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## Influence of perceived breast cancer risk on screening behaviors of female relatives from the Ontario Site of the Breast Cancer Family Registry

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### Abstract

**Background**—Few studies have examined the influence of perceived risk on breast screening behaviors among women with an increased familial breast cancer risk.

**Methods**—This study included 1019 women aged 20 to 71 years from the Ontario site of the Breast Cancer Family Registry who had at least one first-degree relative diagnosed with breast and/or ovarian cancer. Information was obtained from a self-administered questionnaire completed at the time of recruitment and a follow-up telephone questionnaire. The associations between breast screening behaviors and perceived risk of developing breast cancer, measured on both a numerical and Likert-type verbal scale, were estimated using logistic regression analyses.

**Results**—Women who rated their risk of developing breast cancer as greater than 50% compared to less than 50% were significantly more likely to have a screening mammogram within the last 12 months (OR: 1.91, 95% CI: 1.15 – 3.16). Women were significantly more likely to have a screening mammogram (OR: 1.82, 95% CI: 1.17 – 2.81) in the past 12 months if they rated their risk as above or much above average compared to same as average or below.

**Conclusion**—These findings may inform educational messages for improving risk communication of women at elevated familial breast cancer risk.

### Keywords

Breast cancer; breast screening; family history; perceived risk

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## Introduction

In Ontario, in 2009 an estimated 8,700 women will be diagnosed with breast cancer and 2,100 will die of the disease [1]. Compared to women without a family history of breast cancer, women with an affected first-degree relative are about twice as likely to develop breast cancer with the risk being higher when the relative was diagnosed before the age of 50, and when the number of diagnosed relatives increased [2,3]. A recent review of randomized controlled trials has shown that screening mammography reduces breast cancer mortality [4]. Although this review did not differentiate effectiveness by familial breast cancer risk, others have shown that mammography and clinical breast examination (CBE) permit early breast cancer detection in women at higher familial risk of breast cancer [5–7]. The Canadian Task Force on Preventive Health Care recommends screening for breast cancer by mammography and CBE every 1 to 2 years for average-risk women aged 50 to 69 [8]. For high-risk women, annual breast screening examinations including mammogram, CBE, and Breast Self Examinations (BSE) [9] are recommended before 50 years of age [10–12]. Previous research has demonstrated that women with a first degree relative who has been diagnosed with breast cancer are more likely to return for screening [13–15] and to start screening at an earlier age [16] when compared to women without a family history of breast cancer.

Perceived risk is an important concept in models explaining and predicting health behavior. Both the Health Belief Model and the Precaution Adoption Process model consider one's perceived risk of developing an illness a precursor to preventive actions [17,18]. A recent meta-analysis reported that women with a family history of breast cancer were significantly more likely to perceive their risk of developing breast cancer as higher than other women and found a positive association between higher perceived risk and mammography screening [19]. However, most of the studies in the meta-analysis included women at average risk.

Fewer studies have examined the association between perceived risk and breast cancer screening behaviors among women at increased risk of family history. Of the studies that used a numerical scale, one cross-sectional study of first degree relatives of women diagnosed with breast cancer reported similar utilization of mammography and CBE, and slightly higher BSE practice in the past 1 or 2 years for women who reported a perceived lifetime risk of developing breast cancer of 50% or more compared to less than 50% [20]. Another cross-sectional study of women attending a high risk clinic that compared women's perceived risk on a numerical scale to their actual risk, found no significant association between risk perception and compliance with mammography, although women who over-estimated their risk of breast cancer had significantly poorer compliance to BSE [21].

Other studies have used a verbal Likert-type scale to measure a woman's perceived risk of developing breast cancer. Cross-sectional studies of women attending genetic counseling [22] or with at least one first-degree relative [23] found no significant association between perceived risk as compared to other women their age and adherence to mammography or CBE screening recommendations. In addition, a prospective study that measured mammography uptake in the following year [24], and a retrospective study that measured mammography and CBE in the past 3 years [25] both found no significant association between perceived risk estimated on a Likert-type scale and screening uptake.

The majority of previous studies have not shown a positive association between perceived risk and breast screening behaviors among women with a higher familial risk. However, most of these studies included convenience samples of female relatives of breast cancer patients attending genetic counseling and risk assessment programs, and sample sizes were small. The purpose of this study was to examine the association between perceived risk of

developing breast cancer, measured on both a numerical and verbal scale, and breast screening behaviors among a large population cohort of women who had a least one first-degree relative diagnosed with breast and/or ovarian cancer.

## Methods

### Study population

This study identified a cohort of female relatives of incident cases of invasive breast cancer from the Ontario site of the Breast Cancer Family Registry (BCFR) funded by the United States National Cancer Institute. The details of the BCFR and the Ontario site of the BCFR have been previously described [26]. Briefly, cases of invasive breast cancer (probands), pathologically confirmed, and diagnosed between 1996 and 1998 were identified from the Ontario Cancer Registry. Physicians were contacted to obtain permission to mail their patients a cancer *Family History Questionnaire (FHQ)*. Respondents meeting a defined set of family history criteria, and a random sample (25%) of those not meeting the criteria were asked to participate in the Ontario site of the BCFR. Of those eligible (N=2587), 1851 (72%) probands participated.

These probands were asked for address information and permission to contact specific living relatives (first degree, those affected with breast, ovarian, or certain other cancers, and their first degree relatives). An invitation letter to participate in the Ontario site of the BCFR was sent to relatives, and those who agreed to participate were mailed an *Epidemiology Questionnaire (EQ)* between 1998 and 2004. Our study was conducted a few years after the initial recruitment of relatives. In this study, we identified all female relatives enrolled in the Ontario site of the BCFR who completed an *EQ*; were alive at the start of the study and 20 to 69 years of age; and were unaffected by breast cancer at the time of the proband's diagnosis date. From the 3374 participating female relatives, we identified 2066 (61%) who were residents of Ontario and of these, 1514 (73.3%) met our study criteria.

Of the 1514 women sent a *Personal History and Screening Questionnaire (PHSQ)* between November 2005 and March 2007, 1308 (86.4%) were contacted and 1112 (85.0%) consented to be interviewed. Further exclusions included 37 women who had a breast cancer diagnosis, 32 women who had only second-degree relatives with breast cancer, 6 women who had undergone a bilateral mastectomy and 18 women who lacked information on their perceived breast cancer risk. The final study cohort consisted of 1019 women. This study was approved by the Research Ethic Boards of Mount Sinai Hospital and the University Health Network.

### Data Collection

Information was obtained from the *EQ* that was self-administered during the recruitment of female relatives into the Ontario site of the BCFR and from a follow-up telephone questionnaire (*PHSQ*). The *PHSQ* updated changes in health behaviors and key demographic characteristics as well as collected detailed information on breast cancer screening examinations and perceived breast cancer risk. Eligible participants were sent a copy of the *PHSQ* and an introductory letter approximately two weeks prior to being contacted by phone. This allowed time for the participants to recall specific dates and events and allowed them to refer back to the questionnaire during the interview.

The *PHSQ* asked two questions regarding perceived lifetime risk of developing breast cancer. The first question measured perceived risk on a numerical scale and asked "On a scale from 0 to 100%, where 0 = certain not to happen, and 100 = certain to happen, how likely are you to get breast cancer in your lifetime?" The second question assessed perceived risk on a verbal Likert-type scale and asked "Compared to other women your age, how

likely are you to get breast cancer in your lifetime? Responses were much below average, below average, same average risk, above average, or much above average”.

Mammography and CBE screening behaviors of the participants were characterized by reason and time since the last examination as derived from the *PHSQ*, which asked for the date (month and year) or age at last examination. The *PHSQ* also asked whether the main reason for the last mammogram and CBE was for screening (“part of a regular check-up”, “part of the Ontario Breast Screening Program”, or due to a “family history of breast cancer”) or non-screening purposes (due to a “breast problem or symptom”, “follow-up of a previous breast problem”, or “participation in a research study”). Using the same information, another variable was created that considered time since last screening mammography and/or CBE jointly. The frequency of conducting BSE was based on a *PHSQ* question which asked “On average, how often do you examine your own breasts for lumps?” Responses were “once a year or less, every 2 to 6 months, or once a month or more”. Another question asked whether participants ever had a genetic test for the breast and ovarian cancer susceptible genes *BRCA1* or *BRCA2*.

Age at interview was calculated as the difference in years between the date of birth and the date of the *PHSQ* interview. Descriptive analyses employed age categories < 40, 40 – 49, 50 – 59, and ≥ 60, but regression models were adjusted using age as a continuous variable. The highest level of education attained and the average annual frequency of visiting a health care facility in the past two years was determined using responses to the *PHSQ*. Body mass index of the participants in kg/m<sup>2</sup> was derived from information on height (*EQ*) and weight (*PHSQ*). Both the *EQ* and the *PHSQ* assessed prior history of benign breast disease, with a positive history of benign breast disease being defined as a “yes” response to either questionnaires.

Classification of family history risk of breast and/or ovarian cancer was based on information collected from the *FHQ* completed by the relative’s proband using a modified definition of previously referenced groups for familial breast cancer risk [5,10]. Women were classified as having a low familial-risk if they had only one first-degree relative diagnosed with breast cancer after the age of 40. Women were classified as having a moderate familial-risk if they had 1) a self-reported Ashkenazi Jewish background; and/or 2) one first-degree relative with breast cancer diagnosed before the age of 40; or 3) one first-degree relative with ovarian cancer; or 4) one first-degree relative with breast cancer diagnosed after the age of 40 and two or more second-degree relatives with breast cancer. Finally, women were classified as having a high familial-risk if they had 1) two or more first-degree relatives with breast and/or ovarian cancer diagnosed at any age; and/or 2) one or more first-degree relative(s) with both breast and ovarian cancer diagnosed at any age; and/or 3) one or more first-degree relative(s) diagnosed with bilateral breast cancer at any age; and/or 4) a personal history of ovarian cancer.

## Statistical Methods

Chi-square tests assessed the association of perceived risk of developing breast cancer with each demographic or personal characteristic. Logistic and polytomous regression models were used to analyze screening behaviors with two or more than two levels, respectively and perceived risk [27]. Women with a perceived risk rated as 50% and greater than 50% were compared to women with a perceived risk rated as less than 50%. Women with either above or much above average perceived risk were compared to those with much below, below, or same as average perceived risks. The least vigilant screening behavior categories were used as reference groups, and all models were adjusted for potential confounders. Since many study participants were related and might share common cancer screening behaviors, a robust variance estimate was used to adjust for potential correlation due to family clustering

[28,29]. All statistical analyses were conducted using SAS version 9.1 [30], and significance of all statistical tests was evaluated using two-sided *P*-values at a 5% level.

## Results

Study participants completing the *PHSQ* included 1019 women from 639 unique families of which 394 (62%) had one family member, 159 (25%) had two family members, and 86 (13%) had 3 to 8 family members. On the numerical scale, 230 (23.2%) women rated their perceived risk of developing breast cancer as below 50%, 251 (25.3%) rated their risk as exactly 50%, 315 (31.7%) rated their risk as greater than 50% but no more than 75%, and 196 (19.8%) rated their risk as greater than 75% (Table 1). We compared women who reported perceived risks above, below and exactly on 50%. Those with the highest estimates (greater than 50%) were more likely to be younger (less than age 50), heavier (body mass index greater than 30 kg/m<sup>2</sup>) and to seek health care more frequently (attend a health care facility at least twice annually).

In comparison to other women the same age, 52 (5.3%) women perceived their risk of developing breast cancer as much below or below average, 290 (29.5%) perceived their risk as average, 548 (55.6%) perceived their risk as above average, and 95 (9.6%) perceived their risk as much above average (Table 2). Compared to women who perceived a breast cancer risk of much below, below, or same as average, women who rated their risk as above or much above average were more likely to be younger (than age 50), have a higher education (at least some post-secondary), have visited a health care facility at least two times a year. The internal consistency estimate, measured using Cronbach's alpha, between the verbal and numerical perceived risk measures was 0.65.

Women who rated their risk as exactly 50% or greater than 50% were significantly more likely to have a screening mammogram more than 12 months ago (OR: 2.41, 95% CI: 1.29 – 4.49; OR: 1.94, 95% CI: 1.08 – 3.49, respectively) and within the last 12 months (OR: 2.09, 95% CI: 1.15 – 3.79; OR: 1.91, 95% CI: 1.15 – 3.16, respectively) compared to women with a perceived risk of less than 50% (Table 3). Women reporting a perceived risk of 50% were also more likely to have a screening CBE within the last 12 months (OR: 1.79, 95% CI: 0.82 – 3.92) or more than 12 months ago (OR=1.97; 95% CI: 0.88–4.44), although these associations were not statistically significant. Having a greater frequency of monthly BSE or a genetic test for the presence of the *BRCA1* or *BRCA2* susceptible genes did not appear to be significantly associated with perceived risk measured on a numerical scale.

Women who rated their risk as above or much above average were significantly more likely to have a screening mammogram within the last 12 months (OR: 1.82, 95% CI: 1.17 – 2.81) and to perform BSE once a month or more (OR: 1.64, 95% CI: 1.02 – 2.63) compared to women who rated their risk as average or below (Table 4). No significant associations were observed between perceived risk measured on a verbal scale and having a screening CBE or ever having a genetic test for the breast cancer susceptible genes.

## Discussion

Overall this study reported a positive association between perceived lifetime risk of developing breast cancer, measured either on a numerical or verbal scale, and breast screening among women who had at least one first-degree relative diagnosed with breast and/or ovarian cancer. Women who rated their risk as 50% or greater were more likely to have a screening mammogram compared to women with a perceived risk of less than 50%, irrespective of time. In addition, women who rated their risk as above or much above average risk were significantly more likely to have a mammogram in the past 12 months and

more likely to practice BSE once a month or more compared to women who rated their risk of developing breast cancer as same as or below average.

Our results that women with a greater perceived risk of developing breast cancer measured on a numerical or verbal scale were almost twice as likely to have a screening mammogram differs from other cross-sectional studies of high-risk women. Previous cross-sectional studies examining perceived risk on a numerical or verbal scale have either observed a similar utilization of screening mammography among women with a perceived risk of 50% or more compared to less than 50% [20] or have observed no significant association between risk perception and compliance to mammography [21–23]. Both a prospective study that measured mammography uptake in the following year [24] and a retrospective study [25] that measured mammography in the past 3 years also did not report significant associations between perceived risk estimated on a verbal Likert-type scale that asked general likelihood of getting breast cancer someday during their lifetime and mammography uptake. Differences may have occurred as most of these studies had much smaller sample sizes than ours. In addition, many of the studies recruited convenience samples of women participating in high risk clinics or genetic counseling that may have resulted in self referral bias as compared to our study that identified women from a population-based familial breast registry.

Similar to our study, other investigations did not report a significant association between higher perceived risk measured on a numerical [20] or verbal scale [22,25] and having a screening CBE. However, our study did find that women, who reported an above average perceived risk were significantly more likely to practice BSE once a month or more. One other cross-sectional study also observed slightly more frequent BSE performance in women with a perceived risk of 50% or more compared to less than 50%, although the difference was not statistically significant [20]. However, another study observed that women who over-estimated their actual breast cancer risk on the numerical scale had significantly poorer self-reported compliance of BSE [21]. A few studies have examined performance of excessive BSEs (weekly or daily) in women with a first-degree relative with breast cancer. One study found that women were significantly more likely to perform excessive BSE if they perceived a risk that was higher or much higher compared to other women without family histories [31]. Another study, using a perceived risk measure that encompassed both numerical and comparative estimates, also found women who performed excessive BSE had significantly higher perceived risk [32]. These studies suggested that high risk women might benefit from education about appropriate BSE technique to reduce their anxiety and tendencies to conduct excessive examinations.

In our study, elevated perceived risk measured on a numerical or verbal scale was not associated with having a genetic test for the *BRCA1* or *BRCA2* genes. This is likely because these genetic tests require physician referral based on family history of breast and/or ovarian cancer and our study adjusted perceived risk by the woman's familial risk of breast cancer. Although a meta-analytic review reported that women who perceive a higher breast cancer risk were more likely to pursue genetic testing [19], the studies reviewed only examined interest in genetic testing or participation in genetic counseling. The only other study that, like our study, examined utilization of the genetic test also found a lack of significant association between perceived risk of breast cancer measured on a numerical scale and having a genetic test for the *BRCA1* or *BRCA2* genes in high-risk female participants [33].

A few studies have suggested that a distinction be made between whether perceived risk is measured on a numerical or verbal scale [19,34,35]. There are indications that women tend to over-estimate their risk of developing breast cancer when asked on a numerical scale and under-estimate their risk when asked to compare themselves on a verbal-scale to their peers

[19]. A recent study examined the utility of both the numerical and verbal measures, and results supported the utilization of both under different research objectives. Specifically, for identifying women with very high or very low risk perceptions, both measures performed well with the numerical scale having the higher specificity and the verbal scale having the higher sensitivity [34]. Generally, our results suggest that similar associations for breast cancer screening behaviors were found regardless of whether perceived risk was measured on the numerical or verbal scale.

The present study had several strengths. Firstly, this study included a large cohort of female relatives of breast cancer cases thus providing adequate power to examine associations. Secondly, participants were identified from a population-based cohort of breast cancer cases which will have minimized self-referral bias. Thirdly, since women who had undergone bilateral mastectomy might have appreciably different breast cancer screening practices, they were excluded from all analyses. This exclusion criterion was only applied in one previous study [22]. Another unique aspect of our study was that we measured perceived risk on both a numerical and verbal scale.

Nevertheless, results from this study should be interpreted while considering the limitations. Given the cross-sectional nature of our data, we were unable to determine the direction of the relationship between perceived risk and screening behaviors. That is, perceived risk may have been influenced by previous screening or educational experiences. Misclassification may have also occurred through the use of self-reported data to measure breast screening behaviors. Although self-reported mammography data has been found to be accurate for determining whether a woman has had a mammogram, self-reported data is less accurate in determining the time since last mammogram [36] and women tend to under-estimate the time since their last mammogram resulting in an overestimation of recent mammography use [37,38]. To minimize recall inaccuracy, the *PHSQ* was mailed to the participants to allow recollection of dates and events prior to the telephone interview. To estimate the magnitude of recall bias, the self-reported date of the last mammogram was validated against medical records upon informed consent. Approximately 92% of women reported their last mammogram to be within 12 months from the actual date. Finally, the findings of this study may have limited generalizability to other populations. Participants in this study were family members of breast cancer cases identified from a population-based registry in the Canadian province of Ontario where universal health care coverage and an organized breast cancer screening program for women 50 years of age or older are available.

Increased perceived risk of developing breast cancer measured on either numerical or verbal scales was significantly associated with having a screening mammogram within a large cohort of female relatives of women with breast cancer. These findings could inform educational messages and improve risk communication for women at elevated familial breast cancer risk.

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## References

1. Canadian Cancer Society. Canadian Cancer Statistics. Toronto (ON): Canadian Cancer Society; 2009.
2. Collaborative Group on Hormonal Factors in Breast Cancer. Familial breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies including 58,209 women with breast cancer and 101,986 women without the disease. *Lancet*. 2001; 358:1389–1399. [PubMed: 11705483]
3. Pharoah PD, Day NE, Duffy S, Easton DF, Ponder BA. Family history and the risk of breast cancer: a systematic review and meta-analysis. *Int J Cancer*. 1997; 71:800–809. [PubMed: 9180149]
4. Humphrey L, Helfand M, Chan B, Woolf S. Breast cancer screening: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med*. 2002; 137:347–360. [PubMed: 12204020]
5. Cortesi L, Turchetti D, Marchi I, Fracca A, Canossi B, Rachele B, et al. Breast cancer screening in women at increased risk according to different family histories: an update of the Modena Study Group experience. *BMC Cancer*. 2006; 6:210. [PubMed: 16916448]
6. Halapy E, Chiarelli A, Klar N, Knight J. Breast screening outcomes in women with and without a family history of breast and/or ovarian cancer. *J Med Screen*. 2004; 11:32–38. [PubMed: 15006112]
7. Kerlikowske K, Carney P, Geller B, Mandelson M, Taplin S, Malvin K, et al. Performance of screening mammography among women with and without a first-degree relative with breast cancer. *Ann Intern Med*. 2000; 133:855–863. [PubMed: 11103055]
8. Morrison, BJ. Screening for breast cancer. Ottawa, Ontario: Health Canada; 1994.
9. Ulcickas Yood M, McCarthy BD, Lee NC, Jacobsen G, Johnson CC. Patterns and characteristics of repeat mammography among women 50 years and older. *Cancer Epidemiol Biomarkers Prev*. 1999; 8:595–599. [PubMed: 10428196]
10. Eccles D, Evans D, Mackay J. Guidelines for a genetic risk based approach to advising women with a family history of breast cancer. UK Cancer Family Study Group (UKCFSG). *J Med Genet*. 2000; 37:203–209. [PubMed: 10699057]
11. Evans DG, Lalloo F. Risk assessment and management of high risk familial breast cancer. *J Med Genet*. 2002; 39:865–871. [PubMed: 12471197]
12. Warner E, Heisey R, Goel V, Carroll J, McCready D. Hereditary breast cancer. Risk assessment of patients with a family history of breast cancer. *Can Fam Physician*. 1999; 45:104–112. [PubMed: 10889863]
13. Bobo JK, Shapiro JA, Schulman J, Wolters CL. On-schedule mammography rescreening in the National Breast and Cervical Cancer Early Detection Program. *Cancer Epidemiol Biomarkers Prev*. 2004; 13:620–630. [PubMed: 15066928]
14. Halabi S, Skinner CS, Samsa GP, Strigo TS, Crawford YS, Rimer BK. Factors associated with repeat mammography screening. *J Fam Pract*. 2000; 49:1104–1112. [PubMed: 11132060]
15. Chiarelli AM, Majpruz V, Brown P, Theriault M, Edwards S, Shumak R, et al. Influence of nurses on compliance with breast screening recommendations in an organized breast screening program. *Cancer Epidemiology Biomarkers and Prevention*. 2010; 19:697–706.
16. Lux MP, Ackermann S, Bani MR, Nestle-Kramling C, Goecke TO, Niederacher D, et al. Age of uptake of early cancer detection facilities by low-risk and high-risk patients with familial breast and ovarian cancer. *Eur J Cancer Prev*. 2005; 14:503–511. [PubMed: 16284494]
17. Weinstein ND, Sandman PM. A model of the precaution adoption process: evidence from home radon testing. *Health Psychol*. 1992; 11:170–180. [PubMed: 1618171]
18. Rosenstock, IM. Historical origins of the health belief model. New Jersey: Charles B. Slack, Thorofare; 1974.
19. Katapodi M, Lee K, Facione N, Dodd M. Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. *Prev Med*. 2004; 38:388–402. [PubMed: 15020172]
20. Sheinfeld G, Albert S. The meaning of risk to first degree relatives of women with breast cancer. *Women & Health*. 2003; 37:97–117.



21. Lindberg NM, Wellisch D. Anxiety and compliance among women at high risk for breast cancer. *Ann Behav Med.* 2001; 23:298–303. [PubMed: 11761347]
22. Isaacs C, Peshkin B, Schwartz M, Demarco T, Main D, Lerman C. Breast and ovarian cancer screening practices in healthy women with a strong family history of breast or ovarian cancer. *Breast Cancer Res Treat.* 2002; 71:103–112. [PubMed: 11881908]
23. Lerman C, Daly M, Sands C, Balslem A, Lustbader E, Heggan T, et al. Mammography adherence and psychological distress among women at risk for breast cancer. *J Natl Cancer Inst.* 1993; 85:1074–1080. [PubMed: 8515494]
24. Diefenbach MA, Miller SM, Daly MB. Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychol.* 1999; 18:532–536. [PubMed: 10519469]
25. Martin W, Degner L. Perception of risk and surveillance practices of women with a family history of breast cancer. *Cancer Nurs.* 2006; 29:227–235. [PubMed: 16783123]
26. John E, Hopper J, Beck J, Knight J, Neuhausen S, Senie R, et al. The Breast Cancer Family Registry: an infrastructure for cooperative multinational, interdisciplinary and translational studies of the genetic epidemiology of breast cancer. *Breast Cancer Res.* 2004; 6:R375–R389. [PubMed: 15217505]
27. Agresti, A. *Categorical Data Analysis.* New York (NY): John Wiley & Sons Inc; 2002.
28. Binder DA. On the variances of asymptotically normal estimators from complex surveys. *Survey Methodology.* 1981; 7:157–170.
29. Morel G. Logistic regression under complex survey designs. *Survey Methodology.* 1989; 15:203–222.
30. SAS Institute Inc. *Statistical Analysis Software 9.1.2 ed.* Cary (NC): SAS Institute; 2004.
31. Epstein SA, Lin TH, Audrain J, Stefanek M, Rimer B, Lerman C. Excessive breast self-examination among first-degree relatives of newly diagnosed breast cancer patients. *High-Risk Breast Cancer Consortium. Psychosomatics.* 1997; 38:253–261. [PubMed: 9136254]
32. Brain K, Norman P, Gray J, Mansel R. Anxiety and adherence to breast self-examination in women with a family history of breast cancer. *Psychosom Med.* 1999; 61:181–187. [PubMed: 10204971]
33. Lee S, Bernhardt B, Helzlsouer K. Utilization of BRCA 1/2 genetic testing in the clinical setting. *Cancer.* 2001; 94:1876–1885. [PubMed: 11920551]
34. Gurmankin Levy A, Shea J, Williams SV, Quistberg A, Armstrong K. Measuring perceptions of breast cancer risk. *Cancer Epidemiology Biomarkers and Prevention.* 2006; 15:1893–1898.
35. Woloshin S, Schwartz LM, Black WC, Welch HG. Women's perceptions of breast cancer risk: how you ask matters. *Med Decis Making.* 1999; 19:221–229. [PubMed: 10424829]
36. Yang Q, Khoury M, Rodriguez C, Calle E, Tatham L, Flanders W. Family history score as a predictor of breast cancer mortality: prospective data from the Cancer Prevention Study II, United States, 1982–1991. *Am J Epidemiol.* 1998; 147:652–659. [PubMed: 9554604]
37. Degnan D, Harris R, Ranney J, Quade D, Earp J, Gonzalez J. Measuring the use of mammography: two methods compared. *Am J Public Health.* 1992; 82:1386–1388. [PubMed: 1415867]
38. Gordon N, Hiatt R, Lampert D. Concordance of self-reported data and medical record audit for six cancer screening procedures. *J Natl Cancer Inst.* 1993; 85:566–570. [PubMed: 8455203]

**Table 1**

Distribution of demographic and personal characteristics according to perceived risk (numerical scale) for female relatives from the Ontario site of the Breast Cancer Family Registry.

Demographic and Personal Characteristics	Numerical-scale perceived risk [N (%)]			
	< 50% N = 230	= 50% N = 251	> 50% to ≤ 75% N = 315	>75% N = 196
<b>Age at interview *</b>				
< 40	37 (16.1)	51 (20.3)	98 (31.1)	57 (29.1)
40 to 49	60 (26.1)	69 (27.5)	90 (28.6)	70 (35.7)
50 to 59	73 (31.7)	80 (31.9)	81 (25.7)	45 (23.0)
≥ 60	60 (26.1)	51 (20.3)	46 (14.6)	24 (12.2)
<b>Education level</b>				
High school or less	70 (30.4)	87 (34.7)	72 (22.9)	56 (28.6)
Some college/university/vocational/technical school	80 (34.8)	98 (39.0)	131 (41.6)	85 (43.4)
Bachelor's degree or higher	80 (34.8)	66 (26.3)	112 (35.5)	55 (28.0)
<b>Body mass index † ‡</b>				
< 25	131 (58.5)	115 (46.9)	146 (47.9)	82 (42.7)
25 to < 30	59 (26.3)	69 (28.2)	87 (28.5)	60 (31.3)
≥ 30	34 (15.2)	61 (24.9)	72 (23.6)	50 (26.0)
<b>Annual frequency of visiting health care facility * §</b>				
Once a year or less	91 (41.2)	78 (31.8)	98 (31.6)	59 (31.4)
2 to 3 times a year	88 (39.8)	96 (39.2)	138 (44.5)	73 (38.8)
4 or more times a year	42 (19.0)	71 (29.0)	74 (23.9)	56 (29.8)
<b>History of benign breast disease</b>				
No	148 (65.5)	177 (71.4)	216 (69.7)	134 (68.7)
Yes	78 (34.5)	71 (28.6)	94 (30.3)	61(31.3)
<b>Familial breast cancer risk</b>				
Low-risk	120 (52.2)	128 (51.0)	148 (47.0)	98 (50.0)
Moderate-risk	54 (23.5)	63 (25.1)	79 (25.1)	46 (23.5)
High-risk	56 (24.3)	60 (23.9)	88 (27.9)	52 (26.5)

\*  $P < 0.0001$  for perceived risk < 50% vs. > 50%

†  $P < 0.05$  for perceived risk < 50% vs. = 50%

‡  $P < 0.01$  for perceived risk < 50% vs. > 50%

§  $P < 0.05$  for perceived risk < 50% vs. > 50%

**Table 2**

Distribution of demographic and personal characteristics according to perceived risk (verbal scale) for female relatives from the Ontario site of the Breast Cancer Family Registry.

Demographic and Personal Characteristics	Verbal-scale perceived risk [N (%)]			
	Much below/below average N = 52	Same average N = 290	Above average N = 548	Much above average N = 95
<b>Age at interview *</b>				
< 40	0 (0.0)	44 (15.2)	173 (31.6)	23 (24.2)
40 to 49	11 (21.1)	69 (23.8)	176 (32.1)	38 (40.0)
50 to 59	16 (30.8)	98 (33.8)	136 (24.8)	27 (28.4)
≥ 60	25 (48.1)	79 (27.2)	63 (11.5)	7 (7.4)
<b>Education level *</b>				
High school or less	25 (48.1)	103 (35.6)	121 (22.1)	22 (23.1)
Some college/university/vocational/technical school	17 (32.7)	114 (39.5)	221 (40.3)	45 (47.4)
Bachelor's degree or higher	10 (19.2)	72 (24.9)	206 (37.6)	28 (29.5)
<b>Body mass index</b>				
< 25	30 (60.0)	135 (46.9)	270 (50.7)	34 (37.0)
25 to < 30	12 (24.0)	82 (28.5)	154 (29.0)	29 (31.5)
≥ 30	8 (16.0)	71 (24.6)	108 (20.3)	29 (31.5)
<b>Annual frequency of visiting health care facility †</b>				
Once a year or less	16 (32.0)	113 (40.2)	178 (33.3)	18 (19.4)
2 to 3 times a year	23 (46.0)	108 (38.4)	219 (41.0)	45 (48.4)
4 or more times a year	11 (22.0)	60 (21.4)	137 (25.7)	30 (32.2)
<b>History of benign breast disease</b>				
No	35 (68.6)	190 (66.0)	387 (72.3)	55 (57.9)
Yes	16 (31.4)	98 (34.0)	148 (27.7)	40 (42.1)
<b>Familial breast cancer risk †</b>				
Low-risk	24 (46.2)	145 (50.0)	288 (52.6)	41 (43.2)
Moderate-risk	17 (32.7)	79 (27.2)	114 (20.8)	22 (23.2)
High-risk	11 (21.1)	66 (22.8)	146 (26.6)	32 (33.6)

\*  $P < 0.0001$  for perceived risk much below, below and same average vs. above and much above average

†  $P < 0.05$  for perceived risk much below, below and same average vs. above and much above average

Table 3

Adjusted odds ratios (ORs) and 95% confidence intervals (CIs) for the association between perceived breast cancer risk (numerical scale) and screening behaviors for female relatives from the Ontario site of the Breast Cancer Family Registry.

Screening Behaviors	Numerical-scale perceived risk [N (%)]			Adjusted* OR (95% CI)
	< 50% N = 230	= 50% N = 251	> 50% N = 511	
<b>Reason and time since last mammogram</b>				
Never had or non-screening mammogram	68 (30.2)	66 (26.9)	175 (34.9)	1.00
Screening mammogram > 12 months ago	51 (22.7)	66 (26.9)	115 (22.9)	2.41 (1.29 – 4.49) †
Screening mammogram ≤ 12 months ago	106 (47.1)	113 (46.2)	212 (42.2)	2.09 (1.15 – 3.79) †
<b>Reason and time since last CBE</b>				
Never had or non-screening CBE	23 (10.4)	17 (7.0)	52 (10.4)	1.00
Screening CBE > 12 months ago	67 (30.3)	81 (33.3)	171 (34.0)	1.97 (0.88 – 4.44)
Screening CBE ≤ 12 months ago	131 (59.3)	145 (59.7)	279 (55.6)	1.79 (0.82 – 3.92)
<b>Time since last mammogram and/or CBE ‡</b>				
Screening mammogram or CBE >12 months ago	29 (13.9)	33 (14.1)	82 (17.4)	1.00
Screening mammogram and CBE >12 months ago	33 (15.8)	43 (18.4)	70 (14.9)	1.44 (0.63 – 3.28)
Screening mammogram or CBE ≤12 months ago	57 (27.3)	58 (24.8)	147 (31.2)	0.98 (0.47 – 2.05)
Screening mammogram and CBE ≤12 months ago	90 (43.0)	100 (42.7)	172 (36.5)	1.20 (0.57 – 2.53)
<b>Breast self-examination frequency</b>				
Once a year or less	36 (15.9)	38 (15.2)	77 (15.1)	1.00
Every 2 to 6 months	117 (51.5)	92 (36.8)	233 (45.9)	0.68 (0.37 – 1.25)
Once a month or more	74 (32.6)	120 (48.0)	198 (39.0)	1.46 (0.77 – 2.75)
<b>Ever had a genetic test</b>				
Never had genetic testing	183 (85.9)	194 (82.6)	416 (87.6)	1.00
Had genetic testing	30 (14.1)	41 (17.4)	59 (12.4)	1.29 (0.74 – 2.27)

\* All models were adjusted for age, education, history of benign breast disease, body mass index, frequency of visiting a health care facility and familial breast cancer risk and were corrected for familial clustering.

†  $P < 0.05$

‡ Excluded women who never had a mammogram or CBE or had either or both for non-screening purposes (N = 61)



**Table 4**

Adjusted odds ratios (ORs) and 95% confidence intervals (CIs) for the association between perceived breast cancer risk (verbal-scale) and screening behaviors for female relatives from the Ontario site of the Breast Cancer Family Registry.

Screening Behaviors	Verbal-scale perceived risk [N (%)]		Adjusted* OR (95% CI)
	Much below/below / same as average N = 342	Above/much above average N = 643	Above/much above average vs. Much below/below/same as average
<b>Reason and time since last mammogram</b>			
Never had or non-screening mammogram	81 (24.0)	227 (36.1)	1.00
Screening mammogram > 12 months ago	102 (30.3)	133 (21.1)	1.17 (0.75 – 1.83)
Screening mammogram ≤ 12 months ago	154 (45.7)	269 (42.8)	1.82 (1.17 – 2.81) †
<b>Reason and time since last CBE</b>			
Never had or non-screening CBE	25 (7.5)	71 (11.3)	1.00
Screening CBE > 12 months ago	118 (35.6)	196 (31.3)	0.63 (0.35 – 1.14)
Screening CBE ≤ 12 months ago	189 (56.9)	360 (57.4)	0.80 (0.45 – 1.41)
<b>Time since last mammogram and/or CBE ‡</b>			
Screening mammogram or CBE >12 months ago	44 (13.7)	99 (16.9)	1.00
Screening mammogram and CBE >12 months ago	66 (20.5)	79 (13.5)	1.06 (0.58 – 1.88)
Screening mammogram or CBE ≤12 months ago	81 (25.1)	185 (31.6)	1.32 (0.78 – 2.23)
Screening mammogram and CBE ≤12 months ago	131 (40.7)	222 (38.0)	1.65 (0.98 – 2.76)
<b>Breast self-examination frequency</b>			
Once a year or less	52 (15.4)	96 (15.0)	1.00
Every 2 to 6 months	161 (47.6)	278 (43.4)	1.13 (0.72 – 1.75)
Once a month or more	125 (37.0)	266 (41.6)	1.64 (1.02 – 2.63) §
<b>Ever had a genetic test</b>			
Never had genetic testing	275 (84.9)	512 (86.2)	1.00
Had genetic testing	49 (15.1)	82 (13.8)	1.07 (0.68 – 1.69)

\* All models were adjusted for age, education, history of benign breast disease, body mass index, frequency of visiting a health care facility and familial breast cancer risk and were corrected for familial clustering.

†  $P < 0.01$

‡ Excluded women who never had a mammogram or CBE or had either or both for non-screening purposes (N = 61).

§  $P < 0.05$

CBE Clinical breast examination