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Dense breast tissue notification: Impact on women's perceived risk, anxiety, and intentions for future breast cancer screening

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Abstract

Purpose—To explore how women respond to the wording of dense breast tissue notifications, which are increasingly required by state law after mammogram. This study aims to 1) determine whether perceived lifetime risk for breast cancer and intentions to receive a mammogram increase after reviewing a sample notification, 2) explore individual difference variables (e.g., minority status, insurance coverage) that may impact intentions for additional ultrasound screening, and 3) to assess whether anxiety mediates the relationship between perceived risk and screening intentions.

Methods—184 women above the age of 40 in the United States were recruited from Amazon Mechanical Turk to respond to a dense breast tissue notification as if they had personally received it.

Results—After reviewing a notification, women reported greater perceived risk ($d=0.67$) and intentions for mammograms ($d=0.25$) than before. Most women intended to receive additional ultrasound screening, although to a lesser extent when ultrasounds were vs. were not covered by insurance ($d=1.03$). All screening intentions were lower in women with ambiguity aversion, a tendency to avoid tests without medical consensus, and those who prefer an active decision making role. Anxiety mediated the relationship between perceived breast cancer risk and all screening intentions.

Conclusion—Women who receive dense breast tissue notifications may generally increase their breast cancer screening intentions; however, intention strength varies depending on internal (e.g., ambiguity aversion) and external (e.g., insurance for ultrasound) factors. Although perceived risk increases after notification, it is anxiety that drives women's intentions for future screening.

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Conflicts of Interest: none

Keywords

dense breast tissue; screening intentions; perceived risk; anxiety

Mandatory dense breast tissue notifications have gained momentum since Connecticut passed the first notification law in 2009. As of manuscript drafting (October 28, 2014), 19 states have required notifications and legislation has been introduced in 13 additional states [1, 2]. Since about 50% of all women above the age of 40 have heterogeneously or extremely dense breast tissue [3], notification laws impact a tremendous number of women and may have far reaching consequences on women's perceptions of breast cancer risk, anxiety, and breast cancer screening.

These laws have been controversial. Some editorials have promoted notifications as potentially beneficial in that they can increase patient awareness [4] whereas others have argued notifications may inflate risk perceptions without improving patient health [5]. Although the American College of Radiology (ACR) does not oppose notification laws, a 2012 ACR position paper [6] expressed concern that notifications may unduly increase anxiety about breast cancer risk, encourage widespread ultrasound and MRI screening before randomized controlled trials have established their utility in women with dense breast tissue, and increase screening disparities, as costs will prohibit some women but not others from receiving additional tests.

There is limited information about how women respond to dense breast tissue notifications. Notifications often include information that dense breast tissue may increase the risk of cancer but do not state to what extent [1], leaving women to interpret the notifications for themselves. Subsequently, patients' perceived breast cancer risk and anxiety may increase, which is important since both perceived risk and anxiety are known to increase mammogram intentions [7, 8]. Further research is needed to establish if perceived risk and anxiety increase ultrasound intentions as well. Additionally, it is important to identify individual differences in post-notification screening intentions in order to anticipate groups which may be at risk for over or underutilizing screening.

The overall goal of the study is to examine how women over the age of 40 respond to a hypothetical dense breast tissue notification. Specific hypotheses are as follows: 1) notifications will increase perceived risk for breast cancer and intentions for future mammograms, 2) women will have higher intentions to screen with additional ultrasound when the test is covered by insurance, and 3) the amount of anxiety reported by women after reading the notification will mediate the relationship between perceived risk and screening intentions. A woman's perceived risk may seem more threatening in the context of anxiety, and elevated anxiety may explain how estimates of perceived risk become expressed in screening intentions. Lastly, we will examine if intentions differ by individual difference factors including: demographics, how complex the notification passage is perceived to be, ambiguity aversion- a tendency to avoid medical tests when individuals perceive a lack expert consensus [9], distrust of the health care system [10], and active control preferences in decision making [11].

Methods

Participants

Amazon Mechanical Turk (AMT) is an online marketplace advertising human intelligence tasks (HITs) to anonymous workers. AMT has a demographic composition slightly more diverse than American college samples [12] and studies have shown workers are internally motivated to provide reliable and valid answers [13]. To enhance data validity [14], inclusion criteria required all participants to have completed at least 1,000 HITs, and to have an HIT approval rating of at least 95%. Only AMT workers residing in the United States could view the advertisement for participation. Participants were also asked to only complete the survey if they were women and at least 40 years of age. A total 213 eligible women responded and were compensated \$1 each. Participants who reported previous diagnoses of cancer were excluded from analyses, as cancer survivors have different cancer screening recommendations than the general population.

Procedures

This study was approved by the Icahn School of Medicine at Mount Sinai Program for the Protection of Human Subjects. First, participants completed questions about their medical history, perceived lifetime breast cancer risk, and intentions to receive a mammogram. Then women were asked to read a sample dense breast tissue notification and respond to questions as if they had personally received the notification. The sample notification selected for this study was New York State (see Appendix 1) as it is similar in composition to many other notifications [1, 2] and represents the home state in which the research was conducted. Participants were informed that additional breast cancer screening after mammogram was typically conducted via ultrasound, and if women intended to use ultrasound screening, then physicians would recommend ultrasound in addition to (rather than in place of) mammogram. After reviewing the notification, participants again reported their perceived lifetime risk of breast cancer and intentions to receive future mammograms before completing the measures described below.

Measures

Primary outcome variables—1) Screening Intentions were assessed with the Choice Predisposition (Leaning) measure, which is a validated one item scale [15]. Four separate items were used to assess screening intentions for a) pre-notification mammograms, b) post-notification mammograms, c) post-notification ultrasounds that are covered by insurance and d) post-notification ultrasounds without insurance coverage. 2) Perceived lifetime risk for breast cancer was measured with two questions. All participants were asked the likelihood they would develop breast cancer in their lifetime on a scale of 0 to 100% before and after reading the notification. This is a commonly used measure of perceived risk for illness with construct validity [16]. 3) Anxiety was assessed with the validated 6-item tension-anxiety subscale of the Short Form of the Profile of Mood States (POMS-SF) [17].

Individual difference variables—1) Perceived complexity of dense breast tissue notifications was assessed with a single item asking women “Do you think the information you just read about dense breast tissue was very complex?” 2) Decision-Making Role

questions were modeled on the Control Preferences Scale, a valid and reliable measure [11], assessing women's preferred role in decision-making about ultrasound and mammography. 3) The Ambiguity Aversion Medical scale is a six-item questionnaire that assesses individual avoidance of medical treatment or tests when individuals perceive a lack of medical consensus about said treatment or tests [9]. 4) The Health Care System Distrust [10] scale was administered to all participants and assessed the degree to which individuals distrusted the medical system.

Past screening, medical, and personal history—Women were asked to report 1) whether or not they had additional workups after an abnormal mammogram, 2) if they had been told by a physician that they had higher than average breast cancer risk, 3) if they had been told by a doctor that they had dense breast tissue (Y/N/unsure), 4) whether or not they currently had health insurance (Y/N), and 5) whether or not a close friend or family member had been previously diagnosed with breast cancer.

Demographics—Items assessed for age, income, education, and employment status. Race and ethnicity were used to create a minority status variable (Y/N). Participants were considered non-minorities if they were Caucasian and not Hispanic.

Instructional manipulation check. Instructional manipulation checks have been demonstrated to increase the reliability of a dataset by identifying when participants are not attending to instructions. One item adapted from previous work [18] instructed participants to select response option “5” to demonstrate they read and attended to instructions.

Data analyses—Dependent sample *t*-tests were run to examine the differences between perceived lifetime breast cancer risk and intentions to have a mammogram before and after a hypothetical dense breast tissue notification. A dependent sample *t*-test was also used to examine differences in ultrasound screening intentions that were or were not covered by insurance.

Next, predictors for screening intentions were examined in a two-phase approach. First, in exploratory analyses, correlations between possible predictors and post notification screening intentions for future mammograms and ultrasound with and without insurance coverage were examined. Second, predictors with a *p*-value of .10 or less were included in separate multivariate analyses predicting the three post notification screening intentions. In all models, perceived lifetime breast cancer risk, perceived notification complexity, and anxiety post notification were included as predictors. Perceived lifetime breast cancer risk pre-notification was also included as a control variable. Non-significant variables were trimmed from the final model.

Lastly, mediation analyses used bootstrapping procedures to examine if anxiety mediated the relationship between post notification perceived risk and screening intentions for post notification mammogram, and ultrasounds with and without insurance coverage. For every 10,000 bootstrapped samples a 95% confidence interval was computed using the PROCESS syntax [19] in IBM SPSS Statistics 20 [20]. Significant predictors in multivariate regressions were included as covariates in mediation.

Results

Data preparation

A total of 213 participants began the survey. Of these, 11 participants provided partial data (i.e., only completed a few questions and then exited the survey) and were therefore eliminated from the database. Next, 15 participants with a previous history of cancer were excluded.

The data was examined for validity in two steps. First, responses to an instructional manipulation check were examined. All 187 women remaining in the dataset checked “5” when asked to do so by the instructions to demonstrate non-random responses. Second, the difference between perceived lifetime breast cancer risk before and after reading the dense breast tissue notification was compared. Three participants were flagged because their post notification perceived risk was 55% lower than their initial perceived risk. In contrast, the mean difference was an 8.03% increase. As the 55% decrease was likely due to participant inattention or typos, all data points from these participants were subsequently excluded from analyses. Results indicated that 16.8% of women had already been told by their physicians that they had dense breast tissue, however, perceived risk, anxiety, and screening intentions did not differ as a function of who had been notified and so these women were not removed from the sample. The final sample was $N= 184$ women.

Breast density notification impact

Two dependent sample t -tests were conducted to examine the effects of notification on perceived lifetime breast cancer risk and intentions to receive future mammograms. Results indicated that women perceived significantly greater lifetime breast cancer risk after notification ($M= 27.82$, $SE=1.53$) than before ($M=19.79$, $SE=1.29$), $t(183)= -8.80$, $p < .001$, $d= 0.67$. Women were also more likely to intend to complete a mammogram after notification ($M=12.17$, $SE=.30$) than before ($M=11.35$, $SE=.35$), $t(183)= -3.29$, $p= .001$, $d= 0.25$.

Predicting screening intentions

Overall, the majority of women intended to receive all forms of breast cancer screening after reading the notification. Women indicated they would continue to get mammograms even after being told they had dense breast tissue ($M=12.17$, $SD=4.09$). Women intended to get additional ultrasound screening whether it was covered by insurance ($M=12.59$, $SD=3.43$) or not ($M=8.20$, $SD=4.63$), although intentions to receive ultrasound were lower without insurance coverage $t(183)= 13.61$, $p < .001$, $d= 1.03$.

Correlations between potential predictors and screening intentions are presented in Table 2. Predictors with a p -value of .10 or less were included in multiple regressions predicting the three screening outcomes. Multivariate analyses indicated that the predictors explained 16% of the variance (adjusted $R^2=.16$, $F(4, 183)= 9.73$, $p < .001$) of ultrasound intentions with insurance coverage, 18% of the variance (adjusted $R^2=.18$, $F(6, 183)= 7.74$, $p < .001$) of ultrasounds without insurance coverage, and 21% of the variance (adjusted $R^2=.21$, $F(5, 183)= 10.67$, $p < .001$) of future mammograms. For specific predictors in each model, refer

to Table 3. In all multiple regressions, perceived lifetime breast cancer risk after notification did not predict screening intentions ($p > .34$).

Mediation

Results indicated that the relationship between perceived lifetime breast cancer risk and the three screening intention outcomes were mediated by the level of anxiety women experienced after reading the dense breast tissue notification. The indirect effect via anxiety was .01 ($CI=.003-.021$) for future mammograms, .01 ($CI=.001-.016$) for ultrasounds that were not covered by insurance, and .01 ($CI=.005-.021$) for ultrasounds that were covered by insurance. Significant effects are indicated as the 95% confidence intervals do not include zero.

Discussion

After reading a sample dense breast tissue notification, women's perceived risk of breast cancer and intentions to get a mammogram increased. The majority of women also intended to receive additional ultrasound screening, although to a lesser extent if ultrasound was not covered by insurance. Screening intentions were not uniform across women. Psychological factors predicted screening intentions more consistently than demographic factors. Anxiety significantly increased all screening intentions, and the degree to which a woman felt anxiety after reading the notification mediated the relationship between her perceived cancer risk and how strongly she intended to screen. Although two women could hold similar levels of perceived risk, it is the amount of anxiety she experiences that determines how motivated she is to screen.

Factors associated with increased screening intentions

Anxiety was the only predictor to increase all three screening intentions. Greater intentions were present in minorities when ultrasounds were covered by insurance and in individuals with greater health care distrust when ultrasounds were not covered by insurance. These results are somewhat surprising, as distrust and minority status typically relate to less health care use [36]. Distrust, however, can take many forms. Here, women may be suspicious of the medical system's rationale for denying insurance coverage (e.g., rationing care) or worry they will be denied care regardless of official policies, without distrusting the accuracy of ultrasound test results. It possible women were motivated to get additional testing rather than trust the system to provide and pay for appropriate health care.

Factors associated with decreased screening intentions

Women with higher levels of ambiguity aversion, a tendency to avoid tests when lack of medical consensus is perceived, and greater interest in active decision making had lower intentions for all three screening behaviors. For women with ambiguity aversion, the information that mammograms are less helpful for women with dense breast tissue may spark questions about the overall helpfulness of breast cancer screening that these women find especially difficult to resolve, leading to decreased screening intentions. For women who prefer active decision making roles, notifications presented outside of a physician's

office may influence them to decide to seek additional screening or not before they consult with medical professionals to receive individualized feedback.

Lastly, women who perceived the notification passage to be more complex were less likely to intend to screen with future mammograms and ultrasounds covered by insurance. Analysis of the sample passage indicated the notification was written at an average 8.5 grade level [37], just above the 6–7 grade level recommended for medical brochures by NIH [38]. At present, notifications may be written too complex a fashion and may inadvertently dissuade less health literate women from further testing.

Limitations

Since this study did not assess how women responded to real life dense breast tissue notifications, these findings may not accurately represent the anxiety, perceived risk, and subsequent screening intentions of women after a personal notification. Additionally, study outcomes assessed screening intentions instead of behavior, and while intentions predict screening, behavior is also subject to other motivating factors [39].

Future studies

Additional studies are needed to determine if predictors of screening intentions also predict screening behavior. Although fewer women intended to use ultrasound when it was not covered by insurance, there were no differences in screening intentions as a function of current insurance status, income, or full time employment. Individual differences between who opts for ultrasounds as a function of insurance coverage may widen when screening behavior is studied instead of intentions. Further research is also needed to identify what types of information women may want to consider when making screening decisions (e.g., information about sensitivity and specificity for ultrasounds).

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Appendix

Appendix 1

Sample Lay Paragraph implemented in New York notifying patients of Dense Breast Tissue as mandated by Public Health Law 2404-c

"Your mammogram shows that your breast tissue is dense. Dense breast tissue is very common and is not abnormal. However, dense breast tissue can make it harder to find cancer on a mammogram and may also be associated with an increased risk of breast cancer. This information about the result of your mammogram is given to you to raise your awareness. Use this information to talk to your doctor about your own risks for breast cancer. At that time, ask your doctor if more screening tests might be useful, based on your risk. A report of your results was sent to your physician."

http://assembly.state.ny.us/leg/?default_fld=&bn=A09586&term=2011&Summary=Y&Text=Y

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Table 1

Demographics

| <i>Variable</i> | <i>M (SD)</i> |
|--|---------------|
| Age | 49.40 (8.07) |
| | <i>N (%)</i> |
| Education | |
| High school or equivalent (GED) | 28 (15.2) |
| Some college or technical school | 61(33.2) |
| College degree and higher | 95(51.6) |
| Currently married or living with partner | 106(57.6) |
| Race * | |
| White | 163 (88.6) |
| African American | 16 (8.7) |
| Other | 8 (4.3) |
| Hispanic | 9 (4.9) |
| Minority status | 31 (16.8) |
| Currently insured | 140 (76.1) |
| Employed for wages fulltime | 105 (57.1) |
| Income | |
| Less than \$20,000 | 39(21.2) |
| \$20,000-\$39,000 | 54(29.3) |
| \$40,000-\$59,000 | 35(19.0) |
| \$60,000 or more | 55(29.9) |

* exceeds sample size of 184 as participants could check more than one race category

Table 2

Correlations between demographics, predictor variables, and screening intentions

| | Ultrasound with insurance coverage | Ultrasound without insurance coverage | Future mammogram |
|--|---|--|-----------------------------|
| Minority status | -.04 | .20** | -.02 |
| Married or living with partner | .11 | .12* | .06 |
| Insurance coverage | .03 | .12 | .12 |
| Income | .07 | .09 | .16** |
| Education | -.11 | .07 | .00 |
| Employed for wages full time | .01 | .17** | .07 |
| Age | .08 | -.16** | -.02 |
| Close friend with breast cancer | .08 | .10 | .12* |
| Family with breast cancer | .02 | .06 | .03 |
| Higher than average breast cancer risk | .11 | .03 | .10 |
| Had further workups after mammograms | .07 | .09 | .13* |
| Ambiguity Aversion | -.21** | -.22** | -.29** |
| Medical Mistrust | .12 | .24** | .29** |
| Decision making role ultrasound | .20** | .20** | - |
| Decision making role mammogram | - | - | .23** |

*
 $p < .10$ **
 $p < .05$

Table 3

Multiple regressions predicting intentions for ultrasound with insurance coverage, without insurance coverage, and future mammograms

| | <i>B</i> | <i>SE B</i> | β | <i>p</i> | Adjusted <i>R</i> ² | |
|---|----------|-------------|---------|----------|--------------------------------|-----|
| <u>Ultrasounds with insurance coverage</u> | | | | | | |
| Total Model | | | | | <.001 | .16 |
| Constant | 13.72 | 1.29 | | <.001 | | |
| Anxiety | .20 | .05 | .32 | <.001 | | |
| Ambiguity Aversion | -.18 | .05 | -.23 | .001 | | |
| Perceived complexity | -.72 | .23 | -.23 | .002 | | |
| Decision Making Role* | .64 | .26 | .17 | .013 | | |
| <u>Ultrasounds without insurance coverage</u> | | | | | | |
| Total Model | | | | | <.001 | .18 |
| Constant | 9.57 | 3.20 | | .003 | | |
| Minority status | 2.43 | .84 | .20 | .004 | | |
| Age | -.10 | .04 | -.18 | .01 | | |
| Health Care System Distrust | .14 | .05 | .19 | .007 | | |
| Anxiety | .11 | .06 | .13 | .052 | | |
| Ambiguity Aversion | -.23 | .07 | -.22 | .002 | | |
| Decision Making Role* | .83 | .34 | .17 | .02 | | |
| <u>Future mammograms</u> | | | | | | |
| Total Model | | | | | <.001 | .21 |
| Constant | 8.90 | 2.13 | | <.001 | | |
| Health Care System Distrust | .16 | .04 | .25 | <.001 | | |
| Anxiety | .18 | .05 | .24 | .001 | | |
| Ambiguity Aversion | -.23 | .06 | -.25 | <.001 | | |
| Perceived complexity | -.59 | .27 | -.15 | .03 | | |
| Decision Making Role* | .83 | .29 | .19 | .004 | | |

* Higher scores on decision-making role indicates preference for a passive decision making role