The Effect of an Educational Intervention on the Perceived Risk of Breast Cancer

Nicole E. Alexander, Jonathan Ross, MD, Walton Sumner, MD, Robert F. Nease, Jr., PhD, Benjamin Littenberg, MD

OBJECTIVE: **To appraise women's perceived risk of developing breast cancer and the effects of a physician's educational intervention on this perception.**

DESIGN: **Longitudinal before-and-after study involving four measures of participants' risk of developing breast cancer. Eligible women provided the data needed to calculate an objective estimate of their individual risk of developing breast cancer before age 80 using the Gail formula. They also provided a subjective estimate of their individual perceived risk. Then, each participant met with a general internal medicine physician who provided personalized information and education. Immediately after education, and again several months later, we reassessed each woman's perceived risk.**

SETTING: **Physician's office.**

PARTICIPANTS: **A convenience sample of 59 women participating in the Tamoxifen Breast Cancer Prevention Trial. Twenty-nine women returned for the follow-up risk assessment.**

MEASUREMENTS AND MAIN RESULTS: **The median calculated risk of breast cancer before age 80 (by the Gail formula) was 15%, but the median perceived risk before educational intervention was 50%. The perceived risk after educational intervention fell to 25%. At late follow-up, the median perceived risk remained at 25%. The difference between the pre-educational perceptions and the calculated estimates was significant ($p < .0001$). After educational intervention, perceived risk measures shifted closer to the calculated value, but still remained significantly higher ($p < .0001$).**

CONCLUSIONS: **Women often substantially overestimate their chances of getting breast cancer. Educational intervention by a physician, including explanation of an individual's calculated risk, can reduce this error. The effect of education appears to persist at least for several months.**

KEY WORDS: **breast cancer; patient education; informed consent; physician-patient relations; risk.**
J GEN INTERN MED 1995;11:92–97.

The Tamoxifen Breast Cancer Prevention Trial (BCPT) is an ongoing five-year study conducted by the National Surgical Adjuvant Breast and Bowel Project (NSABP) on the effects of administering paclifaxel (Tamoxifen) to women at high risk of developing breast cancer. Women who have a risk of breast cancer greater than the five-year risk of an average 60-year-old woman (as determined by epidemiologic risk factors) are eligible to participate in the trial. After selection, the BCPT randomized subjects to receive either daily paclitaxel or placebo. The major outcome measure of the trial will be the five-year incidence of breast cancer.[1]

We noticed that many potential participants had unrealistically high perceptions of their likelihood of developing breast cancer. Other populations of women also have elevated perceptions, including women under 50 years of age,[2] and women at high risk of breast cancer.[3–5] Overestimation of breast cancer risk is important for at least two reasons. First, women may make poorly informed decisions regarding breast cancer screening and risk reduction, including the decision to enter the BCPT. Second, women may suffer from misplaced anxiety. Such anxiety may keep women from seeking appropriate preventive care.[6] We attempted to measure women's perceptions of breast cancer risk and use personalized education to provide more accurate risk estimates. We focused our analysis on two questions: (1) How do women's personal perceptions compare to an objective measurement of their risk?; and (2) What is the effect of personalized education on women's perceptions?

METHODS

Design

We determined up to four measurements of each woman's probability of developing breast cancer. The Gail formula served as the objective measure of risk based on epidemiologic risk factors.[7] The remaining three measures of risk were personal estimations using the computer assessment tool, U-Titer.[8]

On the first office visit, participants assessed their perceived risk of developing breast cancer before age 80 with a U-Titer questionnaire. Then the subjects each met with a general internist who instructed them about their objective risk of breast cancer, as calculated by the Gail formula, and informed them about the intents of the study. In this 90-minute session, the doctor reviewed the protocol and the informed consent document for the BCPT. The doctor and participant then discussed the participant's personal risk assessment and her Gail-generated probability. The doctor shared the result of each participant's Gail-generated probability both visually and verbally, then defined the risk factors included in the Gail formula. The doctor discussed all of the participant's

Received from Washington University School of Medicine (NEA, RFN, BL), Dartmouth-Hitchcock Medical Center (JR), University of Kentucky (WS).

Address correspondence to Dr. Littenberg: Campus Box 8005, Washington University School of Medicine, St. Louis, MO 63110-1093. Reprints are not available.

questions. Immediately following the educational intervention, U-Titer was used to reassess the participant's perceived risk.

Twenty-nine of the participants returned for a follow-up visit. They completed a third self-assessment with the U-Titer program. These participants received no further education as part of the study before the third perceived risk assessment.

Calculated Risk

We used the Gail formula for estimating the risk of developing breast cancer. It is based on white women screened annually for mammography. The model is age-specific and utilizes four major risk predictors: the number of first-degree relatives with beast cancer, age at first live childbirth, age at menarche, and the number of previous (benign) breast biopsies.[7] The model is an unconditional logistic regression with relative associations of the four risk factors. It calculates a woman's relative risk of developing breast cancer compared with the lowest risk possible for a woman of the same age. Then it determines an individualized absolute risk of developing breast cancer within a certain period.[9] The baseline rate for this study was the breast cancer incidence rate for women 60 to 64 years old based on data from Surveillance Epidemiology and End Results (SEER). We used the Gail formula to determine each participant's probability of developing breast cancer before age 80.

The Instrument

U-Titer is a Macintosh Hypercard software package developed for utility assessment.[8] Each assessment takes the form of an interactive questionnaire that is designed to minimize certain common biases such as "anchoring," "framing," avoidance of small numbers, and others. The program begins by collecting demographic data and then administers an assessment of perceived risk.

A combination of pie graphs and text present various levels of risk. At each level of risk, the participant makes a binary choice to indicate whether she feels her risk is higher or lower than the risk displayed. Then the computer adjusts the risk presentation in response to the participant's choice, attempting to close in on her perceived risk. The participant also has the option of overriding the automatic program and adjusting the risk directly. The assessment stops when the patient is satisfied that her level of risk is equal to that displayed (Figure 1).

Study Population

We chose a convenience sampling of women who had enrolled in the BCPT at the Dartmouth-Hitchcock Medical Center site. Each eligible woman had an age-specific hazard rate equal to or greater than that of an average 60-year-old woman as defined by the Gail formula. This corresponded to a 10% probability of developing breast cancer before age 80. The study population included primarily white women over 40 years of age. We excluded women over 70 years of age. We fully informed participants about the study, which was approved by the Institutional Review Board.

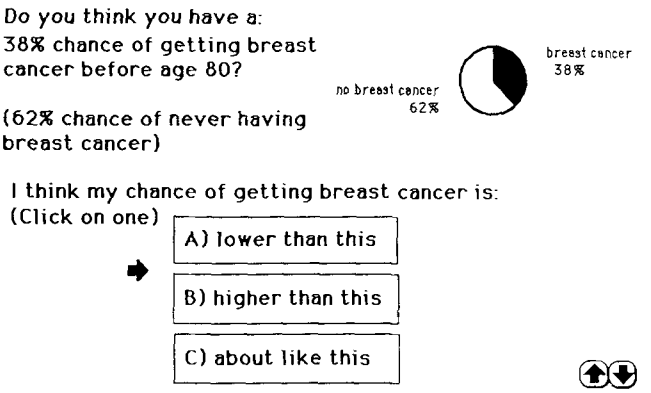

FIGURE 1. The study instrument.

Data Analysis

Because neither the risk measures nor their paired differences were normally distributed, we used nonparametric statistics. We calculated the median differences among the four assessments and applied the Wilcoxon rank sum test to evaluate statistical significance. We also stratified results by two risk factors: age (stratified at 50 years) and presence of cancer in a first-degree relative. We used the Mann-Whitney U test for these analyses.[10] We did not adjust for multiple comparisons.

RESULTS

Patient Characteristics

Fifty-nine women completed preeducation and post-education assessments of their perceived risk. Twenty-nine of the women completed another perceived risk assessment on a return visit. The median follow-up time was five months. The majority of the women were white. Their median age was 53, and they ranged in age from 39 to 70 (Table 1).

The median calculated risk of all participants was 15%, reflecting their probability of developing breast cancer before age 80. Forty-one (69%) of the women had mothers who had breast cancer. None of the women developed breast cancer during the study.

Initial Perceived Risk

Before the educational intervention, none of the participants' perceived risks matched their calculated risk. Of the 59 women, 54 (91.5%) overestimated their risk,

Table 1. Population Characteristics

	All Subjects	Late Follow-up
Number	59	29
Median age	53	51
Age range	39–70	42–69
Number with first-degree relative with breast cancer	41	22
Number without first-degree relative with breast cancer	18	7
Number over age 50	35	16
Number under age 51	24	13

71% by a factor of 3.0 or more. The median estimated risk was 50% (Table 2). The median difference between the initial perceived risk measure and the calculated risk of those overestimating was 41.5%; for the five underestimaters it was 4%. The preeducation estimates differed significantly from the calculated risks ($p < .0001$).

Although most women greatly overestimated their risk, their estimations *were* associated with specific clinical risk factors. For example, there was an association between high initial perceived risk and women who had mothers with breast cancer. Of the 59 women, 18 (31%) reported no first-degree relative with breast cancer, and their initial median risk assessment was 37.5%. The remaining 41 women had mothers with breast cancer, and their median initial perceived risk was 50% ($p = .03$). The calculated risk for these women reflected the same responsiveness (median; 13% vs 16%, $p = .02$).

Initial perceived risk of developing breast cancer was higher for women under age 50 than for women over age 50 (median: 68.5% vs 50%, $p = .03$). This pattern reflected that women under 50 had a higher calculated risk due to greater exposure time than women over 50 (median: 20% vs 13%, $p = .001$).

Effect of Educational Intervention

Immediately following the educational intervention, we reassessed each participant's risk perception. Most participants' perceived risk shifted toward their calculated risk. The median absolute difference between the calculated risk and the perceived risk dropped from 39% before education to 1% after education ($p < .0001$; see Figure 2). Some participants admitted to a certain disbelief in their calculated risk. Even after education, these women rated their risk higher than the calculated risk "just in case" (Table 2).

Twenty-nine patients participated in a third risk assessment (with no intervening education) on a return visit. This subset of women did not significantly differ from the initial population in age, calculated risk, perceived risk at initial visit, or family history of breast cancer. The return time varied from 2.5 to 11 months. The follow-up risk estimate showed no significant change from the assessment conducted immediately after educational intervention. The median difference between the third risk perceptions and the initial risk perceptions was 31% ($p < .0001$). At follow-up, the median difference between perceived risk and the calculated risk was 4%. Thus, the effect of the educational intervention was initially dramatic and appeared constant over a period of months, as shown in Figure 2.

DISCUSSION

These women's perceptions of their likelihood of developing breast cancer were greatly inflated. Although the women were aware of some of their individual risk factors, they were unaware of the magnitude of effect these risk factors had on their chance of developing breast cancer. After educational intervention, including a discussion of an epidemiologically determined risk measure, these women modified their risk perceptions appropriately. The effect of education appeared to persist for months.

Although our results are almost certainly not due to chance, they may not be generalizable to other populations. Our subjects were all volunteers for a trial to re-

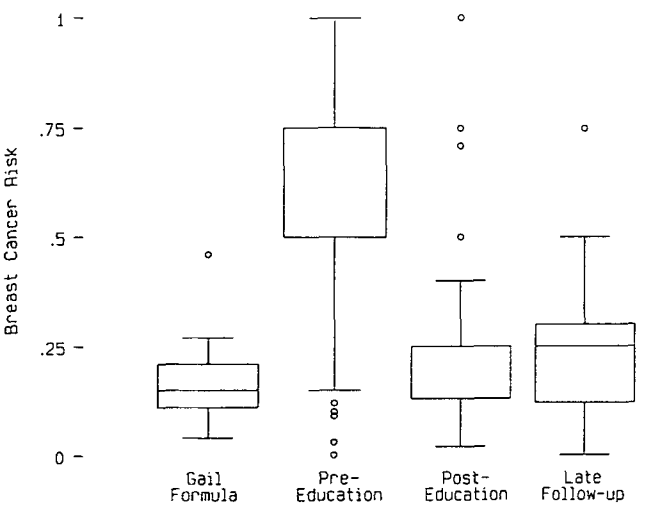

FIGURE 2. Estimated probability of breast cancer before age 80. The distribution of each estimate is displayed using a box-and-whisker plot. The middle of the box represents the median of the distribution. The top and bottom of the box represent the 25th and 75th percentiles. The whiskers represent the range of the distribution. Extreme outliers are represented by small circles. For preeducation, both the 25th percentile and the median are 0.50. For posteducation, both the 75th percentile and the median are 0.25.

Table 2. Median Risk Estimates

	Calculated Risk	Subjective Estimates		
		Pre education	Post education	Late Follow-up
All subjects	15%	50%	25%	25%
First-degree relative with breast cancer	16%	50%	25%	25%
No first-degree relative with breast cancer	13%	37.5%	12%	19%
Age over 50	13%	50%	15%	22.5%
Age under 51	20%	68.5%	25%	25%

duce breast cancer risk. They may have self-selected on the basis of high perceived risk.

Our results do appear similar to other studies on high-risk populations. Lerman and colleagues studied a population composed entirely of women reporting first-degree relatives with breast cancer in 1993.[11] They exhibited an association between high perceived risk and personal risk factors, including no children and late age at first childbirth. Lerman also reported that older women perceived themselves to be at lower risk than younger women.

Our study relies on the Gail formula as an objective estimate of risk. The calibration of the Gail formula has been prospectively examined in at least two independent samples. In the Texas Breast Screening Project, it performed well in white women with at least one first-degree relative with breast cancer who were screened annually according to American Cancer Society (ACS) guidelines.[12] For women who did not follow the guidelines, the Gail formula tended to overestimate their risk. In the Nurses' Health Study, it tended to overesimtate risk of breast cancer in a large study population of predominantly white women who did not necessarily follow the ACS guidelines.[13] This overestimation may be explained by the fact that many nurses did not comply with screening guidelines.[9] Also, the Nurses' Health Study population did not necessarily represent a high-risk population.[13] In our subject population, the number receiving annual mammography screenings was most likely higher than in most populations as the women were aware of their risk factors and interested in participating in the BCPT. If the calculated risk is an overestimate of risk in some of our subjects, then our subjects' overestimations are even more striking. Indeed, the Gail formula would have to underestimate risk by a factor of more than 3.0 to explain our findings.

Our study used a nonexperimental design. It is possible that some secular trend or unintended event occurred during the study, introducing a confounder. However, the preeducation and posteducation assessments were very near in time: both occurred within 90 minutes. During that time, the women were continually involved in the process of the study and were unlikely to be exposed to other information. It is possible that other stimuli intruded between the posteducation assessment and the late follow-up, although the very small difference in these two assessments argues against this possibility.

Our results exhibited the same trends as a recent randomized control study by Lerman and colleagues.[5] It addressed the effect of intervention in a population of women who all had first-degree relatives with breast cancer. The investigators assessed the perceptions of these women by phone interview before and after a structured intervention. Then they compared the participants' perceptions with their calculated risk. The intervention group improved more than the control group. However, in both groups, more than 67% of the women still significantly overestimated their risk at the follow-up assessment.

Although the two studies were similar, ours differed from Lerman's in several important ways. First, the two studies used different measures of perceived risk. In general, probabilities can be measured directly (by asking for a number between 0 and 1) or indirectly (by a comparison of two different wagers or risks). In the indirect measurement, one wager is altered until the subject is indifferent between the two. The risk value is then inferred.[14] The U-Titer instrument falls between these two extremes. As an indirect method, it may be more effective in aiding women to choose their self-perceived risk. The Lerman group used the direct method.

Second, the two studies performed postintervention assessments at different times. In the Lerman study, the follow-up interval was three months. In our design, this time was 90 minutes. The quick follow-up time may have reinforced the discussed clinical risk factors and Gail values. This reinforcement appeared to be a lasting effect: on repeated follow-up several months later, our subjects' perceptions remained constant.

Third, the populations in the two studies differed, possibly accounting for some of the difference in the effect of intervention. Subjects in the Lerman study were all directly related to women with breast cancer. They most likely had more family experience with breast cancer and perhaps more associated anxiety. This is speculative as we did not assess our participants' breast cancer preoccupation.

Finally and most importantly, the interventions may have differed in their content or intensity. More exploration is needed to determine effective interventions for specific populations.

Why was our intervention effective? It may be that it modified the doctor-patient interaction by explicitly incorporating precise numerical estimates rather than vague words.[15] Words are unreliable transmitters of quantifiable

ideas such as risk.[16] Our results indicate that, at least in some settings, it is possible to use numbers to educate and inform patients about risk.

The utilization of appropriate numbers in risk communication has been helpful in other settings. In medical education, Wigton and colleagues conducted studies on students learning how to predict risk.[17] Either probability feedback, which returned the exact risk value to the student, or cognitive feedback, which returned weighted risk factors but no exact risk value, was incorporated into student exercises. The students receiving probability feedback performed better than those with cognitive feedback alone. We believe both cognitive and probability feedback were included in our intervention. The doctor explained all the risk factors involved and illustrated a personal clinical risk estimate. Thus, we corrected for missing risk factors and disproportionate estimates of the weight of risk factors.

Fischhoff and colleagues distinguish three perspectives useful in risk communication: the mental model analysis, calibration analysis, and value-of-information analysis.[18] Mental model analysis attempts to understand all aspects of the subject's intuitive risk perception and correct for misconceptions. In calibration analysis, the biggest errors in a subject's perceived risk estimate are corrected. In value-of-information analysis, information with the greatest impact on the risk is presented to the subject. One of these methods (or a variant) may be appropriate when time and resources are limited. The needs of the participant should correspond to the chosen analysis method. Our intervention may conform most closely to mental model analysis, a comprehensive but labor-intensive approach.

Why did our subjects overestimate their risk of breast cancer? The availability heuristic may be one possible explanation for our subject's high estimates.[19] The availability bias is a result of disproportionate visibility, such as substantial media coverage or personal experience with breast cancer in the immediate family, which lead to high risk estimates.[14,18] Our subjects may be more preoccupied with breast cancer because of the topic's availability.

What are the consequences of overestimating risk? The most important consequences may occur in choosing therapies or screening protocols. Women who overestimate their chance of cancer may request mammograms, drug therapy, or even prophylactic mastectomy with little benefit. This phenomenon may partially explain the tremendous demand for mammography, even among populations such as young women for whom benefit is highly speculative.[20] Or inversely, inflated perceptions among high-risk women may heighten stress levels[6] and deter adherence to mammography screenings and other preventive measures.[21–23] Because patients are prone to serious errors of this type, special attention must be paid during informed consent for standard as well as experimental therapy.

A future consequence of high perceived risk may include demands for genetic testing. Clinical genetic testing for the major breast and ovarian cancer susceptibility gene, *BRCA1*, may soon be possible. Public demand for this test has been shown to depend on perceived risk.[24]

Our study demonstrated a method for measuring patient's risk perception and an effective procedure of clinical risk communication. That our subject's misperceptions were largely correctable and that the correction was stable over time leaves us optimistic. We have demonstrated that a structured conversation with an informed personal physician, who has access to a decision aide such as the Gail formula, can dramatically improve patients' understanding of their risk of disease. It takes time, effort, and skill to educate patients effectively. Although it is possible that the burden on the provider is too great, we are hopeful that further experience will prove this approach widely useful in primary care.

REFERENCES

1. Fisher B. NSABP Protocol P-1. A clinical trial to determine the worth of Tamoxifen for preventing breast cancer. National Surgical Adjuvant Breast and Bowel Project, Pittsburgh, PA. January 24, 1992.
2. Black WC, Nease RF Jr, Tosteson ANA. Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. J Natl Cancer Inst. 1995;87:720–6.
3. Evans DGR, Burnell LD, Hopwood P, Howell A. Perception of risk in women with a family history or breast cancer. Br J Cancer. 1993;67:612–4.
4. Stefanek M. Counseling women at high risk for breast cancer. Oncology. 1990;4:27–33.
5. Lerman C, Lustbader E, Rimer B, et al. Effects of individualized breast cancer risk counseling: a randomized trial. J Natl Cancer Inst. 1995;87:286–92.
6. Lerman C, Daly M, Sands C, et al. Mammography adherence and psychological distress among women at high risk for breast cancer. J Natl Cancer Inst. 1993;85:1074–80.
7. Gail MH, Brinton LA, Byar DP, et al. Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. J Natl Cancer Inst. 1989;81:1879–86.
8. Sumner W, Nease R, Littenberg B. U-Titer: a utility assessment tool. In: Proceedings of the Fifteenth Annual Symposium on Computer Applications in Medical Care. Washington, DC: McGraw-Hill, 1991:701–5.
9. Gail MH, Benichou J. Validation studies on a model for breast cancer risk. J Natl Cancer Inst. 1994;86:573–5.
10. Siegel S. Non-parametric Statistics. New York: McGraw-Hill, 1956.
11. Lerman C, Sands CB, Balshem A. Breast cancer risk factors are underestimated among high risk women. [abstract] Breast Cancer Res Treat. 1993;27:177.
12. Bondy ML, Lustbader ED, Halabi S, Ross E, Vogel VG. Validation of a breast cancer risk assessment model in women with a positive family history. J Natl Cancer Inst. 1994;86:620–5.
13. Spiegelman D, Colditz GA, Hunter D, Hertzmark E. Validation of the Gail et al. model for predicting individual breast cancer risk. J Natl Cancer Inst. 1994;86:600–7.
14. Schwartz S. Medical Thinking: The Psychology of Medical Judgment and Decision Making. New York: Springer-Verlag, 1986.
15. Mazur DJ, Merz JF. How age, outcome severity, and scale influence general medicine clinic patients' interpretations of verbal probability terms. J Gen Intern Med. 1994;9:268–71.
16. Littenberg B, Nease RF. When numbers get serious. J Gen Intern Med. 1994;9:295–6.

17. Tape TG, Kripal J, Wigton RS. Comparing methods of learning clinical prediction from case simulations. Med Decis Making. 1992;12:213–21.
18. Fischhoff B, Bostrom A, Quadrel MJ. Risk perception and communication. Annu Rev Public Health. 1993;14:183–203.
19. Tversky A, Kahenman D. Judgment under uncertainty: heuristics and biases. Science. 1974;185:1124–31.
20. Fletcher SW, Black W, Harris R, Rimer BK, Shapiro S. Report of the international workshop on screening for breast cancer. J Natl Cancer Inst. 1993;85:1644–56.
21. Polednak AP, Lane DS, Burg MA. Risk perception, family history, and use of breast cancer screening tests. Cancer Detect Prev. 1991;15:258–63.
22. Hailey BJ. Family history of breast cancer and screening behaviors: an inverted U-shaped curve? Med Hypotheses. 1991;36:397–402.
23. Kash KM, Holland JC, Halper MS, Miller DG. Psychological distress and surveillance behaviors of women with a family history of breast cancer. J Natl Cancer Inst. 1992;84:24–30.
24. Lerman C, Daly M, Masny A, Balshem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. J Clin Oncol. 1994;12:843–9.