic counselor by telephone at one of two counseling centers to schedule a genetic counseling session.

The consent form and T1 questionnaire were returned at the counseling session. The counselor reviewed the consent form with the participant and answered questions prior to beginning the counseling session. Counseling was conducted by a board-certified or board-eligible genetic counselor (N = 3). This is consistent with recommendations set forth in the Standard Protocol from the Familial Cancer Risk Counseling Association,²⁶ which includes a discussion of the benefits and risks of genetic testing. Sessions lasted 1 to 2 hours. One to 2 days following the counseling session, a member of the research team other than the genetic counselor conducted the T2 telephone interview. The T2 telephone interview contained questions from a larger study investigating the response to counseling and testing for *BRCA1/2* mutations. Each participant's decision to proceed with testing was obtained by the genetic counselor in a subsequent phone call. A second informed consent form was completed for participants opting to be tested for *BRCA1/2* mutations. Blood was drawn from all individuals electing to be tested. Testing was done by a laboratory approved by the Clinical Laboratory Improvement Amendments using standard methods for the Ashkenazi Jewish panel.²⁷ For those testing, a follow-up counseling session was scheduled with a genetic counselor to provide test results and discuss the implications of test results.

Measures

Background Data

The questionnaire items covering demographic data included gender, age, years of education, annual family income, and European country of familial origin. For purposes of some analyses, number of years of education was

dichotomized as with or without some graduate/professional school. Risk of having a mutation was determined based on pedigree analysis of family members with cancer using the BRCAPRO model^{28,29} within the Cancer Gene Program.³⁰ Personal history of cancer was gleaned from medical records or, if medical records were not available, by self-report.

Receipt of Results

Two days after the T2 interview, the genetic counselor phoned participants to get their receipt of results for mutations in the *BRCA1* and *BRCA2* genes. Individuals receiving results were considered testers, and those not receiving test results were considered nontesters.

Assessment of the Impact of Counseling on Knowledge of Genetics

The questionnaire designed to assess the impact of genetic counseling was based on information from the Standard Protocol. Each of the following sections describes a specific topic in genetic counseling and the items used to assess it. Questions were reviewed by a group of researchers, clinicians, and Ashkenazi Jewish individuals. The readability of the questionnaire as assessed with the Flesch-Kincaid scale^{31,32} was grade level 11.5. Items were asked at T1 and T2 and are reported in Table 2. Correct answers for each item (when known) are included in parentheses. After factor analyses determined factor structure (some items were eliminated), a mean score was computed for each subscale. For each of the mean scales, T1 knowledge was subtracted from T2 knowledge to determine the change in knowledge over time.

Mechanisms of Cancer Inheritance — Terms such as *DNA*, *chromosomes*, *genes*, *chromosome* and *gene pairings*, *dominant genes*, and *mutations* were explained in writing and accompanied by illustrations. Genetics specific to cancer were then discussed. Each of the following items assessed mechanisms of cancer inheritance: (1) all cancer is a result of changes in genetic material (true), (2) if a woman inherits a mutated (nonworking) copy of the *BRCA1* or *BRCA2* gene from her father, she has an increased chance of developing breast or ovarian cancer (true), and (3) cancers with a strong inherited component can occur in both breasts (true). Each item had a 5-item response scale (disagree strongly, disagree, neither agree nor disagree, agree, agree strongly). A higher score on the mean scale indicated a more accurate response.

Meaning of a Positive Test Result — Counseling discussed the benefits and risks of positive results. The items to assess understanding of positive test results were as follows: (1) even if a woman has a mutation in *BRCA1*, she may not develop cancer (true), (2) even if a woman has a mutation in *BRCA2*, she may not develop cancer (true), and (3) if a woman is positive for a mutation being

tested but does not develop breast or ovarian cancer, her child may also have that mutation (true). Each item had a 5-item response scale (disagree strongly, disagree, neither agree nor disagree, agree, agree strongly). A higher score on the mean scale indicated a more accurate response.

Meaning of a Negative Test Result — The meaning of a negative genetic test result varies as a function of knowledge of test results of family members. If a family member (eg, a mother) who has had breast cancer has a positive test, a negative test in the daughter means that she is at the same level of risk for cancer as the general population. If no member of the family has tested positive, a negative result does not mean that the participant's risk is at the level of the general population, as a hereditary mutation other than the *BRCA1/2* founder mutations may be the source of cancer risk for that family. The items used were as follows: (1) if I am negative for the mutations being tested, my relatives (not including my children) may be positive (true), (2) if I test negative and no one else in my family has been tested for the mutations being tested, my chance of developing breast or ovarian cancer is (higher than the general population), and (3) if someone else in my family is positive for the mutations being tested and I

am negative, my chance of developing breast or ovarian cancer is (same as the general population). Item #1 had a 5-item response scale (disagree strongly, disagree, neither agree nor disagree, agree, agree strongly). Items #2 and #3 had a 4-item response scale (zero, less than the general population, same as the general population, higher than the general population). A higher score on the mean scale indicated a more accurate response.

Frequency of Inherited Cancer — Participants were counseled that the frequency of inherited breast cancer is 5% to 10% and the frequency of inherited ovarian cancer is also 5% to 10%. The frequency of inherited cancer was assessed with 2 items: (1) what percentage of breast cancer is inherited, and (2) what percentage of ovarian cancer is inherited? Items had a percentage response scale from 0% to 100%. A lower score on the mean scale indicated a more accurate response.

Efficacy of Interventions — Though a plan for cancer screening may be developed for those testing positive, the efficacy of health interventions is unknown, and no scientific data have shown that increased surveillance and regimented diet and exercise will increase survival time for those with a *BRCA1* or *BRCA2* mutation. Items that

Table 2. — Means and Standard Deviations for Knowledge and Belief Items and Scales

	T1		T2	
Factor 1: Meaning of a Positive Result (Total Scale)	4.05	(.66)	4.27	(.61)
Even if a woman has a mutation in <i>BRCA1</i> , she may not develop cancer.	3.90	(.79)	4.20	(.70)
Even if a woman has a mutation in <i>BRCA2</i> , she may not develop cancer.	3.90	(.78)	4.19	(.71)
If a woman is positive for a mutation being tested but does not develop breast or ovarian cancer, her child may also have that mutation.	4.15	(.59)	4.33	(.64)
Factor 2: Personal Behaviors (Total Scale)	3.61	(.74)	3.79	(.72)
Factors such as personal behavior and environmental conditions are important in getting breast or ovarian cancer.	3.66	(.91)	3.90	(.75)
Factors such as personal behavior and environmental conditions are important in getting breast or ovarian cancer if you have mutation in the <i>BRCA1</i> or <i>BRCA2</i> genes.	3.48	(1.02)	3.76	(.89)
Scientific data has shown that increased surveillance and regimented diet and exercise will increase the chances of surviving cancer for those who have inherited a mutation in <i>BRCA1</i> or <i>BRCA2</i> .	3.49	(.83)	3.74	(.90)
Factor 3: Practitioner Knowledge (Total Scale)	3.14	(1.02)	2.68	(1.11)
A healthcare practitioner can tell me my actual chance of developing breast or ovarian cancer if I have a mutation in the <i>BRCA1</i> gene.	3.18	(1.00)	2.74	(1.13)
A healthcare practitioner can tell me my actual chance of developing breast or ovarian cancer if I have a mutation in the <i>BRCA2</i> gene.	3.15	(1.00)	2.71	(1.09)
Factor 4: Meaning of a Negative Result (Total Scale)	3.32	(.57)	3.31	(.47)
If I test negative and no one else in my family has been tested for the mutations being tested, my chance of developing breast or ovarian cancer is:	3.24	(.60)	3.26	(.58)
If someone else in my family is positive for the mutations being tested and I am negative, my chance of developing breast or ovarian cancer is:	3.40	(.65)	3.36	(.55)
Factor 5: Mechanism of Cancer Inheritance (Total Scale)	3.83	(.63)	4.14	(.59)
Cancers with a strong inherited component can occur in both breasts.	4.04	(.67)	4.30	(.56)
If a woman inherits a mutated (nonworking) copy of the <i>BRCA1</i> or <i>BRCA2</i> gene from her father, she has an increased chance of developing breast or ovarian cancer.	3.53	(.80)	3.91	(.87)
Factor 6: Frequency of Inherited Cancer Factor (Total Scale)	36.87	(26.13)	27.06	(24.71)
What percentage of breast cancer is inherited?	37.39	(27.61)	30.36	(27.55)
What percentage of ovarian cancer is inherited?	37.64	(26.62)	29.28	(26.58)

assessed the efficacy of interventions included the following: (1) factors such as personal behavior and environmental conditions are important in getting breast or ovarian cancer (true), (2) factors such as personal behavior and environmental conditions are important in getting breast or ovarian cancer if you have mutation in the *BRCA1* or *BRCA2* genes (false, at the time of study), and (3) scientific data have shown that increased surveillance and regimented diet and exercise will increase the chances of surviving cancer for those who have inherited a mutation in *BRCA1* or *BRCA2* (false, at the time of study). Each item had a 5-item response scale (disagree strongly, disagree, neither agree nor disagree, agree, agree strongly). A mean was created for this subscale, and a lower score indicated a more accurate response.

Healthcare Practitioner Knowledge — Although scientific models can estimate risk of cancer with a *BRCA1* or *BRCA2* mutation, no healthcare provider can know if a cancer will occur or when a cancer will occur for each individual. Beliefs about healthcare practitioner knowledge were assessed with 2 items: (1) a healthcare practitioner can tell me my actual chance of developing breast or ovarian cancer (prompt: whether or not you will get cancer) if I have a mutation in the *BRCA1* gene (false), and (2) a healthcare practitioner can tell me my actual chance of developing breast or ovarian cancer (prompt: whether or not you will get cancer) if I have a mutation in the *BRCA2* gene (false). Each item had a 5-item response scale (disagree strongly, disagree, neither agree nor disagree, agree, agree strongly). A lower score on the mean scale indicated a more accurate response.

Statistical Analysis

We generated distributions, frequencies, ranges, means, and standard deviations along with other indices of normality to describe the sample. A Principal Components Factor Analysis with oblique rotation was conducted on the 16 knowledge and belief items to guide construction of subscales. Factor loadings greater than .45 were sought. Factors with Eigenvalues greater than 1 were selected for subscales. Cronbach alphas were computed to determine the internal consistency of the subscales. Means were computed for each of the subscales.

A multivariate repeated-measures analysis of variance was conducted to determine change in knowledge and beliefs regarding personal behavior, mechanisms of cancer inheritance, meaning of a positive result, practitioner knowledge, frequency of inherited cancer, and meaning of a negative result from pre- to post-counseling with the between subjects variable of education (with or without graduate training) and personal history of breast or ovarian cancer (personal history or family history only), and with BRCAPRO estimated risk of having a mutation entered as a covariate. Further, a series of Mann-Whitney *U* tests for the independent variable of receipt of results

(yes or no) and the dependent variables of education and change in personal behavior, mechanisms of cancer inheritance, meaning of a positive result, practitioner knowledge, frequency of inherited cancer, and meaning of a negative result from pre- to post-counseling were computed to determine if individuals testing differed from those not testing. Nonparametric analyses were chosen due to unequal sample sizes in the receipt of results variable; those testing ($n = 103$) far outnumbered those not testing ($n = 17$).

Results

Knowledge and Belief Subscales

A Principal Components Analysis with oblique rotation was performed on the 16 knowledge and belief items at T1. One item was dropped because it loaded on more than 1 item, and another item was dropped because its factor loading did not reach .45. A second Principal Components Analysis with oblique rotation was performed on the remaining 14 items at T1, and a solution was reached after 10 iterations. Six factors had Eigenvalues greater than 1, and factor loadings ranged from .65 to .99 (factors are listed in Table 2). A Principal Components Analysis with oblique rotation was performed on the 14 items at T2. Five factors had Eigenvalues greater than 1, and factor loadings ranged from .64 to .98. The factor structure at T2 was similar to the factor structure at T1, except that mechanisms of cancer inheritance and meaning of a positive result formed 1 factor at T2. It was decided that the factor structure at T1 would be used as this structure more closely paralleled the counseling protocol.

Internal consistency was examined for the 6 factors (subscales). Cronbach alphas were greater than .6 for meaning of a positive result (T1: $\alpha = .87$; T2: $\alpha = .81$), personal behavior (T1: $\alpha = .76$; T2: $\alpha = .76$), practitioner knowledge (T1: $\alpha = .99$; T2: $\alpha = .96$), meaning of a negative result (T1: $\alpha = .80$; T2: $\alpha = .72$), and frequency of inherited cancer (T1: $\alpha = .94$; T2: $\alpha = .98$). The internal consistency was lower for mechanisms of cancer inheritance (T1: $\alpha = .55$; T2: $\alpha = .40$), but we include it here as it was a factor resulting from the T1 factor analysis and captures a key topic in genetic counseling.

Change in Knowledge

A repeated-measures analysis of change in 6 knowledge subscales (meaning of a positive result, personal behavior, practitioner knowledge, meaning of a negative result, mechanisms of cancer inheritance, and frequency of inherited cancer) from pre- to post-counseling was conducted with the between subjects variables of education (with or without graduate training) and cancer history (with or without personal history of breast or ovarian can-

cer) with BRCA1/2 estimated risk of having mutation entered as a covariate. Means and standard deviations for the 6 knowledge subscales at pre- and post-counseling are shown in Table 2. We found a main effect for change in knowledge [$F(6,83) = 2.70, P=.02$], a main effect for education level [$F(6,83) = 2.27, P=.04$], and a main effect trend for cancer history [$F(6,83) = 2.16, P=.06$]. Knowledge of mechanisms of cancer risk inheritance [$F(1,88) = 4.34, P=.04$], meaning of a positive result [$F(1,88) = 3.85, P=.05$], and practitioner knowledge [$F(1,88) = 4.29, P=.04$] improved from pre- to post-counseling.

Between-subjects effects also emerged. Those with graduate education [T1: $M = 34.36$ ($SD = 24.36$); T2: $M = 20.29$ ($SD = 20.65$)] had lower ratings of the frequency of inherited cancer (more accurate) than those without graduate education [T1: $M = 39.60$ ($SD = 27.97$); T2: $M = 34.45$ ($SD = 26.82$); $F(1,88) = 5.02, P=.03$], and those with graduate education [T1: $M = 3.99$ ($SD = .57$); T2: $M = 4.27$ ($SD = .57$)] had higher ratings of the mechanisms of cancer inheritance (more accurate) than those without graduate education [T1: $M = 3.68$ ($SD = .66$); T2: $M = 4.00$ ($SD = .59$); $F(1,88) = 6.57, P=.01$]. A trend emerged such that those without a personal history of breast or ovarian cancer [T1: $M = 40.69$ ($SD = 26.15$); T2: $M = 28.80$ ($SD = 25.09$)] had higher ratings of the frequency of inherited cancer (less accurate) than those with a personal history of breast or ovarian cancer [T1: $M = 32.51$ ($SD = 25.73$); T2: $M = 25.08$ ($SD = 24.43$); $F(1,88) = 2.97, P=.09$]. There were no interaction effects and no main effect for the covariate objective risk of having a mutation.

Receipt of Results

Most participants (86%) proceeded with testing. A series of Mann-Whitney U tests for the independent variable of receipt of results (yes or no) and the dependent variables of education and change in personal behavior, mechanisms of cancer inheritance, meaning of a positive result, practitioner knowledge, frequency of inherited cancer, and meaning of a negative result were computed to determine if individuals testing differed from those not testing. Only the Mann-Whitney U test for change in knowledge of mechanisms of cancer inheritance was significant (Mann-Whitney U test, $z = -2.08, P=.04$). Those testing [$M = .35$ ($SD = .59$)] had greater improvement in knowledge of the mechanisms of cancer inheritance than those not testing [$M = .09$ ($SD = .54$)]. The 2 items within the mechanisms of cancer inheritance scale were further explored for their relationship to receipt of results. Only knowledge of the association of multiple primary cancers with hereditary cancer was associated with the receipt of results (Mann-Whitney U test, $z = -2.14, P=.03$). Those testing [$M = .30$ ($SD = .65$)] had greater improvements in knowledge of the association of multiple primary cancers with hereditary cancer than those not testing [$M = -.06$ ($SD = .56$)].

Discussion

Cancer genetics knowledge did not improve in all topic areas covered by genetic counseling. This was not expected, given that prior studies showed increases in knowledge about cancer genetics following counseling.⁷⁻¹⁴ Areas showing improvements in knowledge from pre- to post-counseling were mechanisms of cancer inheritance (increase), meaning of a positive result (increase), and practitioner knowledge (decrease). Yet, personal behavior, meaning of a negative result, and frequency of inherited cancer did not change as a result of genetic counseling. We believe that meaning of a negative result and frequency of inherited cancer are sophisticated concepts, especially as they are measures of risk — the former assessing comparative risk (compared to those in the general population) and the latter assessing absolute risk (percentage). This belief is supported by the finding that education level was a factor in the level of knowledge of mechanisms of cancer inheritance (increased) and frequency of inherited cancer (decreased). Those with graduate training had greater levels of knowledge than those with a high school or college education. The finding that personal behavior did not change is likely to have more to do with psychological factors such as optimism than a lack of learning from genetic counseling. Additional research is needed to determine the role of psychosocial factors in changes in knowledge and beliefs.

Further, a trend suggested that individuals who have a personal history of breast or ovarian cancer have a better understanding of the frequency of inherited cancer than those without such a history. We located no studies comparing knowledge levels of cancer genetics for participants who did and did not have a personal history of cancer. A possible explanation for this finding could be that having a prior personal experience with cancer provides them with a more realistic and less distressing view of cancer. Finally, improvements in mechanisms of cancer inheritance were associated with the receipt of results. This finding contrasts with that of Cappelli et al¹⁸ who found no relationship between knowledge and the receipt of results, which is likely due to our ability to consider topics in genetic counseling independent of an overall knowledge scale. One item in the mechanisms of cancer inheritance scale — knowledge of the association of multiple primary cancers with hereditary cancer — was higher in those receiving test results. It appears that those testing increased in knowledge of the association, but those not testing decreased in knowledge. Rather than a decrease in knowledge as a result of genetic counseling, it is more likely that individuals may have discounted the association of multiple primary cancers with hereditary cancer. Again, a psychosocial factor such as anxiety about cancer may have led to a desire not to consider multiple primary cancers and not to receive genetic test results.

Finally, a majority (86%) of people in our study received genetic test results, unlike the low levels noted in

previous studies.^{11,18} The high level of testing may be due to the relevance of genetic testing for participants in the current study (eg, the Ashkenazi Jewish population with a personal or family history of cancer). In fact, a recent study of Norwegians who were testing for a specific mutation common in the Norwegian population reported high uptake of genetic counseling.³³

Overall, levels of cancer genetics knowledge were highly variable even after genetic counseling. It is important to remember that these difficulties in attaining genetic knowledge appeared in a high income, highly educated sample of participants drawn from a culture that places a high value on education. Indeed, a number of participants had graduate training in areas in which we would anticipate high levels of numeracy. In response to these findings, a number of questions emerge for further study. If highly educated individuals for whom genetic testing is most relevant cannot attain high levels of cancer genetics knowledge, how will less educated others fair? Is knowledge of genetics found only among those with extensive training in genetics and genetic counseling? Can individuals at risk for genetic disease assimilate the information needed to make informed and rational decisions about genetic testing and subsequent health behaviors? Could greater increases in knowledge allow individuals to make better-informed decisions?

Limitations

Certain limitations of the study should be noted. To begin, the results from our cancer genetics knowledge items are not directly comparable to those using the Cancer Genetics Consortium Scale as this scale was not available at the onset of our study. Further, the differences in number of individuals testing/not testing necessitated the use of multiple nonparametric tests, increasing the probability of a Type I error. Also, because a number of families participated in the study, discussion within families may have contaminated the data, although this contamination should be random among those with differing levels of education and with differing cancer histories. Finally, the sample was of relatively high socioeconomic status, and this may affect the generalizability of our findings.

Conclusions

Cancer genetic knowledge appears to play a role in the receipt of results. Genetic counseling is one tool shown to increase genetic knowledge; however, genetic counseling alone may not be able to achieve the gains in knowledge necessary to optimize decision-making as evidenced in this highly educated Ashkenazi Jewish sample for whom genetic testing was highly relevant. Longitudinal studies are needed to understand the effects and effectiveness of

cancer risk communications and genetic testing. The current findings suggest that additional educational efforts may be needed to assist individuals in understanding risk, especially for those receiving negative results in families where a mutation has not been detected. Studies providing supplemental educational materials and computerized tailoring of risk information have also seen gains in knowledge of cancer genetics.^{12,34} Most importantly, as advocated by McNerney,³⁵ an overall societal approach to increasing genetic literacy and its role in prevention is needed.

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