

Women's Views on Breast Cancer Risk and Screening Mammography:

A Qualitative Interview Study

E. SILVERMAN, PhD, S. WOLOSHIN, PhD, L. M. SCHWARTZ, PhD, S. J. BYRAM, PhD, H. G. WELCH, PhD, B. FISCHHOFF, PhD

Background. To promote informed decision making about mammography, clinicians are urged to present women with complete, relevant information about breast cancer and screening. Understanding women's current beliefs may help guide such efforts by uncovering misunderstandings, conceptual gaps, and areas of concern. **Objective.** The authors sought to learn how women view breast cancer, their personal risk of breast cancer, and how screening mammography affects that risk. **Methods.** Forty-one open-ended semistructured telephone interviews with women selected from a national database by quota sampling to ensure a wide range in demographics of the participants. **Results.** Almost all respondents viewed breast cancer as a uniformly progressive disease which begins in a silent curable form (typically found by mammograms) and, unless treated early, invariably grows, spreads, and kills. Some women felt that any abnormality found must be treated, even if it was not malignant. None had heard of potentially nonprogressive cancers, and when informed, most felt that the uncertain prognosis of such lesions reinforced the need to find and treat disease as soon as possible. Women expressed a wide range of views about their personal risk of breast cancer. Although some saw breast cancer as a central threat to their health, many others cited heart disease, other cancers, violence, and trauma as greater concerns. Most recognized the importance of "uncontrollable" factors for breast cancer such as age, sex, family history, and genetics. However, other "controllable" factors with little or no demonstrated link to breast cancer (e.g., smoking, diet, toxic exposures, "bad attitudes") were given equal or greater prominence, suggesting that many women feel considerable personal responsibility for their level of breast cancer risk. Similarly, although women recognized that mammography was not perfect, almost all believed that failure to have mammograms put one at risk for premature and preventable death. When asked how mammography worked, almost all repeated the message that "early detection saves lives," suggesting that advanced cancer (and perhaps most cancer deaths) reflected a failure of early detection. The belief in the benefit of early detection was so strong that some women advocated scaring other women into getting mammograms because it is "better to be safe than sorry." **Conclusions.** Women view breast cancer as a uniformly progressive disease rarely curable unless caught early. The exaggerated importance many attribute to a variety of controllable factors in modifying personal risk and the "danger" seen in failing to have mammograms may lead women diagnosed with breast cancer to blame themselves. **Key words:** breast cancer; decision making; communication. (*Med Dec Making* 2001;21:231-240)

Received 14 August 2000 from the VA Outcomes Group, White River Junction, Vermont (ES, LMS, SW, HGW); the Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, New Hampshire (LMS, SW, HGW); Norris Cotton Cancer Center, Lebanon, New Hampshire (LMS, SW); Carnegie Mellon University, Pittsburgh, Pennsylvania (SJB, BF); and Batelle Pacific Northwest National Laboratory, Richland, Washington (SJB). Revision accepted for publication 9 January 2001. Drs. Woloshin and Schwartz are supported by Veterans Affairs Career Development Awards in

Health Services Research and Development and a New Investigator Award from the Department of Defense Breast Cancer Research Program (DAMD17-96-MM-6712). The views expressed herein do not necessarily represent the views of the Department of Veterans Affairs or the United States Government.

Address reprint requests to Dr. Schwartz: VA Outcomes Group (111B), Department of Veterans Affairs Medical Center, White River Junction, VT 05009.

Background

To promote informed decision making about mammography, clinicians are urged to present women with complete, relevant information about breast cancer and screening.¹⁻³ The expectation that clinicians can effectively communicate such information to their patients is based on a number of key assumptions. One fundamental assumption is that clinicians and patients think about breast cancer and screening in ways that are essentially similar. To the extent that clinicians and patients do not have similar “mental models” about these issues, communication becomes increasingly difficult.⁴ For example, a physician counseling a 50-year-old to undergo screening mammography may be met with fear and resistance because the patient believes that breast cancer is almost never treatable, that the radiation exposure from mammography is substantial, and that most women who undergo screening will find out they have cancer.

Although there have been countless efforts to teach women facts about breast cancer and mammography, little attention has been devoted to ensuring that women have the appropriate conceptual framework to make these facts meaningful. The purpose of this study is to better understand women’s current set of knowledge and beliefs about breast cancer and screening mammography as a 1st step in helping clinicians and other communicators more effectively counsel patients.

Methods

BACKGROUND ON MENTAL MODELS

Work by experts in risk communication has demonstrated the importance of designing communications about technical subjects (e.g., radon in the home, electromagnetic fields) in ways that help the nonexpert audience adjust its mental model closer to that of the experts. Otherwise, presenting facts without the appropriate conceptual framework may result in confusion rather than education. One method for designing effective communications developed by Fischhoff and others at Carnegie Mellon University consists of 3 basic

steps:⁴ 1st, summarizing the available scientific evidence in a way that reflects how an expert would view things; 2nd, learning how the nonexperts in the target audience views the same phenomena by conducting in-depth interviews taking care to be as nondirective as possible (to avoid introducing new concepts to the interviewee); and 3rd, by comparing these expert and nonexpert mental models, it is possible to identify misunderstandings and conceptual gaps that will need special attention in any subsequent communication.

OVERVIEW

To complete the 2nd step of the mental models methodology,⁵ we conducted in-depth interviews with women to better understand how they think about their personal risk of breast cancer and the potential benefits of screening.

SAMPLING

The purpose of this study was to elicit beliefs held by women about breast cancer and mammography rather than to test a specific set of hypotheses. Our sampling strategy was therefore designed to identify a relatively small number of women across a wide array of demographic variables to undergo intensive, in-depth interviews. Prior experience suggests that about 30 to 40 subjects are sufficient (after this number of interviews, few new ideas emerge).⁴

Women were randomly selected from a commercially maintained sample frame (National Decision Systems [NDS], Atlanta, Georgia). Selected women were contacted by phone and asked about their age, race, education, income, and whether they had had breast cancer. Because the focus of this study was on screening, women with a history of breast cancer were excluded. Participants were offered \$20 for completing the interview and a personalized breast cancer risk assessment based on the Gail model.⁶ To obtain a sociodemographically diverse sample of women (to capture a broad range of views on mammography), we used quota sampling to select women in each of 4 age categories (younger than 40, 40 to 49, 50 to 69, older than 70), 2 household income categories (\$25,000 per year or less, more than \$25,000 per year) and 3 ethnicity categories (white, black, other).

Table 1 • Participant Characteristics (*N* = 41)

	Percentage
Demographics	
Age	
Younger than 40	15
40 to 49	37
50 to 69	34
70 or older	15
Race	
White	51
Black	24
Asian	12
Hispanic	7
Native American	5
Annual household income	
Less than \$25,000	51
Education	
Did not finish high school	20
High school graduate	41
College degree	39
Ever had a mammogram	80
Breast cancer risk factors	
Family history of breast cancer	12
Personal history of breast biopsy	23

To fill our quota sampling, we approached 191 women randomly selected within strata defined by census tract income and age provided by NDS (a commercially available sampling frame). Ninety-eight women were disqualified because they did not meet racial, age, or socioeconomic criteria, 52 refused, and 41 agreed to participate. Of note, 35 of these women requested the personalized breast cancer risk report, and all 41 accepted the \$20 payment.

Table 1 shows the resulting demographics of 41 women in the final sample.

INTERVIEWS

We used an open-ended protocol designed to let respondents express themselves completely before the interviewer introduced new or unfamiliar concepts. The 1st question, for example, was "Please tell me everything you know about mammograms." Women were allowed to respond and then the following prompts were used to encourage them to tell more:

"Anything else?"

"Can you tell me more?"

"Anything else—don't worry about if it's right, just tell me what comes to mind."

"Can you explain why?"

The interviewer kept track of concepts raised and followed up on each concept. For example, the interviewer might say, "You mentioned that mammograms sometimes miss things, please tell me more about what you meant." Once the spontaneously mentioned concepts were exhausted the interviewer probed any other areas on the checklist that had not been discussed (Table 2 summarizes the domains of interest). These probes were carefully worded to avoid giving the respondent information or leading her to a particular response. For example, respondents were asked to explain what a mammogram is and why it is used before they were asked about its effectiveness. Throughout the process, interviewers were given a "stop" rule to avoid creating undue pressure to "say something." When a subject said, "I don't know," and it appeared as if her knowledge was exhausted (after gentle probing), the interviewers did not probe further or ask additional questions on that particular topic. The stop rule acknowledged that "I don't know" is a valid and desirable response (if it reflects the respondent's knowledge).

Each interview took about 1 h. All interviews were audio-recorded with the respondent's permission and transcribed for later analysis.

INTERVIEWER TRAINING

Before beginning the study, we conducted 12 pilot interviews using a local registry of female veterans from northern New England. Two interviewers conducted all interviews. (Both interviewers had master's-level education and 1 was a doctoral candidate in Behavioral Decision Theory.) To reduce the variability between them, the interviewers reviewed the protocol and completed these pilot interviews. After an iterative review process of these 12 pilot interviews, the interviewers attained similar levels of response detail and interview length.

CODING

After transcription, each response (sentence or group of sentences) was coded using a prespecified protocol based on the following domains: natural history of breast cancer, personal risk of breast cancer, screening mammography, emotional re-

Table 2 • Examples from Coding Protocol

Domain	Specific Component of Coding	Examples of Women's Responses
Natural history of breast cancer	Breast cancer is uniformly progressive	At first it's benign, and then it reaches some point where it goes crazy . . . like a malignancy. And the malignancy kills you . . . during the early window when it's benign . . . it can be removed
	Only early disease is treatable	If you catch it early, you can stop the cancer. If the cancer spreads before you have had the mammogram . . . it cannot be helped
Personal risk of breast cancer	Breast cancer is devastating or deadly	I think there's not a woman in the world that doesn't know about breast cancer, that doesn't worry about it because it is such a horrible, horrible thing.
	Breast cancer is the biggest threat to health	I would say it's probably the biggest threat to women my age. I consider it a threat as much as anything else.
Screening mammography	Early detection saves lives	If I get a mammogram in time . . . life can be saved. [Early detection] saves lives by not letting it spread to the rest of your body. I depend [on mammograms] to save my life actually.
	Less "bad" treatment 100% accurate	[Early detection] makes the difference between you losing your breasts or not. They claim it's supposed to be 100%, so I'll go by what they say. . . . whereas mammography, you know nothing was missed.
	Very accurate	It's pretty, pretty accurate. It must be really good, otherwise they wouldn't have it.
Emotional response to testing	Gives peace of mind	It always makes me feel better when it comes out good. It's just a sense of relief I have after finding out that everything is OK for this year.
	Causes anxiety	I think a lot of people fear it so much that they almost don't want to know.
	Desire to know stronger than potential anxiety	So that might be a consequence . . . you would know if something is wrong. Even if it turns out that it isn't. Then you kind of worry for a while, but to me it's a worthwhile thing to know.
Recommendations and decision making	No uncertainty about having a mammogram	I feel every woman should have one. If someone objected to having it done, why they're taking their own life in their hands I guess. Ignorance is why someone would not get a mammogram.

response to testing, mammography recommendations, and decision making.

Table 2 gives some examples of individual codes within each domain of interest and some of the women's responses assigned to those codes. To assess reliability of the coding, one-third of the interviews were coded independently by 2 investigators. Interrater reliability was "substantial" ($\kappa = 0.72$).⁷

ANALYSIS

Women's responses were analyzed using a combination of 2 methods. Responses to specific questions were tabulated using the coding scheme described. To supplement the coding, we used a free text database (NUD*IST®) to help identify recurrent themes. NUD*IST® (Non-numerical Unstructured Data Indexing Searching and Theorizing) is a computer software package designed to support qualitative analyses where text can be linked to specific codes. We linked each interview to the manual codes. This allowed us to go back and read

all the coded text on a particular concept (e.g., all statements about the potential harms of mammography).

Results

PARTICIPANT CHARACTERISTICS

The quota sampling recruited women with diverse demographic characteristics (see Table 1). The age of participants ranged from 27 to 84, with a mean of 53. Racial groups represented were white, black, Hispanic, Asian, and Native American. Approximately half of the women estimated their annual household income to be less than \$25,000 (200% of poverty level). Eighty percent had a high school diploma or higher. Eighty percent of participants had had at least 1 mammogram, a finding in line with data from a recent, nationally representative survey sponsored by the National Centers for Disease Control.⁸

HOW WOMEN VIEW THE NATURAL HISTORY OF BREAST CANCER

Figure 1 compares the women's view with a plausible biological model of the natural history of breast cancer. Women viewed breast cancer as a uniformly progressive disease, highly curable at an early stage, but deadly and devastating if found late. Although women distinguished between benign breast disease and breast cancer, there seemed to be a recurrent theme among some women that even "benign" abnormalities in the breast (e.g., cysts) had the potential to develop into cancer. As 1 woman described it, "At first it's benign, and then it reaches some point where it goes crazy . . . like a malignancy. And the malignancy kills you During the early window when it's benign . . . it can be removed"

In contrast, the biological model of breast cancer is one of a heterogeneous disease, associated with a chance that some early disease may not progress or, in fact, may regress.^{9,10} Thus, whereas there is considerable uncertainty in the medical community about the natural history of potentially non-progressive cancers such as Ductal Carcinoma In Situ (DCIS), only 1 woman (of the 41 interviewed) had heard of potentially nonprogressive breast cancers. Additionally, from a biological standpoint, benign disease is viewed as a separate entity, not as a stage in the progression of malignancy.

HOW WOMEN VIEW THEIR PERSONAL RISK OF BREAST CANCER

Figure 2 classifies responses to perceived risk factors as either controllable or uncontrollable. Although a similar number of women mentioned controllable and uncontrollable factors at least once (36 vs. 38, respectively), controllable factors were mentioned more often (176 mentions vs. 118 mentions of uncontrollable factors). We present the number of mentions in the figure rather than simply count how many women mentioned something at least once to give a better representation of the strength of beliefs.

To assess how much of a personal threat women felt from breast cancer, they were asked the following questions: "How much of a threat do you consider breast cancer to be?" and "Compared to average women your age, do you think your risk of breast cancer is higher, lower, or about the same?"

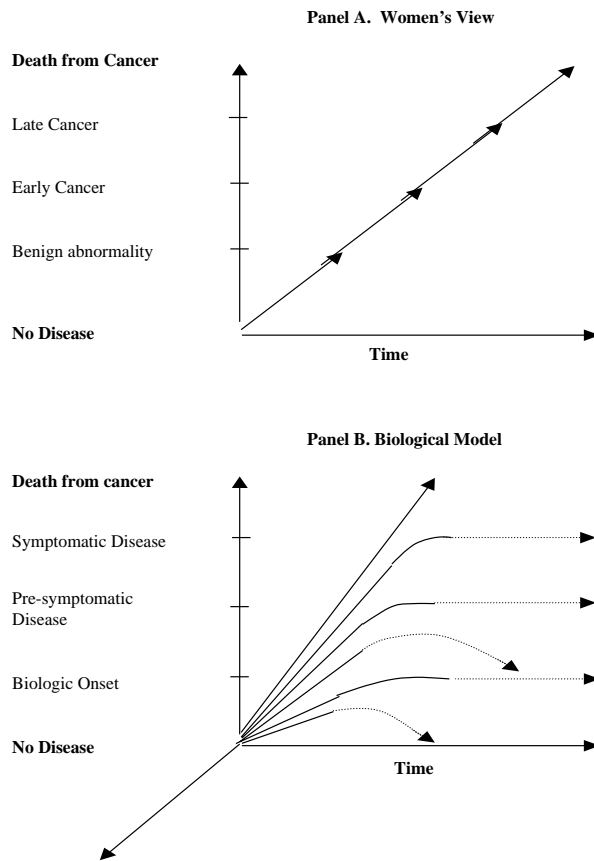


FIGURE 1. Compares the women's view of the natural history of breast cancer to a biological model. Women viewed breast cancer as a naturally progressive disease, some believing that even "benign" abnormalities could develop into cancer. In contrast, the biological model classifies benign disease as a separate entity and breast cancer as a heterogeneous disease, not all of which may progress.

(see Table 3). Most women (71%) recognized other potential threats to their health, the most common being cardiovascular disease. Forty-six percent of women felt that other health threats were more important than breast cancer. Only one-quarter of women felt that breast cancer represented the biggest threat to their health, or that it was "as big as anything else." In thinking about breast cancer, one-third of the women spontaneously related anecdotes about a friend or family member who had suffered from breast cancer and expressed fear of similarly dying young or leaving children behind.

HOW WOMEN VIEW THE VALUE OF SCREENING MAMMOGRAPHY

Table 4 lists women's responses to questions about the benefits and harms of mammography. All

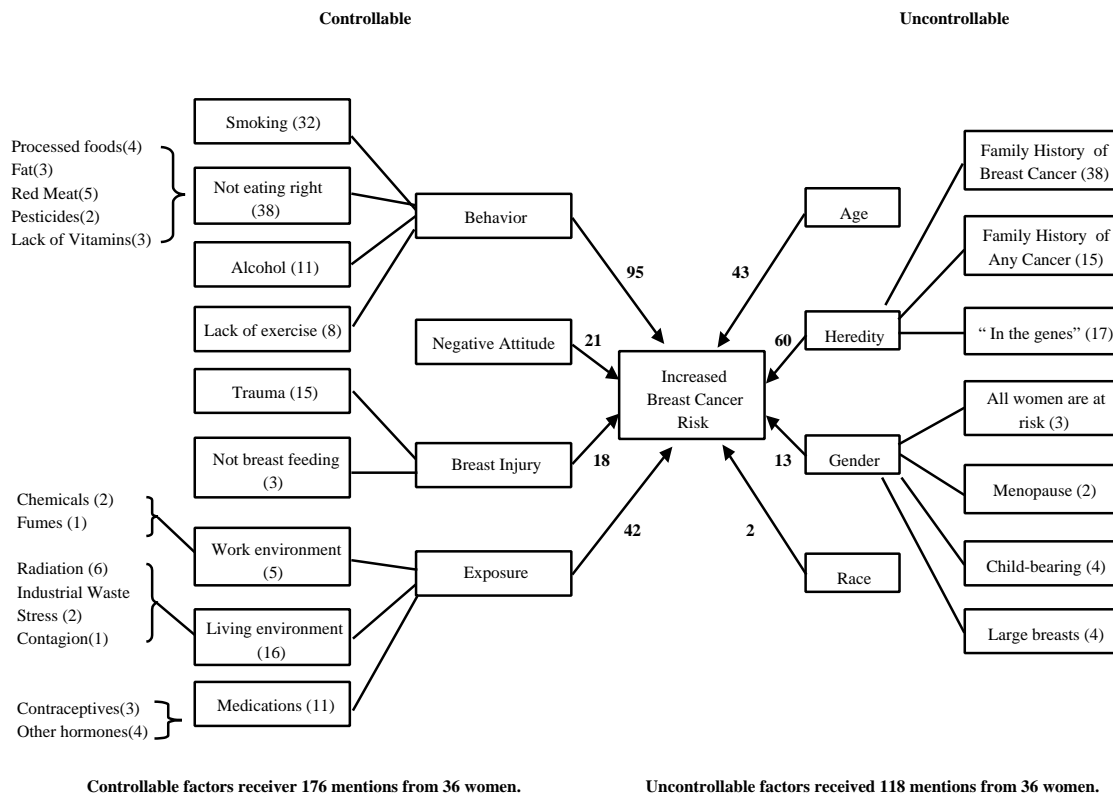


FIGURE 2. Women’s view of breast cancer risk factors. Numbers indicate the total mentions each factor received.

but 1 woman felt mammography was beneficial, paraphrasing the idea that “early detection saves lives.” Failure to have a mammography is seen as putting oneself at risk of preventable death. More than half of the women saw getting a mammography as a way of minimizing potential regret, or, in several women’s words, “better safe than sorry.” The value of knowing—good or bad results—was important to most women. Many women viewed this as an opportunity to take action, although some never linked the value of knowing with any specific treatment benefit. Gaining peace of mind from a negative test was also important to most women.

Most women had confidence in the accuracy of mammography. Nearly half thought that mammograms were either 100% accurate or very accurate, and 85% felt that mammography seldom missed cancers. The idea that false negative results were possible was unnerving. Although most women were fairly accepting, saying, “If it happens, it happens,” others stated, “You just keep watching it,” and “that’s why I do a monthly exam,” perhaps reflecting fears of not detecting disease early enough. Many women (56%) recognized that false positive results occur. In contrast to the published

Table 3 • Women’s views of threats to their health (N = 41)

	Percentage
Breast cancer	
View breast cancer as	
Biggest threat or “as big as anything else”	24
Moderate threat	7
Small threat	32
No threat	7
Response could not be categorized	30
“Compared to other women your own age, your risk of breast cancer is”	
Lower than average	22
Average (the same as)	56
Higher than average	22
Associate deadliness and devastation of breast cancer with late detection	73
Health threats other than breast cancer	
Mentioned any perceived health threat other than breast cancer	71
Specific threats:	
Cardiovascular	
“Heart problem”	39
Hypertension	12
Stroke	7
High cholesterol	7
Other cancers (especially related to family history of cancer)	24
Other chronic health conditions (e.g., diabetes, asthma, arthritis)	24
Motor vehicle accidents	7
Violence	5

Table 4 • Benefits and Risk of Mammography (N = 41)

	Percentage
Benefits	
Physical benefits	
“Early detection saves lives” (less breast cancer deaths, more cures)	93
Less morbidity from cancer (less advanced disease, less “bad” treatment)	88
Psychological benefits	
Importance of knowing (good or bad results)	93
“Peace of mind” with negative test	78
Minimizes potential regret	58
Harms	
Spontaneously answers:	
“No downsides to mammography”	49
After prompting to discuss side effects:	
Pain	73
Radiation or x-rays	54
Anxiety, embarrassment	46
Potential for unnecessary surgery (false positives)	5
Detection of potentially nonprogressive cancer	0

views of many experts stressing the harms of false positive results,¹¹⁻¹⁴ the women viewed false positives as an acceptable part of screening. They were equally accepting about the cascade of events that might follow a screening mammogram.

Concern about other potential harms of mammography was not prominent. Half of the women spontaneously answered “no” when they were asked if mammography had any downsides. With prompting to discuss side effects more in depth, however, women most often mentioned the physical pain of getting a mammogram. Most found mammograms to be painful and about half recognized that there was some radiation exposure.

EMOTIONAL RESPONSE TO TESTING

Although nearly half of the women associated getting a mammogram with anxiety or embarrassment, the sense of relief from having a “normal” result seemed to outweigh any emotional or physical discomfort. A large majority (88%) stated they would be fearful upon learning that they had had an abnormal mammogram, even though they realized that an abnormal mammogram would not necessarily mean cancer. A similar percentage assumed that an abnormal mammogram would lead to further tests or a biopsy. Forty-six percent of women explicitly viewed additional tests as desirable, because the sense of relief and safety that would come from a negative biopsy would overwhelm any potential downsides. Figure 3 is a

schematic depiction of the potential cycle of dread and relief women may experience as a result of screening.

MAMMOGRAPHY RECOMMENDATIONS AND DECISION MAKING

When asked what information they thought was important for making decisions about mammography, more than half (51%) of women focused on the mechanics of how a mammogram is done. Twenty percent said that knowing what a mammogram is looking for was important, and 20% wanted information on the benefits of mammography. Only 3 women mentioned wanting to know more about accuracy. In terms of global recommendations, 20 women made the statement that every woman should have a mammogram, and

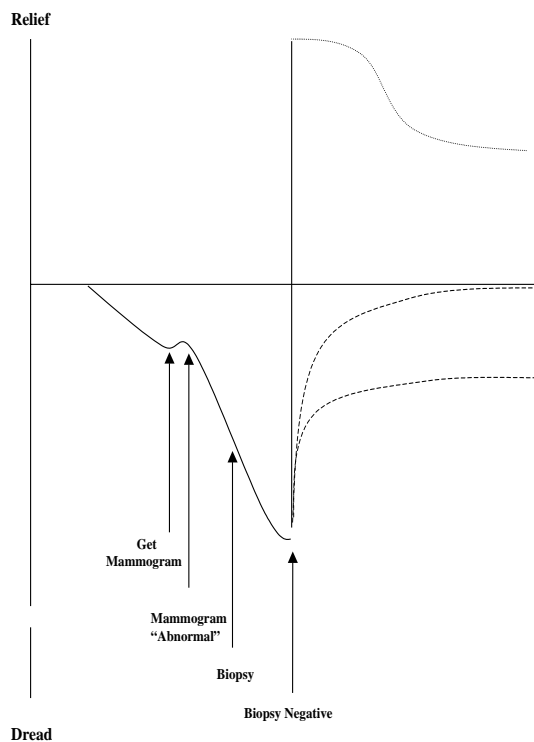


FIGURE 3. Emotional response to false positives. The potential cycle of dread and relief women may experience as a result of screening. The net emotional effect of a false positive mammogram is unknown. Women's views on false positive mammograms were as follows: 46% acknowledged some fear or anxiety in getting a mammogram, 88% said they would be scared or upset if their mammogram were “abnormal,” 95% knew that an abnormal mammogram did not necessarily mean cancer, 85% believed that an abnormal mammogram would require further tests (repeat mammogram or biopsy), and 46% explicitly viewed further tests as desirable.

most of those said they would encourage a family member or friend to have one. More than one-third of the women interviewed (37%) went as far as to say that any woman who did not have a mammogram was “stupid” or “crazy.”

Comment

The concept of informed decision making assumes that the decision maker has assimilated the relevant facts and can therefore make decisions based on preferences. In deciding about screening mammography, a woman would be considered informed if she understood the potential benefits and harms of screening. Although similar mental models need not lead to similar decision making (i.e., preferences may differ), the more closely the woman’s mental model of mammography resembled that of an “expert,” the more informed her decision would be.

The women’s model did differ from the expert model in several important ways (see Table 5). Women interviewed tended to see breast cancer as both a more aggressive and a more preventable disease than do experts. Moreover, only 1 woman knew about the possibility of nonprogressive cancer. In contrast to experts, women believed that even benign lesions have malignant potential—making it “safer” to remove them. Finally, women had an exaggerated sense of the importance of controllable factors in determining risk—many of which have weak or unproven relationships with breast cancer risk.

Women and experts valued the potential harms of screening differently. Although women were aware of the imperfections of mammography such as false negative and false positive results (including the idea of downstream consequences such as “unnecessary biopsies”), they seemed to be less bothered by such outcomes than many of the experts writing in the screening literature.^{11–14} Half the respondents did not spontaneously note any harms, and even with prompting, few emerged. False positive results (and related downstream consequences) were typically seen as an acceptable consequence of screening but not as a harm. In essence, the utility of learning one did not have cancer outweighed the dysutility of the false alarm. Moreover, since many women felt any abnormality

Table 5 • Comparison of Women’s and Experts’ Models of Breast Cancer and Mammography

Concept	Women’s Model	Expert Model
Natural history	Uniformly progressive	Heterogeneous spectrum Recognize existence of potentially nonprogressive forms
Curability	Generally only if caught “early”	Prognosis decreases with higher stage, but cure still possible Recognize a chronic form of disease
Benign lesions	Have malignant potential and it may be “safer” to remove them	Recognize a distinct set of benign lesions with no malignant potential
Risk factors	Correctly recognize uncontrollable factors such as family history/genetics, endogenous hormones Mistakenly attribute risk to breast size Mostly controllable factors such as smoking, diet (e.g., red meat, processed foods), radiation exposure, pollution	Primarily uncontrollable factors such as age, race/ethnicity, genetics/family history, endogenous estrogen exposure Few controllable factors (all with weak association such as exercise, alcohol use, exogenous hormones)

had malignant potential, no biopsy was really “unnecessary.”

Our study has a number of limitations that must be acknowledged. First, since our purpose was to learn about the range of ideas women hold about breast cancer and mammography, we performed a relatively small number of in-depth interviews with women across a spectrum of age, income, and race/ethnicity. Although we believe our method allowed us to pick up on ideas that occur with some frequency, however, we cannot use our data to estimate the prevalence of ideas. Moreover, because 80% of participants reported having had at least 1 mammogram, our findings may not reflect the views of women who have never undergone mammography. Further research should be undertaken to explore the views of women who have not undergone mammography. Second, the coding of interviews is subjective. Although we were careful to train the interviewers and were able to demonstrate substantial agreement between coders, other coders may have interpreted responses differently.

The differences noted between the women’s and the experts’ mental models raise important

questions about the extent to which women—based on their current understanding of the issues—can make informed decisions about screening. For example, many women seem to have internalized the idea that almost any breast abnormality can lead to cancer, that they live in an environment replete with breast cancer causing factors, and that their best hope is to find and aggressively treat all cancers early. It is easy to appreciate why, under this model, a number of respondents thought women who did not go for mammograms were “crazy.”

Finally, only a single respondent understood that some cancers might be nonprogressive or progress so slowly that they never affect the woman's health. Thus, although some experts worry about overtreatment of lesions destined to never progress (such as many DCIS,^{15–17} an increasingly common form of screen detected breast cancer), the idea of overtreatment (and the associated surgical risk, physical deformity, psychological trauma) may be completely foreign to the majority of women. If informed decision making is a real goal, we need to help women fill in this important gap in how they understand the phenomenology of breast cancer. Knowing what to say about potentially nonprogressive lesions or the possibility of overdiagnosis is a great challenge to those counseling women about screening. A start might be to simply acknowledge 2 things. First, not all “cancers” detected by mammography progress. Second, because the natural history of ductal carcinoma in situ is not well understood, women diagnosed with these lesions face great uncertainty.

There are 2 disturbing implications of our work. The 1st relates to women deciding about screening mammography. The messages that women are receiving about mammography are skewed in favor of screening. Some may argue that, given the data about the efficacy of screening mammography, the whole point of public messages about mammography is to increase the number of women complying with screening recommendations. In fact, this message has been widely institutionalized in performance measures or “report cards” (such as the Health Plan Employer Data and Information Set, “HEDIS,” a standardized test of the quality of care provided by health plans) that reward high screening rates whether or not patients make informed decisions. On the other hand, others may argue that fundamental respect for patients requires balanced messages that help patients make

decisions concordant with their own values, even if such decisions violate professional recommendations.

The 2nd implication, perhaps even more concerning, applies to women who develop breast cancer. The model we observed suggests that women diagnosed with (or dying of) breast cancer may blame themselves. Since most of the perceived risk factors are controllable (such as smoking, diet, and attitude), it is easy for everyone concerned—family, friends, providers, and the patient herself—to assume that a woman with breast cancer indulged in some risky behavior and is therefore responsible for her disease. Furthermore, if the woman had not been getting regular screening mammographies, she had failed to (in one respondent's words) “do the least she could” to protect herself.

The authors would like to thank Lisa Lee for help with coding and Brenda Sirovich, MD, for technical help.

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