Breast Cancer Worry and Mammography Use by Women with and without a Family History in a Population-based Sample

M. Robyn Andersen, Robert Smith, H. Meischke, D. Bowen, and N. Urban


Abstract

Worry about breast cancer risk has been found to be a barrier to mammography use by women with a family history of breast cancer in some studies, although worry is generally found to increase mammography use among average-risk women. Our study sought to examine the association of worry with mammography use in a population-based sample of women stratified by family history associated risk for breast cancer. A population-based sample of 6512 women completed a telephone interview. Fourteen percent (n = 948) of these reported a family history suggestive of elevated risk, including at least one affected first-degree relative. To examine the effects of worry on mammography use in women, a logistic regression model, including family history associated risk, age, and worry, was tested. Although family history was a significant predictor of mammography use in bivariate examinations, in the multivariate model it was not significant after adjustment for age and worry, which remained statistically significant predictors of mammography use (P < 0.05). The association between worry and mammography use was best described by a quadratic term. Interaction terms for family history-associated risk and worry were not statistically significant predictors of mammography use. Worry about breast cancer risk appears to be associated with mammography use in an inverted u-shaped pattern. Women reporting moderate levels of worry were more likely to use mammography annually than those who were either mildly or severely worried. Severe worry may be a barrier to mammography use for all women not only those with a family history.

Introduction

Women with a family history of breast or ovarian cancer are at greatly increased risk for breast cancer as compared with women without such a history. The amount of this increased risk varies among women according to the number and degree of their affected relatives. Those with a single affected relative who developed breast cancer late in life may be at only slightly elevated risk compared with those with no family history. In contrast, those with multiple first-degree relatives (e.g., mother, sisters, or daughters) who experienced ovarian cancer or breast cancer early in life are at substantial risk for carrying a mutation in the BRCA1 or BRCA2 genes (1). These women have been estimated to have a lifetime risk of breast cancer between 46 and 85% (2–4). The risk for women with a single affected first-degree relative is lower than that for women with multiple affected relatives but has been estimated to be 2–15-fold over those with no family history (5).

Although genetic testing is an option for women with high-risk family histories, it does not directly reduce a woman’s risk for breast cancer (6). For high-risk women who do not choose prophylactic surgery, regular screening with mammography is important for early identification of disease reducing the risk of dying of breast cancer (6).

Studies of women at elevated risk for breast cancer because of a family history of disease in first-degree relatives have found that those at elevated risk because of family history, including those with a single affected first-degree relative, experience high levels of worry about their risk (7–12). Some studies have found that high levels of worry can be a barrier to mammography screening use for women and that this leads to a negative association between mammography use and worry about risk (8, 9). However, this negative association has not been found consistently (13), it has only been found in studies of women with at least a single affected first-degree relative. Most studies of women in the general population have found positive associations between worry and mammography use (13–15). Past studies that have found reduced use of screening associated with increased worry recruited only among women at elevated risk because of a family of breast cancer. One possible explanation for the inconsistent findings of prior studies is that the association of worry about cancer risk and mammography use follows an inverted u-shaped pattern (16). This hypothesis suggests that compared with very low levels of worry, moderate levels of worry support an optimal level of arousal and vigilance that motivate people to use screening. High levels of worry and fear in contrast are hypothesized to provoke cognitive defenses, including efforts to reduce immediate distress. Efforts to reduce distress may include denial and efforts to avoid reminders of risk. Denial and avoidance could reduce screening use. Theoretically, this effect of high levels of worry would be equally true for all women, not just those with a family history. Past studies may have identified the phenomena only in women at elevated risk because of a family history. Perhaps because rates of severe worry are low in average-risk women, and rarely, do investigators have sufficiently large samples of severely worried average-risk women to have...
statistical power to test such an association. Although no study to date has found both slopes of the hypothesized inverted u-shaped association, several reviews have concluded that the hypothesis has considerable theoretical support and that the findings of studies, to date, are not inconsistent with it (7, 8, 13, 16).

In this study, we sought to expand on prior studies by examining the association of worry about breast cancer risk and mammography use in a large population-based sample of women that included a significant number of women with affected relatives. In this analysis, we wanted to learn about the association of worry about breast cancer risk and mammography use generally and in women with and without family histories, including affected relatives. On the basis of the theory that worry and mammography use have an inverted u-shaped pattern of association (7, 8, 16), we hypothesized that moderate levels of worry serve to promote screening use, whereas severe worry acts as a barrier to screening and that this is true of all women regardless of risk status. Past studies have found reduced levels of mammography use only in worried women with first-degree affected relatives and few have included both women with and without a family history of disease in a single study, analyses examining the association of worry and mammography use were also conducted with the sample stratified by family history.

**Materials and Methods**

Participating women were between the ages of 50–80 and lived in 40 communities in predominantly rural areas of Washington state. These women were participants in a randomized community trial of mammography promotion and were interviewed as part of an examination of their use of mammography for that trial. Data to be reported here were collected as part of telephone interviews conducted in 1997 with a population-based sample of 6685 women who were free of breast cancer and participating in the follow-up survey for the CTMP. These women had been surveyed previously in 1994 when they participated in the baseline survey for this project. The CTMP is a randomized community trial examining the effectiveness of mammography promotion interventions in rural communities (17). The trial examined the relative effectiveness of two strategies for community intervention by volunteers to increase mammography use among women who were not regular users of mammography and found modest (2.9%) but statistically significant improvement in mammography use associated with the community activities strategy for promotion of mammography but only for the prevention of relapse by regular users of mammography (17). The intervention was based on a public health model and did not emphasize fear appeals or the role of family history in breast cancer risk.

The 1994 CTMP survey was conducted using a sampling frame of 44,080 women ages 50–80 living in the 40 communities representing all such women who could be identified. Interviews were conducted with 9484 women, 86.5% of eligible women sampled (Table 1). Between April and July of 1997, follow-up interviews were attempted with the women who had completed the survey in 1994. Women were ineligible for reinterview in 1997 if they reported a prior personal history of breast cancer (n = 485), double mastectomy (n = 18), or if they were not between the ages of 50 and 80 (n = 74) at baseline. Of the 8907 women believed to be eligible for reinterview in 1997, 791 were lost to follow-up and could not be located or contacted, and 268 were ineligible for reinterview because they were deceased (n = 234) or institutionalized (n = 34). Of the remaining 7848 women, 6685 participated in interviews. These interviews represent 85.2% of the women determined to be eligible for reinterview at follow-up (77.4% of those not determined to be ineligible). Eligible women who did not participate included 939 women who refused the follow-up interview. Two hundred twenty-four women participated in interviews but were not included in analyses because they did not respond to key questions and were dropped as incomplete. An additional 93 women completed interviews but were found to be ineligible for screening mammography at follow-up because of breast cancer (n = 76) or double mastectomy (n = 17) between 1994 and 1997. These women were also considered ineligible for this analysis.

**Measures**

**Family History of Breast and Ovarian Cancer.** As part of the follow-up telephone interview, women were asked if any of their blood relatives had cancer as part of an extended question sequence in which women were asked specifically about all possible first- or second-degree relatives. Respondents were asked about multiple relatives within a category where appropriate (e.g., sisters, aunts, and so on) and could indicate whether the relative was from the maternal or paternal lineage [maternal aunt(s) versus paternal aunt(s)], as well as whether they were half versus full siblings. The type of cancer (breast, ovarian, lung, colon, and so on) and age of relative at diagnosis (≥50 or <50 years) was then collected for the first three relatives indicated by the interviewee. Reported diagnoses were not confirmed. On the basis of information collected on the first three blood relatives listed, women were classified into two breast cancer risk groups: high/elevated and average.

Women were considered at high risk if their family history indicated a significant chance of a **BRCA1** or **BRCA2** gene mutation in the family. This was determined by creating a pedigree and evaluation of the family pattern of affected rela-

<table>
<thead>
<tr>
<th>Table 1 Retention of the CTMP trial cohort and eligibility of cohort members for analyses examining the association between cancer worry and screening mammography</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort members identified in 1994</td>
</tr>
<tr>
<td>Not eligible for recontact because of ineligibility for screening mammography in 1994</td>
</tr>
<tr>
<td>Because of prior breast cancer</td>
</tr>
<tr>
<td>Because of prophylactic mastectomy</td>
</tr>
<tr>
<td>Not between 50 and 85 years of age in 1994</td>
</tr>
<tr>
<td>Cohort members potentially eligible for recontact in 1997</td>
</tr>
<tr>
<td>Women not completing interviews in 1997</td>
</tr>
<tr>
<td>Deceased</td>
</tr>
<tr>
<td>Institutionalized</td>
</tr>
<tr>
<td>Lost to follow-up</td>
</tr>
<tr>
<td>Contacted women who refused to complete interview</td>
</tr>
<tr>
<td>Completed interviews</td>
</tr>
<tr>
<td>Women not eligible for inclusion in the analyses presented here</td>
</tr>
<tr>
<td>Did not provide complete data; e.g., did not answer one or more questions about risk or family history</td>
</tr>
<tr>
<td>Not eligible for screening mammography</td>
</tr>
<tr>
<td>Because of breast cancer 1994–1997</td>
</tr>
<tr>
<td>Because of prophylactic mastectomy 1994–1997</td>
</tr>
</tbody>
</table>

---

3 The abbreviation used is: CTMP, Community Trial of Mammography Promotion.
Breast Cancer Worry and Mammography Use

The guidelines for evaluation were based on those outlined by the American Society of Clinical Oncology (1). The family history patterns used to determine whether a woman was at very high risk included: (a) two or more breast cancer cases and one or more ovarian cancer cases diagnosed at any age, among first- or second-degree relatives of the same lineage; (b) three or more breast cancer cases diagnosed before the age of 50, among first- or second-degree relatives of the same lineage; (c) a family history that includes sister pairs with two of the following cancers: two breast cancers diagnosed before the age of 50 or a breast cancer diagnosed before the age of 50 and an ovarian cancer diagnosed at any age; and (d) two or more ovarian cancer cases (any age) among first- or second-degree relatives of the same lineage. When women did not report pedigrees that fit these American Society of Clinical Oncology criteria, they were classified as elevated risk if they had any first-degree relatives diagnosed with breast cancer. The remaining women (85.9% of the population) were classified as at average family history-associated risk because they reported no significant family history of breast cancer. These women are at approximately average risk for breast cancer.

Worry about Breast Cancer Risk. Worry about breast cancer risk was assessed using a set of five questions. Three of these questions were developed by Lerman et al. (18). The questions asked women how often they thought about their risk of developing breast cancer, how often those thoughts affected their mood, and how often those thoughts affected their ability to perform daily activities. Two additional questions were also asked. One question was similar to Lerman et al. questions and asked women how often they worried (versus thought) about their risk of developing breast cancer. The other question asked women to describe feelings of distress specifically about their risk of breast cancer. The first four frequency questions had possible answers on a four-point scale including “Not at all or rarely” (1), “Sometimes” (2), “Often” (3), and “Almost all of the time” (4). The last question about feelings of distress also had a four-point scale this scale included “Generally happy and free from worry” (1), “Occasionally distressed” (2), “Often distressed” (3), and “Almost always or extremely distressed” (4). These questions are shown in an appendix.

Because there were only a few items, each with four possible responses and these items were designed to capture different levels of distress associated with worry about cancer risk, simple summation of scores was inappropriate to create a linear scale of equal intervals. Therefore, Rating Scale Analysis (19), referred to as Rasch Analysis in the dichotomous case, was used to create a linear scale. The linear worry scale was created using the rating scale software BIGSTEPS (20). The BIGSTEPS algorithm creates a linear scale with interval measurement properties through mathematical transformation of the response item scores and estimation of thresholds weighting each response to each item based on it’s difficulty. These thresholds and weightings of each item response are based on the data provided by the sample studied and allow for examination of the consistency of collected data with an intuitive model of how we would expect individuals to respond to these items. For example, answering “Almost all of the time” to the question “How often do your thoughts affect your ability to perform daily activities?” was found to be a strong indicator of high levels of worry than giving the same response to “How often do you think about developing breast cancer?”

Women’s responses to the items fit the Rasch model for scale development well. Few women reported severe symptoms such as distress, difficulties with mood, or difficulties performing daily activities without also reporting more less severe symptoms such as worry and thoughts about their risk to be frequent. Women’s scores ranged from the lowest possible where women indicated never or rarely to all worry items and indicated that they were generally happy and free from worry to the highest possible where one woman indicated difficulties almost all of the time on all worry items and reported being almost always or extremely distressed. Scores on the scale ranged from −5.68 to 5.87, but the vast majority (99.32%) of women indicated little worry, thereby, scoring less than zero. Almost 69% (68.69%) of women scored the lowest possible score of −5.68, indicating that they rarely thought or worried about their risk for breast cancer.

Use of Mammography. Women were also asked about their use of mammography using a set of questions developed in conjunction with the NCI Breast Cancer Screening Consortium (21). Women were asked if they had ever had a mammogram, about the dates of their most recent mammograms, and how often they planned to have exams in the future. Those who did not remember the date of their most recent mammogram (3.7% of women) were asked questions designed to assist them in the recall of that date. If this failed, they were asked whether the mammogram occurred within the year before the interview or within a period two years before the interview. Responses to these questions were used to create a variable describing a woman’s use of mammography screening. Women reporting use of mammography within 12 months of the interview were considered annual users. This variable was considered the primary outcome variable used for analyses. Use of mammography within 24 months or 2 years of the interview was also calculated.

Analysis Methods. $\chi^2$ analyses were conducted to examine whether various women’s characteristics, worry about breast cancer risk, and use of mammography differed according to family history associated risk status. Multivariate associations between worry and screening use were then examined in the sample as a whole. Logistic regression analysis designed to test for an interaction effect of risk group and worry on mammography use was conducted to determine whether the association between worry and mammography use differed according to family history-associated risk group.

Results

Sixty (0.9%) of the women surveyed did not respond to all of the questions included in these analyses and were dropped from analyses in a process of list-wise deletion. Those who were dropped did not differ significantly from those retained for analysis in age, income, employment, or family history-associated risk of developing breast cancer ($P > 0.05$ in all comparisons). Rates of worry between the dropped and retained groups could not be compared as 85% of those dropped were dropped because they failed to answer questions about their level of worry about their risk of breast cancer. An additional average-risk woman who appeared to have misunderstood the scale and reported extremely high levels of worry (reporting that worry about her risk always affected her daily activities) was also dropped.

*Women’s reports of worry about risk did not vary according to intervention arm of the CTMP study ($P = 0.41$).

The percentage of women failing to recall the date of their most recent mammogram did not vary by risk group ($P > 0.05$).
Overall, the study population was 97% white and non-Hispanic, married (74%), and well educated. Most women reported completing high school (37%) or attending college (49%). Although 21% reported incomes of <$15,000, most reported having incomes between $15,000 and $35,000 (36%) or ≥$35,000/year (43%).

Of the 6512 women completing the survey, 1745 (26.8%) reported a family history of breast or ovarian cancer in at least one first- or second-degree relative. This group included 45 women (0.7% of the population surveyed) reporting high-risk cancer in at least one first- or second-degree relative. This group was at elevated risk, reporting breast cancer in at least one first- or second-degree relative.

### Bivariate Differences between Women according to Risk Group

Differences between high-/elevated- and average-risk family history-associated risk groups in cancer worry, and mammography use are shown in Table 2. In general, the risk groups did not vary on demographic characteristics frequently associated with mammography use. Women in the high-/elevated- and average-risk groups according to family history-associated risk did not differ in marital status, income, education, employment, ethnicity, or smoking status (P > 0.05). Those in the high-/elevated-risk group were slightly older than those in the average-risk group [χ² (1) = 14.4; P < 0.001] with 42.6% over the age of 65 years, whereas 36% of those in the average-risk group were >65 years of age.

The frequency with which women thought and worried about their risk also varied according to family history [χ² (2) = 35.5; P < 0.0001; χ² (2) = 28.0; P < 0.0001, respectively], as did the frequency with which women reported that thoughts about their risk caused them distress [χ² (2) = 18.5; P < 0.0001]. Although statistically significant, these differences may be of minor importance as few women reported that thoughts about their risk for breast cancer affected their mood or ability to engage in daily activities. The average worry scale score of women in the high-/elevated-risk group was ~0.85, as compared with an average score of ~0.578 in the average-risk group. These small differences in the scale scores are not statically significant.

Mammography use varied significantly according to family history-associated risk group. Women in the high-/elevated-risk group were more likely to be annual users of mammography than those in the average-risk group [χ² (1) = 16.1; P < 0.0001]. Rates of use in the past year were 64.8% for the high-/elevated-risk women and 57.8% for the women in the average-risk group, and rates of use in the past 2 years were 83.4% in the high-/elevated-risk group and 76.7% in the average-risk group.

### The Association of Worry and Mammography Use in Women Differing in Family History-associated Risk

To examine whether worry affects mammography use and whether this relationship differs in women according to their degree of family history-associated risk, a logistic regression model, including main effects of family history, age, worry, a quadratic term for worry (allowing for the hypothesized u-shaped curve), and interaction terms for family history group and worry, was created. This model was used to test the statistical significance of the main effects, a quadratic term, and of the interaction term included. The results of this logistic regression are included as Table 3. They revealed the main effect associated with family history-associated risk group to be nonsignificant after adjustment for the effects of worry and age. Worry modeled linearly also appears to have no significant main effect when a quadratic term for worry is also included in the model. The quadratic term testing for a u-shaped relationship between worry and risk was statistically significant at the 0.01 level. The interaction term testing for differences in the pattern of association between worry and mammography use, according to family history-associated risk, was not statistically significant. Inclusion of age as a covariate revealed a significant main effect of age. Additional models created to examine possible interaction effects of age and worry or age and family history on mammography use found no evidence of interactions.

Fig. 1 provides a graphical display of the curves estimated separately for high-/elevated- and average-risk women.
en’s use of mammography in each of the family history groups was graphed separately using quadratic regression procedures to fit lines to the actual survey data (also presented in Fig. 1). Women’s use of mammography appears to follow the inverted "u"-shaped pattern hypothesized. Annual mammography use appears to be highest among women who reported moderate levels of worry (scoring between −4 and 2 on the created continuous measure).

Although the association between use and worry appears to differ among women according to their family history-associated risk, it should be remembered that the interaction term in the logistic regression was nonsignificant, suggesting that any apparent differences between the two risk groups were likely the result of random chance.

Discussion

Worry about risk for breast cancer is associated with mammography use. In the population as a whole, this association appears to be in the shape of an inverted "u" as has been previously hypothesized. Intermediate levels of worry appear to be associated with modestly increased levels of screening use over very low or very high levels of worry. Suggesting that while some level of concern about one's risk can be a motivator of screening use, high levels of worry provoke denial or other psychological efforts to reduce distress, and these may prevent very worried women from getting mammograms. The slopes of the hypothesized curves are, however, fairly flat. Peak rates of use are only modestly elevated from the rates of use reported by the majority of women who report thinking about their risk for breast cancer rarely (and never worrying about their risk). These differences in use may not be statistically significant in the high-/elevated-risk sample or of practical significance in the average-risk group.

Although an association between reduced levels of mammography use and severe worry has been found to be statistically significant only among women at elevated risk because of a first-degree family history in past studies (8, 9) and appears to be more significant among women at high/elevated risk in this analysis, the nonsignificant finding in our test for an inter-action of risk group and worry on mammography use suggests that severe worry can act as a barrier to mammography use regardless of family history-associated risk. Nevertheless, the curves for the two groups do appear to differ, and these differences might be statistically significant in a larger sample. The barrier effect of severe worry may be more common in women with affected relatives because they are somewhat more likely to be severely worried about their risk. Additional research examining the effects of severe worry about breast cancer risk on average-risk women would be helpful.

Limitations of the current study include the cross-sectional and self-report nature of the data used. Although most studies like this have reported on cross-sectional associations of worry and screening use because if the relationship was most likely to be worry, affecting mammography use and not use affecting worry, both interpretations of this relationship should be considered possible. Prospective longitudinal studies of severely worried women in a situation in which actual mammography use data could be collected would help to clarify the true effects of worry on screening use. Unfortunately, in this population, information on women’s risk for breast cancer and levels of worry about breast cancer were only measured at follow-up preventing a longitudinal analysis of the data. In addition, women’s self-reports of mammography use had to be used in the absence of actual use data because confirmation of women’s mammography use through contact with all possible mammography facilities could not be conducted. Research on self-reported mammography use has found self-reports of recent use (within 1 year) to be reasonably accurate (22, 23).

These findings highlight the need for additional research in this area. These findings may have practical implications for those promoting mammography use. Worry is associated with mammography use, but the relationship is not one of simple linear increase. Women who report little or no worry frequently get mammograms, and moderate levels of worry are not associated with dramatic increases in mammography use, suggesting that efforts to inspire fear or worry about breast cancer risk are not likely to be effective. Severe worry, besides presenting a potential risk to a woman’s quality of life, appears to be
counterproductive and is associated with reduced levels of use. Changing awareness of risk and worry about risk may thus not be the ideal means by which to attempt to influence women in efforts to increase mammography use. Increasing women’s awareness of their level of risk may be of little help and become counterproductive if it causes worry to become severe. Whether worry is more of a barrier to screening use for women with affected relatives than it is for women of average-risk women is unclear, however, the results of this study do suggest that severe worry can be a barrier to screening for any woman.

Appendix

During the past month, how often have you thought about your own chances of developing breast cancer?

<table>
<thead>
<tr>
<th>Not at all, or rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

During the past month, how often have you worried about your own chances of developing breast cancer?

<table>
<thead>
<tr>
<th>Not at all, or rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

During the past month, how often have you thought about your chances of getting breast cancer affected your mood?

<table>
<thead>
<tr>
<th>Not at all, or rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

During the past month, how often have you thought about your chances of getting breast cancer affected your ability to perform your daily activities?

<table>
<thead>
<tr>
<th>Not at all, or rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

This next question asks about any feelings of distress you may have about your risk of breast cancer.

During the past four weeks, which of the following best describes you?

<table>
<thead>
<tr>
<th>Generally happy and free from worry</th>
<th>Occasionally distressed</th>
<th>Often distressed</th>
<th>Almost always or extremely distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

If yes to 4 ask

Would you say you have been so extremely distressed that you require hospitalization?

If Yes then question response coded as 5 (replaces 4)
If no then leave question response coded as 4.

References


Breast Cancer Worry and Mammography Use by Women with and without a Family History in a Population-based Sample

M. Robyn Andersen, Robert Smith, H. Meischke, et al.


Updated version
Access the most recent version of this article at:
http://cebp.aacrjournals.org/content/12/4/314

Cited articles
This article cites 20 articles, 5 of which you can access for free at:
http://cebp.aacrjournals.org/content/12/4/314.full.html#ref-list-1

Citing articles
This article has been cited by 10 HighWire-hosted articles. Access the articles at:
/content/12/4/314.full.html#related-urls

E-mail alerts
Sign up to receive free email-alerts related to this article or journal.

Reprints and Subscriptions
To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org.

Permissions
To request permission to re-use all or part of this article, contact the AACR Publications Department at permissions@aacr.org.