

Breast Density Awareness and Knowledge, and Intentions for Breast Cancer Screening in a Diverse Sample of Women Age Eligible for Mammography

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Abstract The objectives of this study were to assess breast density knowledge and breast density awareness, and to identify information associated with intention to complete routine and supplemental screening for breast cancer in a diverse sample of women age eligible for mammography. We quantitatively (self-report) assessed breast density awareness and knowledge ($N = 264$) in black (47.7%), Latina (35.2%), and white (17%) women recruited online and in the community. Most participants reported having heard about breast density (69.2%); less than one third knew their own breast density status (30.4%). Knowing their own breast density, believing that women should be notified of their breast density in their mammogram report, and feeling informed if being provided this information are associated with likelihood of completing mammogram. Intending mammogram completion and knowledge regarding the impact of breast density on mammogram accuracy are associated with likelihood of completing supplemental ultrasound tests of the breast. These findings help inform practitioners and policy makers about information and communication factors that influence breast cancer screening concerns and decisions. Knowing this information should prepare practitioners to better identify women who may have not been exposed to breast density messages.

Keywords Breast density, survey, health literacy · Community health · Cancer screening

Introduction

Breast density has been identified as a barrier for mammography sensitivity to detect breast cancer [1–3]. In addition, women with extremely dense breasts have a greater risk of developing breast cancer than women with breasts that are almost all fatty tissue [4–7]. As rates of breast cancer begin to increase after age 40 years, women at that age and older tend to have moderate awareness of breast density. A low proportion of women know their own breast density, and there is lack of knowledge regarding the effect of breast density on breast cancer risk and detection. Increased breast density knowledge seemed to be associated with sociodemographic and screening history factors, such as race, ethnicity, household income, and history of diagnostic evaluation after a mammogram [8]. Findings also illustrated that there are limited studies on how much women know about factors influencing breast cancer screening and personal risk.

Breast density notification laws have been enacted in 24 states in the USA [9]. Health care providers supply notification letters to patients whose mammograms indicate heterogeneously or extremely dense breasts. In this letter, patients are encouraged to ask their doctor if more screening tests might be beneficial based on their breast cancer risk. The law requirements differ significantly among states, with some laws requiring only that patients be notified of their breast density status, while others offer supplemental screening. Only four states (Connecticut, Indiana, Illinois, and New Jersey) mandate insurance to cover additional supplemental testing [10]. Findings from an initial report of the New York State breast density notification law showed that, from 2013 to mid-2014,

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close to 50,000 patients were notified of their breast density (they were determined to have heterogeneously dense breast tissue or extremely dense breast tissue), but only 971 patients returned for screening breast sonographic examinations [11]. The objective of this study was to assess breast density knowledge and awareness, and intention to complete routine and supplemental screening for breast cancer in women at age eligible for mammography living in the state of New York.

Methods

Three methods for recruitment and data collection were used: (1) an online survey administered using Amazon Mechanical Turk (MTurk); (2) in-person recruitment among participants of health promotion programs in the community; and (3) an online survey made accessible to users of a website for a New York City-based breast cancer awareness and health disparities foundation. Eligibility criteria for participation included (1) self-identified as black, Latina, or white women; (2) being 40–74 years old; (3) English or Spanish speaking; (4) report at least one mammogram in the past; and (5) being a New York resident. Data were obtained by self-report. The protocol was deemed exempt by the institutional review board.

The online survey (made available in New York only) was administered via PsychData among women using MTurk [12–15]. The survey took complete. In addition, the online survey was made accessible to users of the “Kicked it in Heels” website [16]. The Kicked it in Heels foundation, established in New York City, aims to further the end of health care disparities in breast cancer by focusing on breast cancer survivors, specifically women of color, providing basic information on screening and survivors’ experiences. We also conducted in-person recruitment to include participants of the Witness Project of Harlem and Esperanza Y Vida educational programs [16, 17].

The survey, prepared in English and Spanish, included questions regarding demographic (e.g., age, education level, income, race, ethnicity), health history, perceived health status, and health care use (including breast health care) information. In addition, breast density awareness, own breast density knowledge, general breast density knowledge, and intentions for breast cancer screenings were assessed [18, 19]. The items (yes/no) to assess breast density awareness were “Have you ever heard of something called breast density?” and “Have you ever heard of the New York State Breast Density Notification Law?”. Breast density knowledge items were (yes/no): “Do you know your breast density?”, “Does having breast that are mostly fat (or dense) on a mammogram put women at increased risk for breast cancer?”, “If a woman has dense breast, does it impact the ability of a mammogram to correctly detect cancer?”, “Doctors and scientists do not agree at this time on whether women with dense breasts benefit from having additional types of breast imaging

tests in addition to regular mammograms. Would you still want to know if you have dense breast?”, “Would knowing your breast density make you feel anxious/informed to make decisions regarding your breast health/confused about what to do regarding your breast health?”. The item “It is a New York State law that all mammography centers must notify women of their mammogram interpretation by letter. Do you think that the letter should include information about your breast density?” was modified [18]. To assess intentions for breast cancer screening, we used two items (Rhodes et al. [18]): “If you were told that the chance of your mammogram finding a cancer was no better than a flip of a coin (50% cancer, how likely would you be to get mammograms in the future? (very likely/somewhat likely/not at all likely)” and “Again, imagine that the chance of your mammogram finding a cancer was no better than a flip of a coin. Would you want to have an additional, supplemental ultrasound screening test of the breast that may find cancers not seen on the mammogram if it improved the chance of finding cancer (yes only if there was no additional cost to me/yes even if there was a small cost to me-copy/yes even if there was a large cost to me/no)” [18].

A brief health literacy scale was used to measure difficulty with reading and comprehension of health-related information [20]. We used three items: (1) “How often do you have someone help you read hospital materials?”, (2) “How confident are you filling out medical forms by yourself?”, and (3) “How often do you have problems learning about your medical condition because of difficulty understanding written information?”. Using data collected for the present study, the calculated Cronbach’s alpha for the health literacy assessment is 0.79. Results from previous research show that these questions are effective to identify health literacy [20]. This assessment was included in the study to examine reading difficulties in our sample. Low health literacy and suboptimal medication adherence are more prevalent in racial/ethnic minority groups. Most of the participants in our study are members of racial/ethnic minority groups.

The data were analyzed using SPSS 20 [21]. The outcomes for two separate regression models were likelihood of getting a mammogram in the future and likelihood of having additional/supplemental ultrasound screening tests of the breast. Independent variables of interest were entered into the regression equations (breast density knowledge and awareness variables). Demographic control variables were entered into an initial regression analysis by themselves. Only those variables that were associated with the outcomes at $p < 0.05$ were controlled for in the analyses for both outcomes.

Results

Participants were recruited during community events ($N = 100$) and online ($N = 164$, which includes participants

who accessed MTurk, $N = 150$, and the Kicked it in Heels website, $N = 14$) (see Table 1 for descriptive results). All participants were female, and the average age was 54.16 (SD = 11.04). Most participants were single (52.1%), had a college or postgraduate degree (43.3%), had a household income between \$25,000 and \$49,000, were black (47.7%), had a regular doctor or health care provider (92.3%), had private health insurance (47.7%), and described their health status as “excellent or very good” (39.3%). Regarding health literacy, the majority of the participants responded “never” (50%) to “How often do you have someone help you read hospital materials?”, “extremely” (47.5%) to “How confident are you filling out medical forms by yourself?”, and “never” (54.1%) to “How often do you have problems learning about your medical condition because of difficulty understanding written information?”. Most participants reported breast density awareness (69.2%), but only 30.9% reported awareness regarding the New York State breast density notification law (see Table 2). Around one quarter of the participants reported being told they have dense breasts (28.4%). Participants were asked “if yes, who was it that told you that you have dense breasts?” The options offered as response were as follows: “The health care provider who order my mammogram,” “A radiologist who read my mammogram report,” “An imaging/x-ray technician,” or “Someone else, please specify....” Among those who were told that they have dense breasts, the majority (47.1%) reported that the radiologist who read their mammogram report was the person who told them. Regarding breast density knowledge, around one third of the sample reported knowing their own breast density (30.4%). Most participants correctly agreed with a statement describing that having dense breast increases breast cancer risk (60.6%), and also that breast density impacts the ability of a mammogram to correctly detect cancer (66.3%). A small amount (8.7%) of the participants reported being told they have/had breast cancer. There were no significant differences on breast density awareness, knowledge, and beliefs by breast cancer history. Of the participants who accessed the Kicked it in Heels website, just one participant reported past breast cancer diagnosis.

Participants were asked “If you were told that the chance of your mammogram finding a cancer was no better than a flip of a coin, how likely would you be to get mammograms in the future?”, the majority answered “very likely” (54.5% vs. 31.4% “somewhat likely” vs. 12.1% “not at all likely”). In addition, participants were asked “Again, imagine that the chance of your mammogram finding a cancer was no better than a flip of a coin. Would you want to have an additional, supplemental ultrasound screening test of the breast that may find cancers not seen on the mammogram if it improved the chance of finding cancer?”, the majority answered “yes, even if there is a copay” (40.5% vs. 8.9% “no” vs. 35.1% “yes, only if there is no additional cost” vs. 15.4% “yes, even if there was a large cost to me”).

Analyses showed that there are no differences between women who reported knowing their breast density and those who reported not knowing their breast density in any of the knowledge and intention variables. There was a significant difference in awareness ($\chi^2(1, 260) = 32.82, p < 0.001$), that is, a higher proportion of women who knew their breast density classification have heard about breast density in the past (41.4%) compared with women who did not know their own breast density (6.3%). Women who knew whether they had fatty or dense breasts tended to be the ones aware of breast density.

Results of an initial regression analysis with control variables and intentions to complete mammograms in the future showed that these variables were not significantly associated with this outcome. As shown in Table 3, knowing their own breast density ($\beta = 0.172, p < 0.05$), believing that knowing their breast density (would) make them feel informed to make decisions regarding their breast health ($\beta = 0.130, p < 0.05$), and wanting to be informed about their breast density in their mammography report/letter, even when doctors and scientists do not agree at this time whether women with dense breast benefit from having additional types of breast imaging test in addition to regular mammograms ($\beta = 0.146, p < 0.05$) were associated with higher likelihood of getting mammograms in the future.

Regarding intentions to complete additional breast cancer screening (no/only if no cost vs. yes even with cost), results of an initial regression analysis with control variables indicated that income was significantly associated with this outcome. Knowing about the impact that breast density has on the ability of a mammogram to correctly detect breast cancer ($\beta = 0.288, p < 0.001$), likelihood of getting mammograms in the future ($\beta = 0.190, p < 0.05$), and income ($\beta = 0.213, p < 0.05$) were associated with intentions to have additional, supplemental ultrasound screening test of breast that may find cancers not seen on mammograms.

Discussion and Conclusion

Discussion

These findings indicate that breast density knowledge is, in different ways, associated with intentions to complete breast cancer screening. Overall, having the correct information about breast density and its effect on breast cancer risk and detection facilitates breast cancer behaviors. There was an association between having (and wanting to have) information regarding own breast density (whether their breasts are mostly breast and connective tissue) or not and how likely women in the study would get mammograms in the future. Intentions to complete supplemental ultrasound screening, knowing that dense breasts can make it more difficult to find breast cancer

Table 1 Demographic information

Variables	<i>N</i> = 264
Age	<i>M</i> = 54.16 (<i>SD</i> = 11.04)
Marital status	
Single/widowed/divorced/never married	52.1%
Married/with partner	47.9%
Education level	
No HS	8.4%
HS or GED	16.0%
Some college/tech/vocational	32.3%
College/post	43.3%
Income	
\$0–\$24,999	32.8%
\$25,000 to \$49,999	34.0%
\$50,000 or more	33.2%
Country of origin	
USA	75.1%
Dominican Republic	6.2%
Puerto Rico	3.8%
Other	14.9%
Ethnicity/race	
Latina	35.2%
Black	47.7%
White	17.1%
Latino origin (Latinas only)	
Mexican	8.7%
Puerto Rican	31.5%
Dominican	32.6%
South American	10.9%
Other	16.3%
Doctor/provider	
Yes	92.3%
No	7.7%
Type of insurance	
Public	45.7%
Private insurance	47.7%
No insurance	6.2%
Other	0.4%
Recent past doctor visits	
None	11.4%
1–2 times	41.8%
3+	46.8%
Medical care postponed	
Yes	36.3%
No	63.7%
Did not follow medical care/test	
Yes	29.7%
No	70.3%
Health status	
Excellent/very good	39.3%

Table 1 (continued)

Variables	<i>N</i> = 264
Good	38.9%
Fair/poor	21.8%
Recruitment site	
Community	37.9%
Online	62.1%

on a mammogram (since both cancer and dense breast tissue look white or light gray on a mammogram, it may affect the accuracy of breast cancer screening tests to detect a tumor), and intentions to complete mammograms were associated with likelihood to have additional, supplemental ultrasound screening tests. At this time, there are no screening guidelines specifically for women with dense breasts, but research is trying to identify whether a combination of screening tests

Table 2 General knowledge and breast density (BD) awareness questions

Variables	Percent
Heard of BD	
Yes	69.2
Heard of NY BD notification law	
Yes	30.9
Have you ever been told that you have dense breasts?	
Yes	28.4
No	71.6
(If yes) Who told you?	
Health care provider	35.3
Radiologist	47.1
Other	17.6
Do you know your own breast density?	
Yes	30.4
Does having breasts that are mostly dense on a mammogram put women at increased risk for breast cancer?	
Yes	60.6
If a woman has dense breasts, does it impact the ability of a mammogram to correctly detect cancer?	
Yes	66.3
Doctors and scientists do not agree at this time on whether women with dense breasts benefit from having additional types of breast imaging tests. Would you still want to know if you have dense breasts?	
Yes	81.9
Would knowing your breast density make you feel anxious (uneasy, worried, or nervous)?	
Yes	40.3
Would knowing your breast density make you informed to make decisions regarding your breast health?	
Yes	77.3

Table 3 Predictors of intentions for breast cancer screening

Variables	<i>B</i>	<i>SE</i>	β	<i>p</i>
Likelihood mammogram in the future				
Own BD	0.257	0.117	0.172	0.030
BD and breast cancer risk	0.054	0.107	0.038	0.618
BD and impact on mammogram	−0.006	0.121	−0.004	0.960
Want to know BD	0.167	0.141	0.088	0.239
BD knowledge would cause anxiety	−0.023	0.113	−0.016	0.839
BD knowledge would cause feeling informed	0.232	0.132	0.130	0.049
BD knowledge would cause confusion	0.115	0.124	0.074	0.355
Should be informed BD in letter	0.388	0.189	0.146	0.042
Heard of BD	0.232	0.165	0.129	0.160
Has dense breast	0.157	0.121	0.102	0.196
Intentions for supplemental screening				
Own BD	0.115	0.086	0.109	0.176
BD and breast cancer risk	−0.072	0.076	−0.71	0.347
BD and impact on mammogram	0.307	0.086	0.288	0.000
Want to know BD	−0.102	0.101	−0.076	0.316
BD knowledge would cause anxiety	−0.057	0.080	−0.056	0.481
BD knowledge would cause feeling informed	0.099	0.094	0.079	0.298
BD knowledge would cause confusion	0.009	0.089	0.008	0.920
Should be informed BD in letter	−0.223	0.136	−0.119	0.104
Heard of BD	−0.101	0.118	−0.079	0.394
Has dense breast	−0.054	0.087	−0.050	0.537
Likelihood mammograms in the future	0.134	0.053	0.190	0.013
Income	0.042	0.019	0.213	0.030

BD breast density, *B* unstandardized weight, *SE* standard error, β standardized weight, *p* *p* value

(e.g., mammography and ultrasound) improves breast cancer detection in women with dense breasts with mixed results. Results of a 4-year retrospective chart review (2009–2013) of patients in Connecticut with dense breasts screened with bilateral ultrasound indicated that positive predictive value of ultrasound increased to 20% by the fourth year (from under 10% in the previous 3 years), adding four additional cancers in the first year and then 3.2 cancers per thousand in the three following years when compared to mammography alone [22]. A retrospective study to determine the utility of directed ultrasound and digital mammogram for evaluating focal breast pain in women with different mammographic breast densities reported that less than 1% of cases that received follow-up screening mammography subsequently developed breast cancer [23]. Differences in methodology for the assessment of the detection ability of supplemental screening tests may affect findings and potential conclusions regarding the impact these tests may have on breast cancer detection among women with dense breasts.

Income was the only control variable associated with intentions to complete ultrasound screening to improve the chance of finding cancer. Results of a study to assess advance imaging utilization trends in privately insured patients from

2007 to 2013 indicated that payments (adjusted for inflation) per person-year for outpatient ultrasound procedures increased every year covered by the study due to increase in utilization [24]. Breast density notification laws do not tend to require insurance coverage for supplemental screening. There has been a large increase in patient utilization of these procedures after law enactments, showing a minimum relative increase of 176.90% and a maximum relative increase of 335.56% in patient utilization of screening breast sonography in one of the US states where patients are eligible to receive screening breast sonography coverage from their insurance carriers [25]. The investigators further included an estimation of an increased direct cost for insurers of \$4,910,899.18 to \$9,848,897.96 for a given month. This coverage is not available in most states, but it intends to reduce the number of patients who may have difficulties paying out-of-pocket expenses.

Previous studies have shown that having access to information about mammography, particularly tailored information, may increase mammography intake and reduce decisional conflict regarding the completion of this test [26–28]. An online study to evaluate the impact of breast density notification on women's response found that, after reading a dense

breast tissue notification as if they had personally received it, women reported greater perceived risk ($d = 0.67$) and intentions to undergo mammography ($d = 0.25$) than before [29]. Most women intended to undergo additional ultrasound screening, and all screening intentions were lower in women with ambiguity aversion, a tendency to avoid tests without medical consensus. Anxiety mediated the relationship between perceived breast cancer risk and all screening intentions. Results from an assessment of decision-making before initiating screening mammography in women 40–44 years old illustrated that less than half (47%) of the sample reported discussing the benefits of screening with their health care providers, 23% the uncertainties, and only 7% the harms, showing that informed decision-making before initiating breast cancer screening is limited [28].

The strengths of the study include its inclusion of a diverse sample of women age eligible for mammography. Another strength is the recruitment of participants in the community. Our sample consisted of English- and Spanish-speaking women from three ethnic/racial groups. It was limited to the New York City area. These constraints could have limited the heterogeneity of the sample and the generalizability of the findings. An examination of race and breast density on related cognitive and emotion outcomes showed that white women are more likely to have been told about breast density by a health care provider than black women, and that this knowledge was directly related to the increased likelihood of communication about breast density with their health care provider [30]. The present study described breast density awareness and knowledge, and intentions for breast cancer screening, which can provide insight to breast cancer detection education efforts that target individuals based on the level of knowledge. Additionally, the measures of individual aspects of breast density knowledge used in the study may have not been able to comprehensively capture all the potential angles of the information people are exposed to. The cross-sectional design of the study, which allowed us to collect observational data at a specific point in time, does not allow us to describe a cause and effect relationship. It is possible that women who had completed ultrasound screening are more aware or had conversations with their health care providers about breast density and other factors increasing breast cancer risk.

Conclusion

The potential impact of breast health education is tremendous. Breast cancer prevention, detection, and control information may be a woman's first exposure to cancer information; it can be influential in the formulation of cancer screening beliefs. Breast cancer detection policies have made an impact in the population's beliefs and behavior. Breast density information is a significant component to consider when assessing the

concerns about breast cancer screening and can play an important role in intervention efforts.

Breast density notification laws have been put into effect in 31 states. Breast density notification laws vary but are intended to inform women who have undergone mammography about the risks posed by breast density. In most cases, the notification letters are mailed, and the content of the letter varies considerably across the states. The first state to pass the breast density notification was Connecticut in 2009. In this state, the notification text sent to patients with dense breasts reads "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." This text is similar to the notification that is used by most states. An online assessment of current strategies and standards of care provided by $N = 223$ breast imagers (62% were private practice physicians) showed that when asked who determines whether patients are "high risk" and might benefit from additional screenings, 24% of respondents replied the primary/referring physician, 19% a radiologist or radiology computer-generated risk calculator, 54% a combination of the prior, while 3% chose other [31]. When asked if letters/reports to patients explicitly offered the option of supplemental screening (among respondents in states with notification laws), 55% of respondents sent letters which mentioned additional screening options while 45% of respondents claimed that they routinely only reported breast density without mention of supplemental imaging. Respondents were asked which health care provider in their practice was responsible for discussing breast density and supplemental screening; 61% assigned this task to the primary care physician (or ordering physician), 20% claimed a radiology representative was responsible, and 19% had no dedicated liaison. Results also showed that more respondents in states without notification laws claimed that a general lack of resources, money, staff, and time was a main challenge anticipated or faced due to mandatory breast density reporting (28.7%) than those in states with notification laws (6.2%). It shows the standards of care associated with breast density notification.

The present study highlights the potential strength of improving health knowledge. Breast cancer screening remains a medical need in women living in NYC, as they report higher breast cancer rates New York State residents [32]. It is important to build trust between at-risk women and the medical community. An examination of radiologists' knowledge about breast density legislation as well as their perceived practice changes resulting from the enactment of breast density

notification legislation in the New England area showed that 69 of respondents' percent felt that breast density notification increased patient anxiety about breast cancer, but also increased patient (74%) and provider (66%) understanding of the effect of breast density on mammographic sensitivity [33]. An assessment of pre- and post-legislation supplemental testing completion in California and New Jersey showed increases in magnetic resonance imaging completion [34, 35]. At the same time, effects of supplemental screening on breast cancer outcomes remain unclear. As next steps, it will be important to determine the impact of breast density notification and education on the population at large. In addition, well-designed, long-term, prospective, comparative studies of supplemental breast cancer screening will be needed to identify the clinical outcomes on breast cancer rates.

Practice Implications

Our findings help inform practitioners and policy makers about information and communication factors that influence breast cancer screening concerns and decisions. Knowing this information should prepare practitioners to better identify women who may have not been exposed to breast density messages. These results illustrate how much research is needed to determine the best format, medium, and nature of information to promote breast health. In June 2016, New York implemented a new law requiring health insurance to cover all screening and diagnostic imaging exams for the detection of breast cancer [36]. The law includes supplemental imaging for women with dense breast issue. It goes into effect January 1, 2017. A shift in intentions and behavior will be expected once this law goes into effect, and it is important to make sure the population has the (correct) information that will improve clinical encounters, when health providers may not be able to counsel patients regarding their breast health- and cost-related concerns.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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