

Listening to Women: Expectations and Experiences in Breast Imaging

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Introduction

THOSE WHO DISCUSS breast cancer detection and diagnosis with women know that many patients have misconceptions and anxieties about mammography. Some patients may misunderstand screening recommendations of their primary care provider or receive misinformation from friends, family, or other sources. Other women might be confused by changes or updates in official recommendations about the frequency for screening mammography or the age to begin obtaining mammograms. Still others might not be aware of breast cancer mammography screening coverage by the Patient Protection and Affordable Care Act (ACA), requiring that all new private insurance and Medicare plans eliminate cost-sharing by patients. Furthermore, healthcare providers can add to the confusion if they are not informed about the latest guidance.

Anxiety about breast cancer screening can occur especially in women who have been called back for additional tests based on an inconclusive mammogram. In a recent database review of 1,723,139 women who received a screening mammogram between January 2011 and June 2013, Alcusky and colleagues found that 15% were recalled,¹ while other studies reported recall rates between 10–14%.^{2,3} Most recalls result in “false positives,” meaning that additional testing ultimately yielded a benign outcome. Additional tests can include diagnostic mammography, breast ultrasound, breast biopsy, or magnetic resonance imaging. The majority of recalls reveal normal tissue, cysts, or other benign processes.⁴ The denser the breast tissue^{5–8} and the more annual mammograms a woman has had, the greater the probability of a callback and a false positive finding. False positives have been shown to increase patient anxiety in the short term,⁹ temporarily reduce quality of life,¹⁰ and lead to worries about breast cancer that can last for several years beyond the resolution of a false positive diagnosis.¹¹

Anxiety and fear have been reported to have a major impact on breast cancer screening behaviors.¹² As Harvey and colleagues note in a recent report, behaviors and responses to healthcare screenings can vary based on race/ethnicity and

socioeconomic factors,¹³ perhaps helping to explain the greater fear of the healthcare system among African-American women.¹⁴ This undoubtedly plays a role in why African-American women present for diagnosis at later stages of breast cancer.¹⁵ We do know that almost all women experience increased anxiety when faced with finding a possible breast screening abnormality.¹⁶

Breast cancer is the most common cancer in U.S. women.¹⁷ The National Cancer Institute (NCI) of the National Institutes of Health projects 231,840 new cases of breast cancer in U.S. women and 40,290 deaths from the disease in 2015.¹⁸ NCI further estimates that 12.3% (1 in 8) of U.S. women with average risk will be diagnosed with breast cancer during their lifetime. Mortality from breast cancer has decreased significantly since 1990, probably related to improved mammography technology and detection, increased public awareness of the value of screening, and more effective treatments. Despite these improvements, breast cancer remains a serious health concern and is the second leading cause of cancer death among all women. There is one notable exception, which is for Hispanic women, in whom breast cancer is the number one cause of cancer death.¹⁷

Mammography screening is highly effective at detecting existing disease and reducing mortality. It has been associated with a 19% reduction in breast cancer deaths.¹⁹ The likelihood that mammography will detect existing breast cancer is 70% to 90% in most women; the exception is women with dense breast tissue where the sensitivity falls to 30 to 48%.²⁰ Newer screening technologies including digital breast tomosynthesis (DBT) may yield even better results. This technology has the ability to both increase invasive cancer detection and decrease false positive results.^{4,21–24}

In 2014, The Society for Women's Health Research conducted a national survey to assess women's knowledge and attitudes regarding mammography. We sought to identify misunderstandings about mammography among women of different racial/ethnic and age groups. We further sought to identify barriers that keep women from seeking screening mammography and motivators that would propel women

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toward screening. We queried participants about their emotional responses to being recalled for follow-up diagnostic testing and about what might lead them to use one mammography center over another for their breast cancer screening.

Our results clearly showed areas where there are successes and areas where there are challenges. Our results demonstrate opportunities and potential ways forward to improve access and utilization of screening mammography. The authors believe that with improved access and utilization paired with new technologies, there may be potential for improved outcomes.

Methods

To assess knowledge, attitudes, and behaviors of women in the U.S. relative to mammography, we engaged Phoenix Marketing International of Rhinebeck, New York, to design and administer a survey questionnaire. The survey was conducted in September to October 2014 to a sample of 3,501 women in four age groups—18–39 years ($n=357$), 40–50 ($n=947$), 51–64 ($n=1243$), and 65–93 ($n=954$)—and of varied race/ethnicity. Women in the youngest age group were most likely referred for mammography by a healthcare provider because of a high risk of breast cancer.

Eligible women participated by Internet via telephone interviews or through personal intercepts in public locales. The participants completed the survey, which averaged around 15 minutes online or in person, or 30 minutes over the phone. The survey was administered in English or Spanish.

Quotas were set in a number of areas to ensure similarity to the 2010 U.S. Census and mammogram utilization rates. Selection of participants was skewed toward women who have had at least one mammogram.

The survey questionnaire was pilot tested and modified to improve clarity. The final questionnaire contained questions to assess knowledge of the benefits of mammography and health insurance coverage under the ACA; to assess barriers to and motivators for acquiring a mammogram; and to assess what women want from insurance coverage and technology advances as it relates to their feelings of acquiring a screening mammogram and to being called back for additional diagnostic testing. The questionnaire consisted of 10 screening questions such as ethnicity, income, and age to make sure sample quota were met, and 39 survey questions.

Participants self-identified as Hispanic, Black or African American, Asian, White, American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, multiracial, or other. For purposes of data analysis, all but Hispanic, Black or African American, and White women were grouped as “Others.”

Hispanic and Black women were intentionally oversampled to better reveal any differences in knowledge, attitudes, and behaviors toward mammography. As such, the data were weighted to account for the oversampling. The sample intentionally does not represent the U.S. population of women.

Comparisons were made across a wide range of demographic characteristics. Other comparisons included health literacy, history of mammography, breast health, and health insurance. Statistical comparisons on data cuts were made at the 95% confidence level. The margin of error for the full

sample of women is ± 1.66 . The margin of error among Black women is $\pm 4.73\%$ and among Hispanic women is $\pm 4.06\%$.

The women were queried about their health insurance status (insured or uninsured) for comparisons to frequency of mammogram (e.g., “How often do you get a mammogram?”). They were also asked to rate items on a list of possible impediments to their scheduling and keeping an appointment for mammography (e.g., high cost, lack of adequate health insurance, lack of transportation, lack of child care). Items were rated on a scale of 0–10, where 0 was strongly disagree and 10 was strongly agree.

Additional questions sought to determine women’s knowledge of the importance and timing of mammography, the awareness of the no-cost-to-patient coverage provided as a benefit of the ACA, and the motivators and barriers to seeking mammography.

“Mammography literacy” was determined by participants’ responses to questions about health benefits and risks associated with mammography (e.g., “I had one normal mammogram, so I don’t need another.”).

Knowledge of the ACA benefit (“ACA literacy”) was determined by respondents answering “yes” or “no” to a question asking, “Were you aware that mammography is provided at no cost as part of the Affordable Care Act (ACA) preventative services benefits?” ACA awareness and mammography literacy were compared across racial/ethnic and age groups and according to whether the women had a prior mammogram.

Participants were presented with a list of possible motivators (e.g., a healthcare provider’s recommendation, a friend’s recommendation, breast cancer awareness ads) for scheduling mammography and asked to rate the motivators on a scale of 0–10. Findings were further stratified by race/ethnicity. The women were also asked to respond to a list of items that would affect their selection of a site for mammography services.

Women who reported a prior mammogram were also questioned about their response (i.e., scared, stressed, sad, angry) to a callback for additional testing and their degree of interest in advanced breast screening technologies that would lower the likelihood of a callback. SPSS software (IBM Corporation, Armonk, NY) and MarketSight software (MarketSight LLC, Newton, MA) were used to conduct the data analysis.

Results

A total of 3,501 women participated in the survey, providing information about their knowledge, attitudes, and behaviors relative to mammography. The women who participated and the weighting approach that was intentionally employed skewed the sample to include women who have had at least one mammogram.

The majority (63%) were age 51 years and older (Table 1), representing the U.S. mammogram incidence; a small number (10%) represented a younger demographic (age 18–39) that had been referred for mammography by a provider. Participants self-identified as Hispanic, Black, White, or Other (Table 1).

Although most women strongly agree that mammograms are important, many are not actually getting them.

TABLE 1. PARTICIPANTS BY AGE AND RACE/ETHNICITY

Age	Hispanic	Black	White	Other	Total no. (%)
18–39	68	36	211	42	357 (10%)
40–50	155	120	618	54	947 (27%)
51–64	208	157	832	46	1243 (36%)
65+	151	116	658	29	954 (27%)
Total	582	429	2319	171	3501 (100%)

Participants rated the importance of mammography on a 0–10 scale. They either agreed (8–10 rating) that mammography is important or felt neutral or disagreed (0–7). Seventy-eight percent (78%) agreed that mammography should be conducted in addition to a breast exam by a healthcare provider and a breast self-exam. Slightly over half (54%) reported having an annual mammogram.

Women with health insurance were two times more likely than their uninsured counterparts to have an annual mammogram (57% vs. 23%, respectively). Sources of health insurance were employer or labor union, healthcare exchange (individual, family, or business), Medicare, Medicare supplemental plan, Medicaid, or the military/U.S. Department of Veterans Affairs. A full 30% of uninsured women report never having a mammogram compared to 10% of insured women. Among uninsured and insured women who do have mammograms, 23% of the former report a 5-year gap between mammograms compared to 9% among the latter (Fig. 1).

Primary barriers to scheduling and attending mammography appointments among those women who have had mammograms were high cost (16%) and lack of adequate insurance coverage (16%). Components of cost included travel cost, wages lost, child care, and other unspecified costs. Younger women and Hispanic women report greater cost issues across the board.

The leading secondary barriers for Hispanic women were “out of the way or inconvenient” and “unable to get a referral.” For Black women, secondary barriers were mainly “lack of transportation” and “unable to get information on cost.” White women and all others report “out of the way or inconvenient” and “lack of transportation” as their leading secondary barriers.

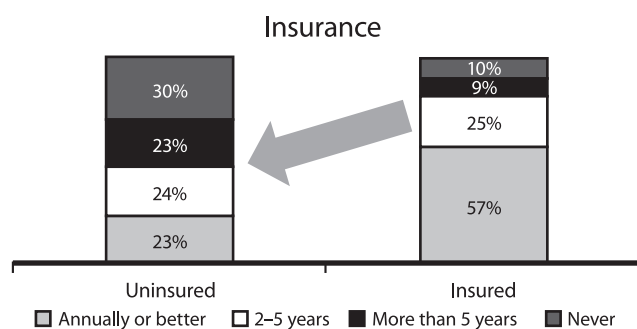


FIG. 1. Insured women and uninsured women having mammograms were similarly likely to undergo mammography every 2–5 years (25% and 24%, respectively). Being uninsured created a disparity between ever and never having a mammogram: 30% of uninsured women compared to 10% of insured women report never having a mammogram.

To assess health literacy with regard to mammography, women were asked to agree or not to agree regarding statements about mammography (Table 2). Thirty-six percent (36%) of women correctly answered at least six of seven questions (Table 2). Thirty-two percent (32%) were aware that mammography is a no-cost-to-the-consumer preventative services benefit under the ACA. The majority (63%) of women were unaware of this ACA no-cost provision; 5% were unsure.

A further breakdown by age showed that women over 50 and women with a prior history of mammography had slightly better knowledge of mammography (see Table 2 for questions) than women in the 40–50 age group, and women under 50 and those without prior mammography were less aware of ACA mammography coverage. Younger women and those with no prior mammogram represent opportunities for educational outreach.

Asked to rate 10 possible reasons for scheduling and obtaining a mammogram, the majority of respondents said that a recommendation from a healthcare provider (56%) and a reminder or assistance scheduling at an annual check-up (53%) were the greatest motivators. Somewhat lesser motivators were personal medical history (40%), family history of breast cancer (38%), concern based on a self-exam (37%), breast cancer awareness ads and information (33%), a family recommendation (32%), a close friend’s history of breast cancer (26%), a friend’s recommendation (24%), and insurance company reminder (22%).

The impact of the motivators for scheduling and obtaining a mammogram differed by race/ethnicity (Fig. 2). The greatest difference was seen in the influence of family and breast cancer awareness ads and information in Hispanics and Blacks compared to Whites.

TABLE 2. SEVEN QUESTIONS PERTAINING TO MAMMOGRAPHY BENEFITS/ACA

- Which of the following statements about mammography do you agree with the most?
 - Prevents the risk of getting breast cancer
 - Reduces the risk of getting breast cancer
 - Does not have any effect on the risk of getting breast cancer
- Rate your level of agreement with each of the following statements:*
 - Mammography is an important examination that should be conducted in addition to the one made by the health care provider and the woman herself.
 - If a mammogram does find something, it is too late.
 - I had one normal mammogram, so I don’t need another.
 - I don’t need a mammogram if I don’t have any symptoms.
 - The amount of radiation exposure during a mammogram is very small and the benefits are more important than the risks.
 - Were you aware that mammography is provided at no cost as part of Affordable Care Act (ACA) preventative services benefits?
 - Yes, I was aware
 - No, I wasn’t aware
 - No, I don’t think this is true

*Correct answers (0–10 scales) means one of three points selected at the correct end of the scale for questions 2–6.

Most Motivating Reasons to Schedule Mammograms

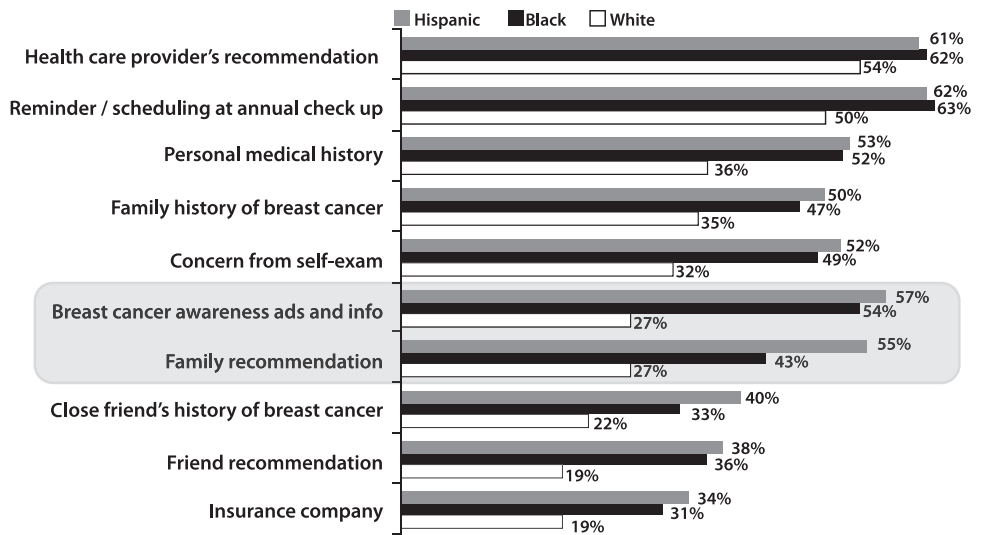


FIG. 2. Motivators for scheduling mammograms differ by race/ethnicity.

Asked about the importance of four specific factors in having a mammogram, all were rated “very important:” mammography covered by insurance, 88%; better and earlier detection, 88%; fewer unnecessary tests, 82%; and lower out-of-pocket costs, 79%.

Asked about factors that “would most likely make you want to go to a certain mammography center and least likely make you want to go there,” the highest-ranked positive factors were “fully covered under my insurance” and “has the best medical equipment.” Among the least important factors were convenient parking and recommendations from friends and family.

The emotional impact of receiving a callback for additional testing was assessed among the 47% of women who reported ever having received such a call. Eighty-nine percent (89%) were false positives. The adjectives most often attributed by the women to being recalled for follow-up testing were scared, stressed, sad, and angry. Scared and stressed were the most common responses. The emotional impact was greatest among women in their 40s (Fig. 3).

Eighty-two percent of women consider it important to have access to a mammogram that could lower the chance of

having to come back for more tests; 81% consider it important to have access to a mammogram that has a better chance than current mammograms of finding breast cancer. Asked whether they would switch insurance companies if only one insurer covered the newest technology, 20% said they would be very likely to do so; 47% said somewhat likely; and 32% said not likely.

Discussion

The current survey assesses knowledge, attitudes, and behaviors of women in the United States relative to mammography. The majority (78%) of the 3,501 participants indicated that they strongly believe that mammography is important. The survey also showed that their understanding of the benefits of mammography is low (36%), especially among Hispanic women.

The main impediments women report to their obtaining regular mammograms were high cost and lack of adequate insurance. Only 32% of participants knew that mammography is provided at no cost to patients under the ACA. Insurance coverage and education are also key factors in underutilization of mammography in this group of women.

The most common motivators for obtaining a mammography were a healthcare provider's recommendation and scheduling (or a reminder to schedule) a mammogram at an annual check-up. This is useful information to direct primary care providers on the importance of reminders.

Forty-seven percent of the women surveyed reported having received a callback at some time for additional testing, of which 89% were determined to ultimately have a benign outcome. The emotional impact of a callback was pronounced, particularly in women between 40 and 50. More than 80% of women expressed interest in having access to mammograms that improve detection and reduce the risk of false positives. These data show that educating women about the equipment available and the skill of the breast imager interpreting the exam will be critical to their experience.

In 2007, the NCI and the Centers for Disease Control and Prevention noted a decline in mammography rates

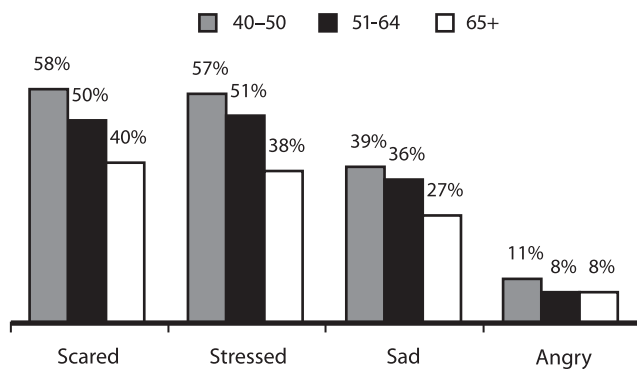


FIG. 3. The emotional impact of being called back for more testing, most pronounced among women in their 40s, following an initial mammogram.

between 2000 and 2005.²⁵ Soon afterward, SWHR brought the concerns about this finding to the attention of the U.S. House of Representatives in a congressional briefing that focused on: (1) ensuring federal funding for research and development of improved techniques to screen breast tissue; (2) ensuring the ability of women to access accredited radiology facilities with mammography capability; (3) appropriate reimbursement rates by Centers for Medicare and Medicaid Services for mammography screening and all imaging; and (4) comprehending the impact on future health outcomes if these issues were not addressed.

Recently published research confirms the downward trend in mammography screening rates, particularly among White, Latina, and Asian women.²⁶ The findings in our survey about low health literacy with regard to mammography as well as barriers to scheduling and obtaining a mammogram may help explain some of the decline. The goal of Healthy People 2020 is a breast cancer screening rate of 81.1%.²⁷ Thus, the current data indicate the continued importance of addressing the barriers and motivators to mammography screening. Among the lesser barriers to obtaining regular mammograms were transportation, scheduling, time away from work, inability to obtain information or schedule an appointment, and lack of child care.

Mammography literacy varied by age in our cohort. Women aged 40 to 50 were less likely to understand the health benefits of mammography (31%) than women 51–64 (39%) or 65 and older (42%). The same trend held for awareness of ACA coverage of mammography. Interestingly, women who had a prior mammogram were nearly three times more likely to understand mammography health benefits, suggesting that a mammography appointment could be a valuable opportunity for educational outreach.

Emotions play an important role in healthcare utilization and avoidance.¹² A callback for additional screening to rule out a suspicious finding on a mammogram is the source of considerable fear and anxiety for most women, according to this survey and other reports.¹⁴ The impact of fear and anxiety is no small matter for patients.²⁸ It can affect family, friends, work, and other aspects of well-being, and could conceivably contribute to uncertainty about the accuracy and value of breast cancer screening. Brodersen and Siersma found evidence of a harmful impact on “inner calmness” of false positive screening mammograms as far as 3 years afterward.¹¹ The effect could be longer as their study only looked at the 3-year window after a false positive result.

Over 80% of women in the current survey said they would value a more accurate mammogram that eliminates callbacks and increases detection. The national callback rate in the United States is more than double that in the United Kingdom.²⁹ In 2010, the cost of callbacks in the United States were \$1.6 billion.³⁰ It is important to reduce this callback rate for cost reasons along with protecting women’s health.

The authors believe that newer breast screening technologies like DBT have the potential to provide this much needed change. It has been shown to improve breast cancer detection rates and reduce callbacks.³⁰ While it is important to note that our survey participants are not fully aware of the potential benefits, potential risks, and additional costs of these newer technologies, our survey shows that better detection of breast cancer and fewer unnecessary recalls is what women seek.^{4,21–24,31–35}

This study has several limitations. The findings may underrepresent patients who do not access healthcare services, have not received a recommendation for a mammogram from a healthcare professional, do not speak English or Spanish, or have limited access to the internet or telephone, among other reasons. Further, the question about frequency of mammography to compare the rate of annual mammograms to the belief in the importance of mammography does not take into account that many insurance payers only permit patients to schedule mammograms after an entire calendar year has passed from the previous exam. Consequently, what women view as an annual visit may stretch into 18–24 month intervals. Current U.S. Preventive Services Task Force recommendations are for 2-year intervals in normal-risk women.

Certain incidence and prevalence rates that can be gleaned from the findings should be taken with the understanding of the limitations of the sample. The research, intentionally, does not represent the U.S. population of all women.

The survey showed that women would highly value mammography that would increase breast cancer detection and reduce false positive results.

Conclusion

Our data showed that the most significant barriers to screening mammography are the perception of high cost and lack of adequate insurance coverage, despite the mandated coverage of screening mammography under the ACA. Our findings confirm the evidence that the ACA policy is not yet having its intended effect of removing patient barriers to mammography screening.²⁴

The survey showed that women want better accuracy from their screening mammogram and fewer additional diagnostic tests. The authors believe that expanded use of advanced breast imaging technology would address both of these issues.

The most motivating reason for scheduling a mammogram for women in this survey was a recommendation from a healthcare provider. This is an opportunity for educational outreach for the use of mammography services.

The data indicate a continuing need to improve education about the costs and insurance coverage of screening mammography and to inform women about the new technologies available that may improve breast cancer detection and that may reduce frequent costly and stressful additional diagnostic evaluations.

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