

# Breast Cancer Risk Perception Among Women Who Have Undergone Prophylactic Bilateral Mastectomy

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**Background:** Prophylactic bilateral mastectomy is a preventive option for women who are at high risk of developing breast cancer. We compared the perceptions of breast cancer risk among women who had previously undergone prophylactic bilateral mastectomy with objective estimates of their breast cancer risk. **Methods:** We asked 75 women in the Canadian province of Ontario who had undergone prophylactic bilateral mastectomy between 1991 and 2000 to provide a complete family history of the cancers that had occurred by the time of their surgery and to indicate their BRCA1 and BRCA2 gene mutation status. This information was used to generate estimates of each woman's risk for breast cancer by using the Gail model, the Claus model, and the BRCAPRO model. Sixty of the women also provided their own estimates of their lifetime risks of developing breast cancer before and after they had prophylactic mastectomy. Risk estimates were compared using Wilcoxon's signed-rank test and Pearson's product-moment correlation analysis. All statistical tests were two-sided. **Results:** The women estimated that their lifetime risk of developing breast cancer before surgery was, on average, 76% (range = 20%–100%) and after surgery was 11.4% (range = 0%–60%). The mean estimated absolute risk reduction the women attributed to prophylactic mastectomy was 64.8%. The average computer-generated risk estimates were 59% for the 14 women who reported that they carried a BRCA1 or BRCA2 gene mutation and 17% for the other women (of whom 43 had a strong family history of breast cancer and 18 had a limited family history). Breast cancer risk was statistically significantly overestimated by all women except for the known BRCA1 and BRCA2 gene mutation carriers. **Conclusion:** Women who undergo prophylactic bilateral mastectomy have an exaggerated perception of their breast cancer risk before surgery. Formal genetic counseling and genetic testing may result in more accurate risk perceptions to guide women in choosing other preventive options. [J Natl Cancer Inst 2002;94:1564–9]

A woman's perception of her susceptibility to developing a disease (e.g., breast cancer) is an important determinant of her health-related decisions. For example, for women who visit genetics clinics, it is often observed at initial consultation that these women have exaggerated breast cancer risk estimates (1–4). Although previous studies have shown that a woman's perceived risk of developing breast cancer affects her compliance with breast cancer screening recommendations (5–8), little is known about how that perceived risk influences her decision to undergo prophylactic bilateral mastectomy. Prophylactic bilateral mastectomy has been reported to reduce breast cancer risk by more than 80% (9). Women who consistently overestimate their risk of breast cancer are often vulnerable to cancer-specific worry (10), which may lead them to take excessive precautions to

prevent breast cancer, such as undergoing prophylactic bilateral mastectomy. The extent to which a woman's decision to undergo prophylactic bilateral mastectomy is based on her actual risk of developing breast cancer versus her perceived risk is unknown.

Breast cancer risk assessment is a way to quantify the lifetime probability of developing breast cancer for a specific woman. Risk assessment is currently based on epidemiologic observations, which are derived from defined study populations rather than for individuals. Three mathematical models for estimating individual breast cancer risk have been proposed (11–13). Of these, the Gail model (11) is the most generally applicable model because it considers, for each woman, the number of her first-degree relatives diagnosed with breast cancer, her age at menarche and at first live birth, the number of breast biopsies she has had, and whether the biopsies showed atypical hyperplasia. The Gail model does not consider family history information for second-degree relatives, nor does it distinguish between pre- and postmenopausal breast cancers in first-degree relatives. The Claus model (12) incorporates more detailed information about a woman's family history than does the Gail model. However, the Claus model does not assign specific relevance to family histories of bilateral breast cancer or ovarian cancer and does not consider nonfamilial risk factors (e.g., age at menarche and previous atypical hyperplasia). BRCAPRO (13) is a Bayesian model that calculates individual breast cancer probabilities based on family history and estimates the probability that a family member carries a mutation in one of the two breast cancer susceptibility genes, BRCA1 and BRCA2. Although the family history information considered by BRCAPRO is the most thorough of the three models, BRCAPRO does not consider nonfamilial risk factors for breast cancer and does not consider the possibility that familial clustering of breast cancer may be due to genes other than BRCA1 or BRCA2.

The purpose of our study was to assess subjective risk estimates of breast cancer in women who had previously undergone prophylactic bilateral mastectomy and to compare those risk estimates to breast cancer risk estimates for each woman, as generated by the three individual risk models.

## SUBJECTS AND METHODS

### Identification of Subjects

Health care in Ontario, Canada, is based on universal access and is largely a single-payer system. All residents are eligible for

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the provincial health plan, which covers the majority of diagnostic and treatment services including prophylactic mastectomy. The Ontario Ministry of Health collects information on all hospital procedures performed in the province. We collaborated with the Central East Health Information Partnership (CEHIP), a consortium of district health councils, boards of health, and universities in Central East Ontario that is funded by the Ontario Ministry of Health, to search the Ontario Ministry of Health's database for hospital procedure and diagnosis codes related to mastectomy. CEHIP identified all women who had had a bilateral mastectomy performed in any Ontario hospital between January 1991 and June 2000 and who were discharged from the hospital with any of the following Canadian clinical procedure codes: 97.13 (bilateral complete mastectomy), 97.15 (bilateral extended simple mastectomy), 97.17 (bilateral radical mastectomy), 97.19 (bilateral extended radical mastectomy), 97.23 (bilateral subcutaneous mastectomy with implantation of prostheses), or 97.24 (bilateral subcutaneous mastectomy without implantation of prostheses). We contacted the hospitals at which at least one bilateral prophylactic mastectomy in the designated time period had been performed and from them obtained ethics approval for this study.

### Medical Chart Review

Inpatient medical charts for all of the women identified by the bilateral mastectomy procedure codes were made available to us by the various hospitals at which the procedures were performed. One of the investigators (K. A. Metcalfe) visited each hospital and performed a comprehensive review of the medical chart for each potentially eligible case patient. A woman was considered to be eligible for our study if she had undergone a bilateral mastectomy with no prior or current diagnosis of invasive or *in situ* breast cancer. Data obtained from the medical charts of such women included patient demographics, surgeon's name, date of surgery, type of surgery, type of reconstruction, pathology report, and indication for surgery, as recorded by the surgeon. This information was collected for all women who had a bilateral prophylactic mastectomy within the specified time period.

### Patient Contact

We contacted the primary care physician of each woman who had undergone a bilateral prophylactic mastectomy between January 1991 and June 2000 to obtain his or her consent to contact those women. We obtained written consent from those physicians and then mailed an introductory letter and study information to all of the women whose physicians had given consent. The women were then contacted by telephone to obtain consent for participation. A written consent form and questionnaires were mailed to each woman who consented. In the questionnaire, the women were asked to estimate what their lifetime risks (from 0% to 100%) of developing breast cancer were before and after they had prophylactic mastectomy. We then made a follow-up telephone call to obtain information on family history of cancer. Information collected during the telephone interview included the number of family members diagnosed with cancer at the time of the woman's prophylactic mastectomy, the types of cancer, and the ages of the family members at the onset of their cancers.

### Statistical Analysis

We entered all of the information on each woman's family history of cancer at the time of her prophylactic mastectomy into CancerGene (14), a software program that generates individual risk estimates for breast cancer using the Gail model, the Claus model, and the BRCAPRO model. This program may be obtained without charge at [http://www.swmed.edu/home\\_pages/cancergene](http://www.swmed.edu/home_pages/cancergene).

All data were coded and entered into an SPSS database (version 10.1.0; SPSS, Chicago, IL). Age was analyzed as both a continuous and a categorical variable ( $\leq 50$  years or  $> 50$  years). Pearson's chi-square test was used to compare nominal data, and Student's *t* test was used to compare continuous variables. Wilcoxon's signed-rank test was used to compare a woman's subjective estimate of her risk of breast cancer with the model-generated risk of breast cancer for that woman. Pearson's product-moment correlation coefficient (*r*) was used to analyze relationships between perceived and model-generated risks of breast cancer. The level for statistical significance was set at 0.05. All statistical tests were two-sided.

## RESULTS

### Response Rate

We identified 122 women through the medical chart review who had undergone prophylactic bilateral mastectomy between January 1991 and June 2000. We obtained written permission from 102 of the physicians listed in the women's medical charts to contact their patients. We attempted to contact all of the women whose physicians gave permission. Of those 102 women, two (2%) had died of causes other than cancer, 10 (10%) could not be located, and 15 (15%) refused to participate. We compared the remaining 75 women who agreed to participate in our study with those who declined participation and with those who were deceased, could not be located, or whose physicians refused permission to contact them, and we found no statistically significant differences between these groups of women in terms of their mean age at time of surgery ( $P = .67$ ), the type of mastectomy they received ( $P = .33$ ), whether they had undergone reconstructive surgery ( $P = .25$ ), or the year of their mastectomy ( $P = .19$ ).

### Family Histories

We obtained complete family histories from all 75 women who agreed to participate in our study. The information collected on family history included the number of relatives who had cancer at the time the woman had her prophylactic mastectomy, the types of cancer those relatives had, and their age at diagnosis. The women were also asked if they had undergone genetic testing for mutations in BRCA1 and BRCA2. On the basis of the family history and genetic information, we subdivided the women into the following three nonoverlapping groups: those who had a strong family history of breast cancer (i.e., either one first-degree relative or two second-degree relatives with breast cancer that was diagnosed at age 50 years or younger, ovarian cancer, or male breast cancer) and who had no known BRCA1 or BRCA2 gene mutations themselves (because they had not previously undergone genetic testing); those who had a limited family history of breast cancer (i.e., no first-degree relative or fewer than two second-degree relatives with breast cancer that

was diagnosed at age 50 years or younger, ovarian cancer, or male breast cancer) and who had no known BRCA1 or BRCA2 gene mutations themselves (i.e., had not undergone genetic testing); and those who had mutations in either BRCA1 or BRCA2. Forty-three (57%) women had a strong family history of cancer, 18 (24%) women had a limited family history of cancer, and 14 (19%) women reported that they had a mutation in BRCA1 or BRCA2. Of the 18 women who were assigned to the limited family history group, 14 (78%) had at least one relative with breast cancer, but all of those breast cancers were diagnosed after menopause. Of the other four women who were assigned to the limited family history group, one had cancerphobia but otherwise had no family history of breast cancer or breast disease, two had mammary dysplasia, and one had fibrocystic breast disease. Two of the women in the strong family history group were sisters, and both reported the same family history. The 14 BRCA1 or BRCA2 gene mutation carriers had received their genetic test results before they underwent prophylactic mastectomy. BRCA1 or BRCA2 gene mutation status was used by these 14 women and by the computer models to assign risk estimates.

Sixty-three (84%) of the women in our study had at least one first-degree relative who had been diagnosed with breast cancer at any age. Of these women, 44 (70%) had a first-degree relative who had been diagnosed with breast cancer at age 50 years or younger, and 30 (48%) had a first-degree relative who had been diagnosed with breast cancer when she was older than 50 years. Forty-nine (65%) of the women in our study had mothers who were diagnosed with breast cancer, and 38 (78%) of those mothers died of breast cancer. The mean age of the women's mothers at breast cancer diagnosis was 50.8 years (range = 27–75 years). One woman had a father who was diagnosed with breast cancer, and 29 (39%) of the women in our study had at least one sister who was diagnosed with the disease. The mean number of breast cancers within the families of the women in this study was 3.0 (range = 0–10). Five (6.7%) women had a first-degree relative with ovarian cancer, and 12 (16%) women reported having at least one relative with ovarian cancer.

### Subjective Estimates of Breast Cancer Risk Before and After Prophylactic Mastectomy

We received completed questionnaires from 60 of the 75 women (80%). Of these, 33 women had a strong family history of breast cancer, 14 women had a limited family history of breast cancer, and 13 women were known to have a BRCA1 or BRCA2 gene mutation. The mean age of those women at the time of their prophylactic surgeries was 43.5 years (range = 20–62 years) and at the time of questionnaire completion was 47.8 years (range = 23–70 years). An average of 52.2 months had passed

between the time of surgery and the completion of the questionnaire. The average age of the women who did not respond to the questionnaire at the time of surgery was 42.7 years (range = 33–62 years). There was no statistically significant difference in age at the time of surgery ( $P = .73$ ) or in family history of breast cancer (by medical chart review for the nonrespondents) ( $P = .32$ ) between the respondents and the nonrespondents.

In the questionnaire, the women were asked to estimate what they thought their lifetime risks of developing breast cancer were before and after they had their prophylactic mastectomy. The women's estimates of their breast cancer risks before surgery ranged from 20% to 100% (mean = 76.2%); 17 (28%) of the women estimated their lifetime risk for developing breast cancer to be 100%. There was no statistically significant difference in the mean presurgery subjective estimates of breast cancer risk between the women in the limited family history of breast cancer group (80%), those in the strong family history of breast cancer group (74%), and those with a BRCA1 or BRCA2 gene mutation (79%) ( $P = .66$ ).

The women's estimates of their breast cancer risks after surgery ranged from 0% to 60% (mean 11.4%); seven (12%) women estimated that their risk of developing breast cancer after having had a prophylactic mastectomy was zero. The mean estimated absolute risk reduction was 64.8% (range = 0%–100%). When risk reduction was analyzed as a proportion of the presurgical risk estimate, the mean risk reduction was 83.3% (range = 0%–100%), and six women believed that prophylactic mastectomy had provided them a 100% reduction in their risk of developing breast cancer. There was no statistically significant difference in the mean risk reduction estimated by the three subgroups (i.e., BRCA1 and BRCA2 gene mutation carriers, those with a strong family history of breast cancer, and those with a limited family history of breast cancer) ( $P = .36$ ).

### Computer-Generated Estimates of Breast Cancer Risk

We entered the family history information reported by each of the 75 women in our study into CancerGene to generate three estimates of lifetime breast cancer risk for each woman based on the Gail model, the Claus model, and BRCAPRO. The mean risk of breast cancer for all 75 women was 25.8% (range = 6.2%–69.4%) based on the Gail model, 24.2% (range = 9.2%–43.7%) based on the Claus model, and 26.3% (range = 6.9%–82.1%) based on BRCAPRO (data not shown). Lifetime estimates of breast cancer risk for each of the three subgroups of women according to each of the three models are presented in Table 1.

We next compared the model-generated risk estimates with estimates of breast cancer risk before surgery made by the 60 women who completed the questionnaire. The results of that comparison are presented in Table 2. The total number of

**Table 1.** Model-generated estimates of the lifetime risk of breast cancer among women who had a prophylactic mastectomy\*

Subgroup	Gail model		Claus model		BRCAPRO model	
	N	% Lifetime risk (range)	N	% Lifetime risk (range)	N	% Lifetime risk (range)
BRCA1 or BRCA2 mutation carrier	13	19.7 (9.0–35.4)	13	23.7 (9.4–43.4)	14	66.2 (33.2–82.1)
Strong family history of breast cancer	33	30.4 (6.2–69.4)	41	26.8 (11.0–43.7)	43	19.3 (7.5–40.8)
Limited family history of breast cancer	14	20.6 (11.5–36.9)	13	16.7 (9.2–28.1)	18	12.0 (6.9–29.6)

\*Total number of women varies by model due to availability of information for risk estimation (e.g., the Gail model requires additional information, including age at menarche and number of biopsies).

**Table 2.** Comparison between perceived pre-surgery estimates of breast cancer risk for women who had prophylactic mastectomy and model-generated estimates of their risk of breast cancer\*

Subgroup	Model used to estimate risk	No. of women included in risk estimate	Mean perceived risk, % (95% CI)	Mean model-generated risk, % (95% CI)	P†
BRCA1 or BRCA2 mutation carrier (total No. of women = 13)	Gail	13	78.8 (63.9 to 93.6)	19.7 (15.2 to 24.2)	.001
	Claus	12	81.2 (65.9 to 96.4)	24.9 (17.5 to 32.2)‡	.002
	BRCAPRO	13	78.8 (63.9 to 93.6)	65.3 (56.3 to 74.3)‡	.1
Strong family history of breast cancer (total No. of women = 33)	Gail	32	73.6 (65.2 to 82.1)	30.4 (26.1 to 35.2)	<.001
	Claus	30	75.2 (66.6 to 83.9)	26.8 (22.8 to 30.7)	<.001
	BRCAPRO	33	73.6 (65.2 to 82.1)	19.3 (16.2 to 22.4)	<.001
Limited family history of breast cancer (total No. of women = 14)	Gail	12	80.0 (64.7 to 95.3)	20.6 (15.8 to 25.8)	.002
	Claus	9	77.8 (58.3 to 97.3)	17.8 (12.2 to 23.4)	.008
	BRCAPRO	14	80.0 (64.7 to 95.3)	12.4 (8.8 to 16.0)	.002

\*CI = confidence interval.

†P value (two-sided) from Wilcoxon's signed-rank test.

‡Mean model-generated risk estimates differ from those presented in Table 1 because the questionnaire assessing subjective risk was not completed by all women.

women included in each model-generated risk estimate did not equal the total number of women in each subgroup because not all women answered all of the questions on the questionnaire (which was necessary for estimates using the Gail model) and because some women with a limited family history of breast cancer had no affected first-degree relatives, which was necessary for estimates using the Claus model. There was little correlation between the women's subjective risk estimates and the estimates of their breast cancer risk as generated by the Gail model ( $r = .034$ ;  $P = .80$ ), by the Claus model ( $r = .24$ ;  $P = .09$ ), or by BRCAPRO ( $r = .14$ ;  $P = .30$ ). The majority of the women who completed the questionnaire overestimated their risk of developing breast cancer compared with the model-generated estimates; 96.3%, 98.0%, and 92.9% of the women overestimated their risk compared with risks estimated by the Gail model, the Claus model, and BRCAPRO, respectively (data not shown). The average degree of breast cancer risk overestimation by the women was 2.5 times that based on the Gail model, 2.7 times that based on the Claus model, and 3.4 times that based on BRCAPRO (data not shown). Women who did not carry BRCA1 or BRCA2 gene mutations greatly overestimated their risk of breast cancer (Table 2). By contrast, the subjective risks of the 14 BRCA1 and BRCA2 gene mutation carriers were comparable to the BRCAPRO estimates (Table 2). However, the Gail and Claus models do not take BRCA mutation status into account, and therefore estimates from these models are less valid for BRCA mutation carriers than BRCAPRO estimates.

The level of education a woman had achieved did not affect the magnitude of her perceived risk of developing breast cancer (data not shown). For example, women who had a high school education or less estimated their lifetime risk of breast cancer to be 76.7%, whereas those with an educational level beyond high school estimated their risk to be 75.8% ( $P = .89$ ).

We examined potential associations between the year in which a woman had prophylactic mastectomy and subjective estimates of breast cancer risk. Genetic testing for BRCA1 and BRCA2 gene mutations was introduced in 1995; all 14 women with a BRCA1 or BRCA2 gene mutation had their surgery in 1996 or later. When we classified the women according to whether they had surgery before 1996 or in 1996 or later, we found that the individual risk estimates for the two year-of-surgery categories did not differ statistically significantly from the risk estimates that were based on either the Gail model ( $P = .86$ ) or the Claus model ( $P = .67$ ). However, there was a

statistically significant difference between the extent of personal risk overestimation for the two year-of-surgery categories and the risk estimate that was based on BRCAPRO. For example, women who had surgery between 1991 and 1995 overestimated their breast cancer risk by an average of 60.3%, and those who had surgery between 1996 and 2000 overestimated their risk by an average of 35.9% ( $P = .002$ ).

## DISCUSSION

A woman's decision to have a prophylactic mastectomy is influenced by many factors, including her perceived risk of developing breast cancer. Ours is the first study we know of to examine perceptions of breast cancer risk among women who have previously undergone a prophylactic mastectomy. In our study, almost all of the women who had had preventive breast surgery statistically significantly overestimated their lifetime risk of developing breast cancer, with the exception of those that had BRCA1 and BRCA2 gene mutations. Other studies have reported that women overestimate their breast cancer risk both in genetics clinics and in general practice (2–4,8,15). Unlike previous studies, which included patients attending a single clinic, ours was a population-based study. We attempted to contact all women within the province of Ontario who had undergone bilateral prophylactic mastectomy within a designated time period. Our study also reports on actual behaviors (i.e., among women who had a prophylactic mastectomy), whereas most previous research reported on intentional behaviors (i.e., among women who intended to undergo prophylactic mastectomy).

The only women in our study who estimated their lifetime risk of developing breast cancer prior to surgery with accuracy were the BRCA1 and BRCA2 gene mutation carriers. This group of women estimated that their risk of breast cancer was 78.8%; these women had an average lifetime risk of 65.3% based on BRCAPRO risk estimates. By contrast, the women who had not undergone genetic testing in those two genes estimated that their risk of breast cancer was 75.4%, whereas the mean computer-generated risk estimate (BRCAPRO) for those women was only 17.2%. These data suggest that genetic counseling might help women better estimate their personal risk of developing breast cancer, because all of the BRCA1 and BRCA2 gene mutation carriers received genetic counseling during the course of genetic testing. There was a statistically significant difference in the extent to which women overestimated their

breast cancer risk when we divided the women according to whether they had surgery before 1996 (which was roughly when genetic counseling for breast cancer and testing for BRCA1 and BRCA2 gene mutations became available in Ontario) or in 1996 or later. Women who had surgery prior to 1996 were more likely to overestimate their risk of developing breast cancer. This also suggests that, with the introduction of genetic testing for BRCA1 and BRCA2, and therefore genetic counseling, women may have had a more accurate understanding of personal risk.

It is worth noting that approximately 77% of the women who were not known to have mutation in BRCA1 or BRCA2 estimated that their lifetime risk of breast cancer exceeded 50%. However, for an unaffected woman in a family with a dominant cancer syndrome, the probability of inheriting a mutation is 50% or less, and the cancer risk is therefore below 50%. Indeed, the highest breast cancer risk estimate generated by the Claus model for any of the 75 subjects was 43.7%.

The personal overestimation of breast cancer risk in women considering prophylactic mastectomy has been observed previously. A study by Morris et al. (16) found that nearly half the women who were referred to a genetic counseling program for breast cancer had considered having prophylactic mastectomy prior to counseling. Many of those women initially considered having prophylactic mastectomy because they believed that they were at high risk for developing breast cancer but changed their minds about having surgery after undergoing formal genetic evaluation, consultation, and, in some cases, genetic testing for mutations in BRCA1 and BRCA2. However, that study did not report whether the women subsequently had prophylactic mastectomies.

Although genetic counseling was found to help clarify risk in the previously described study involving women considering prophylactic mastectomy, there is some controversy about the extent to which genetic counseling enables an individual to understand and to retain information about cancer risk. Evans et al. (1) found that women retain information about their own breast cancer risk for at least 1 year after counseling. However, Lloyd et al. (17) found that, despite undergoing genetic counseling, many women continue to misinterpret their lifetime risk of breast cancer, suggesting a failure to understand or retain risk information.

Approximately 24% of the women in our cohort of prophylactic mastectomy patients would not be considered to be at high risk for breast cancer according to current standards because they did not have a strong family history of breast cancer or were not known to have mutations in BRCA1 or BRCA2. Therefore, something other than a family history of breast cancer must have motivated the women with lower breast cancer risk to have preventive breast surgery. It is possible that they received inaccurate counseling by their surgeons or by other health care providers. However, a more likely explanation for why these women chose to undergo prophylactic mastectomy was cancer worry (i.e., fear of developing breast cancer). Cancer worry has been shown to be more closely associated with perceived risk than with actual risk, i.e., risk that is based on breast cancer risk models (15,17). A previous study found that consideration of prophylactic mastectomy was associated with levels of breast cancer anxiety and self-estimated breast cancer risk but not with objective cancer risk (18). Although prophylactic mastectomy may be an appropriate option for women who are at high risk of developing breast cancer, women who are at moderate risk of the

disease should be counseled about alternate interventions aimed at reducing breast cancer anxiety and correcting exaggerated breast cancer risk perceptions.

One limitation of our study was its retrospective design, which was necessary because each year such a small number of women have a prophylactic bilateral mastectomy. Our results may, therefore, be biased in the sense that a woman's subjective estimate of her risk when she decided to have a prophylactic mastectomy differed from that at the time of this study several years later so that a high risk estimate given at the time of this study reflects a woman's psychological effort to justify having had a bilateral mastectomy.

Overestimation of breast cancer risk may not be detrimental if the consequences of prophylactic surgery (e.g., decreased psychological distress) are positive and the women benefitted psychologically from prophylactic mastectomy in terms of perceived risk reduction. However, formal genetic counseling may have clarified, for all of the women in our study, their actual risks of breast cancer and relieved their cancer worry, which may have led to fewer women undergoing surgery. The results of our study, together with results from previous research (16), suggest that women should be strongly encouraged to seek genetic counseling before they make the decision to undergo prophylactic mastectomy. This counseling should include formal breast cancer risk assessment using established risk models and genetic testing for mutations in BRCA1 and BRCA2. Psychological assessment may also be warranted for some women. The genetic counselor should provide an individualized estimate of a woman's risk of breast cancer and discuss other preventive options, such as the use of tamoxifen (19,20) and oophorectomy (21).

## REFERENCES

- (1) Evans DG, Blair V, Greenhalgh R, Hopwood P, Howell A. The impact of genetic counselling on risk perception in women with a family history of breast cancer. *Br J Cancer* 1994;70:934-8.
- (2) Dolan NC, Lee AM, McDermott MM. Age-related differences in breast carcinoma knowledge, beliefs, and perceived risk among women visiting an academic general medicine practice. *Cancer* 1997;80:413-20.
- (3) Black WC, Nease RF, Tosteson AN. Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J Natl Cancer Inst* 1995;87:720-31.
- (4) Hopwood P, Shenton A, Lalloo F, Evans DG, Howell A. Risk perception and cancer worry: an exploratory study of the impact of genetic risk counselling in women with a family history of breast cancer. *J Med Genet* 2001;38:139.
- (5) Vernon SW, Vogel VG, Halabi S, Bondy ML. Factors associated with perceived risk of breast cancer among women attending a screening program. *Breast Cancer Res Treat* 1993;28:137-44.
- (6) Polednak AP, Lane DS, Burg MA. Risk perception, family history, and use of breast cancer screening tests. *Cancer Detect Prev* 1991;15:257-63.
- (7) Drossaert CC, Boer H, Seydel ER. Perceived risk, anxiety, mammographic examination uptake, and breast self-examination of women with a family history of breast cancer: the role of knowing to be at increased risk. *Cancer Detect Prev* 1996;20:76-85.
- (8) Hebert-Croteau N, Goggin P, Kishchuk N. Estimation of breast cancer risk by women aged 40 and over: a population-based study. *Can J Public Health* 1997;88:392-6.
- (9) Hartmann LC, Schaid DJ, Woods JE, Crotty TP, Myers JL, Arnold PG, et al. Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. *N Engl J Med* 1999;340:77-85.
- (10) Watson M, Lloyd S, Davidson J, Meyer L, Eeles R, Ebbs S, et al. The impact of genetic counselling on risk perception and mental health in women with a family history of breast cancer. *Br J Cancer* 1999;79:868-74.
- (11) Gail MH, Brinton LA, Byar DP, Torle DK, Green SB, Schairer C, et al.

- Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. *J Natl Cancer Inst* 1989; 81:1879–86.
- (12) Claus EB, Risch N, Thompson WD. Autosomal dominant inheritance of early-onset breast cancer. Implications for risk prediction. *Cancer* 1994;73: 643–51.
- (13) Berry DA, Parmigiani G, Sanchez J, Schildkraut J, Winer E. Probability of carrying a mutation of breast-ovarian cancer gene BRCA1 based on family history. *J Natl Cancer Inst* 1997;89:227–38.
- (14) Euhus DM. Understanding mathematical models for breast cancer risk assessment and counseling. *Breast J* 2001;7:224–32.
- (15) Watson M, Duvivier V, Wade Walsh M, Ashley S, Davidson J, Papaikononou M, et al. Family history of breast cancer: what do women understand and recall about their genetic risk? *J Med Genet* 1998;35:731–8.
- (16) Morris KT, Johnson N, Krasikov N, Allen M, Dorsey P. Genetic counseling impacts decision for prophylactic surgery for patients perceived to be at high risk for breast cancer. *Am J Surg* 2001;181:431–3.
- (17) Lloyd S, Watson M, Waites B, Meyer L, Eeles R, Ebbs S, et al. Familial breast cancer: a controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counselling. *Br J Cancer* 1996;74:482–7.
- (18) Meiser B, Butow P, Friedlander M, Schnieden V, Gattas M, Kirk J, et al. Intention to undergo prophylactic bilateral mastectomy in women with an increased risk of developing hereditary breast cancer. *J Clin Oncol* 2000; 18:2250–7.
- (19) Fisher B, Costantino JP, Wickerham DL, Redmond CK, Kavanah M, Cronin WM, et al. Tamoxifen for prevention of breast cancer: report of the National Surgical Adjuvant Breast and Bowel Project P-1 study. *J Natl Cancer Inst* 1998;90:1371–88.
- (20) Narod SA, Brunet JS, Ghadirian P, Robson M, Heimdal K, Neuhausen SL, et al. Tamoxifen and risk of contralateral breast cancer in BRCA1 and BRCA2 mutation carriers: a case-control study. Hereditary Breast Cancer Clinical Study Group. *Lancet* 2000;356:1876–81.
- (21) Rebbeck TR, Levin AM, Eisen A, Snyder C, Watson P, Cannon-Albright L, et al. Breast cancer risk after bilateral prophylactic oophorectomy in BRCA1 mutation carriers. *J Natl Cancer Inst* 1999;91:1475–9.

## NOTE

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