article

The impact of family history of breast cancer and cancer death on women's mammography practices and beliefs

Kelly A. Tracy, PhD[1,2], John M. Quillin, PhD, MPH[1,2], Diane Baer Wilson, EdD[2,3], Joseph Borzelleca, MD[4], Resa M. Jones, MPH, PhD[2,5], Donna McClish, PhD[2,3,6], Deborah Bowen, PhD[7], and Joann Bodurtha, MD, MPH[1,2]

Purpose: To summarize the impact of a family history of breast cancer on mammography practices and beliefs. **Method:** Survey data concerning breast health practices and beliefs were utilized for a cross-sectional analysis. Participants were 899 racially diverse nonpregnant women 40 years and older without breast cancer. The impact of various aspects of cancer family history on mammography, perceived barriers to and benefits of screening, and perceived breast cancer risk was assessed. **Results:** More women with a first-degree relative with breast cancer reported a mammogram within the past year and rated their breast cancer risk higher. Death of a first-degree relative impacted the belief that breast cancer can be cured with early detection. Degree of relatedness of affected relative impacted mammography practice and risk perceptions. **Conclusion:** Family history of breast cancer impacted mammography adherence, beliefs about outcomes with early detection, and risk perceptions. Breast cancer death in a family may be a better predictor of beliefs about breast cancer detection and cure than family history of cancer alone. These findings have implications for how screening recommendations and risk information are communicated to patients with different familial cancer experiences. ***Genet Med*** **2008:10(8):621–625.**

Key Words: *breast cancer, family history, mammography, perceived risk, cancer screening*

The integration of family history information broadly and for specific conditions in health care remains a theoretical and practical challenge. A woman's own knowledge and understanding of her family history of breast cancer may impact perceived risk for cancer and thus have implications for health behaviors and beliefs about the benefits of such behaviors.[1–4] A positive family history may reflect genetic susceptibility and potentially both a perceived and actual strong risk for the disease. It might motivate a woman to adhere to recommended health screening practices; alternatively, it might contribute to worry and blunting and reduce a woman's capacity to follow screening recommendations.[5] It is important to note that risk perceptions based on experiences with affected family members are not necessarily driven by a biological understanding of heritable risk. Absetz et al.[6] reported that women without knowledge of heritable risk for breast cancer and women who experienced breast cancer in a close nonbiologically related individual also perceived their risk as higher.

From the [1]Department of Human and Molecular Genetics, [2]Massey Cancer Center, and Departments of [3]Internal Medicine, [4]Obstetrics and Gynecology, [5]Epidemiology and Community Health, and [6]Biostatistics, Virginia Commonwealth University, Richmond, Virginia; and [7]Department of Social and Behavioral Sciences, Boston University, Boston, Massachusetts.

Kelly A. Tracy, PhD, Department of Human Genetics, Virginia Commonwealth University, 1101 Marshall St., Box 980033, Richmond, VA 23298. E-mail: tracyka@vcu.edu

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In general, studies have found that a family history of breast cancer predicts mammography adherence but may not predict adherence to other screening methods such as clinical breast exam[3,7–10]. de Bock et al.[11] found that low compliance with mammography recommendations in women with a family history of breast cancer may be related to a lack of confidence in surveillance and failure to remember to do preventive screening activities. Cohen[3] found that having a family history of breast cancer was related to higher perceived cancer susceptibility and to higher frequencies of breast self-exams. They also observed that women with a family history of breast cancer perceived fewer barriers to screening, which may be another contributor to increased compliance among such women.

Although there is evidence that a woman's awareness of her family history of breast cancer may impact her screening practices, it is unclear if specific aspects of that family history have a greater influence. For example, death in a family member due to cancer may further influence breast health practices and beliefs. Zakowski et al.[12] demonstrated that women who experienced death of a parent due to cancer had higher levels of intrusive thoughts, avoidance, and perceived risk of cancer. Additionally, the degree of relationship to the family member diagnosed with cancer may impact screening behaviors where a closer biological relationship to a cancer patient could predict higher risk perception and more vigilant screening practices.

We sought to understand the relationship of two particular aspects of a family history of cancer (survival status and degree of relation) with self-reported breast screening practices and

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beliefs, perceived barriers to screening, and breast cancer risk perception in a population of women age 40 and older.

MATERIALS AND METHODS

Participants were patients in an urban Women's Health Clinic, enrolled in a trial investigating the effect of breast cancer risk communication on breast health behaviors. Eligible women were at least 40 years old, were not pregnant, and did not have breast cancer. We made 2332 recruitment attempts of eligible patients. This number might include multiple attempts at recruiting the same individuals if they returned to the clinic repeatedly during the recruitment period. Ultimately, 1048 patients gave informed consent to participate, and 899 completed the baseline survey and study enrollment. Recruitment for this study has been described in detail elsewhere.[13] Data were collected on a self-administered survey at the time of baseline recruitment, which occurred from April 2003 through March 2005. Available data included age, race, educational background, reported length of time since last mammogram, intent to get a mammogram in the coming year, perceived barriers to mammography (e.g., cost, pain, and embarrassment), perceived benefits of early detection (e.g., cure, effective treatment, and breast saving procedures),[14] and reported family history of cancer. Perceived benefits of early detection were assessed with a 5-point Likert scale (extremely unlikely, somewhat unlikely, unsure, somewhat likely, and extremely likely). Responses to these items were highly skewed to the positive, and we elected to dichotomize these items divided at "extremely likely" to improve power to detect a difference between the most optimistic responders and others. Risk perception was measured by 1 quantitative and 2 qualitative items. The quantitative item asked women to rate their chance of developing breast cancer "someday" as $<$15%, 15–30%, or $>$30%. The first qualitative item asked women to rate their risk for breast cancer as "usual," "moderate," or "strong." The last qualitative item asked women to rate their breast cancer risk compared with other women on a 5-point scale ranging from "much lower than average" to "much higher than average" (see Quillin et al.[15] for more detailed description).

Family history information included the biological relationship(s) of affected relative(s) to the participant, the type of cancer(s) each relative had, the age at which each relative was diagnosed, and whether each relative died from cancer (see Quillin et al.[15] for detailed description). A positive family history of breast cancer was defined by participant report of either (1) a mother, sister, or daughter with breast cancer (first-degree relatives); (2) a grandmother, aunt, or niece with breast cancer (second-degree relatives); or (3) a cousin, great-aunt, or great-grandmother with breast cancer (third-degree relatives).

Initial analyses considered breast cancer in first-degree relatives only as a positive family history. Subsequent analyses compared first-degree relatives with more distant relatives (second- or third-degree). Predictive value of reported family history of breast cancer was evaluated by ordinal or nominal logistic regression for each variable. We assessed the impact of having a family history of breast cancer on screening practices, perceived benefits of screening, perceived barriers to screening, and perceived cancer risk. The impact of death of a family member with breast cancer was evaluated in the subset of subjects who reported breast cancer in a first-degree relative. Differences in these variables between relatives of differing degrees of biological relation were also evaluated by comparing women who reported a family history of breast cancer in a first-degree relative with women who reported a family history in only a second- or third-degree relative.

The Virginia Commonwealth University Institutional Review Board approved the study and informed consent was obtained for all participants. No adverse outcomes occurred.

RESULTS

Family history status (+ or −)

The total sample ($n = 899$) had a mean age of 50.1 years and was 45% African American; these demographics were not significantly different between those with a positive family history in a first-degree relative (+FH) and those with a negative family history in a first-degree relative (−FH). Although 62% of all participants reported having had their most recent mammogram 1 year ago or less, those with a family history of breast cancer in a first-degree relative were significantly more likely to have had a mammogram in the past year compared with women who did not report a family history (75.7% vs. 60.2%, $P < 0.01$). Women with a family history of breast cancer were not significantly more likely to indicate that they definitely intended to get a mammogram than those without a family history ($P = 0.50$).

Most women did not consider cost (47%), embarrassment (12%), or pain (32%) to be barriers to mammogram screening. Seventy-eight percent of women believed that breast cancer could be cured if caught early and 83% believed that early detection leads to more effective treatments.

Family history did not seem to impact perceptions of barriers to breast cancer screening or most beliefs about the benefits of early detection. However, the belief that it is extremely likely that the breast can be saved with early detection was significantly higher among those with a positive family history compared with those without (56% vs. 46%, $P = 0.04$). Women with a family history of breast cancer considered their breast cancer risk to be higher on all three measures of risk perception than those without a family history ($P < 0.01$ for all three measures).

Survival status of relative

Table 1 presents information on differences in breast health practices, beliefs about early detection, and risk perceptions by survival status of first-degree relatives with breast cancer. Women who had a first-degree relative die from breast cancer were significantly more likely to have had a mammogram in the previous year compared with women without a family history (OR: 3.3; 95% CI: 1.5 – 7.5).

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Table 1
Differences in breast health practices and beliefs by family history and survival status of first degree relatives with breast cancer

	Family history of breast cancer (+FH) and death (+FH/death) of first-degree relatives		
	+FH/no death ($n = 73$) vs. − FH ($n = 784$)	+FH/death ($n = 42$) vs. − FH ($n = 784$)	+FH/Death ($n = 42$) vs. +FH/no death ($n = 73$)
Mammogram within last year	1.64 (0.97–2.77)	3.31 (1.45–7.53)	2.02 (0.78–5.26)
Definitely intend to get a mammogram in coming year	0.90 (0.55–1.45)	1.79 (0.93–3.45)	2.00 (0.91–4.41)
Cost as a barrier to mammogram	1.06 (0.66–1.72)	1.05 (0.56–1.95)	0.99 (0.46–2.11)
Embarrassment as a barrier to mammogram	1.64 (0.87–3.11)	0.58 (0.18–1.93)	0.34 (0.10–1.33)
Pain as a barrier to mammogram	0.92 (0.55–1.56)	0.77 (0.38–1.56)	0.83 (0.36–1.96)
Extremely likely that breast cancer can be cured if detected early	1.65 (1.01–2.68)	0.71 (0.37–1.34)	0.43 (0.20–0.94)
Extremely likely that if you had breast cancer, it could be cured	1.59 (0.98–2.59)	0.83 (0.45–1.56)	0.52 (0.24–1.13)
Extremely likely that early detection leads to effective treatment	1.49 (0.88–2.50)	1.24 (0.64–2.40)	0.83 (0.37–1.88)
Extremely likely that breast can be saved	2.01 (1.22–3.30)	0.92 (0.49–1.74)	0.46 (0.21–1.00)
>30% chance of you developing breast cancer	4.03 (2.19–7.41)	6.98 (3.51–13.86)	1.73 (0.75–3.99)
Rate your risk for developing breast cancer as strong	5.43 (2.69–10.96)	12.32 (5.89–25.77)	2.27 (0.94–5.47)
Your risk compared to other women greater than average	4.81 (3.05–7.57)	8.72 (4.85–15.69)	1.81 (0.90–3.64)

Ordinal or nominal logistic regression odds ratios with 95% confidence intervals.

Women who had a first-degree family history of breast cancer but no death were more likely to be optimistic about the benefits of early detection than both women without a family history and women with a family history and death. Women with a family history and death were significantly less likely to believe that breast cancer can be cured with early detection compared with women with a family history and no death (OR 0.4, 95% CI 0.2–0.9). This trend was also evident in the belief that the breast could be saved with early detection but the difference did not reach statistical significance (OR 0.5, 95% CI 0.2–1.0). However, comparing women with a breast cancer survivor in the family with the other two groups combined (no family history and family history with death) did show a significant difference in both the belief that the breast could be saved with early detection (OR 2.0, 95% CI 1.2–3.3, $P < 0.01$) and the belief that early detection can lead to a cure (OR 1.7, 95% CI 1.0–2.7, $P = 0.04$).

Risk perception was also influenced by death of a relative. Although not statistically significant, risk perceptions as measured by three separate variables (chance of developing breast cancer >30%, risk for developing breast cancer as strong, risk for developing breast cancer greater than the average woman's risk) were consistently higher in women who had a breast cancer death in a first-degree relative compared with those with a family history and no death.

Biological relationship (first degree compared with second or third degree)

Table 2 shows the results for comparisons of women without a family history of breast cancer versus those with first-degree relatives and those with second- or third-degree relatives with breast cancer, and a comparison of those with affected first-degree relatives versus those with second- or third-degree relatives. Women with a first-degree relative with breast cancer were 2.1 times more likely to have had a mammogram in the past year compared with those without a family history and 1.8 times more likely compared with those with only more distant relatives with breast cancer (95% CI 1.4–3.4 and 1.1–3.1 respectively). Women with a second- or third-degree relative with breast cancer were statistically no more likely to have had a mammogram in the past year than women without any family history of breast cancer. Women with a positive family history in a first-degree relative rated their risk for breast cancer as higher than women with a more distant relative on all three measures of risk perception. Additionally, women with a first-degree family history more often indicated that they believed it extremely likely that the breast could be saved with early detection compared with women with a more distant affected relative.

DISCUSSION

Specific aspects of cancer family history seemed to variably impact mammography practices in this large, diverse group of women. Degree of relation of relatives with breast cancer affected likelihood of having had a mammogram in the previous year. There was also a trend showing that women with a breast cancer death in the family were more likely to have had a recent mammogram compared with women with only a breast cancer survivor in the family although it was not statistically significant. Several explanations for these trends may be considered. Women may be aware of the implications that having a family history of cancer has on their personal risk and subsequently are exhibiting greater compliance with mammography recommendations. Alternatively, these results may reflect behaviors

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Table 2
Differences in breast health practices and beliefs by degree of relationship in family history of breast cancer.

	Among all relatives with a family history of breast cancer		
	+FH first degree (n =115) vs. − FH (n = 595)	+FH second or third degree (n =189) vs. − FH (n =595)	+FH first degree (n = 115) vs. +FH second or third degree (n = 189)
Mammogram within last year	2.13 (1.35–3.37)	1.17 (0.84–1.65)	1.82 (1.08–3.05)
Definitely intend to get a mammogram in coming year	1.27 (0.85–1.90)	1.53 (1.09–2.13)	0.83 (0.52–1.33)
Cost as a barrier to mammogram	1.03 (0.69–1.54)	0.91 (0.65–1.26)	1.14 (0.71–1.81)
Embarrassment as a barrier to mammogram	1.23 (0.69–2.21)	1.02 (0.61–1.69)	1.21 (0.61–2.42)
Pain as a barrier to mammogram	0.87 (0.56–1.34)	1.01 (0.71–1.43)	0.86 (0.52–1.43)
Extremely likely that breast cancer can be cured if detected early	1.19 (0.80–1.78)	0.93 (0.67–1.30)	1.28 (0.80–2.03)
Extremely likely that if you had breast cancer, it could be cured	1.22 (0.82–1.82)	0.88 (0.63–1.22)	1.38 (0.87–2.20)
Extremely likely that early detection leads to effective treatment	1.49 (0.97–2.29)	1.36 (0.96–1.92)	1.10 (0.67–1.81)
Extremely likely that breast can be saved	1.46 (0.97–2.18)	0.86 (0.62–1.20)	1.69 (1.06–2.70)
>30% chance of you developing breast cancer	6.48 (3.79–11.09)	2.26 (1.29–3.94)	2.87 (1.58–5.22)
Rate your risk for developing breast cancer as strong	10.98 (5.68–21.20)	2.86 (1.37–5.98)	3.84 (1.91–7.68)
Your risk compared to other women greater than average	7.91 (5.34–11.71)	2.75 (2.02–3.74)	2.88 (1.86–4.44)

Ordinal or nominal logistic regression odds ratios with 95% confidence intervals.

of physicians incorporating family history information into their mammogram and referral practices.

Reported risk perceptions are consistent with expected actual risks based on family history. Having a first-degree relative with breast cancer may reflect a higher actual risk for breast cancer compared with women who have a second- or third-degree relative with breast cancer. Although the differences in perceived risk between the death/no death groups were not statistically significant, it is important to note that odds ratios for all risk perception measures were greater than one. This indicates a relatively higher perceived risk for those who have experienced a breast cancer death in the family. Confidence intervals were wide suggesting that the sizes of these samples (death n = 42, no death n = 73) may not provide enough power to detect a difference if there is one truly present.

Likewise, there seems to be a trend that women who have a first-degree relative who is a breast cancer survivor were more optimistic in their beliefs about the benefits of early detection compared with women who experienced a breast cancer death in the family. One of these belief items (breast cancer can be cured with early detection) was statistically significant and one bordered on significance (breast can be saved with early detection). Comparing only the death and no death groups, it first seems that women with a breast cancer death in the family were more pessimistic about the benefits of early detection. However, when including the negative family history group in the analysis we see that women with a family history of breast cancer death are not different in their beliefs than women without a family history of breast cancer. This suggests that it may be more accurate to claim that women who have a breast cancer survivor in the family are more optimistic than either group. Further analysis comparing women with a surviving relative with breast cancer with all other women in the study (those with no family history and those with a relative who died from breast cancer) supports this hypothesis. Women with a positive family history did not differ in perceived barriers of pain, cost, and embarrassment to mammography.

In contrast to several studies that have examined the impact of positive family history of breast cancer on preventive breast health practices, our sample was not a high risk group. Madlensky et al.[16] reported that breast cancer survivors with a strong family history did not report undertaking more preventive lifestyle behaviors, including more frequent follow-up, compared with breast cancer survivors without a family history. Primary physician recommendations for breast and ovarian cancer screening even have a significant independent association in high-risk women with or at a 50% risk for having a *BRCA1/2* mutation.[17] Screening at 1-year intervals may remain important in older women with a positive family history to detect interval cancers.[18] Watson et al.[19] found that similar to women in the general population, most women with a family history do not seem to experience high levels of anxiety associated with mammographic screening. The high self-reported mammography rate we found may be a reflection of partici-

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pants putting themselves in a favorable light when responding to questions or the combined work of providers and patients optimizing screening.

Having more relatives who had died from breast cancer was associated with greater distress on a number of measures in a pilot study in California.[20] Our results may be seen as consistent with this as we see an increase in risk perception and a decrease in belief of a cure associated with having had a family member die. Survival status of family members with breast cancer may be an important dimension to consider in education of patients about breast cancer risk and screening. Although women with a breast cancer death in the family were not as optimistic in their beliefs about risk and cure, they also indicated that they were more informed about breast cancer in general compared with women with a family history but no breast cancer death in the family (data not shown).

One limitation of this study might be the uncertainty of the accuracy of family history. Self-reported family history relies on participant knowledge of who in the family has had cancer and what type of cancer he/she had. However, accuracy of self-reported breast cancer family history has been shown to be reasonably high.[21–23] Additionally, while accurate family history is critical for accurate risk assessment, the evaluation here is on how family history impacts behaviors and beliefs and therefore the participant's perception of her family history is the important aspect regardless of actual family history. Participants who did not complete the family history section of the survey were assumed to have no family history of cancer.

Alternative strategies for assessing breast cancer risk, including computerized algorithms available on the Internet, are available, and generally include some aspect of family history. A challenge remains in applying our awareness of current and evolving knowledge of hereditary risk to a broad population in a practical way, given the variation in hereditary risk models.[24] Family history information can have value apart from just risk assessment. A patient's breast cancer screening behavior and beliefs about the benefits of such early detection practices seem to be influenced by not only presence or absence of a family history of cancer, but other dimensions of family history as well. Thus consideration of survival status of family members with cancer, degree of relation of family members with cancer, and type of cancer can be useful in patient education and assessment of patient attitudes and beliefs. Ultimately understanding how family history information impacts breast cancer screening practice can aid in effectively using this information to improve compliance with screening recommendations and subsequently increase the percentage of cancers detected earlier. This can result in decreased breast cancer related mortality.

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