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Cancer risk awareness and concern among women with a family history of breast or ovarian cancer

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Abstract

Women with a documented deleterious mutation in *BRCA1* or *BRCA2* are at substantially elevated risk for ovarian cancer. To understand what percentage of women with high risk family histories know their risk is elevated we surveyed 1,885 women with a high or moderate risk family history and no personal history of breast or ovarian cancer, and asked about their perceived risk of breast and ovarian cancer. Among high-risk women, fewer than 20% reported use of genetic counseling, and knowledge of elevated risk of ovarian cancer was low. Prior genetic counseling was associated with greater perceived risk for ovarian cancer. Results suggest that most high-risk women (> 75%) do not know their risk for ovarian cancer. Identification of potentially high-risk women for referral to genetic counseling may improve informed ovarian cancer risk management.

Keywords

genetics; ovarian cancer; breast cancer risk; worry

Women with a family history of breast or ovarian cancer suggestive of a deleterious mutation in one of two genes known as *BRCA1 and BRCA2* are at substantially elevated risk of being diagnosed with and dying from breast and ovarian cancer (1, 2). A strong family history of breast cancer may suggest a risk of carrying a *BRCA* mutation, and estimates of the lifetime risk of ovarian cancer among *BRCA* mutation carriers range from 16 to 45% (3,

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4). Unfortunately, unlike breast cancer, most (85%) ovarian cancer diagnoses occur at late stage when disease has spread and prognosis is poor; only 27% of women with advanced disease at diagnosis survive 5 years (5). Surgical prevention can reduce a high-risk woman's risk for both breast and ovarian cancer, and is recommended for women known to be at high hereditary risk (6). As early diagnosis is associated with better prognosis, screening is recommended for high risk women who seek to delay or avoid surgery even though it has not been shown to be efficacious (1, 2).

Education about hereditary cancer risk and provision of genetic testing to identify women with deleterious mutations can be provided by a woman's primary care physician or some other provider. In large hospital and academic setting this information is often provided by specialty genetic counselors who provide risk information and counseling, order appropriate genetic testing, and explain options including surgical prophylaxis to reduce cancer risk (7, 8). Specialist counselors may be particularly important when a hereditary condition potentially causes cancer at multiple sites, as is the case with *BRCA1 and BRCA2* mutations. In such cases, a medical professional may need adequate time to provide a patient with information about multiple cancer risks, screening tests, and prevention options.

Options available to reduce risk of getting or dying from ovarian cancer (9) include several kinds of surgery, chemoprevention, and screening. Prophylactic bilateral risk-reducing salpingo-oophorectomy (RRSO) can greatly reduce the risk of ovarian cancer among *BRCA* mutation carriers (RR 0.04 for ovarian cancer) (10), as may surgery to remove fallopian tubes and tubal ligation. Some surgical approaches may not be acceptable options for women who have not yet completed their families (9), or who want to retain ovarian function (11). Although it has not been shown to reduce mortality (12–15), intensive ovarian cancer screening through high-risk screening programs is often recommended for mutation carriers who have chosen to delay surgery and retain their ovaries (15, 16). Such programs usually include annual or more frequent measurement of serum CA125 and/or transvaginal ultrasound. Screening and surgery can also be used to reduce breast cancer risk for these women. Screening options for high-risk women include frequent mammograms starting at younger ages, and use of Magnetic Resonance Imaging (MRI). Surgical removal of breasts or ovaries also reduces risk of breast cancer by approximately 50% (10).

This study examined the hypothesis that many women with a family history of breast cancer, although aware of their risk for breast cancer may, unless specifically informed, be unaware of their potentially elevated risk for ovarian cancer (17). Risk perception for breast cancer is well studied (18–20), but few studies have examined high-risk women's awareness of and beliefs about ovarian cancer risk, or use of services that may reduce risk of ovarian cancer. Low rates of awareness of ovarian cancer risk and very low rates of use of ovarian cancer screening (less than 10%) among those at high risk due to family history were reported (17) in 2002–2003 when genetic education and testing regarding *BRCA1/2* risk had only recently become available. That study noted that knowledge of ovarian cancer risk among women, including those at high risk, was low (75% of high-risk women reporting have heard or read little about ovarian cancer); awareness was somewhat higher among women with a family history including ovarian cancer. Since then, use of genetic counseling has increased greatly but although studies have described some outcomes of genetic counseling, no studies have

reported on uptake of ovarian cancer screening and surgical prevention services by high-risk women.

In this study, we examine awareness and beliefs about ovarian cancer risk in a sample of women with a family history of breast cancer who had a mammogram during a 28-month window at a local multi-campus tertiary care institution with a large oncology program. We hypothesized that women's lay theories of hereditary disease may focus primarily on the disease their family members actually had. This would mean that although women with a family history of breast cancer are likely to be aware of their elevated risk for breast cancer, their awareness of their ovarian cancer risk might be low, unless they had a family history of ovarian cancer or had previously participated in genetic counseling. As surgery and screening are recommended for mutation carriers and for women from high-risk families who choose not to undergo genetic testing, we also sought to identify factors associated with the use of ovarian cancer screening tests (CA125 blood tests and ultrasound) and interest in risk-reducing surgery. Surgery and screening are recommended for mutation carriers and for women from high-risk families who choose not to undergo genetic testing.

Materials and Methods

Participant identification, recruitment and eligibility

Participants in this study were a subset of those identified for possible participation in a randomized controlled trial (RCT) (www.ClinicalTrials.gov, # NCT01851109), designed to test the effect of offering genetic counseling on rates of RRSO among high-risk women. Family history data collected routinely and stored in a Mammography Reporting System© (MRS) database were used to identify women who received a mammogram between January 2006 and April 2008 at any of three facilities at the Swedish Medical Center in Seattle, WA. Women between 35–80 years old who reported a personal or family history of breast cancer, no prior ovarian cancer diagnosis and no prior surgeries to remove their ovaries, were sent an invitation to participate, a consent form for the screening questionnaire, and a 3-page questionnaire to determine study eligibility. The questionnaire was used to assess risk of a *BRCA1 or BRCA2* mutation and associated eligibility for the RCT. Data collected included age at diagnosis for women with a personal history of breast cancer, male relatives with breast cancer, family history of ovarian cancer, and Ashkenazi Jewish ancestry, which were not available in the MRS database. Women were told that they were selected for contact by the research program based on their past participation in the mammography program, and that they might be offered the opportunity to participate in cancer research based on their survey results. All study procedures were reviewed and approved by the Human Subjects Internal Review Boards of the Fred Hutchinson Cancer Research Center and Swedish Medical Center in Seattle, WA.

A total of 12,918 consent forms and questionnaires were mailed, of which 560 were returned by the post-office and the woman could not be contacted. From the remaining 12,358, 2,755 questionnaires were completed and returned with consent forms for a study response rate of 23%. For the current report, 870 of the respondents were excluded due to prior breast or ovarian cancer, prior ovarian surgery or missing data (details provided in results). Women with prior breast and ovarian cancer were excluded because they would be expected to have

very different levels of worry about their cancer risk than unaffected women. The remaining 1,885 were included in the current study, including 738 RCT-eligible women classified as "high-risk" based on a pedigree warranting referral to genetic counseling, and 1147 RCT-ineligible women classified as "moderate-risk" based on at least one first or second degree relative with breast or ovarian cancer.

For the current report, women were considered high-risk if they met NCCN V4.2013 Breast and Ovarian Cancer Genetic Assessment Guidelines recommendation for referral to a genetics professional, except that due to data limitations, family history of non-breast or ovarian cancers or in 3rd degree relatives were not specifically included. To ensure that high-risk women were not missed, also included were women reporting 1) a deleterious mutation in *BRCA1, BRCA2,* or *TP53*, positivity for hereditary nonpolyposis colon cancer (HNPCC), or a first or second degree relative positive for HNPCC; 2) Ashkenazi Jewish ancestry with any family history of breast cancer among first or second degree relatives; and 3) a first degree relative, or multiple second degree relatives with breast cancer diagnosed before age 50. Characteristics of women associated with classification as high risk are detailed in Figure 1.

Survey Measures

The questionnaire included an assessment of each woman's personal history of ovarian and breast cancer and oophorectomy status to determine eligibility. Women provided detailed family history information about whether or not their mother, grandmothers, sisters, daughters, paternal and maternal aunts, and nieces had ever had breast cancer and if so whether or not the diagnosis occurred before age 50. Women were also asked if any of these female relatives had ever had ovarian cancer, and if any of their male relatives had been diagnosed with breast cancer. Women were also asked to indicate their race and whether or not they were of Ashkenazi Jewish ancestry.

Women were queried about their awareness of breast and ovarian cancer in terms of how much they had read or heard about each cancer. Response categories for these questions include "very little," "some," "a fair bit," and "a lot" (17, 20, 21). Women were also asked to indicate if they felt their chances of getting each cancer compared to other women their age was "much lower", "a little lower", "about the same", "a little higher", or "much higher". These items have been used in prior studies (17, 20, 21).

To measure prior awareness of risk for inherited susceptibility, women were asked if they had ever received genetic counseling and if they had CA125 assessed and/or pelvic ultrasound done regularly to screen for ovarian cancer. To measure interest in risk-reducing surgeries, women were asked whether they would consider having their breasts removed to decrease their risk of getting cancer, and if they would consider having their ovaries removed to decrease their risk of getting cancer. For all of these questions, women were given the response categories "definitely not," "probably not," "probably yes," and "definitely yes."

Worry about cancer risk

Worry about breast and ovarian cancer risk was assessed using modified versions of the Lerman cancer worry scale, which was developed for the purpose of assessing worry about breast cancer and has been used with women at high risk for cancer due to family history (22). This measure has been reported to have internal consistency equivalent to a Cronbach's alpha of .63 (22).

The scales for breast and ovarian cancer worry used in this work were modified from those described in the original publication primarily in how they are scored. The three questions asking about 3 aspects of cancer worry are the same as in the original publication for the breast cancer scale and differ only with reference to ovarian cancer for the ovarian cancer worry scale. They ask about worry during the past month, including (question #1) the frequency with which women worry, (question #2) the frequency with which thoughts about cancer affect mood, and (question #3) whether worry affects ability to perform daily activities. Responses to each item include "Not at all or rarely", "Sometimes", "Often", and "almost all the time". From these responses, women's levels of cancer worry were categorized as "Not worried" if they responded "Not at all or Rarely" to all three questions, "Mild" if they responded with "sometimes" to question #1, "Moderate" if they responded with "often" or greater to question #1 or "sometimes" to question #2, and "Severely" if they responded with "often" or greater to question 2 or "sometimes" or greater to question #3. This coding method has been used for both the breast and ovarian cancer versions of the modified scale and has been reported in prior studies (17, 19, 23, 24).

In addition to the categorical worry scales, we use a Rasch Model (25) to create a monotonic linear measure of worry with respect to each cancer based on the same items (19). The resulting monotonic scores increase with increasing levels of worry. The Rasch modeling process takes into account that differences in adjacent categories may represent different changes in the level of worry, allowing for the creation of a linear scale result that can be used in statistical models such as ordinary least squares regression that expect linear responses. While the Rasch score is useful for measuring worry in a continuous manner, it is not easily interpretable, in part because a standardized unit for worry does not exist.

Analysis

We examined the association between ovarian cancer risk (moderate vs. high) and awareness of each cancer, perceived risk, worry, awareness of genetic counseling, use of genetic counseling, and use of screening tests using descriptive analyses. Categorical and Boolean variables were compared across groups using Fisher's exact test, and continuous variables were compared using Student's t-test. All analyses were conducted using the R statistical language (26). Multivariable regression analyses were conducted to examine the degree to which the presence of ovarian cancer in a woman's family history and use of genetic counseling were associated with: awareness of each cancer, perceived risk and worry about risk for each cancer, and reported prior use of screening and risk reduction services. Finally, within the high-risk population, we examined the degree to which prior participation in genetic counseling was associated with beliefs about risk, worry about risk, use of

screening including CA125 blood tests and transvaginal ultrasound (TVU), and interest in risk reduction services.

Results

Out of the 2,755 survey respondents, women with a personal history of breast (n=652) or ovarian (n=6) cancer, without ovaries (n=135), without a family history of breast or ovary cancer (n=133), or who failed to respond to any of these questions (n=42) were excluded from this analysis, some for multiple reasons. Among the 1,885 included respondents, 1,147 (60.8%) were considered to be at moderate-risk and 738 (39.1%) at high-risk as defined above. Of the 738 high-risk women, 14 (1.9%) did not provide definitive data on their prior use of genetic counseling (1.2% indicated that they were “not sure” whether they had attended counseling, and 0.7% did not answer the question) and were excluded from analyses regarding genetic counseling. Twenty three moderate-risk women also failed to provide definitive data on their use of genetic counseling (9 women indicated they were “not sure” and were treated as “no counseling” and 14 women did not answer the question and were dropped from analyses using this variable). Demographic characteristics of the moderate and high-risk respondents are reported in Table 1. Moderate- and high-risk women did not differ significantly with respect to age or in self-reported race, although high-risk women were more likely to report Hispanic ethnicity. Consistent with risk classification criteria, high-risk women were more likely to report a family history of ovarian cancer and having Ashkenazi Jewish heritage.

High-risk women were significantly more likely than moderate-risk women to report awareness of breast cancer (having read or heard “a bit” or “a lot” about a cancer) and of genetic counseling and testing, and perceiving their risk for breast cancer to be higher than that of others their age (65.7% vs 42.1%; $p < 0.05$). In contrast, levels of ovarian cancer awareness were low when compared to levels of breast cancer awareness. Approximately 21.8% of high-risk women perceived their risk for ovarian cancer to be higher than average, as did 7.4% of moderate-risk women. High-risk women were also significantly more likely than moderate-risk women to report themselves as candidates for genetic testing and to have participated in genetic testing and counseling (Table 1). High-risk respondents were more likely than those at moderate-risk to report “Probably Yes” or “Definitely Yes” for regular CA125 testing (15.9% versus 11.6%; $p < 0.05$), and regular TVU (11.7% versus 5.1%; $p < 0.05$). Willingness to consider surgical prophylaxis for either breast or ovaries did not differ between high- and moderate-risk respondents. Consistent with other studies, removal of ovaries was rated more acceptable than prophylactic mastectomy by our study participants (51% reported willingness to consider ovarian removal and 32% mastectomy). Willingness to consider removal of ovaries did not vary by age in this sample, but this may reflect the fact that only 6% of our participants were under 40 years of age, and none were under 35. Many had likely completed their families.

We compared levels of cancer worry using the categorical evaluation previously described to the continuous measure obtained from a linear rating scale model. There was a strong association between the categorical and the continuous methods of coding the scales for both breast and ovarian cancer (Figure 2 & 3): women categorized to higher levels of worry

tended to have higher scores on the linear worry scale. There was considerably more spread in the linear scale among those categorized as moderately and highly worried than among women who indicated milder levels of worry.

Factors associated with elevated levels of awareness, perceived risk and worry about cancer risk, including prior genetic counseling and a family history of ovarian cancer, are reported in Table 2. The differences in scores for each variable are reported for those with and without the associated factor. Both genetic counseling and a family history of ovarian cancer were associated with higher awareness of ovarian cancer, perceived risk for ovarian cancer, and use of the ovarian cancer screening tests CA125 and TVU ($p<0.05$). Family history of ovarian cancer was also associated with greater worry about ovarian cancer risk ($p<0.05$). Prior genetic counseling was associated with self-reported awareness of breast cancer, perceived risk of breast cancer, and worry about risk for breast cancer ($p<0.05$). Having a family history of ovarian cancer, which is associated with an elevated risk for having a *BRCA1/2* mutation, was associated with less self-reported awareness of breast cancer ($p<0.05$), and with lower reported use of mammography for breast cancer screening ($p<0.05$).

Prior use of genetic counseling was twice as high among high-risk versus moderate-risk women (14.8% vs 6.5%; p=<0.001), but low in both groups (Table 3). In the subgroup of 724 high-risk women, prior participation in genetic counseling was associated with a greater proportion reporting that they were aware, having heard or read “a fair bit” or “a lot”, about breast cancer ($p<0.001$), ovarian cancer ($p<0.001$) and genetic testing ($p<0.001$). Only 40.4% of high-risk women who had attended genetic counseling, and 26.4% of those who had not, reported having heard or read “a fair bit” or “a lot” about ovarian cancer, while a majority of the women who reported prior genetic counseling also reported awareness of breast cancer (87.2%) and genetic testing (67.5%). Among the high-risk women, genetic counseling was also associated with significantly increased levels of perceived risk for both breast ($p<0.003$) and ovarian cancer ($p<0.001$), increased use of ovarian cancer screening including CA125 ($p<0.003$) and TVU ($p<0.001$), and increased willingness to consider undergoing prophylactic surgery to reduce risk for both breast and ovarian cancer ($p<0.01$).

Discussion

This study included women with any family history of breast or ovarian cancer but no personal history of either cancer, and subdivided them into high-risk women with pedigrees likely to warrant genetic counseling and moderate-risk women with pedigrees unlikely to be associated with a deleterious mutation. We postulated that lay theories of hereditary illness focus on the specific illnesses presenting in one’s family, and that without education or counseling other illnesses related to a deleterious mutation would be ignored. Thus, we hypothesized ovarian cancer risk would not be a focus of awareness or activity among women at risk for a *BRCA1/2* mutation based on a family history of breast cancer alone. We found that although the majority of women reported having read or heard “a fair bit” or “a lot” about breast cancer, less than a third reported similar awareness of ovarian cancer. In addition, although high levels of worry *about cancer risk* have been reported among women with a family history of breast cancer, particularly those seeking genetics services (19, 27)

few studies have focused on worry about ovarian cancer. We found that rates of awareness and worry in this population were moderately elevated in a majority of high-risk women only for breast cancer. Reported levels of awareness of ovarian cancer and of the possibility of elevated levels of risk, even among those with significant family histories, were quite modest (19, 28). Even among the high-risk women, while most were aware of being at elevated risk for breast cancer, fewer than 25% reported awareness of elevated risk for ovarian cancer.

Use of mammography was very high in this sample based on the recruitment strategy used, which included only women with a family history of disease who had received at least one recent mammogram. In this population selected for use of cancer screening, use of ovarian cancer screening services was appropriately modest among moderate-risk women. These screening tools have not been shown to reduce mortality in either moderate- or high-risk groups (15), but ovarian cancer screening is recommended for high-risk women who have not had genetic testing and those with mutations who forego or postpone RRSO.

Only 15% of the women in this sample at high risk for a mutation reported having received genetic counseling prior to the survey. High-risk women who had not received genetic counseling appeared to be unaware of their potentially elevated risk of ovarian cancer although aware of their potentially elevated breast cancer risk. Among high-risk women, those with prior genetic counseling demonstrated higher levels of awareness and knowledge about ovarian cancer, were more likely to use screening, and reported greater willingness to consider preventive services, suggesting that genetic counseling may increase awareness of ovarian cancer risk and willingness to consider prophylactic risk-reducing surgery, or that women considering these options are more likely to seek genetic counseling. This finding is consistent with prior studies examining the effectiveness of genetic counseling for high risk women on breast cancer knowledge (27, 29), but unique in that most prior studies have focused on perceived risk and knowledge of breast and not ovarian cancer.

It is encouraging that the association of genetic counseling with increased awareness and use of risk reduction services is not accompanied by increased worry about ovarian cancer. Given high rates of worry about breast cancer risk in this population and ovarian cancer's poor prognosis, information about ovarian cancer risk could potentially increase women's levels of worry about cancer and act as a barrier to risk reduction. However, we found that among women with a family history of breast or ovarian cancer, prior genetic counseling was not associated with ovarian cancer worry. Prior use of genetic counseling was associated with elevated levels of worry about breast cancer but this may be due to high-risk women seeking counseling because of worry about breast cancer risk associated with their family history (19, 28). Within the high-risk population, prior genetic counseling was associated with a trend toward increased levels of worry about risk for ovarian cancer, but levels of worry were very modest in the counseled group. Very few women reported moderate or severe worry about ovarian cancer.

The finding that women with a family history of ovarian cancer were both more likely to use ovarian cancer screening services and simultaneously LESS likely to report high levels of awareness of and perceived risk for breast cancer was unexpected given that these women

also had a family history of breast cancer. We can only speculate that because of its poor prognosis, ovarian cancer is more likely than breast cancer to have resulted in the death of a relative, causing concern about ovarian cancer risk to partially eclipse concern about breast cancer risk. Further study of this phenomenon could be of interest in understanding coping with hereditary cancer risk syndromes associated with cancer at multiple organ sites.

Limitations

The 23% response rate for the survey introduces the possibility of selection bias. Because our purpose was recruitment for a RCT, only motivated women were of interest. Women who completed the survey without any reminder may be more organized, interested in medical care generally, and more compliant than those who did not. We hope that selection bias with respect to cancer worry was minimal because the study materials did not mention risk, suggesting only that the survey was an opportunity to participate in women's cancer research. Dependence on self-report without chart review to confirm family history and use of services introduces the possibility of recall bias. Studies of self-report data on mammography use and on family histories of breast cancer in first degree relatives have found these reports to be sufficiently accurate for comparative research of this sort (30, 31). The validity of self-reports of CA125 blood tests and TVU imaging are unknown.

In addition, this study was conducted in an urban/suburban area in a single region of the U.S.A. where the population is generally well educated, predominantly white, and likely insured. The participating women had all received mammograms within the previous 28 months at facilities associated with a large hospital offering both specialty genetic counseling and an ovarian cancer-screening program for high-risk women. The metropolitan area also includes both a large managed care system and an academic medical center that provide specialty genetic counseling for high-risk women. Inclusion of three facilities in different parts of the city may somewhat improve generalizability, but results may overstate the levels of knowledge regarding risk for ovarian cancer, and use of genetic counseling and ovarian cancer screening, relative to those found in future studies in other parts of the country where similar services are less available.

Finally, we did not identify, even through self-report, women who had had genetic testing prior to the study. This omission may have led to classification of a few women as high-risk who, though possessing a high-risk family history, had previously tested negative for a deleterious mutation and knew themselves to be at closer to average risk. Such individuals are likely to be few, but they are possible. We also excluded women who had had prior surgery to remove their ovaries; accordingly we cannot report on the likelihood of RRSO following genetic counseling or on views of women who elect RRSO. The significant association of prior genetic counseling with reported use of CA125 and TVU tests as screening tests for ovarian cancer suggests that counseling may increase use of at least some services intended to reduce risk of ovarian cancer death in high-risk women.

Conclusion

Overall, these findings suggest that high-risk women are largely unaware of their risk for ovarian cancer and that only about a fifth of high-risk women have received genetic counseling. Identification of high-risk women and referral for genetic counseling could improve high-risk women's ability to make informed decisions regarding use of ovarian cancer risk-reducing strategies including prophylactic surgery and use of screening tests. Physicians caring for high-risk women have an opportunity to assure that their patients receive services that will help them reduce their risk of having and dying of both breast and ovarian cancer. It appears that without explicit education, women with a strong family history of breast cancer are often unaware of the ovarian cancer risk associated with a *BRCA1/2* mutation. When a mutation is associated with cancer at multiple sites, educational efforts may be particularly important.

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To be categorized as high-risk participants must have met at least one of the following criteria:

1. **History of Breast Cancer only**
   - A male relative with breast cancer diagnosed at any age.
   - One or more first-degree female relatives (self, mother, sister, daughter) with breast cancer diagnosed before or at age 50.
   - Two breast cancers in first or second degree female relatives (grandmother, aunt) in the same lineage, with at least one breast cancer diagnosed before or at age 50.
   - Three or more first or second degree female relatives in the same lineage, with breast cancer diagnosed at any age.
2. **Two or more first or second degree relatives in the same lineage with ovarian cancer diagnosed at any age.**
3. **History of Breast and Ovarian Cancer**
   - One first or second degree relative in the same lineage with ovarian cancer diagnosed at any age, and one first or second degree relative in the same lineage with breast cancer diagnosed at any age.
   - One first or second degree relative with both breast and ovarian cancer diagnosed at any age (two primaries in the same person).
4. **Ashkenazi Jewish and any family history of breast or ovarian cancer among first or second degree relatives.**
5. **A Personal or Family history for inherited susceptibility for hereditary nonpolyposis colon cancer (HNPCC) or a deleterious mutation in *BRCA1*, *BRCA2*, or *TP53*.**

Figure 1.
High-risk Criteria.

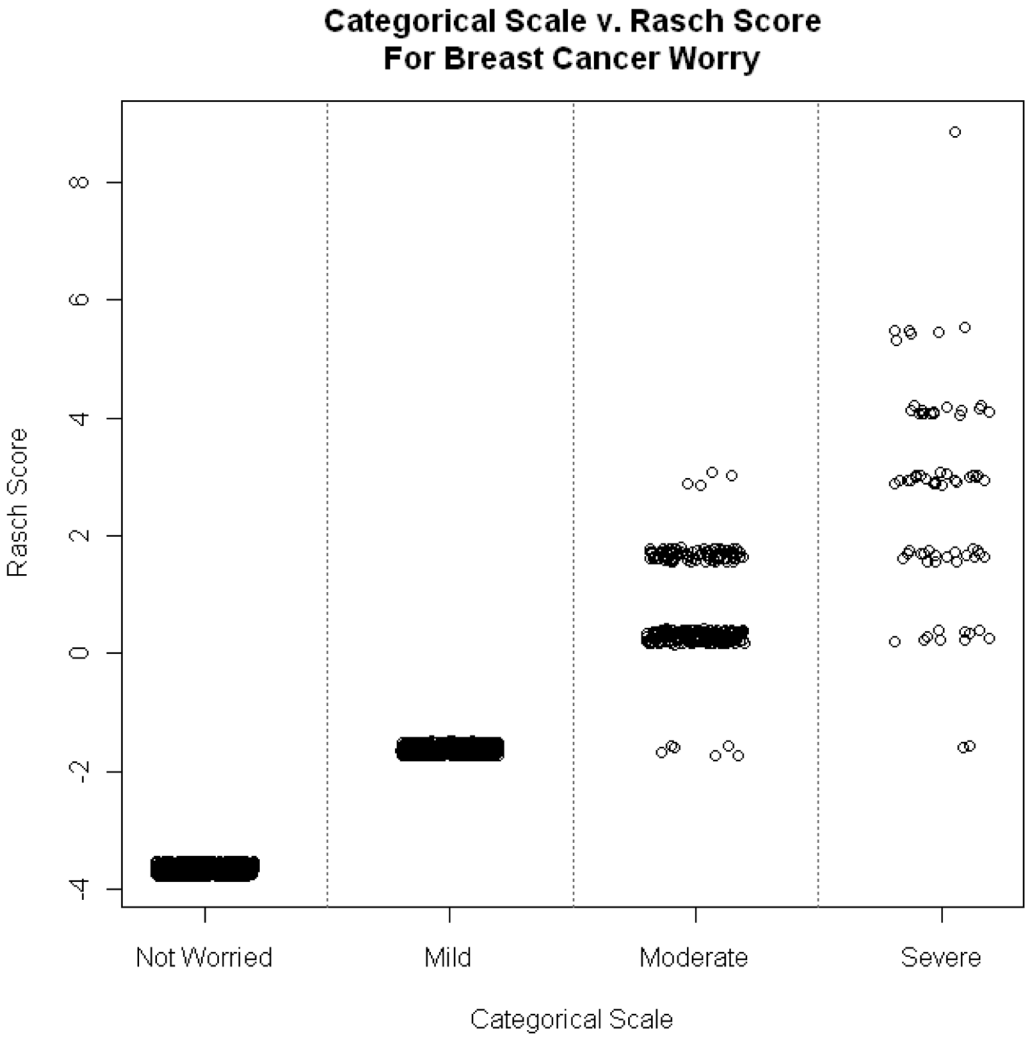

Figure 2.
Association between Rasch model scores for breast cancer worry and the categorical breast cancer worry scale results.

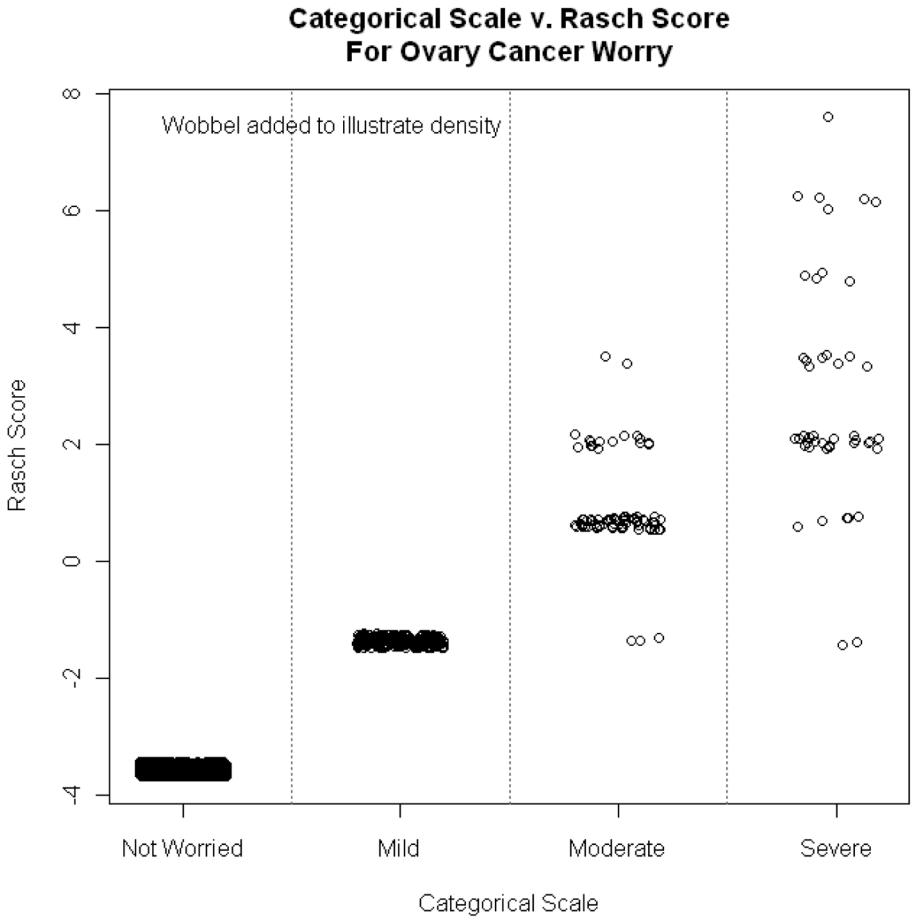

Figure 3.

Association between Rasch model scores for ovarian cancer worry and the categorical Ovarian Cancer worry scale results.

Table 1

Demographics, Perceptions of Risk, Self-reported Awareness and Candidacy for Genetic Testing by Risk Level

Question	Response Category	Risk Level		p-value
		Moderate	High	
Number of Participants		1147	738	
Years of Age	Mean (SD)	53(10)	52(11)	0.798
Race	White/Caucasian	93.5%	92.1%	
	Other	0.9%	1.9%	
	Asian	3.8%	3.1%	
	American Indian/Alaska Native	0.4%	0.5%	
	Black or African American	1.0%	1.9%	
	Native Hawaiian or other Pacific Islander	0.3%	0.3%	0.331
Hispanic Ethnicity		2.0%	5.7%	0.004
Ashkenazi Jewish		0.7%	24.1%	< 0.0005
Family history of ovary cancer *		3.1%	22.0%	< 0.0005
Family history of breast cancer *		99.0%	97.7%	0.030
Attended prior genetic counseling		6.5%	14.8%	< 0.0005
Chances of getting breast cancer compared to women my age are:	Lower	21.7%	10.1%	
	About the same	36.2%	24.3%	
	Higher	42.1%	65.7%	< 0.0005
Chances of getting ovarian cancer compared to women my age are:	Lower	33.5%	19.9%	
	About the same	59.2%	58.3%	
	Higher	7.4%	21.8%	< 0.0005
How much have you read or heard concerning breast cancer?	Very little/None	3.7%	2.2%	
	Some	31.0%	26.8%	
	A fair bit	36.1%	37.0%	
	A lot	29.1%	34.0%	0.021
How much have you read or heard concerning ovarian cancer?	Very little/None	26.8%	28.7%	
	Some	45.8%	42.9%	
	A fair bit	20.1%	19.5%	
	A lot	7.3%	9.0%	0.375
How much have you read or heard concerning genetic testing?	Almost nothing	28.8%	21.7%	
	Relatively little	48.2%	45.2%	
	A fair bit	21.1%	27.5%	
	A lot	1.9%	5.6%	< 0.0005
Would you Consider prophylactic breast surgery?	Definitely not	23.9%	21.9%	
	Probably not	45.5%	45.5%	
	Probably yes	23.5%	22.6%	

Question	Response Category	Risk Level		p-value
		Moderate	High	
	Definitely yes	7.2%	10.0%	0.185
Would you Consider prophylactic ovarian surgery?	Definitely not	16.8%	17.9%	
	Probably not	32.6%	30.2%	
	Probably yes	32.5%	32.4%	
	Definitely yes	18.1%	19.6%	0.657
Have you had CA125 tests done regularly for ovarian cancer?	Definitely not	62.6%	61.0%	
	Probably not	25.8%	23.1%	
	Probably yes	7.6%	7.9%	
	Definitely yes	4.0%	8.0%	0.003
Have you had ultrasound tests done regularly for ovarian cancer?	Definitely not	79.4%	75.5%	
	Probably not	15.5%	12.7%	
	Probably yes	2.6%	5.5%	
	Definitely yes	2.5%	6.2%	< 0.0005

* Family history defined as one or more affected first or second degree relative.

Table 2

Prior Counseling and Family History of ovarian cancer associations with levels of awareness, perceived risk, worry about risk and use of screening tests among high risk women (N=724).

Cancer Type	Dependent Variable	Prior Genetic Counseling		Family History of Ovarian Cancer	
		Coefficient*	P-value	Coefficient*	P-value
Breast	Self-Reported Awareness	1.13	< 0.001	−0.46	0.016
	Perceived Risk	0.80	0.002	−0.34	0.067
	Worry about risk**	0.81	< 0.001	−0.05	0.772
Ovary	Self-Reported Awareness	0.70	0.002	0.68	< 0.001
	Perceived Risk	1.26	< 0.001	1.82	< 0.001
	Worry about risk**	0.22	0.186	0.81	< 0.001
	Regular use of CA125	0.78	0.002	0.87	< 0.001
	Regular use of TVU	1.09	< 0.001	1.22	< 0.001

* Coefficient for awareness, perceived risk, and regular use of CA125 or TVU were obtained via logistic regression with the dependent variable explained by Genetic Counseling and Family history in a simultaneous regression model. Individual coefficients are interpreted as an increase in the log odds of reporting the dependent variable adjusting for the other independent variable.

** Coefficients for worry about risk were obtained using ordinary least squares regression with prior genetic counseling and family history of ovarian cancer to simultaneously explain the site specific worry scores. Positive coefficients represent increasing worry associated with the explanatory variable adjusting for the other explanatory variable. The coefficients are comparable within the specific site only because the scales of worry are estimated separately for breast and ovarian cancer.

*** Responses from 14 individuals who failed to respond to the question about prior genetic counseling were dropped from this analysis.

Table 3

Ethnicity, Family History, Perceptions of Risk, Self-reported Awareness and genetic counseling among High Risk women (n=724) by self-reported prior genetic counseling

Question	Response	Reported Prior Genetic Counseling		p-value
		No	Yes	
		615	109	
FH of Ovary Cancer (1 or more)	Yes	22.8%	16.5%	Ns
Chances of getting BC compared to women my age are:	Lower	10.7%	6.5%	
	About the same	26.4%	13.9%	
	Higher	62.8%	79.6%	0.003
Chances of getting OC compared to women my age are:	Lower	20.8%	16.3%	
	About the same	60.3%	46.2%	
	Higher	18.9%	37.5%	<0.001
How much have you read or heard concerning Breast Cancer	Very little/None	2.6%	0.0%	
	Some	29.1%	12.8%	
	A fair bit	37.6%	34.9%	
	A lot	30.6%	52.3%	<0.001
How much have you read or heard concerning Ovarian Cancer	Very little/None	30.6%	18.3%	
	Some	43.1%	41.3%	
	A fair bit	19.4%	21.2%	
	A lot	7.0%	19.2%	0.001
How much have you read or heard concerning genetic testing	Almost nothing	24.5%	7.4%	
	Relatively little	48.6%	25.0%	
	A fair bit	24.5%	44.4%	
	A lot	2.4%	23.1%	<0.001
Categorical Ovarian Cancer Worry Scale	Not Worried	468 (76.9%)	82 (75.9%)	
	Mild	88 (14.5%)	13 (12.0%)	
	Moderate	35 (5.8%)	8 (7.4%)	
	Severe	18 (3.0%)	5 (4.6%)	Ns
Categorical Breast Cancer Worry Scale	Not Worried	256 (42.1%)	23 (21.1%)	
	Mild	201 (33.1%)	49 (45.0%)	
	Moderate	121 (19.9%)	28 (25.7%)	
	Severe	30 (4.9%)	9 (8.3%)	<0.001
Would you consider having your breasts removed to decrease the risk of getting breast cancer?	Definitely not	139 (23.8%)	11 (10.3%)	
	Probably not	265 (45.3%)	51 (47.7%)	
	Probably yes	128 (21.9%)	28 (26.2%)	
	Definitely yes	53 (9.1%)	17 (15.9%)	0.004
Would you consider having your breasts removed to decrease the risk of getting ovarian cancer?	Definitely not	114 (19.0%)	11 (10.4%)	
	Probably not	185 (30.9%)	29 (27.4%)	
	Probably yes	193 (32.2%)	36 (34.0%)	

Question	Response	Reported Prior Genetic Counseling		p-value
		No	Yes	
	Definitely yes	107 (17.9%)	30 (28.3%)	0.026
Have regular CA125 tests?	Definitely not	368 (62.2%)	61 (56.5%)	
	Probably not	140 (23.7%)	20 (18.5%)	
	Probably yes	47 (7.9%)	8 (7.4%)	
	Definitely yes	37 (6.3%)	19 (17.6%)	0.003
Have regular ultrasounds of ovaries?	Definitely not	468 (77.5%)	71 (65.7%)	
	Probably not	77 (12.8%)	13 (12.0%)	
	Probably yes	33 (5.5%)	5 (4.6%)	
	Definitely yes	26 (4.3%)	19 (17.6%)	<0.001