NUMERACY, SOCIODEMOGRAPHIC CHARACTERISTICS AND THE ACCURACY OF BREAST CANCER RISK PERCEPTIONS

by

Susan Lynn Davids

THESIS

Presented to the Department of Public Health and Preventive Medicine
and the Oregon Health Sciences University
School of Medicine
in partial fulfillment of
the requirements for the degree of
Master of Public Heatlh
July, 2001

School of Medicine
Oregon Health Sciences University

CERTIFICATE OF APPROVAL

This is to certify that the M.P.H. thesis of

SUSAN DAVIDS

has been approved

[redacted]

Thomas Becker, M.D., Ph. D. Committee Chair

[redacted]

Marilyn Schapira, M.D., M.P.H

[redacted]

Lori Lambert, M.S.

Richard Mauer, Associate Dean of Graduate Studies

TABLE OF CONTENTS

APPENDIX

ACKNOWLEDGEMENTS

While completing this degree, I greatly expanded my knowledge in the various aspects of public health. However, I found that mentorship is key to success. I have had the privilege of working with some of the most outstanding mentors. I cannot begin to express the entirety of my gratitude towards these people. First, I thank Dr. Tom Becker, for his immeasurable dedication to the successful and timely completion of my MPH training. He has always been very gracious about the countless questions, phone calls, and e-mails throughout the past 3 years. Next, I would like to express my deepest appreciation to Dr. Marilyn Schapira, my mentor. She not only allowed me to use her data for this thesis, but also spent countless hours mentoring me throughout every stage of the process. Despite her very busy schedule, she has always made herself available to me whenever needed. Without the mentorship of Drs. Becker and Schapira this project would have not been possible. I extend my appreciation to Lori Lambert for her willingness to be part of my thesis committee although we had never met in person until two months prior to the oral presentation. I must extend great thanks to her for excellent statistical guidance, suggestions and exceptional proof reading skills. Although I had access to excellent statistical guidance in Oregon, the research and analysis took place in Wisconsin. I am very grateful to have had statistical help of Dr. Tim McAuliffe. I extend my thanks to him for his outstanding statistical guidance and patience while refreshing my memory about biostatistics. I would also like to thank Laura Eparvier. As the research assistant involved in this study, she did an outstanding job with every aspect of the project. Much of her work was complete by the time I became involved, however, she was always available for my numerous questions. I would also like to acknowledge

the many editors of my thesis including, Dr. Becky Wang-Cheng, Dr. Ralph Schapira, and Dr. Mary Ann Gilligan. Finally, to my family, especially my Mom and Dad, my husband and my precious daughter Emma, for their endless support in everything I do.

My passion has always been to improve the medical care to women and minorities. It is my hope to re-create this study in a population of American Indian women.

This study was funded by the American Cancer Society, principal investigator: Marilyn Schapira, MD, MPH.

ABSTRACT

Objectives: Women are known to greatly overestimate their risk of breast cancer. The influence of sociodemographic factors, breast cancer risk factors and numeracy on breast cancer risk perception is less clear. Educational and counseling interventions have been found to be effective in improving the accuracy of risk perceptions, however they have been time intensive. The primary purpose of our study is to better understand breast cancer risk perception by: 1) Examining the effects of sociodemographic factors and numeracy on risk perception in a diverse population, 2) Examining the role of numeracy on both baseline breast cancer risk perceptions and on the efficacy of an intervention to improve risk perceptions, and 3) Testing the effect of an intervention that uses numeric and graphic formats to convey both five-year and lifetime tailored breast cancer risk information.

Methods: We conducted a randomized controlled trial comparing the experimental intervention, a tailored pamphlet containing individualized breast risk estimates, to a control intervention consisting of a pamphlet about general breast health. Two hundred and fifty-four (254) English speaking women ages 40 to 85 years old were recruited from two primary care clinics associated with faculty practices at the Medical College of Wisconsin. Women with a personal history of breast cancer, dementia, or a life expectancy of less than 2 years were excluded. The main outcome measures were: 1) Baseline estimation error, defined as the absolute value of the difference between perceived and calculated risk (based upon the Gail model), and 2) Change in estimation error defined as pre-intervention minus post-intervention estimation error. Multivariate

linear regression models were built to predict baseline estimation error and post-intervention change in estimation error.

Results: The mean absolute difference of perceived and calculated risk (estimation error) was 29.5% for lifetime risk and 24.8 % for five-year risk. In multivariate linear regression, models predicting baseline lifetime and five-year risk estimates showed that a higher number of first-degree relatives with breast cancer or a higher number of previous breast biopsies was predictive of larger estimation error. Lower numeracy scores were predictive of a larger estimation error for lifetime risk. White race and fewer years of education were predictive of larger estimation errors for five-year risk. The intervention tool was effective in reducing median estimation error for both lifetime and five-year risk estimates. Median post-intervention change in estimation error was 6.2% ($p=0.01$) and 5% ($p=0.002$) for lifetime and five-year estimates, respectively. In multivariate analysis, women of higher income had greater benefit from the intervention for both lifetime and five-year risk. Other predictors of a greater change in estimation error (improvement) for lifetime risk was younger age and for five-year risk was a higher number of relatives with breast cancer.

Conclusion: Breast cancer risk factors, including family history and number of previous breast biopsies, are the most consistent predictors of long and short-term risk estimation error. Higher numeracy is associated with more accurate baseline lifetime risk estimates, but is not a predictor of the efficacy of the intervention. A five-minute intervention presenting numeric and graphic tailored breast cancer risk information is effective in improving the accuracy of short and long-term breast cancer risk perceptions.

INTRODUCTION

Breast cancer is the leading cause of cancer in women. The American Cancer Society reports that a woman's risk of developing invasive breast cancer in her lifetime is one out of eight (Cancer Statistics 2001). However, understanding what this statistic means to an individual woman and how it affects her personal breast cancer risk perception is not well understood.

Women are known to significantly overestimate their personal risk of breast cancer (Black, 1995, Harris, 1991, Alexander, 1996). In a study by Black, et al., women were found to overestimate their risk of developing breast cancer over a 10-year period by six-fold. In addition, they overestimated their risk of dying from breast cancer within ten years by 22.3 fold (Black, 1995). In another study of women at high breast cancer risk who were enrolled in the Breast Cancer Prevention Trial at Dartmouth-Hitchock medical center, 91.5% overestimated their risk of breast cancer, with 64% overestimating by a factor of three or more (Alexander, 1996). In a study of 113 African-American women, 23% overestimated their risk of breast cancer and 36% extremely overestimated their risk (Bowen, 1997).

Overestimation of risk may partially be explained by difficulty in interpreting risk information. Interpretation is subject to multiple biases, such as framing, presentation effects, hindsight bias, loss aversion, and preference for status quo and availability bias (Malenka, 1993, Naylor, 1992, Forrow, 1992, Fischoff, 1993, Weinstein, 1996). For example, presentation bias was demonstrated in one study which showed that patients made different decisions depending on whether risk was presented using survival or mortality statistics (Malenka, 1993). In addition, physicians have been found to make

different health care decisions regarding their patients when they were presented risk information in the form of absolute risk rather than relative risk (Forrow, 1992, Naylor, 1992).

An important methodologic issue in the study of risk perceptions is the performance of the scale used to assess risk. A variety of scales have been used to assess a patient's perception of her risk for disease, but few studies have established the validity and reliability of these scales. Poor scale performance with regard to validity and reliability may lead to an inaccurate representation of patients' true perceived risk. Woloshin and colleagues examined three different visual analogue scales for their reliability and validity. One of the most common scales used, a "1 in x" scale, performed poorly compared to the other scales tested. Linear word or number scales had the best validity, reliability and test-retest reliability (Woloshin, 1999).

Numeracy, a measure of how one performs with basic probabilities and numerical concepts, is now becoming an area of interest in the study of risk perceptions. Schwartz, et al., examined the presentation of risk in different formats and reported that regardless of the format, numeracy was strongly related to accuracy of predicting the benefit of mammography (Schwartz, 1997). Black and colleagues found that although less numerate women were more likely to overestimate their breast cancer risk, both numerate and innumerate women greatly overestimated their risk of breast cancer (Black, 1995).

Few studies have examined how perceived risk affects women's health behavior. Bowen, et al., found that women who overestimated their risk had higher scores on measures of depression, anxiety and less coping abilities compared to underestimators (Bowen, 1997). Women at high risk for breast cancer have been found to have anxiety or

emotional distress related to the heightened awareness of breast cancer risk (Kash, 1995). One may intuitively think that because the risk of breast cancer is overestimated, utilization of breast cancer screening would be higher. However, the fear of finding cancer may deter overestimators from recommended screening. Several studies suggest that overestimation of risk not only interfered with a woman's adherence to breast cancer screening recommendations, but could also negatively affect their quality of life (Kash, 1995, Lerman, 1993). Stomper and colleagues found the primary reason a group of 250 women aged 45 and older in New England did not undergo mammography was the fear of finding cancer (Stomper, 1990).

Sociodemographic factors have been associated with the use of breast cancer screening with mammography (BCS-M) (Calle, 1993), however the relationship of demographic factors and risk perception is less clear (Black, 1995, Harris, 1991, Daly, 1996). Prior studies have evaluated isolated sociodemographic factors rather than the relationship of many factors.

Educational and counseling interventions have been developed to improve a woman's accuracy in estimating her breast cancer risk (Alexander, 1995, Lerman 1995, Bowen 1997). Overall, the previous interventions have been successful in improving risk perception. However, the interventions were time intensive and not conducive to a primary care setting.

The primary purpose of our study is to better understand breast cancer risk perception in the following ways: first, to examine the effects of sociodemographic variables and numeracy on risk perception in a diverse population; second, to examine the role of numeracy on baseline breast cancer risk perceptions and in the efficacy of an

intervention to improve risk perceptions; third, to examine the effect of an intervention that uses numeric and graphic formats to convey both 5-year and lifetime tailored breast cancer risk information.

METHODS

Study Population and Study Recruitment

Eligible participants were recruited from two primary clinic sites associated with faculty practices at the Medical College of Wisconsin. Subjects were eligible if they were 40 years through 85 years of age and spoke English. We excluded women with a personal history of breast cancer, dementia, or a co-morbid condition leading to a life expectancy of less than 2 years as judged by a primary care provider. Invitation letters were mailed out to all eligible subjects between June 15, 1999 and June 19, 2000 by the only research assistant working with this study. The last entry date was July 26, 2000. The letter conveyed that the investigators were attempting to improve knowledge regarding preventive health care and did not specifically refer to breast cancer. A phone number was provided for potential participants to call if interested in the study. Each letter was also followed-up with a telephone call by the research assistant to assess interest in the study. Eligibility was determined prior to mailing of invitation letters by electronic review of basic patient information by the research assistant. This information included the patient's birth date, insurance data, previously billed diagnoses, when the patient was last seen in the clinic and if an interpreter was needed for the patient visit. In addition, when the patient was contacted the entry criteria were again reviewed to determine eligibility. Brochures were also placed in waiting rooms with the number to call if patients were interested in participating. Strategies to increase patient enrollment

included flexibility in scheduling, attempts to schedule interviews at the time of routine office visits, payment for parking and $20.00 compensation for time.

We mailed recruitment letters to 1,409 women. Of the 1,409 potentially eligible subjects, 713 declined and 442 were unable to be contacted by telephone. Over 80% of those that declined stated the reason as lack of interest in participating in the study. Our final sample included 254 women (18% of all potential subjects).

Protocol

After a subject agreed to participate in the study, an appointment was made to meet with the research assistant. At the first study interview, eligibility was again confirmed and informed consent was obtained. The subject was randomized to the control or experimental intervention by a random number 0-1 table. The research assistant was blinded to the next group assignment in the random number table while enrolling the subjects.

All subjects were assessed at baseline using a self-administered Pre-Intervention Breast Cancer Risk Perceptions Survey (Appendix). The subjects were given basic instructions about the format of the questionnaire. They filled out the questionnaire on their own and the research assistant was available to answer any questions. One patient was unable to read and the questionnaire was read to that patient. Completion time ranged from 10 minutes up to 45 minutes. The questionnaires were checked for missing answers and subjects were instructed to fill out those missed. Immediately after filling out the questionnaire, the subjects underwent either the experimental or the control intervention. One month later, they were sent the Post-Intervention Breast Cancer Risk Perceptions Survey (Appendix). Reminder letters were sent if questionnaire was not

returned. Seven (7) subjects completed the post-intervention survey over the telephone (3%). Seven (7) subjects did not complete the post-intervention survey (3%). The remainder returned the post-intervention survey by mail.

We included the following sociodemographics and breast cancer risk factors in the questionnaire:

1. Sociodemographic factors: age, race, insurance, years of education, income level.
2. Breast cancer risk factors: number of first degree relatives with breast cancer, number of prior breast biopsies, number of prior abnormal breast biopsies, age at menarche, and age at first live birth (Gail, 1989, Fisher 1998).

We also included questions assessing numeracy, which are described in the section labeled "Instrument Development."

Measurement of Calculated Risk

Calculated risk was based upon the Gail model and modifications by the National Surgical Adjuvant Breast Cancer and Bowel Project (Gail, 1989, Fisher 1998). Using data from the Breast Cancer Detection Demonstration Project, the Gail model was developed to give white women individualized breast cancer risk projections. The original variables in the model included age, number of first-degree relatives with breast cancer, age at menarche, age at first live birth, number of breast biopsies and pathologic diagnosis of atypical hyperplasia. The model was later modified to include race using the 1984-1988 Surveillance, Epidemiology and End Results (SEER) database (Fisher, 1998).

Measurement of Perceived Risk

At baseline and one month after the intervention, the questionnaires assessed risk perception on both a matrix and linear scale for both five-year and lifetime risk. A

matrix scale is a frequency presentation of risk using highlighted human figures (Appendix). In the linear scale, the subject was asked the following question:

> What do you think **your personal risk** or **chance** is of getting breast cancer in your **lifetime**? Please answer on a scale to 0% to 100%.

A graphic was included to illustrate 0% as low risk and 100% as high risk (Appendix). For the purpose of this study, only the linear scale was analyzed.

Experimental and Control Intervention

The research assistant met with all study subjects for approximately one hour including the time for filling out the questionnaire. After the questionnaire was complete, the experimental or control intervention was done. The same research assistant spent approximately 5 minutes reviewing the experimental or control pamphlets with the subjects and was consistent for each intervention.

Experimental Intervention

The experimental intervention was a presentation of tailored breast cancer risk information regarding personal breast cancer risk as well as the benefits of breast cancer screening mammography (Appendix). The National Cancer Institute Breast Cancer Risk Tool based on the Gail model with modifications from the National Surgical Breast and Bowel Project was used to generate the lifetime and five-year risk information for each subject. These risk factors were found in the questionnaire and were entered into the National Cancer Institute Breast Cancer Risk program by the research assistant. The presentation of risk information was centered on the personalized colored pamphlet produced for each woman. The pamphlet content was developed based upon previous focus groups. The risk was presented not only verbally, but graphics were included in the

pamphlet presenting risk in both a linear and matrix format, for lifetime and five-year breast cancer risk (Appendix).

Control Intervention

The control intervention was a pamphlet developed by the American Cancer Society, entitled "Special Touch, A Personal Plan of Action for Breast Health." This pamphlet discusses the risk factors that put women at high risk for breast cancer, and when and how to screen for breast cancer (Appendix). The control pamphlet did not provide numeric or graphic representation of general or tailored breast cancer risk.

Instrument Development

Numeracy, a measure of how one performs with basic probabilities and numerical concepts, was assessed by the following three questions.

a) Imagine that you flipped a coin 100 times. About how many times will the coin come up heads in 100 flips? ____ out of 100

b) 100 people have entered the Spring City Run. 70% of the runners will finish the race. Of the 100 people who enter the race, how many will finish? _____ persons out of 100

c) In the Washington School raffle, 5 people out of 100 who enter will win a prize. What percentage (%) of the people who enter the raffle will win a prize? ____%.

This numeracy scale was developed based upon prior studies by Schwartz and administered by the research assistant as part of a pilot study (Schwartz, 1997). The research assistant, as part of a pilot study, administered the numeracy scale by Schwartz. The pilot study included women aged 40 years and older who were recruited from the waiting room of the clinics involved in the study. The results of the pilot phase showed that none of the eleven women gave correct responses to all three questions. Only 5

(36%) were able to state how many times a coin would be heads if flipped 1,000 times, only 2 (18%) could convert a percent into a ratio, and no one was able to convert a ratio 1 in 1000 to a percent. The questions were then simplified primarily by changing the denominator from 1000 to one hundred. After changing the denominator, the questionnaire was re-piloted to 25 women of whom sixteen (64%) were able to answer all of the questions correctly. The final numeracy scale had adequate internal consistency in our study population (Cronbach's alpha = 0.6251).

The full questionnaire was also piloted in the same group of subjects and was adjusted to improve comprehension of the questions based upon responses in pilot testing. Elements that were adjusted included the visual format and anchors used in the risk assessment scale.

ANALYSIS

Characteristics of the Study Population

Basic descriptive statistics were generated for the demographic survey data. When comparing baseline characteristics between intervention and control groups, a Pearson's chi-square test was used for categorical variables, a t-test for continuous variables, and a rank sum test for ordinal variables. Calculated and perceived risk perceptions were treated as non-parametric distributions. A Kruskal-Wallis test was used to compare Gail calculated risks and perceived risk between the intervention and control groups.

Baseline Univariate Associations with Risk Estimation Error

Estimation error was defined as the absolute difference of the perceived risk minus the calculated Gail risk as portrayed below.

Estimation Error (EE) = |Perceived risk - Gail calculated risk|

Univariate association of subject characteristics with lifetime and five-year estimation error were evaluated using the appropriate nonparametric statistics. Spearman's correlation (for continuous variables and ordinal variables) and Kruskal-Wallis (for categorical variables) were used to check for possible associations.

Baseline Multivariate Associations with Risk Estimation Error

Multivariate linear regression models were developed to predict baseline (pre-intervention) estimation error. The models were built using backwards-stepwise linear regression on Stata version 6.0. The dependent variable of estimation error was transformed using a log transformation (Log (1+ estimation error)) for this analysis, to improve the normality of the distribution. The variables entered into the model included those that were significant by univariate analysis and those that were previously shown to be significant in prior studies. The following variables were entered into the model: age, race, years of education, income level, insurance, numeracy score, family history of breast cancer, age at menses, age at first live birth, number of prior breast biopsies. The variable of income was dichotomized due to the lack of non-white women in the higher income brackets. The income variable was dichotomized to less than $20,000 and equal to or greater than $20,000. The insurance variable was also dichotomized to women who had either fee for service insurance or HMO insurance compared to all other types of insurance. Potential interactions between race and income, race and education, and age and insurance were evaluated, but none were found to be significant.

Evaluation of the Effect of the Intervention

The effect of the intervention was evaluated by comparing the change in estimation error from pre-intervention to post-intervention between groups. Change in estimation error was defined as the pre-intervention estimation error minus the post-intervention estimation error as conveyed below.

Change in EE = Pre-intervention estimation error - Post intervention estimation error.

Change in estimation error was treated as a non-parametric variable in the univariate analysis. In the multivariate analysis, a linear regression model was built to predict change in estimation error. The dependent variable for the multivariate analysis was log transformed as follows:

Log Transformed Change in estimation error =Log (1+ pre-intervention estimation error) -Log (1+ post-intervention estimation error)

A backward stepwise linear regression model was built using STATA 6.0. In addition to the intervention, the same variables that were entered into the baseline model were also entered in this analysis: age, race, years of education, income level, insurance, numeracy score, family history of breast cancer, age at menses, age at first live birth, number prior breast biopsies. The income and insurance variables were again dichotomized. Potential interactions between race and income, race and education, and age and insurance were evaluated, and none were found to be significant.

RESULTS

Study Population

We included 254 subjects in the final analysis. Intervention and control groups did not differ with regard to sociodemographic characteristics (Table 1). The mean age of subjects was 57 years (range 40-84 years). The majority of the participants were white

(70%), graduated high school (81%), had a household income less than 20,000 (50%), and had some form of Government assisted insurance (60%). The intervention group scored higher on the numeracy assessment; 47% answered all 3 questions correctly compared to 36% in the control group. There were no significant differences in breast cancer risk factors between intervention and control groups (Table 2). In addition, there were no significant differences in the Gail calculated breast cancer risk, perceived breast cancer risk, or baseline estimation errors between intervention and control groups (Table 3).

Baseline Breast Cancer Risk Estimates

Subjects greatly overestimated their personal breast cancer risk. The magnitude of overestimation is conveyed by the value of estimation error. The mean estimation error among subjects was 29.5 %, (22.9 SD) for lifetime risk and 24.8 %, (23.9 SD) for five-year risk. Although the majority of the subjects overestimated their risk, some subjects did underestimate their risk of breast cancer. For lifetime and five-year risk 10.7% and17.7% underestimated their risk, respectively. However, the magnitude to which they underestimated their risk was low, the median difference in their perceived risk and the calculated risk was only -4.7% for lifetime and –1.3% for five-year risk. Previous articles have viewed these numbers as accurate estimators (Lerman, 1995). We evaluated the association of sociodemographic and numeracy variables with baseline estimation error. Women of non-white race, lower levels of education, lower income, non-private insurance, and lower numeracy levels were more likely to have an increased estimation error of lifetime breast cancer risk (Table 4). With regard to breast cancer risk factors, women with a higher number of first-degree relatives with breast cancer, younger

age of menarche, and higher numbers of previous breast biopsies were also more likely to have an increased baseline estimation error of lifetime breast cancer risk (Table 5). Fewer variables were associated with the estimation error for 5-year risk. Women with lower levels of education, moderate to low income (<50,000), a strong family history, and higher numbers of breast biopsies had a larger estimation error for five-year breast cancer risk (Tables 4 and 5).

Multivariate Analysis Predicting Baseline Estimation Error of Breast Cancer Risk

We used a multivariate model to evaluate the independent effect of sociodemographic and numeracy variables on estimation error of breast cancer risk after controlling for potential confounders. The model we found to best predict baseline estimation error for lifetime risk was age, numeracy score, insurance, number of prior breast biopsies and first-degree relative with breast cancer. The variables associated with a larger estimation error were lower numeracy scores, a higher number of breast biopsies and more first-degree relatives with breast cancer. Although age was not statistically significant, there was a trend towards younger age with a higher estimation error. For five-year risk, those variables that best predicted baseline estimation error were family history, race, years of education, number of breast biopsies, and insurance. A larger estimation error for five-year risk was seen with a higher number of first degree relatives with breast cancer, white race, less education, and a higher number of breast biopsies (Tables 6 and 7).

Effect of Tailored Risk Intervention

We evaluated the primary outcome of change in estimation error for lifetime and five-year breast cancer risk estimates. Change in estimation error was calculated as the

pre-intervention estimation error minus the post-intervention estimation error. Overall, the median change in lifetime estimation error was 6.2% for the intervention group compared to no median change for the control group (p=0.01) (Table 8). The median change in five-year estimation error was 5.0% for the intervention group, compared to no median change for the control group (p=0.002) (Table 8). Additionally, there was a significant difference in the mean estimation error from the pre-intervention to the post-intervention in those assigned to the experimental intervention in both lifetime (26.5% vs 17.2%) and five-year risk (23.4% vs 15.8%) with significant levels of p <0.0001 and p=0.0001 respectively. However, there was no statistically significant difference in the mean estimation error of those assigned to the control groups, for both lifetime and five-year risk.

We examined univariate predictors of post-intervention change in estimation error. There were no statistically significant differences in the change in estimation error related to sociodemographics and numeracy with lifetime risk. However, there was a trend towards younger age having a greater change in estimation error. For five-year risk estimates, women of white race and an income level between $20,000 and $50,000 were associated with a greater change in estimation error. For both lifetime and five-year risk, there were greater changes in estimation error in women with a higher number of first-degree relatives with breast cancer and higher number of previous breast biopsies (Table 9 and 10).

Multivariate Analysis of Post-Intervention Changes in Estimation Error

We conducted a multivariate analysis to evaluate the effect of the intervention on change in breast cancer lifetime and five-year risk estimation error after controlling for

potential confounding variables. Even after controlling for sociodemographic variables and breast cancer risk factors the intervention tool was significantly associated with a greater change in estimation error in both the lifetime and five-year risk estimates. Since our outcome variable was calculated as a difference of log transformations, we transformed our data to reflect the original values in order to assess the magnitude of the effect of our intervention. Our outcome variable in the multivariate analysis (change in estimation error) was the difference of log transformations, therefore, the exponentiated beta coefficients represent the ratio of the pre-intervention error to the post-intervention error. The exponentiated coefficients for the intervention were 1.76 and 1.80 for lifetime and five-year respectively. This can be interpreted as a greater change in estimation error after the intervention by a factor of 1.76 and 1.80 for lifetime and five-year respectively. In addition to receiving the experimental intervention, younger age, and higher income were predictive of greater change in estimation error for lifetime risk (Table 11). Additional factors predictive of change in five-year risk estimates were a higher number of first-degree relatives, and a higher income (Table 12).

DISCUSSION

We found that a diverse group of women from a primary care practice greatly overestimate their risk of breast cancer. The mean estimation error was 29.5% for lifetime risk and 24.9% for five-year risk. This reflects how much the participants misjudged their true estimate. Given that very few subjects significantly underestimated their risk, this clearly reflects a strong and consistent attitude related to breast cancer risk. The finding of overestimation of risk is consistent with previous research (Black, 1995,

Harris, 1991, Alexander, 1996). We also found a significant improvement in breast cancer risk perceptions in women who underwent our tailored (experimental) intervention for both lifetime and five-year risk after controlling for other variables.

Our study reports important findings regarding the relationship of demographics and breast cancer risk perceptions. Demographic characteristics have been shown to be associated with risk perceptions. Less educated and less numerate women were more likely to overestimate breast cancer risk in a study of women age 40-50 years old in New Hampshire (Black, 1995). Younger women were more worried about breast cancer and considered themselves at higher risk than older women in a study in North Carolina (Harris, 1991). Daly, et al., found that among first degree relatives of women with breast cancer who were 35 years of age or older, overestimators of breast cancer risk were more likely to be white, married, employed, and less than 65 years old (Daly, 1996).

In our study we found that for lifetime risk, many of the sociodemographic variables were significantly associated with overestimation of risk, but by multivariate analysis, none of the variables played a strong role. We did not find age to be significantly associated with estimation error as noted in previous literature. At baseline, a trend was noted between younger age and higher estimation error.

For five-year risk, white women and women with fewer years of education were more likely to have a larger estimation error. These findings are similar to previous literature for lifetime risk; however, short-term risk has not been as widely studied.

Previous investigators reported the association of age and estimation error from univariate analysis only, not controlling for other sociodemographic variables (Harris, 1990, Daly, 1996). Our study differed by having a more diverse population in terms of

sociodemographic characteristics. Our multivariate analysis suggests that age may be a factor, but is not the strongest predictor of overestimation of breast cancer risk.

Our study also reports important findings regarding the relationship of breast cancer risk factors and breast cancer risk perceptions. Smith, et al., reported breast cancer risk perceptions among two populations of women, one from the Massachusetts General Hospital Comprehensive Breast Health Center and one from a primary care practice. They also found a significant overestimation of risk for lifetime and 10-year risk, but did not find that women with a family history of breast cancer were more likely to overestimate their risk (Smith, 1996). Daly, et al., also reported no association of the Gail Model factors to breast cancer risk perception.

In our study, for both lifetime and five-year risk, women at moderate to high risk, (as noted by first-degree relative with breast cancer and higher number of previous breast biopsies) were more likely to overestimate their risk. Our study population differed from that of Smith and Daly, which both enrolled high-risk women. Although part of Smith's study population was from a primary care setting, their sample size was about half the size of our study group, which may have limited their power in the analysis. In addition, multivariate analysis was not done in the Smith study. Our study also differed from Daly's in the analysis. We evaluated estimation error as a continuous variable, whereas Daly dichotomized his outcome variable as correct/underestimators and overestimators. A continuous outcome variable more completely reflects the range of outcomes than a dichotomous variable. Our findings were similar to that of Alexander who reported greater overestimation in women who had a mother with breast cancer (Alexander, 1996). Our data suggest that a positive family history and previous breast biopsies are more

important factors than sociodemographic variables for predicting breast cancer risk perceptions.

The intervention tool in our study was successful in improving the accuracy of risk perceptions. The median estimation error in the experimental intervention group decreased from 21.4% pre-intervention to 6.1% one month after the intervention for lifetime and 13.8% to 8.4% for five-year risk. Both decreases were significant. Although the median change in estimation error for lifetime and five-year risk in the experimental intervention groups were modest in magnitude 6.2% and 5%, respectively, they represented a statistically significant change.

Previous investigators have also reported improved accuracy of breast cancer risk perceptions after an educational intervention. Alexander, et al., assessed 59 women enrolled in the Breast Cancer Prevention Trial whose age-specific hazard rate was equal to or greater than that of a 60-year-old woman as defined by the Gail model (Alexander, 1995, Gail 1989). The subject in that study assessed their risk using a computer-based questionnaire. A physician then reviewed with each patient the result of her Gail score visually and verbally, and discussed their individual risk factors for approximately one and one half hours. Immediately after and between two through eleven months later, the questionnaire was re-administered. The median absolute difference between the Gail score and perceived risk was decreased from 39% before the intervention to 1% immediately after and 4% at follow-up. In a study of first-degree relatives of women with breast cancer, women were randomized to receive either individualized one and half hours of breast cancer risk counseling or an equal amount of time discussing general health information (Lerman, 1995). Twenty six percent (26%) of subjects in the

intervention group improved their risk comprehension compared with 17% in the general health group at 3 months. However, both groups extremely overestimated their risk of breast cancer both before and after the intervention. Additionally, Lerman, et al., found their tool to be most effective in African-American women as compared to white women. Bowen, et al., similarly showed that in a group of African-American women there was an improvement in perceived risk 6 months following an intervention. The intervention consisted of four weekly counseling sessions regarding breast cancer risk assessment and perception, education, stress management and problem solving and social support (Bowen, 1997).

In our study, the experimental intervention of tailored risk information worked best in women of a younger age and higher income, for the estimation of lifetime risk. For the estimation of five-year risk, the experimental intervention worked best in women with a higher number of first-degree relatives with breast cancer and those of higher income. The finding that the experimental intervention improved the estimation error of women with first-degree relatives, has important clinical implications. Women with higher baseline risk are known to have greater anxiety about breast cancer (Kash, 1995). Correction of their overestimation of breast cancer risk may help alleviate anxiety and possibly improve adherence to breast cancer screening recommendations.

Our experimental intervention, consisting of tailored (individualized) breast cancer information, differed from previous interventions in several ways. First, our graphics were prominent and included both a linear and matrix format. Second, our intervention was short; the research assistant only spent five minutes reviewing the information in the pamphlet. This differed from previous interventions where

approximately 1.5 hours or more were spent with the patients. This is clinically important as primary care providers have limited time to discuss risk information with their patients during a routine clinic visit.

We found that women who had better numeracy skills (how one performs with basic probabilities and numerical concepts) had less estimation error, and therefore a more accurate perception of breast cancer lifetime risk at baseline. These results are similar to the previously reported findings by Schwartz and Black (Schwartz 1997, Black 1995). In the estimation of lifetime risk, sociodemographic characteristics were not important in predicting the estimation error; however, numeracy was part of the model. One explanation for this could be that numeracy serves as a proxy for sociodemographic variables. However, numeracy was not a predictor of the post-intervention change. A possible explanation for this finding is that the inclusion of numeric and graphic information could have made comprehension easier for women with all levels of numeracy to comprehend.

Our study has certain limitations. A selection bias, favoring women who wanted to be in a health promotional study, could have been present. Biases may have selected the more educated, or more concerned about breast cancer, and lead to either an over or underestimation. Although our subject population was limited to two primary clinic sites associated with one institution, limiting generalizability, the sociodemographic status of our population was diverse. The risk assessment scales used may have limitations. Many people have problems with numbers and understanding risk (Malenka, 1993, Forrow, 1992, Naylor, 1992). Although some people may classify themselves at average risk, they still may mistakenly record a very high number as a risk estimate. They may

misinterpret the use of percentages to represent likelihood of occurrence of an event. For example, one subject stated her risk was 50%, because she was "as likely as the next person" was to get breast cancer. The test re-test reliability of the scales we used was not known. As the follow-up questionnaire was mailed in or completed by telephone, we also considered whether the improvement seen with the experimental intervention was due to the subjects reading the values directly from their pamphlet. However, only 6 subjects (2.4%) for lifetime risk and 7 subjects (2.8%) for five-year risk, estimated their risk as the exact calculated value. The calculated estimates using the Gail model are prone to error as well. A limitation is the overestimation of risk in women who do not follow breast cancer screening recommendations. The Gail model also underestimates risk in women with paternal family history of breast cancer. The model also does not take into account the menopausal status of the relative with breast cancer, which could underestimate risk if the family member was pre-menopausal (McTiernan 1997).

Our analysis could have limitations as well. We analyzed the data as an absolute difference rather than as ratios as some investigators have done (Smith, 1996, Black, 1995). The use of ratios can inflate lower levels of difference when a woman is near accuracy (estimation error of zero). For example, if a woman's risk were calculated to be 5%, and the woman estimated10%, she would have overestimated by a ratio of 2:1 or 100% overestimation. On the other hand, if a subject overestimated her risk to be 50%, and the calculated risk was 45%, the women's estimate to calculated ratio would be 1.1:1, or 10% overestimation. Although both women had an estimation error of 5%, the use of ratios inflated the number in the former example. By calculating error as a difference, a 5% difference is an equal magnitude along the scale of 0% to 100%. We chose to

analyze the absolute value of the difference because we were interested in overall error of breast cancer risk perceptions. It did not allow one to fully comment on the direction of change, but very few people significantly underestimated their risk.

It is difficult to determine the specific components of the intervention that were effective. Several aspects of the intervention differed from the control. The control subjects did not receive any tailored or general risk information nor graphical risk information. Both of these elements could play a role in the efficacy of the experimental intervention.

Numeracy as measured by our scale, was not as a consistent predictor of risk perceptions and post-intervention change. Further work on validation of a numeracy scale would strengthen inferences one can draw from these findings. However, our questions did have moderate internal consistency and we felt they were an adequate measure of numeracy.

SUMMARY

Our study has several noteworthy conclusions. As previously reported, most women greatly overestimate both their lifetime and five-risk of breast cancer. However, we were better able to characterize how sociodemographic variables, numeracy and breast cancer risk factors played a role in overestimation of breast cancer risk in an average risk population of women. Additionally, we were able to more fully evaluate short-term risk perceptions, which has not been done in the past. We were also able to show an improvement in estimation error with our experimental intervention using tailored breast cancer risk information. We additionally found that spending as little as

five-minutes discussing the tailored information improved the estimation error at one month. We were also able to look at numeracy in more depth, using modified questions based upon Schwartz's original work.

Our tailored intervention tool produced a significant yet modest improvement in estimation error. This improvement was seen despite a very short intervention time of approximately five minutes. Our data have clinically important implications, suggesting that even spending five minutes to review this numeric and graphically displayed breast cancer risk information one can improve a woman's perception of risk.

REFERENCES

Alexander NE, Ross J, Sumner W, Nease RF, Littenberg B, The Effect of an Educational Intervention on the Perceived Risk of Breast Cancer, Journal of General Internal Medicine, 11:92-97, 1996

Banks, SM Salovey P, Greener S, Rothman AJ, Moyer A, Beauvais J, Epel E, The Effects of Message Framing on Mammography Utilization, Health Psychology, 14:178-184, 1995

Benichou J, Gail MH, Mulvihill, Graphs to Estimate an Individualized Risk of Breast Cancer, Journal of Clinical Oncology, 14:103-100, 1996

Black WC, Nease RF, Tosteson AN, Preceptions of Breast Cancer Risk and Screening Effectiveness in Women Younger Than 50 Years of Age, Journal of the National Cancer Institute, 87:720-730, 1995

Bowen DJ, Christensen CL, Powers D, Graves DR, Anderson CAM, Effects of counseling and ethnic identity on perceived risk and cancer worry of African American Women, Journal of Clinical Psychology Medical Settings. 5:365-379, 1998

Bowen D, Hickman KM, Powers D, Importance of Psychological Variables in Understanding Risk Perceptions and Breast Cancer Screening of African American Women, Women's Health: Research on Gender, Behavior, and Policy, 3:227-242, 1997

Calle EE, Flanders WD, Thun MJ, Martin LM, Demographic Predictors of Mammography and Pap Smear Screening in US Women, American Journal of Public Health, 83:53-60, 1993

Daly MB, Lerman CL, Ross E, Schwartz MD, Sands CB, Masny A, Gail model breast cancer risk components are poor predictors of risk perception and screening behavior, Breast Cancer Research and Treatment, 41:59-70, 1996

Edwards A, Hood K, Matthews E, Russell D, Russell I, Barker J, Bloor M, Burnard P, Covey J, Pill R, Wilkinson C, Stott N, The effectiveness of one-to-one risk communication interventions in health care: a systematic review. Medical Decision Making, 20:290-297, 2000

Evans DGR, Burnell LD, Hopwood P, Howell A, Perception of risk in women with a family history of breast cancer, British Journal of Cancer, 67:612-614, 1993

Feldman-Stewart D, Kocovski N, McConnell BA, Brundage MD, MacKillop WJ, Perception of Quantitiative Information for Treatment Decisions, Medical Decision Making, 20:228-238, 2000

Fischhoff, B Bostrom A, Quandrel MJ, Risk Perception and Communication, Annual Review of Public Health, 14:183-203, 1993

Forrow L, Taylor W, Arnold RM, Absolutely Relative: How Research Results Are Summarized Can Affect Treatment Decisions, The American Journal of Medicine, 92:121-124,1992

Gail MH, Brinton LA, Byar DP, Corle DK, Green SB, Schairer C, Mulvihill JJ, Projecting Individualized Probabilities of Developing Breast Cancer for White Females Who Are Being Examined Annually, Journal of the National Cancer Institute, 81, 187-1886, 1989

Harris, RP, Fletcher SW, Gonzalez JJ, Lannin DR, Degnan D, Earp J, Clark R, Mammography and Age: Are We Targeting the Wrong Women? A Community Survey of Women and Physicians, Cancer 67:20102014, 1991

Helzlsouer KJ, Ford DE, Hayward RS, Midzenski M, Perry H, Perceived Risk of Cancer and Practice of Cancer Prevention Behaviors among Employees in an Oncology Center, Preventive Medicine 23:302-308, 1994

Hughes C, Lerman C, Lustbader E, Ethnic Differences in risk perception among women at increased risk for breast cancer, Breast Cancer Research and Treatment, 40:25-35, 1996

Kash KM, Holland JC, Osborne MP, Miller DG, Psychological Counseling Strategies for Women at Risk of Breast Cancer, Journal of the National Cancer Institute 17:73-79,1995.

Kreuter MW, Strecher VJ, Changing Inaccurate Perceptions of Health Risk: Results From a Randomized Trial, Health Psychology, 14:56-63, 1995

Lerman C, Lustbader E, Rimer B, Daly M, Miller S, Sands C, Balshem A, Effects of Individualized Breast Cancer Risk Counseling: a Randomized Trial, Journal of the National Cancer Institute, 87: 86-92, 1995

Lerman C, Schwartz MD, Miller S, Daly M, Sands C, Rimer B, A Randomized Trial of Breast Cancer Risk Counselling: Interacting Effects of Counseling, Educational Level, and Coping Style, Health Psychology, 15:75-83, 1996

Lerman C, Trock B, Rimer Bk, Boyce A, Jepson C, Engstrom PF, Psychological and Behavioral Implications of Abnormal Mammograms, Annals of Internal Medicine, 114:657-661, 1997

Malenka DJ, Baron JA, Johansen S, Wahrenberger JW, Ross JM, The Framing Effect of Relative and Absolute Risk, Journal of General Internal Medicine, 8:543-548, 1993

McTiernan A, Gilligan MA, Redmond C, Assessing Individual Risk for Breast Cancer: Risky Business, Journal of Clinical Epidemiology, 50:547-556, 1997

Rimer BK, Glassman B, Is there a Use for Tailored Print Communications in Cancer Risk Communication?, Journal of the National Cancer Institute, 25:140-148, 1999

Schwartz LM, Woloshin S, Black WC, Welch HG, The Role of Numeracy in Understanding the Benefit of Screening Mammography, Annals of Internal Medicine, 127: 966-972,1997

Schwartz LM, Woloshin S, Welch HG, Risk Communication in Clinical Practice: Putting Cancer in Context, Journal of the National Cancer Institute, 25:124-133, 1999

Smith BL, Gadd MA, Lawler C, MacDonald DJ, Grudberg SC, Chi FS, Carlson K, Comegno A, Souba WW, Perception of breast cancer risk among women in breast center and primary care settings: Correlations with age and family history of breast cancer, Surgery, August 1996, 297-303

Stomper PC, Gelman RS, Meyer JE, Gross GS, New England Mammography Survey Public Misconceptions of Breast Cancer Incidence, Breast Disease 3:1-7, 1990

Vernon, SW, Risk Perception and Risk Communication for Cancer Screening Behaviors: a Review, Journal of the National Cancer Institute, 25:101-119, 1999

Weinstein ND, Optimistic Biases About Personal Risks, Science, 246:1232-1233, 1989

Weinstein ND, Kolb K, Goldstein BD, Using Time Intervals Between Expected Events to Communicate Risk Magnitudes, Risk Analysis, 16:305-849, 1996

Woloshin S, Schwartz LM, Black WC, Welch HG, Women's Perception of Breast Cancer Risk: How You Ask Matters, Medical Decision Making, 19:221-229, 1999

Woloshin S, Schwartz LM, Byram S, Fischhoff B, Welch HG, A New Scale for Assessing Perceptions of Chance, Medical Decision Making, 20:298-307,2000

http://cis.nci.nih.gov/fact/, Cancer facts, National Cancer Institute

Table 1: Characteristics of the Study Population

CHARACTERISTICS	INTERVENTION N=128	CONTROL N=126	*P-VALUE
AGE (Mean-yrs)(SD)	57.3 (11.2)	57.9 (10.1)	.65
RACE (%)			
WHITE	68%	68%	
OTHER	32	32	.96
EDUCATION (Mean-yrs) (SD)	13.0 (2.6)	12.9 (2.9)	.70
FAMILY INCOME (annual)			
<$10,000	34%	36%	
$10,000-19,999	12	19	
$20,000-34,999	14	15	
$35,000-49,999	12	7	
$50,000-74,999	16	8	
>$75,000	12	15	.35
INSURANCE (source)			
Medicare	30%	40%	
Medicaid/GAMP**/T19	24	26	
Fee For Service/HMO	40	28	
None/Other	6	6	.22
NUMERACY (number of correct responses)			
0	11%	19%	
1	16	17	
2	26	28	
3	47	36	.04

* For continuous variables a t-test was used. For categorical variables Pearson chi-square tests were used. Ordinal variables were evaluated with a rank sum test. **Wisconsin health care for uninsured children and parents with income at or below 185% of the federal poverty level

Table 2: Breast Cancer Risk Factors of the Study Population

BREAST CANCER RISK FACTOR	INTERVENTION N=128	CONTROL N=126	*P-VALUE
FAMILY HISTORY OF BREAST CANCER (number of first degree relatives)			
0	83%	81%	
1	12	11	
≥2	5	8	.65
AGE AT MENARCHE (years)			
≤11	20%	23%	
12-13	57	52	
≥14	23	25	.86
AGE AT FIRST LIVE BIRTH (years)			
13-19	31%	39%	
20-24	32	25	
25-29	16	13	
30-39	5	5	
NULLIPAROUS	16	17	.49
NUMBER OF BREAST BIOPSIES			
0	77%	76%	
1	16	13	
2	3	8	
≥3	3	2	.73
ABNORMAL BREAST BIOPSY "ATYPICAL HYPERPLASIA"			
YES	1%	4%	
NO	91	85	
UNKNOWN	8	11	.15

*For categorical variables Pearson chi-square tests were used. Ordinal variables were evaluated with a rank sum test.

Table 3: Baseline Breast Cancer Risk Estimates; Calculated, Perceived and Estimation Error

	INTERVENTION N=128	CONTROL N=126	*P-VALUE
Gail Calculated Breast Cancer Risk			
Lifetime (%) (median, range)	7.0 (1.4-39.5)	7.4 (1.9-35.1)	.82
5 year (%) (median, range)	1.1 (0.3-7.2)	1.2 (0.3-7.5)	.28
Perceived Breast Cancer Risk			
Lifetime (%) (median, range)	30 (0-100)	40 (0-100)	.49
5 year (%) (median, range)	15 (0-100)	20 (0-100)	.34
Estimation Error**			
Lifetime (%) (median, range)	21.4 (0.4-96.3)	30.4 (0.1-97.0)	.08
5 year (%) (median, range)	13.8 (0.1-97.3)	18.8 (0.2-99.2)	.42

* Kruskal-Wallis test used.

**Estimation error calculated as the absolute value of perceived risk minus the absolute value of the Gail calculated risk.

Table 4: Unadjusted Association of Sociodemographic Variables and Numeracy with Baseline Estimation Error for Lifetime and Five-Year Risk Estimates

	n	Lifetime Estimation Error % (mean)	P*	Five-year Estimation Error % (mean)	P*
AGE (quartiles)(years)					
1st (40-50)	71	30.7		24.8	
2nd (51-56)	58	31.4		27.1	
3rd (57-65)	64	28.7		25.6	
4th (66-84)	61	27.0	.33	21.9	.56
RACE					
WHITE	178	27.4		25.5	
OTHER	81	33.9	.02	23.4	.37
EDUCATION (years)					
<12	49	37.9		29.8	
12	81	29.9		25.3	
12-16	97	26.9		25.6	
≥17	27	22.0	.0005	11.8	. 04
FAMILY INCOME (annual)					
<$10,000	87	34.8		27.9	
$10,000-19,999	37	26.8		25.5	
$20,000-34,999	36	34.0		29.9	
$35,000-49,999	23	34.1		32.1	
$50,000-74,999	30	19.5		15.0	
>$75,000	34	21.0	.002	16.8	.03
INSURANCE					
Medicare	89	32.4		25.3	
Medicaid/GAMP**/T19	64	32.3		26.9	
Fee for Service/HMO	86	25.9		23.1	
None/Other	15	20.5	.04	22.7	.58
NUMERACY(number of correct responses)					
0	38	40.1		32.2	
1	42	28.3		24.0	
2	69	30.1		27.8	
3	105	25.8	.006	20.5	.10

*Spearman's correlation was used for continuous variables and ordinal. Kruskal-Wallis was used for categorical variables. Age and Education were analyzed as a continuous variable. ***Wisconsin health care for uninsured children and parents with income at or below 185% of the federal poverty level

Table 5: Unadjusted Association of Breast Cancer Risk Factors with Baseline Estimation Error for Lifetime and Five-Year Risk Estimates

BREAST CANCER RISK FACTOR	n	Lifetime Estimation Error (mean)	P*	Five-year Estimation Error (mean)	P*
FAMILY HISTORY OF BREAST CANCER (number of first degree relatives)					
0	208	27.9		22.2	
1	29	36.2		31.0	
≥2	17	38.0	.005	45.7	.001
AGE AT MENARCHE (years)					
≤11	54	34.3		25.0	
12-13	136	28.9		24.2	
≥14	60	24.8	.04	24.1	.75
AGE AT FIRST LIVE BIRTH (years)					
13-19	8	35.1		27.6	
20-24	73	24.6		23.9	
25-29	37	25.3		24.6	
30-39	12	33.0		32.6	
Nulliparous	43	28.9	.21	18.7	.28
NUMBER OF BREAST BIOPSIES					
0	195	27.9		22.2	
1	38	31.3		32.3	
2	14	39.8		34.5	
≥3	7	42.8	.006	37.9	.004
ABNORMAL BREAST BIOPSY "ATYPICAL HYPERPLASIA"					
YES	6	21.3		18.3	
NO	223	28.5		23.9	
UNKNOWN	24	41	.16	35.2	.10

*Spearman's correlation was used for continuous variables and ordinal variables. Kruskal-Wallis was used for categorical variables.

TABLE 6: Multiple Linear Regression Model Predicting Baseline Estimation Error of Lifetime Risk

Variable	Coeff	SE	P	95% CI
Age	-.011	.007	.096	-.025, .002
# Breast Biopsies	.25	.096	.010	.060, .440
Numeracy	-.137	.068	.046	-.271, -.002
Family history	.249	.123	.043	.008, .491
Insurance(Fee for Service/HMO vs all others)	-.299	.162	.067	-.618, .021
Constant	3.61	.438	<.001	2.75, 4.48

Variables considered in the multivariate analysis include age, race, years of education, income, insurance, numeracy, family history of breast cancer, age of first live birth, number of previous breast biopsies. Potential interactions between race and income, race and education, and age and insurance were evaluated.

TABLE 7: Multiple Linear Regression Model Predicting Baseline Estimation Error of Five-Year Risk

Variable	Coeff	SE	P	95% CI
Family history	.332	.137	.016	.062, .602
Race (other vs white)	-.531	.183	.004	-.892, -.169
Years of Education	-.066	.032	.040	-.128, -.003
# Breast Biopsies	.315	.11	.004	.099, .532
Insurance(Fee For Service/HMO vs all others)	-.327	.180	.070	-.682, .027
Constant	3.27	.478	<.001	2.33, 4.22

Variables considered in the multivariate analysis include age, race, years of education, income, insurance, numeracy, family history of breast cancer, age of first live birth, number of previous breast biopsies. Potential interactions between race and income, race and education, and age and insurance were evaluated.

Table 8: Estimation Errors Before and After Study Intervention for Lifetime and Five-Year Breast Cancer Risk

	ESTIMATION ERROR		
	INTERVENTION	CONTROL	P*
LIFETIME (median, range)			
Pre-intervention	21.4% (0.4-96.3)	30.4% (0.1-97.0)	.08
Post-intervention	6.1% (0.0-86.8)	23.6% (0.1-94.8)	.0001
Change in estimation error	6.2% (-75-92.6)	0%(-94-91.8)	.01
FIVE YEAR (median, range)			
Pre-intervention	13.8% (0.1-97.3)	18.8% (0.2-99.2)	.42
Post-intervention	8.4% (0.0-89.3)	18.8% (0.1-98.3)	.0001
Change in estimation error	5% (-75-89)	0% (-92-80)	.002

*Kruskall-Wallis statistic used for above tests. Estimation error calculated as the absolute value of perceived risk minus the absolute value of the Gail calculated risk.

Table 9: Unadjusted Associations of Sociodemographic Variables and Numeracy with Post Intervention Change in Estimation Error for Lifetime and Five-Year Risk Estimates

	n	Change in Lifetime Estimation Error % (mean)	P*	Change in Five Year Estimation Error % (mean)	P*
AGE (quartiles) (years)					
1st (40-50)	71	11.4		4.0	
2nd (51-56)	58	6.4		4.9	
3rd (57-65)	64	1.4		1.1	
4th (66-84)	61	4.2	.07	2.9	.52
RACE					
WHITE	178	5.5		5.4	
OTHER	81	6.9	.95	-2.0	.01
YEARS OF EDUCATION					
<12	49	4.7		-3.4	
12	81	6.3		3.9	
12-16	97	6.4		6.8	
17+	27	5.4	.97	.05	.14
FAMILY INCOME (annual)					
<$10,000	87	5.8		-1.1	
$10,000-19,999	37	-4.0		-0.7	
$20,000-34,999	36	14.3		10.4	
$35,000-49,999	23	15.9		17.3	
$50,000-74,999	30	3.4		-0.7	
>$75,000	34	5.7	.66	5.5	.053
INSURANCE					
Medicare	89	3.0		-0.5	
Medicaid/GAMP**/T19	64	9.5		1.6	
Fee For Service/HMO	86	8.7		9.1	
None/Other	15	-6.1	.48	-2.5	.12
NUMERACY(number of correct responses)					
0	38	5.8		3.7	
1	42	-2.2		-2.31	
2	69	7.4		2.8	
3	105	8.2	.20	5.4	.16

*Spearman's correlation was used for continuous variables and ordinal variable . Kruskal-Wallis was used for categorical variables. Age and education were analyzed as continuous variables.

Table 10: Unadjusted Associations of Breast Cancer Risk Factors with Post Intervention Change in Estimation Error for Lifetime and Five Year Risk Estimates

BREAST CANCER RISK FACTORS	n	Change in Lifetime Estimation Error % (mean)	P*	Change in Five Year Estimation Error % (mean)	P*
FAMILY HISTORY OF BREAST CANCER (number of first degree relatives)					
0	208	4.4		1.1	
1	29	15.8		11.7	
≥2	17	7.5	.047	14.4	<.001
AGE AT MENARCHE (years)					
≤11	54	9.5		1.6	
12-13	136	4.4		3.1	
≥14	60	5.1	.95	3.8	.59
AGE AT FIRST LIVE BIRTH (years)					
13-19	8	6.9		-0.1	
20-24	73	3.9		5.1	
25-29	37	3.4		5.8	
30-39	12	0.02		10.7	
nulliparous	43	11.3	.32	2.2	.39
NUMBER OF BREAST BIOPSIES					
0	195	4.4		1.4	
1	38	7.6		7.7	
2	14	15.9		12.1	
3+	7	19.2	.04	11.2	.03
ABNORMAL BREAST BIOPSY "ATYPICAL HYPERPLASIA"					
YES	6	10.5		-1.8	
NO	223	5.1		2.9	
UNKNOWN	24	11.6	.80	6.8	.81

* Spearman's correlation was used for continuous variables and ordinal variable. Kruskal-Wallis was used for categorical variables.

Table 11: Multiple Regression Model Predicting Change in Estimation Error of Lifetime Risk

Variable	Coeff	SE	P	95% CI
Intervention	.567	.173	.001	.225, .909
Age	-.022	.009	.013	-.040, -.005
Income (<20,000 vs ≥20, 000)	-.623	.225	.006	-1.06, -.178
Insurance(Fee For Service/HMO vs all others)	-.468	.249	.061	-.958, .021
Constant	1.37	.659	.039	.073, 2.67

Variables considered in the multivariate analysis include intervention, age, race, years of education, income, insurance, numeracy, family history of breast cancer, age of first live birth, number of previous breast biopsies. Potential interactions between race and income, race and education, and age and insurance were evaluated.

Table 12: Multiple Regression Model Predicting Change in Estimation Error of Five Year Risk

Variable	Coeff	SE	P	95% CI
Intervention	.588	.170	.001	.253, .923
Family History	.308	.149	.040	.014, .601
Income (<20,000 vs ≥20,000)	-.420	.170	.014	-.755, -.084
Constant	-.832	.344	.016	-1.51, -.155

Variables considered in the multivariate analysis include intervention, age, race, years of education, income, insurance, numeracy, family history of breast cancer, age of first live birth, number of previous breast biopsies. Potential interactions between race and income, race and education, and age and insurance were evaluated.

March 9, 2000

MEDICAL COLLEGE OF WISCONSIN

Ms. «F_Name» «L_Name»
«Address»
«City», «State» «Zip»

Department of Medicine
Division of General Internal Medicine

Dear Ms. «L_Name»,

A research study about ***Health Care Education for Women*** is being done at the Froedtert Internal Medicine Clinics. The study will try to find out the best way to teach women about their health risks. The American Cancer Society is funding this research.

I would like to invite you to be part of this study. You will be asked to complete two questionnaires, answer questions about yourself and your medical history, and sign a release of medical record information. All personal information will be strictly confidential. You will also receive educational pamphlets. The first questionnaire needs to be filled out at the Froedtert Clinic. It takes about one hour to complete. You will be given a sticker to cover the cost of parking at the clinic the day of the interview. You will also be mailed a check for $20.00 after completion of the interview. The second questionnaire is very short and can be filled out at home and mailed back. I hope you will participate in this study, but please understand it is voluntary.

Laura Eparvier, the study nurse, will be contacting you in the near future to see if you are interested in participating in the study. If you have any questions or would like to schedule an interview please contact Laura at 456-6888 or return the enclosed postcard.

Sincerely,

Marilyn Schapira M.D., M.P.H.
Department of Internal Medicine, Medical College of Wisconsin, and Froedtert Memorial Lutheran Hospital

Froedtert East
9200 W. Wisconsin Avenue
Milwaukee, Wisconsin 53226
(414) 456-6880
Fax: (414) 456-6212

MEDICAL COLLEGE OF WISCONSIN
STATEMENT OF VOLUNTEER CONSENT FOR CLINICAL STUDY

INTRODUCTION: I, _____, hereby agree to participate in the investigation entitled "IMPROVING PERCEPTIONS OF BREAST CANCER RISK IN A PRIMARY CARE SETTING." I understand that while the program will be under the supervision of Marilyn M. Schapira MD, other professional persons may be designated to assist or act for her.

PURPOSE: The purpose of the study is to determine the best way to present health risk information including information about my chances of developing certain diseases and the benefits of regular screening tests.

PROCEDURES: As a participant in this study, I will answer a written questionnaire and receive information about preventive health care. The questionnaire and interview will take approximately 1 hour to complete. A second interview will be scheduled 1 – 2 months later. This interview will be done by phone or through the mail and take approximately 20 minutes to complete.

The experimental aspect of this study is to determine the best way to present information about preventive health care.

My participation in the project will be the questionnaire and interview as outlined above.

I wish to limit my participation as a subject in the investigation as follows (**If none, compared to description of participation above, write "none":**

_____.

RISKS: I have been informed of the inconveniences that I may reasonably expect as part of the study. These include taking the time to complete the questionnaires and interviews.

BENEFITS: I understand that the information which is obtained may be useful scientifically and possibly helpful to others. The benefits to me that may reasonably be expected from participating in this study are a better understanding of certain disease risks and the risks and benefits of screening tests, but this is not guaranteed.

FINANCIAL BENEFIT: I understand that I will receive a voucher for parking at the clinic the day of my interview. I will also be mailed a check for $20.00 after completion of my interview.

ALTERNATIVE PROCEDURES: The alternative procedure is to not participate in the study and to discuss my risk for certain diseases and the benefits of screening tests with my health care provider.

ANSWER INQUIRIES: Dr./Ms./Mr. _____ has explained the above matters to me and I understand that explanation. (S)he has offered to answer my questions concerning the procedures involved in this study.

CONFIDENTIALITY: I have been promised that any information obtained from this investigation that can be identified with me will remain confidential, or will be disclosed only with my permission. However, I am in agreement that scientific data or medical information not identifiable with me resulting from the study may be presented at meetings and published so that the information can be useful to others.

NO PREJUDICE: I have been informed that my decision about whether or not to participate will not prejudice my present or future relationship with the Medical College of Wisconsin, Froedtert Memorial Lutheran Hospital, or the staffs of the institutions; nor will it influence the quantity or quality of care which is otherwise available to me. If I participate, I understand that I am free to withdraw at any time without prejudice, and that withdrawal would not in any way affect the nature of the care or treatment otherwise available to me. I understand that I may contact the Chairman of the Human Research Review Committee of the Medical College at (414) 456-8505 for further information related to the research and my rights as a subject.

COMPENSATION FOR INJURIES: I agree to take the risks listed above. If unexpected injuries which are not discussed in the paragraph entitled "Risks" occur, physician faculty of the Medical College of Wisconsin and Froedtert Memorial Lutheran Hospital will provide me humanitarian emergency care without charging me a physician's fee for such treatment. Such free care does not mean that negligence has occurred; compensation may or may not be payable. I understand that I may contact the Chairman of the Human Research Review Committee of the Medical College at (414) 456-8505 for further information on the provision of medical care without charge under the terms of this paragraph.

FURTHER INFORMATION: If I have further questions concerning this project at any time, I understand that I am free to ask them of Dr. Marilyn Schapira at 456-6876, who will be available to answer them.

_____ _____

Signature of Subject or Authorized Representative Date

_____ _____

Signature of Witness Date

I have defined and fully explained the study as described herein to the subject.

TYPE OR PRINT:

_____

Name of Principal Investigator or Authorized Representative

TYPE OR PRINT:

_____

Position Title

_____

Signature Date

BREAST CANCER RISK

QUESTIONNAIRE

Medical College
of Wisconsin

1999

(Study#) 1. Study # _____

(ID#) 2. ID # _____

Breast Cancer Risk and Mammography Benefit

Questionnaire

The purpose of this survey is to find out how women feel about their chances of getting breast cancer and how important it is to have a breast exam and mammogram. We also want to know which pictures best show the risk or chance of getting breast cancer.

Most of the questions do not have a right or wrong answer but are asking for your opinion. Some questions may look the same, but each one is a little different.

(F/L Name) 3. First Name: _____ 4. Last Name: _____

(Date) 5. Date: _____

(MD) 6. MD: _____

(Loc) 7. Froedtert Clinic Location: _____

(Clinic#) 8. Medical Record Number: _____

Section I: Possible Risk Factors for Breast Cancer

Below is a list of things that some people think may **increase** a woman's chance of getting breast cancer. For each question, circle **yes** or **no** if you think it **increases** the chance of getting breast cancer.

(Circle one number on each line)

	YES	NO
9. Smoking cigarettes (Smokcigs)	1	2
10. Drinking more than 2 alcoholic drinks a day (Drink)	1	2
11. Having frequent sexual activity (Freqsx)	1	2
12. Eating a high fat diet (Fatdiet)	1	2
13. Beginning menstrual periods at 10 years of age or younger (Menses)	1	2
14. Having your first baby after age 30 (Child1)	1	2
15. Not having any children (Child0)	1	2
16. Getting older (Aging)	1	2
17. Getting a bruise on your breast (BrTrauma)	1	2
18. Having a breast biopsy that DID NOT show cancer (*biopsy is when fluid and cells are taken out of the breast by a needle or surgery and tested*) (BrBxNoCa)	1	2
19. Having colon or bowel cancer (ColonCa)	1	2
20. Breast cancer in your mother, sister, or daughter (BrCaFam)	1	2
21. Having a family member with lung cancer (LungCa)	1	2
22. Having a family member with cancer of the ovary (OvaryCa)	1	2

Section II: Expressing the chance of something happening.

Next, please answer the following questions. Using math may help you better understand the questions in the survey about the risk or chance of getting breast cancer and the benefit or helpfulness of a mammogram.

(CoinFlip) 23. Imagine that you flip a coin 100 times. About how many times will the coin come up heads in 100 flips?

_____ times out of 100

(Freq) 24. 100 people have entered the Spring City Run. 70% of the runners will finish the race. Of the 100 people who enter the race, how many will finish?

_____ persons out of 100

(PerCent) 25. In the Washington School raffle 5 people out of 100 who enter will win a prize. What percentage (%) of the people who enter the raffle will win a prize?

_____ %

Section III: Personal Risk Estimates

The questions in this section ask your opinion or feelings about your **risk** or **chances** of getting breast cancer.

(Lifrsk%) 26. What do you think **your personal risk** or **chance** is of getting breast cancer in your **lifetime**? Please answer on a scale of 0% to 100%.

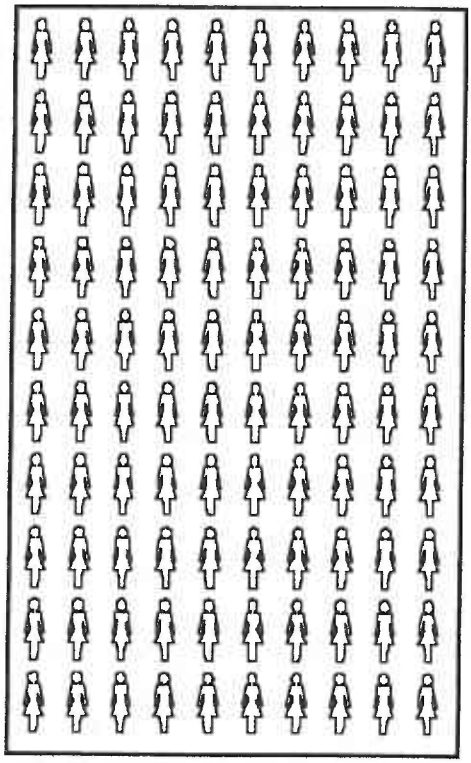
For example;
0% = no risk or chance of getting breast cancer
100% = completely certain to get breast cancer

You can pick any number between 0 and 100.

_____**%**

(Lifrskfq) 27. Here is another way to ask the same question. Picture yourself in a room with 100 women exactly like you. **How many** of you will get breast cancer in your **lifetime**? Please pick a number between 0 and 100.

For Example;
0 = no women out of 100
100 = 100 women out of 100



You can pick any number between 0 and 100.

_____**Out of 100**

(Rsk5yr%) 28. What do you think **your personal risk** or **chance** is of getting breast cancer in the next **5 years**? Please answer on a scale of 0% up to 100%.

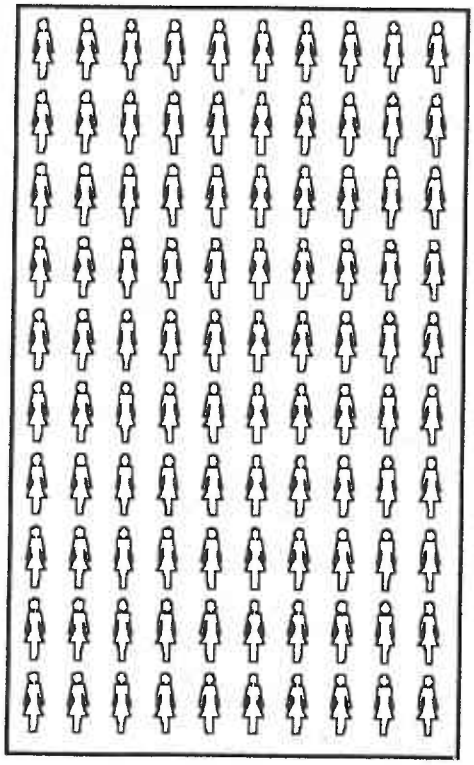
For example;
0% = no risk or chance of getting breast cancer
100% = completely certain to get breast cancer

You can pick any number between 0 and 100.

_____**%**

(Rsk5yrfq) 29. Here is another way to ask the same question. Picture yourself in a room with 100 women exactly like you. **How many** of you will get breast cancer in the **next 5 years**? Please pick a number between 0 and 100.

For Example;
0 = no women out of 100
100 = 100 women out of 100



You can pick any number between 0 and 100.

_____ **Out of 100**

(Qualrsk) 30. Please circle the letter that describes how you feel about **your risk** or **chances** of getting breast cancer compared to other women your age.

(circle one)

A. *Much Below Average:* Circle this if you think you have a lot less risk or chance of getting breast cancer than other women your age.

B. *Below Average:* Circle this if you think you have less risk or chance of getting breast cancer than other women your age.

C. *Average:* Circle this if you think you have exactly the same risk or chance of getting breast cancer as other women your age.

D. *Above Average:* Circle this if you think you have more of a risk or chance of getting breast cancer than other women your age.

E. *Much Above Average:* Circle this if you think you have a much bigger risk or chance of getting breast cancer than other women your age.

Section IV: Breast Cancer Survival and Mammography Benefit

(Srvl5yr) 31. On average, when women get breast cancer what are their chances of living for 5 years or longer?

(circle one)

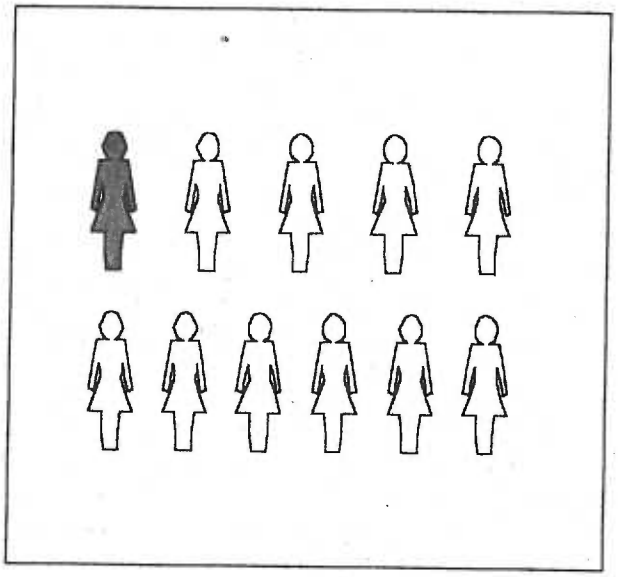
Between 0% and 25% survival 1
Between 26% and 50% survival 2
Between 51% and 75% survival 3
Between 76% and 100% survival..... 4

(Mamobene) 32. For women your age, how much do you think regular mammograms will decrease or lessen the risk or chance of dying from breast cancer?

(circle one)

Not at all..... 1
Between 5% and 25% 2
Between 26% and 50%..... 3
Between 51% and 75%..... 4
Between 76% and 100%..... 5

Section V: Risk Perceptions from Graphics



This picture is one way of showing the risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Look carefully at the picture and answer the questions.

(Liftsk11) 33. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer in her lifetime?

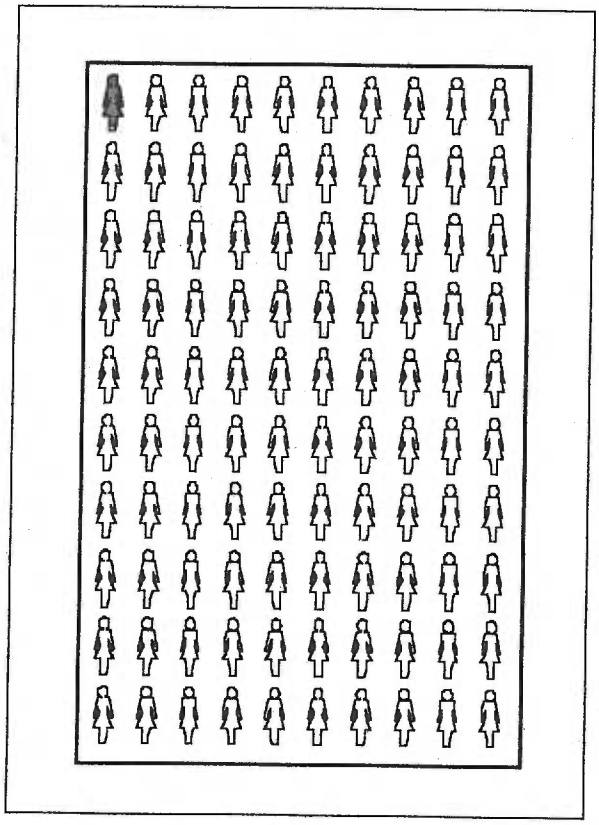
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk33) 34. How accurate or true does this picture look to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



This picture shows the risk or chance of a 50-year old woman getting breast cancer over 5 years, from age 50 to 55. Look carefully at the picture and answer the questions.

(Rsk5yrFG) 35. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer over the next 5 years?

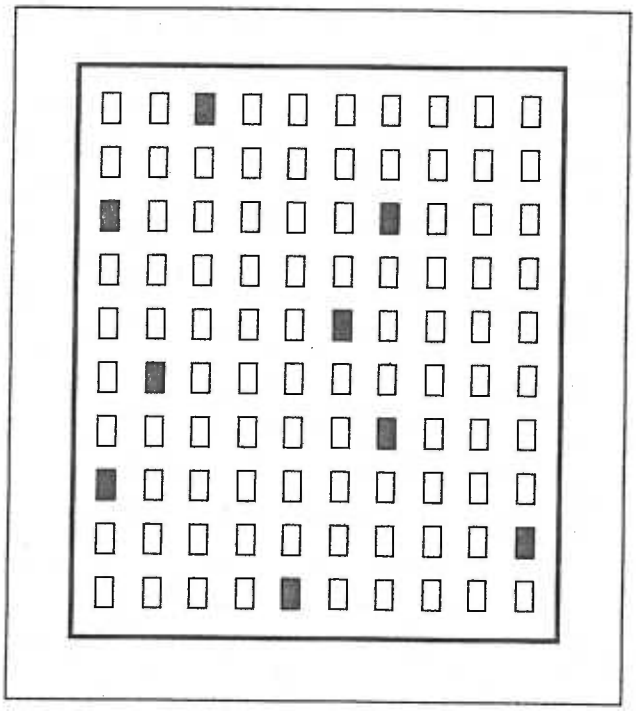
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk35) 36. How accurate or true does this picture look to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



This picture is another way to show the risk or chance of a 50-year-old woman getting breast cancer over her lifetime. Look carefully at this picture and answer the questions.

(LifrskSS) 37. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer in her lifetime?

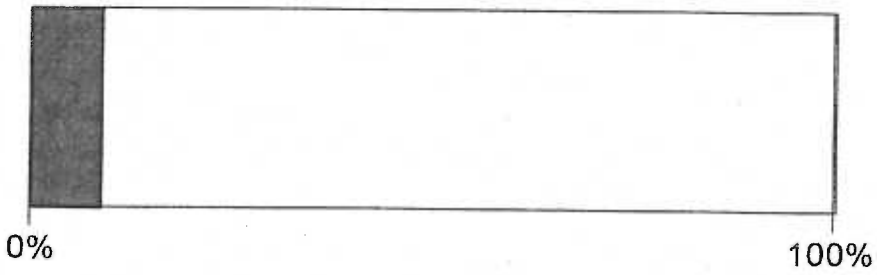
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk37) 38. How accurate or true does this picture to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



This picture also shows the lifetime risk or chance of a 50-year old woman getting breast cancer. Look carefully at this picture and answer the questions.

(LifrskBG) 39. Using the figure in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer in her lifetime?

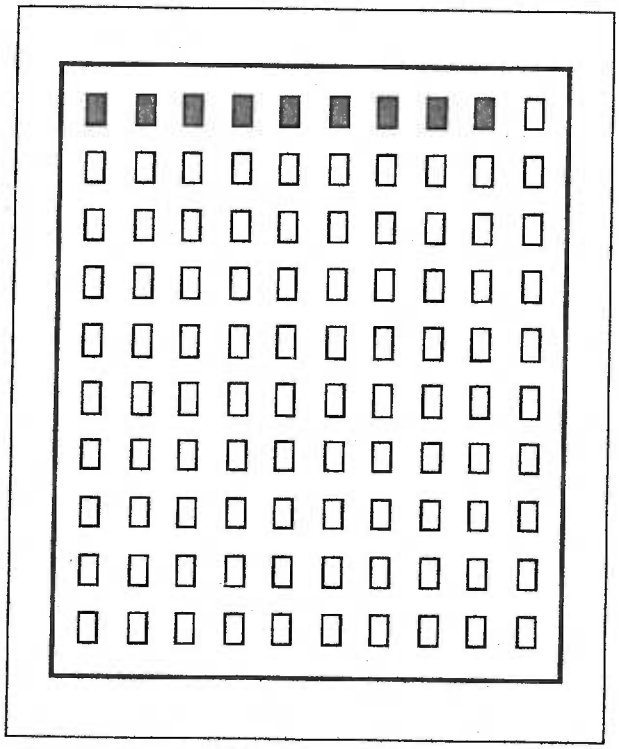
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk39) 40. How accurate or true does this picture look to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



Here is another picture that shows the risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Look at this picture carefully and answer the questions.

(LifrskCS) 41. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer in her lifetime?

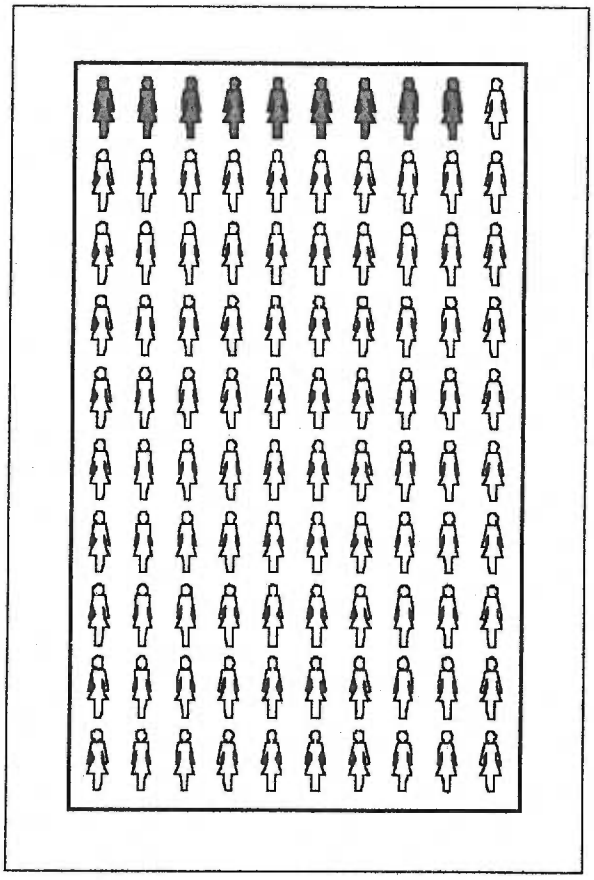
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk41) 42. How accurate or true does this picture look to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



This picture is another way of showing the risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Look carefully at the picture and answer the questions.

(LifriskFG) 43. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting breast cancer in her lifetime?

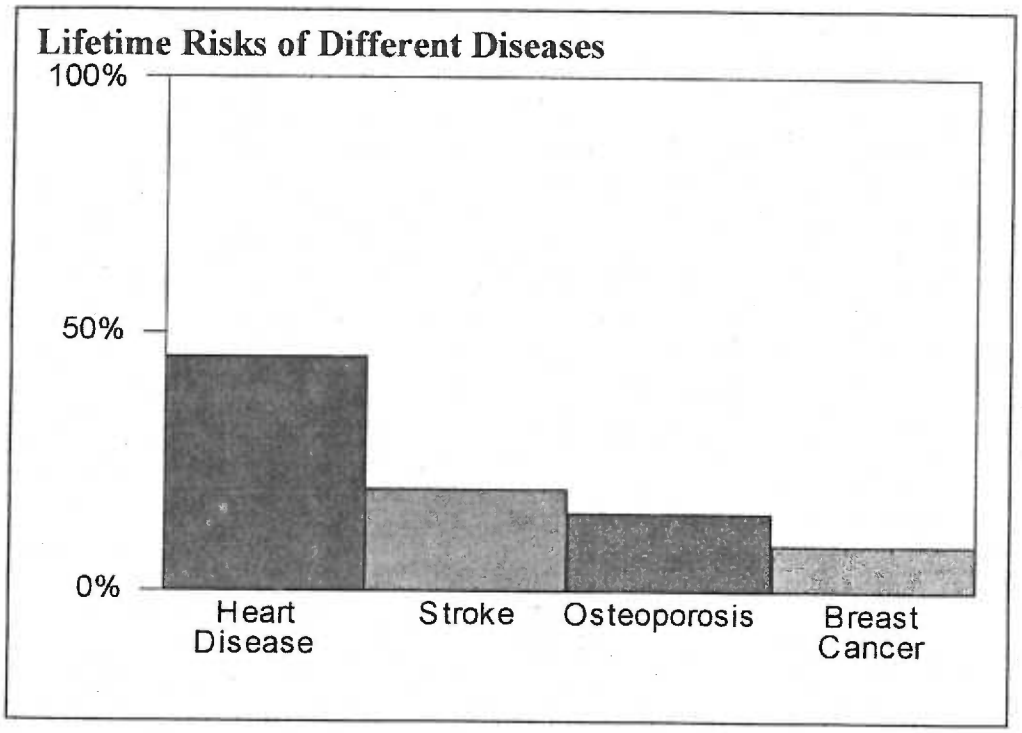
(circle one)

Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk43) 44. How accurate or true does this picture look to you?

(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5



This picture shows the risk or chance of a 50-year-old woman getting heart disease, stroke, osteoporosis (weak bones), and breast cancer in her lifetime.

(Comprsk4) 45. Using the figures in this picture, what would you say is the risk or chance of a 50-year-old woman getting **breast cancer** in her lifetime?

(circle one)

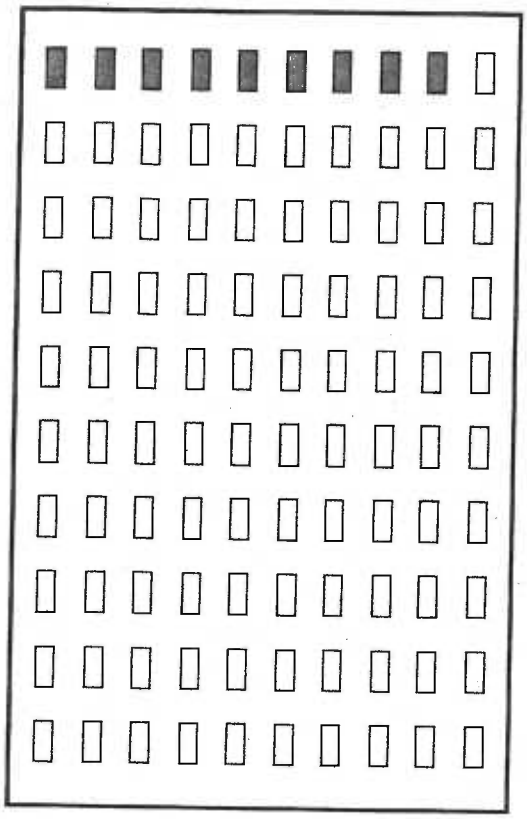
Very high risk 1
High risk 2
Medium risk 3
Low risk 4
Very low risk 5

(Trursk45) 46. How accurate or true does this picture look to you?

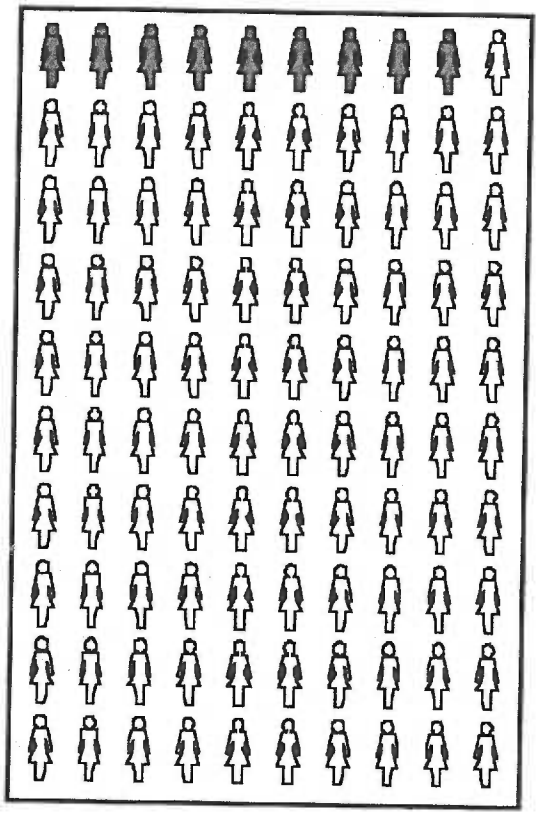
(circle one)

Very true 1
True 2
Neither true or untrue 3
Not very true 4
Very untrue 5

Picture A
Breast Cancer Risk is 9/100



Picture B
Breast Cancer Risk is 9/100

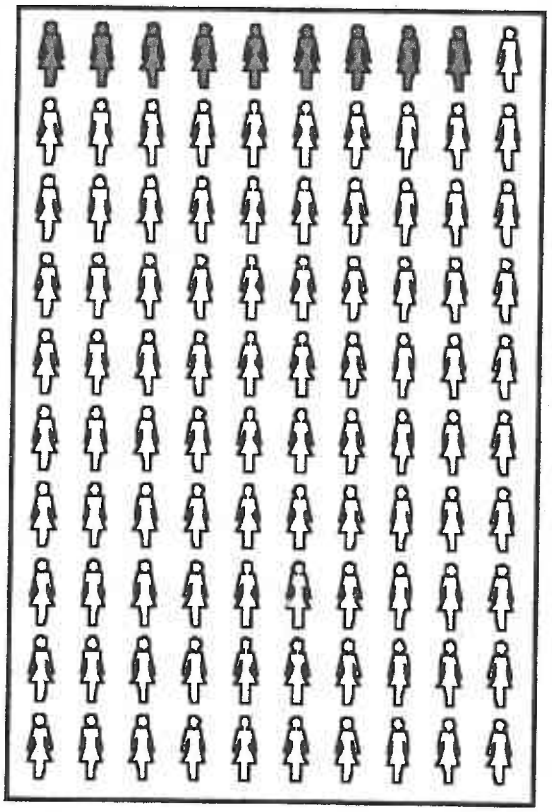


(LfCSvsFG) 47. Pictures A and B both show the same risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Which picture do you like better?

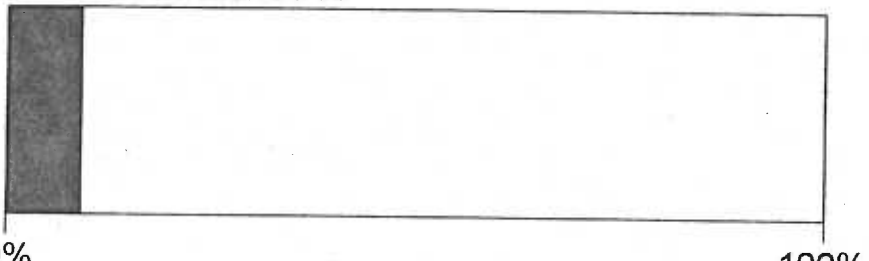
(circle one)

I like Picture A much better 1
I like Picture A a little better 2
I like Picture A and Picture B the same 3
I like Picture B a little better 4
I like Picture B much better 5

Picture A
Breast Cancer Risk is 9/100



Picture B
Breast Cancer Risk is 9%

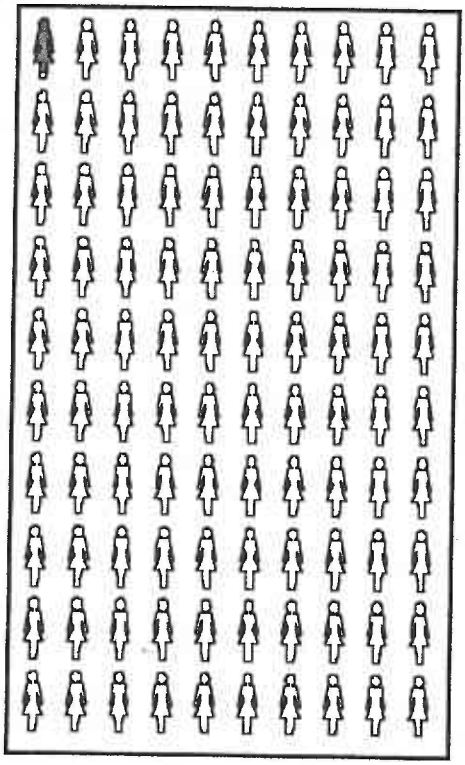


(LfFGvsBG) 48. Pictures A and B both show the same risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Which of these pictures do you like better?

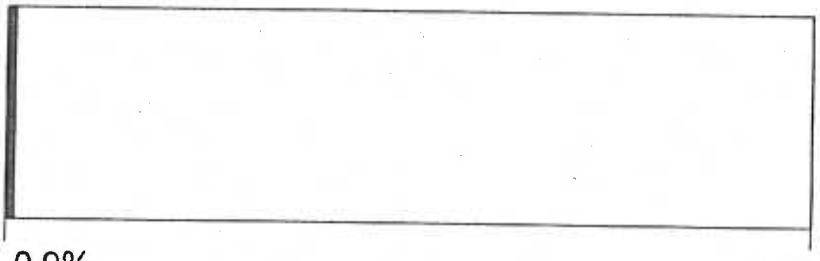
(circle one)

I like Picture A much better.....1
I like Picture A a little better.....2
I like Picture A and Picture B the same.....3
I like Picture B a little better.....4
I like Picture B much better.....5

Picture A
5-year risk is .9/100



Picture B
5-year risk is .9 %

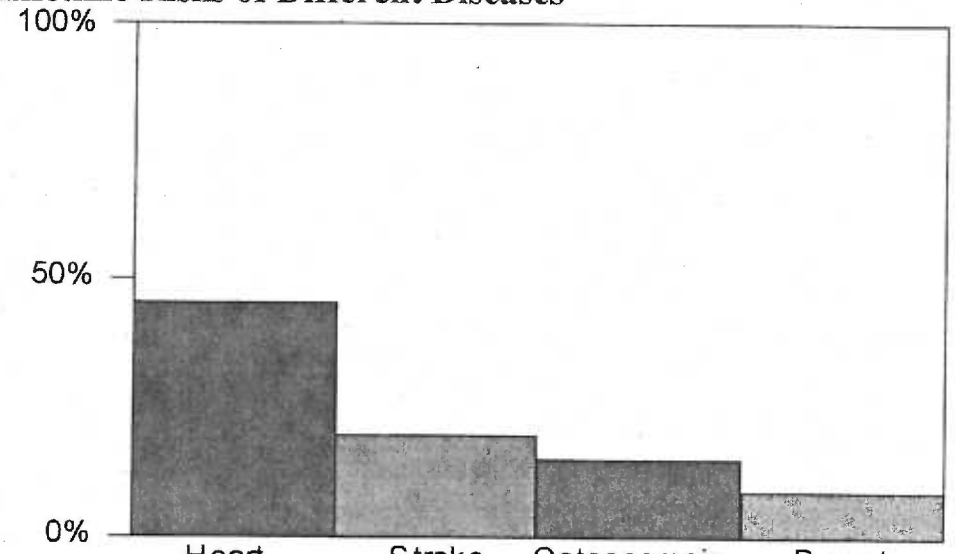


(FGvBG5yr) 49. Pictures A and B both show the same risk or chance of a 50-year-old woman getting breast cancer over the next 5 years. Which picture do you like better?

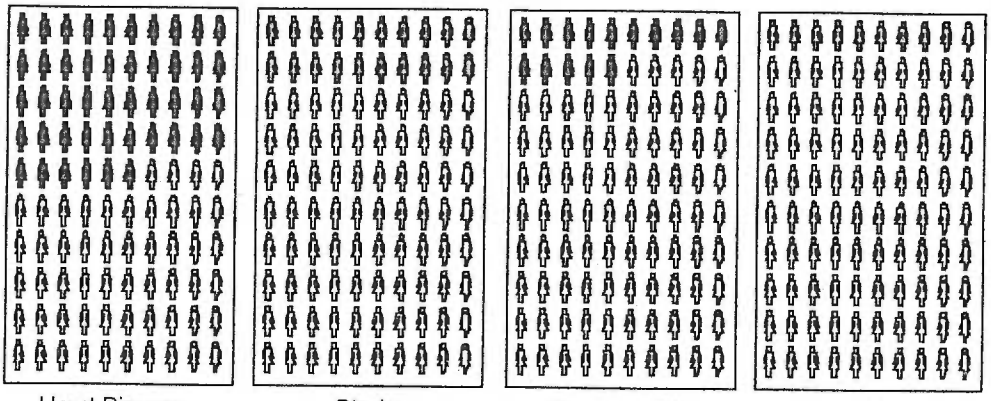
(circle one)

I like Picture A much better.....1
I like Picture A a little better.....2
I like Picture A and Picture B the same.....3
I like Picture B a little better.....4
I like Picture B much better.....5

Picture A
Lifetime Risks of Different Diseases



Picture B
Lifetime Risks of Different Diseases

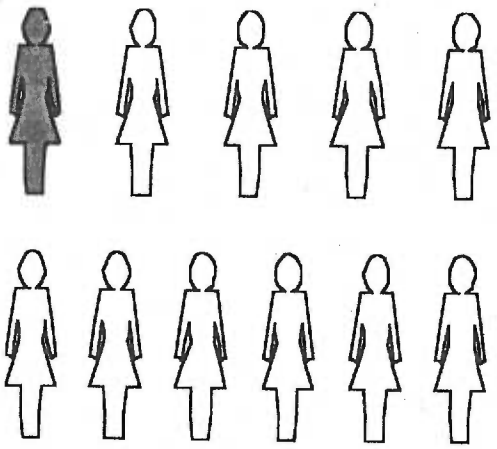


(BGvFG4) 50. Pictures A and B both show the same risks or chances of a 50-year-old woman getting heart disease, stroke, osteoporosis (weak bones), and breast cancer in her lifetime. Which picture do you like better?

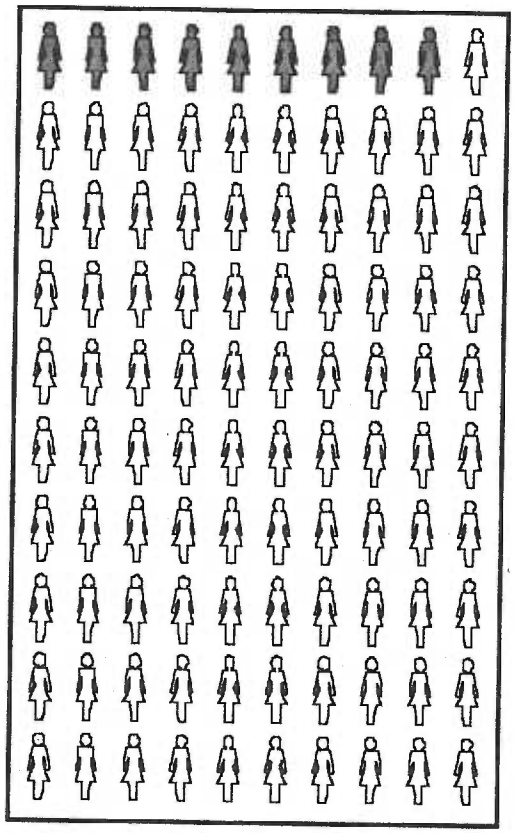
(circle one)

I like Picture A much better.....1
I like Picture A a little better.....2
I like Picture A and Picture B the same.....3
I like Picture B a little better.....4
I like Picture B much better.....5

Picture A
Breast Cancer Risk is 1/11



Picture B
Breast Cancer Risk is 9/100

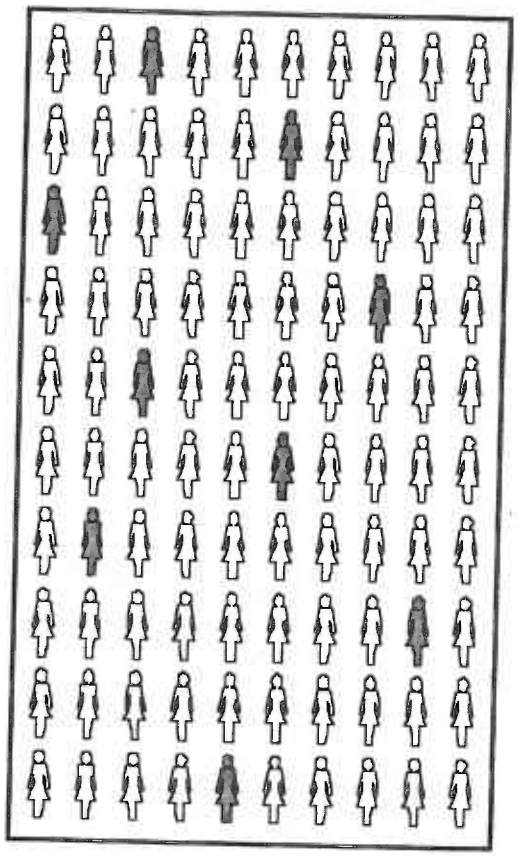


(FG11v100) 51. Pictures A and B both show the same risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Which picture do you like better?

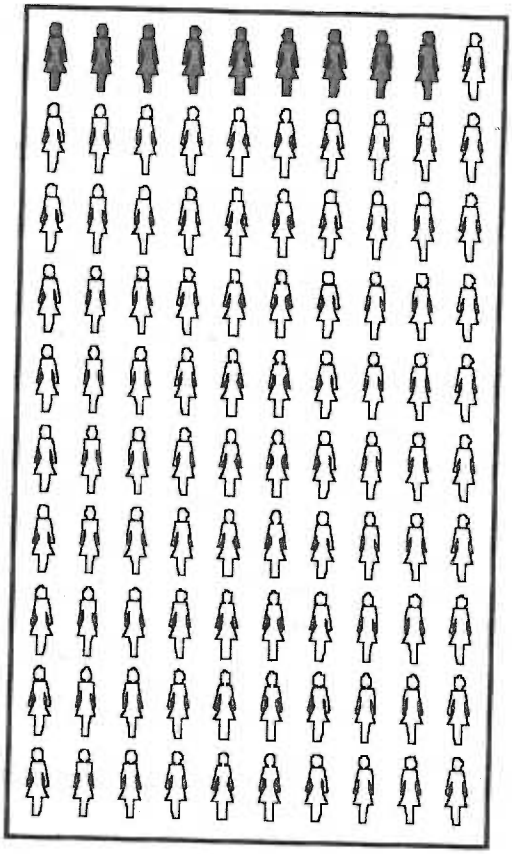
(circle one)

I like Picture A much better.....1
I like Picture A a little better.....2
I like Picture A and Picture B the same 3
I like Picture B a little better.....4
I like Picture B much better 5

Picture A
Breast Cancer Risk is 9/100



Picture B
Breast Cancer Risk is 9/100



(SFGvsCFG) 52. Pictures A and B show the same risk or chance of a 50-year-old woman getting breast cancer in her lifetime. Which of these pictures do you like better?

(circle one)

I like Picture A much better.....1
I like Picture A a little better.....2
I like Picture A and Picture B the same.....3
I like Picture B a little better.....4
I like Picture B much better.....5

Section VI: General Questions about You

(Bday) 53. Please write in your birthday here: _____/_____/_____
month day year

(Race) 54. What is your race or ethnic group?

(circle one)

White or Caucasian, but not Hispanic or Latino 1
Black or African-American, but not Hispanic or Latino 2
Hispanic or Latino 3
Asian or Pacific Islander 4
American Indian or Alaskan Native 5
Other 6

(School) 55. What is the highest year of school or college you have ever completed? Please circle one number.

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	16 +
Grade School								High School				College				Post-grad

(Income) 56. What is your family income?

(circle one)

Under $10,000 1
$10,000-$19,999 2
$20,000-$34,999 3
$35,000-$49,999 4
$50,000-$74,999 5
$75,000 + ...6

(MedIns) 57. What medical insurance do you have?

(circle all that apply)

Medicare 1
Medicaid/Title 19 2
Private Fee-For-Service Insurance 3
Health Maintenance Organization (HMO) 4
Veterans Administration Health Care Benefits 5
Milwaukee County GAMP Program 6
Other, List_____ 7
No insurance 8

Section VII: Medical History

(agetoday) 58. How old are you today? _____

(FamBC#) 59. Have any of your sisters, daughters or your mother had breast cancer? How many all together?

(circle one)

None 0
1.....1
2.....2
3 or more.....3
Unknown 4

(Period1) 60. How old were you when you had your first period or menstrual flow?

(circle one)

11 years of age or less 1
12 or 13 years old.....2
14 years or older 3
Unknown 4

(Anykids) 61. Have you given birth to any children? ___ Yes ___ No

(FrstBaby) 62. If yes, how old were you when you had your first baby?
Please write in your age. _____ years old

(BrBx#) 63. How many breast biopsies have you had? A breast biopsy is when fluid and cells are taken out of the breast with a needle or surgery and tested.

(circle one)

None 0
1.....1
2.....2
3 or more.....3

(BrBxAbno) 64. Have you ever had a breast biopsy that showed "atypical hyperplasia" which is a type of abnormal cell, but not breast cancer?

(circle one)

Yes 1
No.....2
Not sure 3

(OvCaFam) 65. Has anyone in your family had ovarian cancer? Ovarian cancer is cancer of the ovaries.

(circle one)

Yes 1
No 2
Unknown 3

(ColCaFam) 66. Has anyone in your family had colon cancer. Colon cancer is cancer of the bowels or intestines.

(circle one)

Yes 1
No 2
Unknown 3

(Menopaus) 67. Have you been through menopause (no longer having your period)?

Circle one)

Yes 1
No.....2
Unsure 3

(ERT) 68. Have you ever used estrogen?

(circle one)

Never used estrogen 1
Used estrogen in the past but not using now 2
Using estrogen now and have for 5 or more years.....3
Using estrogen now and have for less than 5 years 4

(wt) 69. How much do you weigh? _____ pounds

(Drnk/Day) 70. How many alcoholic drinks do you have a day?

(circle one)

None 1
Occasional (less than 1 a day) 2
1.....3
2.....4
3 or more.....5

(Smoke) 71. Do you smoke cigarettes?

(circle one)

Yes 1
No 2

(MamoEvr) 72. Have you ever had a mammogram?

(circle one)

Yes 1
No 2

(Mamoyr) 73. Have you had a mammogram in the past year?

(circle one)

Yes 1
No 2

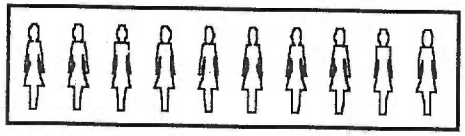
Thank You Very Much for Your Responses

Mammography Benefit

Regular breast screening with mammography decreases the chance of dying from breast cancer. For women in your age group, **50+**, regular mammograms may reduce your chances of dying from breast cancer by **30%**.

Breast Cancer Survival

About 8 out of 10 women, or 80%, with breast cancer will survive 5 years after diagnosis.



For More Information

This information has been designed to help you understand your personal risk for breast cancer. It is part of a Medical College of Wisconsin Research Study. For further questions call The Breast Cancer Risk Study at (414) 456-6888.

March 29, 2001

BREAST CANCER INFORMATION

FOR

SUSAN SAMPLE

Medical College Of Wisconsin 2000

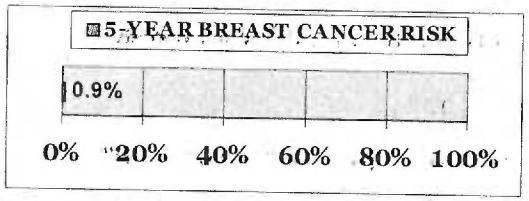
Your breast cancer risk was determined by your medical history using the following risk factors. Breast cancer risk is **increased** by:

- Increased age
- First period at 10 years or younger
- Older age at first child's birth or no children
- First degree relatives with breast cancer
- Previous breast biopsy
- White race

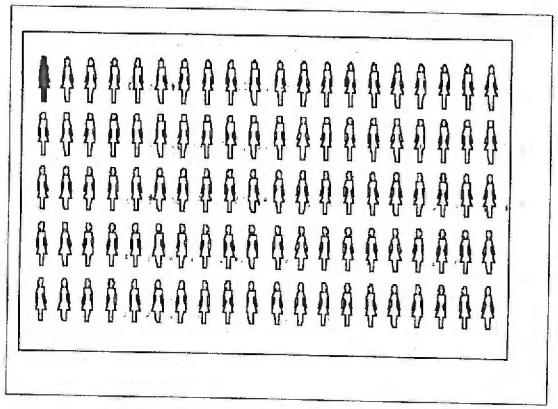
The National Cancer Institute (NCI) developed the computer program used to calculate your breast cancer risk based on the experience of thousands of women. The pictures may help make this information easier to understand.

Your risk of breast cancer in the next 5 years

The estimate of your 5-year risk or chance of getting breast cancer is **.9** %.

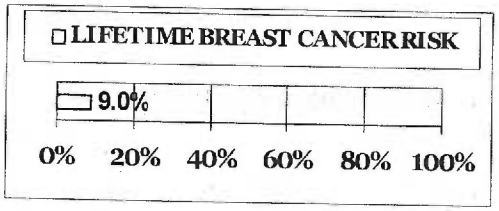


This can be stated another way. Your risk is **.9** out of 100.

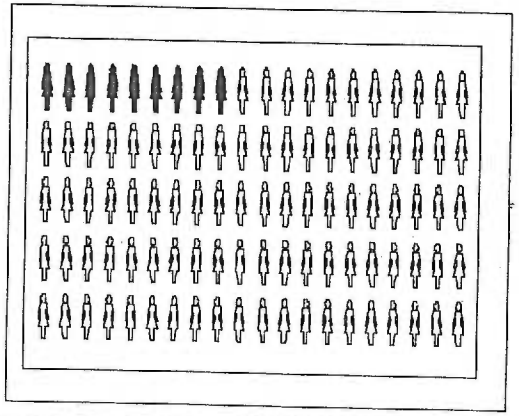


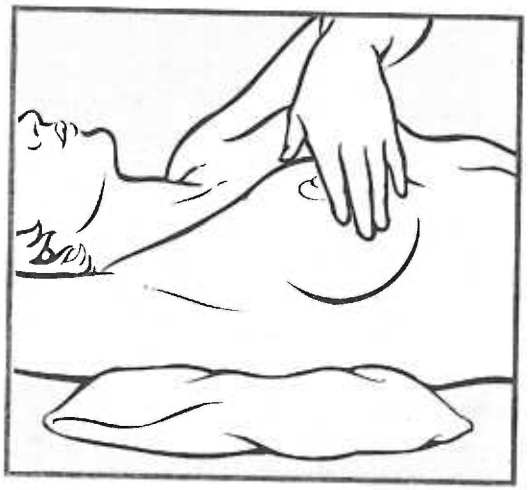
Your risk of breast cancer in your lifetime

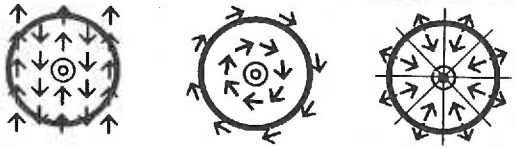
The estimate of your lifetime risk or chance of getting breast cancer is **9** %.



This can be stated another way. Your risk is **9** out of 100.







(a) (b) (c)

If you think you have found a lump or change, see your doctor. Most breast lumps are not cancer, but you won't know if you don't ask.

YOUR CHANCES ARE EXCELLENT...

...If you begin your action plan now. We don't know how to prevent breast cancer. **But we do know how to find it early, when the chance for successful treatment is greatest.**

Put your plan into action right away. Then you can spend your life enjoying your health.

IF YOU ARE 20-39 YEARS OLD, THE AMERICAN CANCER SOCIETY RECOMMENDS THAT YOU:

> Examine your breasts monthly

> Have a breast exam by your doctor or health care provider every three years

IF YOU ARE 40 OR OVER:

> Examine your breasts monthly

> Have a breast exam by your doctor or health care provider every year

> Have a mammogram every year

The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy, and service.

For detailed information about breast self-exams, call toll free **1-800-ACS-2345** or on the Internet **www.cancer.org**

AMERICAN CANCER SOCIETY®

BREAST CANCER NETWORK

97-500M-No. 2095-CC

Special Touch

A Personal Plan of Action for Breast Health

AMERICAN CANCER SOCIETY®

BECAUSE YOU ARE A WOMAN...

...You need to know certain facts about breast cancer.

First, *all women are at risk* for breast cancer. Breast cancer now causes more deaths among women than any other cancer except lung cancer.

You also need to know that many breast cancers may be treated successfully. But *only* if they are found early.

KEEP IN MIND...

...That these risk factors put you at a higher risk for having breast cancer:

> Personal history of breast cancer

> Over age 50

> History of breast cancer in your close family (mother, sister)

YOUR BEST DEFENSE...

...Is to find breast cancer early. And when breast cancer is found in its earliest stages, the chance for successful treatment is greatest.

DECIDE ON A PERSONAL PLAN...

...So that you can enjoy your good health without worry. Set up a plan of action that will include:

> Mammography

> Examination of the breasts by a health care provider

> Self-examination of the breasts

THE MOST IMPORTANT PART OF YOUR ACTION PLAN...

...Is having regular *mammograms.* These simple breast x-rays are quick, easy, and safe. In fact, mammograms use less radiation than a dentist's x-ray.

And a mammogram can give you a big head start on treatment. You and your doctor may feel a lump as small as a pea. But a mammogram can detect some cancers as small as a pin head. That may be up to two years before a lump or a change can be felt.

The American Cancer Society advises you to have yearly mammograms beginning at age 40.

As you grow older, your chances of having breast cancer will increase. Almost half of all breast cancer occurs in women 65 and older.

For guidelines on getting an accurate, high-quality mammogram, call this toll-free number: 1-800-ACS-2345.

YOU'LL NEED...

...To see your health care provider for a *clinical breast exam.* All women over age 20 should have a clinical breast exam once every three years. After the age of 40, have your breasts examined every year.

THE THIRD PART OF YOUR PLAN...

...Will be regular, thorough *breast self-exams.* Starting at the age of 20, all women should check their breasts for lumps, thicknesses, or other changes every month. By examining your breasts on a regular basis, you will know how your breasts normally feel. If a change should occur in your breasts, you will be able to identify it quickly and call it to the attention of your doctor.

First, you should check each breast all over and include the armpit. Use your finger pads and move them in an up and down (a), circular (b), or an in-and-out wedge (c) motion to feel your breasts. Your health care provider can teach you the right way to check yourself. You should also look at your breasts in a mirror. Look for any changes in how your breasts look or for dimpling of the skin.

Plan to examine your breasts at the same time every month. It won't take long. And you'll know you've done your part until your next doctor's exam and mammogram.

MEDICAL
COLLEGE
OF WISCONSIN

Department of Medicine
Division of General Internal Medicine

June 28, 1999

Ms. «F_Name» «L_Name»
«Address»
«City», «State» «Zip»

Dear Ms. «L_Name»,

This is a follow up to the *Breast Cancer Risk Questionnaire* you filled out about six weeks ago at the Medical College of Wisconsin. Please look at the pictures carefully and fill in your answers. There is a stamped addressed envelope enclosed. Please return this short questionnaire as soon as possible. If you would prefer to complete your follow up by phone, call 456-6888 and ask for Laura Eparvier. Thanks again for your help!

Sincerely,

Marilyn Schapira M.D., M.P.H.
Department of Internal Medicine, Medical College of Wisconsin, and
Froedtert Memorial Lutheran Hospital

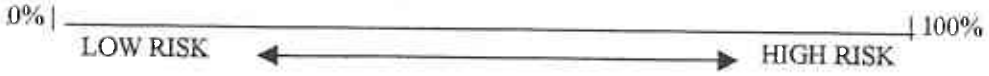
Froedtert East
9200 W. Wisconsin Avenue
Milwaukee, Wisconsin 53226
(414) 456-6880

Personal Risk Estimates

The following questions ask your opinion or feelings about your **risk** or **chances** of getting breast cancer.

(LifPct) 1. What do you think **your personal risk** or **chance** is of getting breast cancer in your **lifetime**? Please answer on a scale of 0% to 100%.

For example;
0% = no risk or chance of getting breast cancer
100% = completely certain to get breast cancer



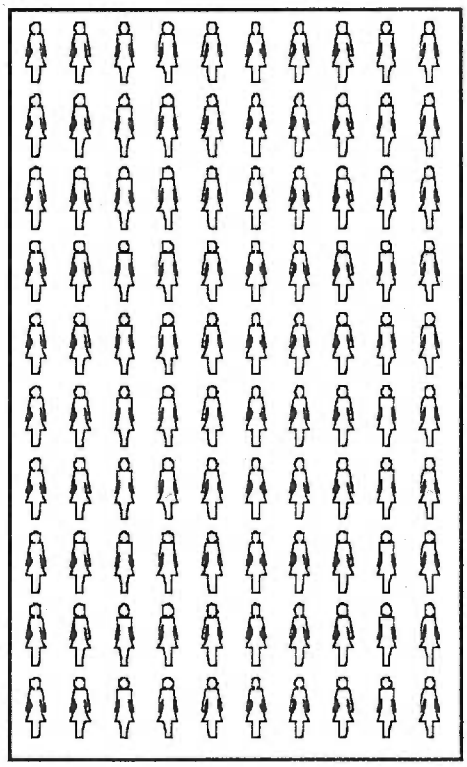
You can pick any number between 0 and 100.

_____%

iffq)

2. Here is another way to ask the same question. Picture yourself in a room with 100 women exactly like you. **How many** of you will get breast cancer in your **lifetime**? Please pick a number between 0 and 100.

For Example;
0 = no women out of 100
100 = 100 women out of 100



You can pick any number between 0 and 100.

_____**Out of 100**

5yr%)

3. What do you think **your personal risk** or **chance** is of getting breast cancer in the next **5 years**? Please answer on a scale of 0% up to 100%.

For example;
0% = no risk or chance of getting breast cancer
100% = completely certain to get breast cancer

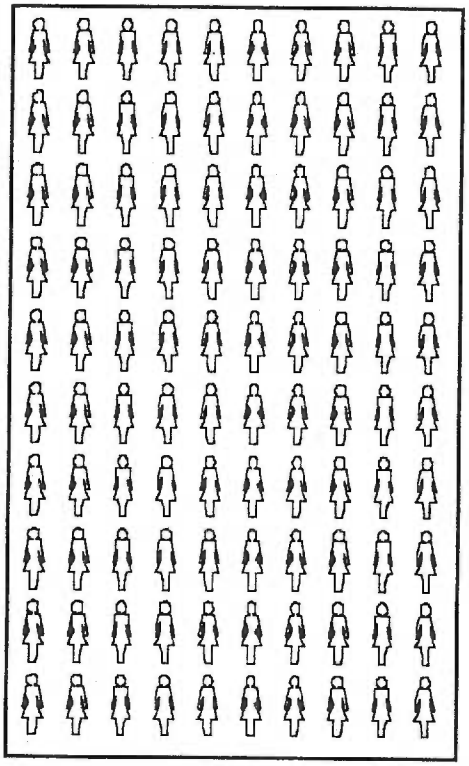
You can pick any number between 0 and 100.

_____%

5yrfqj

4. Here is another way to ask the same question. Picture yourself in a room with 100 women exactly like you. **How many** of you will get breast cancer in the **next 5 years**? Please pick a number between 0 and 100.

For Example;
0 = no women out of 100
100 = 100 women out of 100



You can pick any number between 0 and 100.

_____ **Out of 100**

Please fill out and return as soon as possible.
Thanks for your help!

MEDICAL COLLEGE OF WISCONSIN

Human Research Review Committee

H.R.R.C. ADMINISTRATIVE APPROVAL

EXPEDITED APPROVAL

TO: Marilyn Schapira, M.D.
Internal Medicine
FMLH-East

PLEASE BE ADVISED THAT YOUR PROTOCOL AND INFORMED CONSENT

ENTITLED: Improving Perceptions of Breast Cancer Risk in a Primary Care Setting **IRC#98-211**

AND TO WHICH WE HAVE ASSIGNED THE HRRC NUMBER # 360-98

HAS BEEN APPROVED FOR FROEDTERT MEMORIAL LUTHERAN HOSPITAL

NOTE: **Any changes in the protocol and informed consent and any severe untoward reactions, or death, must be reported in writing immediately to the Human Research Review Committee.**

Federal regulations require that if any advertising is involved in the initiation of this protocol, prior approval must be obtained from the Human Research Review Committee.

Wendy Watson, M.D., Co-Chairperson
David Bresnahan, M.D., Co-Chairperson
FMLH Institutions Research Committee
Date Signed: 11-17-98

Kevin J. Murray, M.D., Chairman
Human Research Review Committee
Date Signed: 11/20/98

11.11.98

8701 Watertown Plank Road
P.O. Box 26509
Milwaukee, Wisconsin 53226-0509