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# Awareness of Breast Density and Its Impact on Breast Cancer Detection and Risk

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Α S R Α C Т R Т

#### Purpose

Legislation mandating disclosure of breast density (BD) information has passed in 21 states; however, actual awareness of BD and knowledge of its impact on breast cancer detection and risk are unknown

#### Methods

We conducted a national cross-sectional survey administered in English and Spanish using a probability-based sample of screening-age women, with oversampling of Connecticut, the only state with BD legislation in effect for > 1 year before the survey.

#### Results

Of 2,311 women surveyed, 65% responded. Overall, 58% of women had heard of BD, 49% knew that BD affects breast cancer detection, and 53% knew that BD affects cancer risk. After multivariable adjustment, increased BD awareness was associated with white non-Hispanic race/ethnicity (Hispanic v white non-Hispanic: odds ratio [OR], 0.23; P < .001), household income (OR, 1.07 per category increase; P < .001), education (OR, 1.19 per category increase; P < .001), diagnostic evaluation after a mammogram (OR, 2.64; P < .001), and postmenopausal hormone therapy (OR, 1.69; P = .002). Knowledge of the masking effect of BD was associated with higher household income (OR, 1.10; P < .001), education (OR, 1.22; P = .01), prior breast biopsy (OR, 2.16; P < .001), and residing in Connecticut (Connecticut v other states: OR, 3.82; P = .003). Connecticut residents were also more likely to have discussed their BD with a health care provider (67% v 43% for residents of other US states; P = .001).

#### Conclusion

Disparities in BD awareness and knowledge exist by race/ethnicity, education, and income. BD legislation seems to be effective in increasing knowledge of BD impact on breast cancer detection. These findings support continued and targeted efforts to improve BD awareness and knowledge among women eligible for screening mammography.

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# INTRODUCTION

Legislation mandating provision of breast density (BD) information after mammography screening has been championed by breast cancer advocates on the premise that the medical community has failed to inform women about BD and its implications.<sup>1</sup> In 2009, Connecticut became the first state to pass BD information legislation; similar legislation has since passed in 20 additional states and been introduced in two states, as well as in a federal bill.<sup>2</sup> Some medical organizations oppose this legislation because of concerns that it will increase expenditures and patient anxiety in the absence of evidence-based recommendations for supplemental screening in women with mammographically dense breasts (MDBs).<sup>3-5</sup>

BD is the proportion of fibroglandular tissue on the mammogram. More than half of women age < 50 years have MDBs, as do at least one third of older women.<sup>6</sup> BD is one of the most important factors contributing to false-negative screening mammography results<sup>7-9</sup> and the primary factor in the lower performance of screening mammography in younger women.<sup>7,9,10</sup> BD is also associated with a three-fold increase in recall rate and false-positive findings.<sup>11-13</sup> Furthermore, BD is a strong, independent predictor of breast cancer risk.<sup>8,10,14-19</sup>

An assumption central to the legislative debate is the "historic lack of communication between the medical community and its patients in regard to the limitations of mammography"20(p634) in MDB; however, little is known about women's awareness and knowledge of BD.<sup>20</sup> A 2010 Harris poll of 600 women age  $\geq$  40 years reported that 95% did not know their BD percentage, 62% did not know that mammography has limitations in detecting cancer in MDBs, and 87% did not know that BD can increase breast cancer risk.<sup>21</sup> Two studies have assessed knowledge of BD; both were small, single-institution studies with low response rates involving women presenting to tertiary breast centers. One study found that one third of women knew their BD, but most were unaware of BD as a breast cancer risk factor; the other study found that approximately two thirds were aware of BD as a risk factor, but only one third had spoken to their providers about their BD. Both studies concluded that further research is needed, particularly in larger, more representative samples.<sup>22,23</sup>

BD awareness and knowledge may have improved since the 2010 poll as a result of legislative efforts and attendant media; however, little is known about other individual-level predictors of awareness and knowledge, such as age, education, and mammography history. Understanding current patterns of BD awareness and knowledge is critical to informing legislation and developing targeted educational strategies to aid breast cancer screening decision making. Using a nationally representative sample, we assessed BD awareness as well as two aspects of BD knowledge relevant to screening decisions: knowledge of the impact of BD on breast cancer detection (masking effect) and knowledge of the association between BD and breast cancer risk. Connecticut, the only state with BD legislation in effect for at least 1 year at the time of survey administration, was oversampled to assess the association of BD legislation with these outcomes.

# **METHODS**

The survey was offered to a randomly drawn subset of women age 40 to 74 years within an existing probability-based Web panel representative of the US population (KnowledgePanel; GfK Custom Research North America, New York, NY).<sup>24-26</sup> The validity of KnowledgePanel methodology has been previously reported,<sup>27,28</sup> and it has been used broadly in the medical literature.<sup>29-31</sup> GfK contacts a scientifically drawn random sample of panel members through random-digit dial telephone- or address-based sampling. Households without Internet access are provided access and hardware at no cost to enable panel participation and eliminate coverage error resulting from lack of Internet access. Participants earn small incentives in exchange for completing surveys. Respondents are weighted to adjust for probability of selection into the panel as well as poststratified to match known US population distributions from the Current Population Survey with respect to sex, age, race/ ethnicity, educational attainment, census region, household income, home ownership status, residence in a metropolitan area (ie, urbanicity), Internet access, and language.<sup>25</sup> Study-specific weights are further adjusted to account for oversampling of Connecticut.<sup>25</sup> Women age < 40 and > 74 years were excluded, because mammography screening is not routinely recommended in these age groups.<sup>32</sup>

#### Survey Design and Administration

The survey was fielded in English and Spanish to 2,311 women in October 2012. Initial nonresponders were sent reminders after 3 and 8 days. Data were obtained by self-report; voluntary participation in the survey constituted informed consent. Demographic data were obtained from baseline KnowledgePanel data.

Survey questions addressed health history, perceived health status, and health care use. Assessment of mammography history included number of mammograms (none, < five, or  $\geq$  five) and history of diagnostic breast imaging and biopsies. Awareness was ascertained by a response of "yes" (v "no" or "not sure") to the following item: "Have you ever heard of something called breast density?" Knowledge of the masking effect of BD was assessed by

months (83.3%).

#### **BD** Awareness

Overall, more than half of US women (57.5%) had heard of BD. Table 1 summarizes demographic and health characteristics among all respondents and presents unadjusted associations between these characteristics and BD awareness. After multivariable adjustment, BD awareness was associated with white non-Hispanic race/ethnicity

response ("easier to see cancer," "does not impact," "more difficult to see cancer," or "I don't know") to the following: "If a woman has dense breasts, what impact does this have on the ability of a mammogram to correctly detect cancer?" To assess knowledge of impact on breast cancer risk, respondents were asked to choose whether "having breasts that are mostly dense on a mammogram" does or does not put a woman at increased risk of breast cancer. In addition, women who reported having heard of BD were asked whether they had discussed their individual BD with a health care provider and, if so, who initiated the conversation, whether they knew their individual BD, and whether they had heard about BD from sources other than their health care provider. The full survey is provided in the Data Supplement. The protocol was deemed exempt by the institutional review board.

#### Analysis

All reported estimates and analyses were weighted to be representative of the female US population age 40 to 74 years, or the same demographic group in Connecticut, as specified. Proportions of respondents with BD awareness and knowledge of BD impact on breast cancer detection and risk were assessed, and these were the three key outcomes. Unadjusted associations between selected respondent characteristics with each outcome were examined using Rao-Scott  $\chi^2$  tests (categorical items) or univariable linear regression (age).<sup>33-35</sup> Comparisons of variables between respondents in Connecticut versus other states were examined using these methods. Adjusted associations were examined with multivariable logistic regression models; each model initially included a set of demographic and health predictors, and a stepwise backward-elimination variable selection process was used to arrive at a set of statistically significant predictors. Adjusted odds ratios (ORs) and 95% CIs from the resulting models were reported. The correlations between predictors were first assessed to ensure the models did not have significant multicollinearity.

To minimize the impact of respondent guessing, adjusted analyses pertaining to BD knowledge were restricted to the subset reporting BD awareness. Similarly, analyses of sources of BD information were restricted to the subset with BD awareness.

In light of the multiple comparisons performed, we considered P values ≤ .01 statistically significant. All analyses were performed using survey procedures incorporating sampling weights from SAS software (version 9; SAS Institute, Cary, NC).

#### RESULTS

#### Participants

Survey cooperation rate was 65% (1,506 responders of 2,311 surveyed). Responders did not differ from nonresponders with respect to region or urbanicity. Although responders were more likely to be white, non-Hispanic, slightly older, wealthier, and more educated than nonresponders, poststratification weighting adjusted for these differences and resulted in a sample of responders representative of US women age 40 to 74 years. Item nonresponse for any item was < 5%. The average age among the respondents was 55.2 years (SE, 0.3). Those who had heard of BD were slightly older than those who had not heard of BD (average, 56.1 years [SE, 0.4]  $\nu$  53.9 years [SE, 0.5]; P <.001). A majority were white non-Hispanic (70.6%), had health insurance (89.0%), and had a routine health care visit in the previous 24

of BD				
	Overall	BD Awareness		
Characteristic	(%)	(%)*	P	
Race/ethnicity			< .00	
White non-Hispanic	70.6	65.0		
Black non-Hispanic	12.0	48.5		
	11.8 5.5	ZZ.9 54.1		
lousehold income	0.0	54.1	< 00	
< \$24.999	18.4	39.1		
\$25,000 to \$49,999	22.8	48.2		
\$50,000 to \$74,000	18.5	59.5		
\$75,000 to \$99,999	14.0	65.4		
≥ \$100,000	26.5	72.8		
ducational attainment			< .00	
< High school	10.9	22.3		
High school	30.5	51.4		
Some college	28.6	62.6		
≥ Bachelor's degree	30.0	71.3		
	14.0	00.4	< .00	
No insurance noted	11.0	29.1		
Public coverage (Medicare/Medicaid)	32.5	54.4		
Employer/private coverage	56.5	64.8		
Overall health status	00.0	0110	< .00	
Excellent/very good	46.2	64.7		
Good	36.3	52.5		
Fair/poor	17.5	49.0		
Aetropolitan statistical area			.75	
Nonmetropolitan	16.0	56.4		
Metropolitan	84.0	57.8		
JS region			.02	
Northeast (excluding Connecticut)	17.8	66.4		
Midwest	22.1	55.9		
South	38.3	57.9		
vvest	21.8	49.9	< 00	
	0.0	01 /	< .00	
Lipited States (excluding	0.0	01.4		
Connecticut)	92.0	57.2		
Nost recent routine health care visit			.04	
Within past 24 months	83.3	59.1		
> 24 months ago	16.7	50.2		
ver had mammogram			< .00	
No	11.0	31.8		
Yes	89.0	60.7		
t yes, total mammograms	04 5		< .00	
2 5 - F	04.5 25.5	65.6 E1 7		
ves age at first mammogram	30.0	51.7		
years			.6	
< 50	90.3	61.8		
≥ 50	9.7	58.9		
yes, most recent mammogram			.46	
Within past 2 years	83.0	61.7		
> 2 years ago	17.0	58.2		
f yes, ever recalled for diagnostic evaluation after any mammogram			< 00	
No	57.4	50.7		
Yes	42.6	74.0		
(continued in n	iext column	)		

Table 1. Overall Respondent Characteristics and Awareness of BD (continued)					
Characteristic	Overall (%)	BD Awareness (%)*	P		
Ever had breast biopsy			< .001		
No	79.9	57.8			
Yes	20.1	72.9			
Hormone therapy (menopausal women)			.02		
No	61.3	57.2			
Yes, currently taking	8.8	70.5			
Yes, in past	29.9	68.4			
Positive history of breast cancer			.02		
Neither	68.5	54.6			
Self only	1.8	81.7			
Relative only	28.2	62.6			
Both	1.5	65.4			

Abbreviation: BD, breast density.

"Percentage of respondents indicating "yes" to question: "Have you ever heard of something called breast density?"

(Hispanic v white non-Hispanic: OR, 0.23; P < .001), household income (OR, 1.07 per category increase; P < .001), education (OR, 1.19 per category increase; P < .001), diagnostic evaluation after a mammogram (OR, 2.64; P < .001), and postmenopausal hormone therapy (OR, 1.69; P = .002; Table 2). Appendix Table A1 (online only) provides results from a model that included a larger set of predictors. BD awareness was higher in Connecticut (81.4%) relative to all other US states (57.2%) and relative to other northeastern states only (67.4%), but these differences were not significant in adjusted analyses.

# **BD Knowledge**

Masking effect of BD. Among all respondents, 48.6% correctly reported that having breasts that are mostly dense makes it more

Table 2. Respondent Characteristics Associated With BD Awareness (multivariable analysis*)						
Independent Variable	OR	95% CI	Р			
Race						
White non-Hispanic (referent)	1.0		Referent			
Black non-Hispanic	0.57	0.35 to 0.93	.03			
Hispanic	0.23	0.13 to 0.40	< .001			
Other/multiple races	0.75	0.31 to 1.80	.52			
Household income (one-category increase)†	1.07	1.03 to 1.11	< .001			
Educational attainment (one-category increase)‡	1.19	1.09 to 1.30	< .001			
Ever recalled for diagnostic evaluation after any mammogram (yes <i>v</i> never/NA)	2.64	1.94 to 3.58	< .001			
Hormonal therapy (ever <i>v</i> never/ nonmenopausal)	1.69	1.21 to 2.38	.002			
nonmenopausal)1.691.21 to 2.38.002Abbreviations: BD, breast density; NA, not applicable; OR, odds ratio.*Single multivariable logistic regression model that includes all predictors in table.†Income categories: < \$5,000, \$5,000 to \$7,499, \$7,500 to \$9,999, \$10,000						

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		Overall			BD Awareness		
Response	All US Women (%)	Connecticut Residents (%)	<i>P</i> *	All US Women (%)	Connecticut Residents (%)	<i>P</i> *	
Impact of mammographically dense breasts on ability of mammogram to correctly detect cancer:			< .001			.006†	
Dense breasts make it easier to see cancer on mammogram	2.5	1.6		2.3	0.0		
Dense breasts do not affect ability to see cancer on mammogram	3.0	2.8		3.9	2.8		
Dense breasts make it more difficult to see cancer on mammogram	48.6	83.0		71.5	89.9		
l don't know	45.9	12.6		22.3	7.3		
Having breasts that are mostly dense on mammogram:			.54			.14	
Does not put you at increased risk for breast cancer	46.8	51.0		41.5	52.7		
Puts you at increased risk for breast cancer	53.2	49.0		58.5	47.3		

Abbreviation: BD, breast density.

\*P for comparison of Connecticut versus all other US States (data not shown; similar to all US women).

†Excluding first response option for statistical testing because of zero cell count.

difficult to see breast cancer on a mammogram; in Connecticut, 83.0% answered correctly (P < .001; Table 3). Among respondents with BD awareness, 71.5% answered correctly; in Connecticut, 89.9% answered correctly (P = .006). Table 4 summarizes demographic and health characteristics among the subset with BD awareness and presents unadjusted associations between these characteristics and knowledge of BD masking effect. Adjusting for selected characteristics (Table 5), the following remained significantly associated with this knowledge: higher income (OR, 1.10 per category; P < .001), more education (OR, 1.22 per category increase; P = .01), having had a breast biopsy (OR, 2.16; P < .001), and residing in Connecticut (OR, 3.82 for Connecticut v other states; P = .003). When compared with other northeastern states, Connecticut residents were more likely to identify correctly the masking effect of BD (P < .001; data not shown). Appendix Table A2 (online only) provides adjusted results for the masking effect of BD and the impact of BD on breast cancer risk, including a larger set of predictors.

Impact of BD on breast cancer risk. Among all respondents, 53.2% correctly reported that BD is associated with an increased breast cancer risk; among respondents with BD awareness, 58.5% provided the correct answer. Residents of Connecticut did not differ in their knowledge of the impact of BD on breast cancer risk (Table 3). Table 4 lists unadjusted associations between demographic and health characteristics and knowledge of BD as a risk factor among the subset with BD awareness. After adjusting for selected characteristics, there were no significant associations with this knowledge (data not shown).

# Sources of Information About BD Among Women With BD Awareness

Fewer than half of respondents (43.1%) who had heard of BD had discussed their own BD with a health care provider (Table 6); among those who had, 71.4% reported having MDBs. The discussion was more often initiated by the provider than the respondent (75.8% v 14%), regardless of whether the respondent reported having MDBs. Among those who reported having MDBs, the source of this information included the ordering provider (52.0%), radiologist (45.1%), and imaging technician (23.7%; respondents selected all applicable op-

tions). Women were more likely to have discussed their BD with a provider if they had undergone prior diagnostic evaluation and/or breast biopsy (both P < .001; data not shown). Connecticut residents were more likely to have discussed their BD with a health care provider (66.8% v 43.1%; P = .001) and to report having MDBs (87.3% v 71.4%; P < .01), as compared with residents of other states.

Among respondents with BD awareness, 37.0% reported having heard of BD from at least one source other than a health care provider, including book, magazine, or newspaper (51.8%); radio or television (29.8%); Internet (17.7%); and friend or family member (35.1%). Connecticut residents were less likely to have heard of BD from sources other than a health care provider (P < .01).

#### DISCUSSION

We provide the first nationally representative estimates to our knowledge of BD awareness and knowledge among women age eligible for mammography screening. Forty-two percent of women reported they were not aware of the term "breast density." Our data reveal awareness disparities based on ethnicity, education, and income. These findings support the need for efforts to raise awareness among all women of screening age as well as particular efforts that target populations vulnerable to disparities in health outcomes and use.

Approximately half of women surveyed demonstrated knowledge of BD impact on breast cancer detection and risk. Among those with BD awareness, < three fourths correctly identified the impact of BD on breast cancer detection and risk. Thus, BD awareness does not necessarily equate with knowledge of the impact of BD on mammography sensitivity or breast cancer risk.

We found that awareness and knowledge of BD impact on breast cancer detection were associated with a history of diagnostic imaging. Given that women with MDBs are at increased risk for recall after screening mammography,<sup>11-13</sup> it is possible that breast diagnostic evaluation provides the setting for BD discussions with providers. Overall, Connecticut residents had higher BD awareness than residents of other US states, but this association attenuated after adjusting

lf

	Knowl BD M Ef		dge of sking ct	Knowledge of BD As Breast Cancer Ris Factor	
Respondent Characteristic	Overall (%)	Correct (%)	Ρ	Correct (%)	Ρ
Race/ethnicity			.21		.61
White non-Hispanic	80.0	73.1		57.5	
Black non-Hispanic	10.2	58.0		65.5	
Hispanic	4.6	77.1		66.8	
Other/multiple races	5.2	67.3		51.9	
lousehold income			< .001		.95
< \$24,999	12.5	51.6		61.8	
\$25,000-\$49,999	18.9	66.1		57.1	
\$50.000-\$74.000	19.2	63.6		56.1	
\$75,000-\$99,999	15.8	72.1		58.4	
≥ \$100.000	33.6	86.0		59.4	
ducational attainment	00.0	00.0	< 001	00.1	07
< High school	4 1	53.8		76.8	.07
High school	27.3	60.2		55.6	
Some college	21.5	68.5		62.0	
> Bachelor's degree	31.3	00.0 84.2		64.0	
	57.5	04.5	02	04.0	4-
	E O	64.0	.03	10.0	.4.
No insurance noted	5.3	64.9		49.8	
Medicaid)	30.9	64.5		61.1	
Employer/private coverage	62.0	75.2		59.0	
	03.9	75.2	63	56.0	5
Excellent/yony good	F2 1	72.2	.00	FQ /	.02
Cood	02.1	70.1		55.4	
Good	33.Z	70.1		00.4 62.0	
	14.7	00.0	1.4	02.0	01
Negrostropolitari Statistical area	15.0	CE O	.14	7 7	.02
Nonmetropolitan	15.8	05.0		47.7 60 F	
	84.Z	12.1	71	60.5	0
S region			.71		.65
Northeast (excluding	20.8	69.0		53.7	
Midweet	20.0	69.5		59.7	
South	21.0	74.0		60.7	
West	10.0	60.7		60.2	
orielation status	19.0	09.7	< 001	00.3	1
Connecticut	10.0	80.0	< .001	17 0	.14
United States (evolution	10.9	03.3		47.3	
Connecticut)	89.1	71 2		58 7	
Aost recent routine health	00.1			50.7	
care visit			.46		.69
Within past 24 months	85.5	72.1		58.8	
> 24 months ago	14.5	67.9		56.4	
ver had mammoaram			.10		.94
No	61	59 4		59 4	
Yes	93.9	72 3		58.7	
ves total mammodrame	55.5	12.0	08	50.7	10
	60.0	74.6	.00	60.9	. 10
< 5 < 5	20.1	74.0		54 1	
NO2 and at first	30.1	00.9	00	54.1	4
yes, age at TIFSt mammogram years			.09		.14
< 50	90 7	73 /		60.3	
~ 50	JU./	70.4 62.2		40.0	
~ 00	9.3	UZ.Z		49.9	

Table 4. Knowledge of BD Masking Effect and Impact on Breast   Cancer Risk Among Women With BD Awareness by   Respondent Characteristics (continued)							
		Knowledge of BD Masking Effect		Knowledg of BD As Breast Cancer Ris Factor			
Respondent Characteristic	Overall (%)	Correct (%)	Ρ	Correct (%)	P		
yes, most recent mammogram	02.0	74.4	.05	60.0	.22		

mammogram			.05		.22
Within past 2 years	83.8	74.4		60.3	
> 2 years ago	16.2	63.4		52.8	
If yes, ever recalled for diagnostic evaluation after					-
any mammogram			.04		.8
No	47.9	68.0		58.1	
Yes	52.1	76.0		59.2	
Ever had breast biopsy			.001		.04
No	75.9	69.1		56.4	
Yes	24.1	81.9		66.0	
Hormone therapy (menopausal women)			.54		.09
No	56.8	68.5		59.6	
Yes, currently taking	10.1	76.8		71.4	
Yes, in past	33.2	67.5		53.2	
Positive history of breast cancer			.02		.42
Neither	64.9	67.9		56.1	
Self only	2.5	79.3		61.5	
Relative only	30.8	77.9		62.7	
Both	1.7	81.1		66.7	
Abbreviation, PD breast density					

Abbreviation: BD, breast density.

for demographic and health characteristics. However, in adjusted analyses of those with BD awareness, Connecticut residents were  $> 3 \times$  as likely as non-Connecticut residents to have knowledge of the masking effect, although they were not more likely to know that BD is a breast cancer risk factor. Connecticut law requires mammography facilities to send the following information on BD masking effect to women after screening mammography: "If your mammogram demonstrates that you have dense breast tissue, which could hide small abnormalities, you might benefit from supplementary screening tests."<sup>36</sup> The letter does not include information about BD impact on breast cancer risk. Our findings are therefore entirely consistent with messaging in the Connecticut letter.

Fewer than half of women aware of BD had discussed their own BD with a provider, and discussions were most often provider initiated. It is plausible that the spread of BD legislation will empower women to initiate these discussions and participate more actively in screening decisions. Among women who had discussed their BD with a provider, almost three quarters reported having MDBs, which is higher than the reported prevalence of MDBs.<sup>37</sup> Although we could not verify self-reported density, it is possible that providers are likelier to initiate BD discussions with women who have MDBs.

Among respondents who had heard of BD, Connecticut residents were more likely than residents of other states to have discussed their individual BD with their provider but less likely to have heard of BD from nonprovider sources. This suggests that BD legislation, along with the discussions it has prompted between providers and women

Table 5. Resp	oondent Chara	cteristics /	Associat	ed With	Know	ledg	e of BD
Masking Effect	(multivariable	analysis*)	Among	Women	With	BD	Awareness

Independent Variable	OR	95% CI	Р
Household income (one-category increase)†	1.10	1.05 to 1.15	< .001
Educational attainment (one-category increase)‡	1.22	1.05 to 1.42	.01
Legislation status (Connecticut v non-Connecticut)	3.82	1.56 to 9.32	.003
Ever had breast biopsy (yes <i>v</i> never/ NA)	2.16	1.38 to 3.38	< .001

Abbreviations: BD, breast density, NA, not applicable; OR, odds ratio. \*Single multivariable logistic regression model for each outcome that includes all predictors in the table.

Thecome categories: < \$5,000, \$5,000 to \$7,499, \$7,500 to \$9,999, \$10,000 to \$12,499, \$12,500 to \$14,999, \$15,000 to \$19,999, \$20,000 to \$24,999, \$25,000 to \$29,999, \$30,000 to \$34,999, \$35,000 to \$39,999, \$40,000 to \$49,999, \$50,000 to \$59,999, \$60,000 to \$74,999, \$75,000 to \$84,999, \$85,000 to \$99,999, \$100,000 to \$124,999, \$125,000 to \$149,999, \$150,000 to \$174,999, or ≥ \$175,000. ‡Education categories: no formal education, 1st/2nd/3rd/4th grade, 5th/6th grade, 7th/8th grade, 9th grade, 11th grade, 12th/no diploma, high school

graduate or equivalent, some college/no degree, Associate's degree, Bachelor's degree, Master's degree, or professional/doctoral degree.

undergoing mammography, may be responsible for the increased knowledge of the masking effect of BD among Connecticut respondents, rather than media coverage surrounding legislation.

A primary concern about raising BD awareness, expressed by the American College of Radiology, is lack of "randomized trial data that shows that adding either ultrasound or MRI [magnetic resonance imaging] to mammography screening saves lives."4 Although supplemental screening with magnetic resonance imaging for high-risk women is well established,<sup>38</sup> supplemental screening in women with MDBs not at high risk is controversial, and there is no consensus on imaging modality; randomized, multicenter trials will be necessary to elucidate benefits and harms. BD awareness is further complicated by lack of a standard classification for dense breasts. Currently, the Breast Imaging Reporting and Data System categories of breast composition are routinely used to describe density based on visual estimation of fibroglandular density tissue content<sup>39</sup>; mammograms categorized as heterogeneously or extremely dense are considered dense, but reproducibility of assessments is a concern.<sup>40</sup> The Breast Imaging Reporting and Data System density lexicon recently changed to highlight the potential for masking and remove quantitative values associated with categories. In addition, some mammography facilities use automated density algorithms, such as Volpara and Quantra, to provide a volumetric measure of density. Improving consistency in BD classification will be important for patient education, risk assessment, and supplemental screening guideline development.

However, BD awareness, even without supplemental screening consensus or precise BD classification, is important. No other routine screening test performance varies so widely based on a known patient characteristic. To make fully informed screening decisions, women should be aware of the differential performance characteristics of mammography based on breast density. Second, it is important for women with MDBs to understand the higher false-negative rate of mammography, so that they are vigilant about reporting breast changes even after undergoing a mammogram that is interpreted as negative or benign. Lastly, given the impact of hormone therapy on breast density and mammography sensitivity, along with the increased

Table 6. Sources	of Information in Connecticut Versus Other US St	ates
	Among Women With BD Awareness	

Response	All US States (%)	Connecticut Only (%)	P*
Have you discussed your BD with health care provider?			.001
No	56.9	33.2	
If yes, what led to your discussion about BD? I asked my health care provider	43.1	00.8	.44
about my BD	14.0	8.5	
brought up topic of BD Something else	75.8 10.2	74.6 16.8	
Do you have dense breasts?			< .01
No Yes	28.6 71.4	12.7 87.3	
If yes, who told you that you have dense breasts?			
Health care provider who ordered my mammogram	52.0	50.5	.89
Radiologist who read my mammogram/mammogram	45 1	12.2	07
Imaging or x-ray technician	23.7	28.0	.67
Have you heard about BD from non-health care provider sources?			< .01
No	63.0	79.4	
Yes	37.0	20.6	
If yes, from what other sources have you heard about BD?			
Book/magazine/newspaper	51.8	62.5	.33
Radio/television	29.8	20.6	.30
Internet	17.7	16.2	.85
Family/friend	35.1	37.7	.81

Abbreviation: BD, breast density.

\*P value comparing Connecticut with all other US states (data not shown; similar to all US states).

risk of breast cancer (and advanced-stage breast cancer) among women with extremely dense breasts who use hormone therapy, BD awareness is important in hormone therapy decision making.<sup>41-45</sup>

As with all surveys, representativeness of the population could be of concern. KnowledgePanel recruits representative samples into its panels, providing Internet access to those without, thereby minimizing coverage error associated with opt-in Web panels.<sup>46</sup> Moreover, by weighting to national control totals, the potential impact of differential survey nonresponse by subpopulations is minimized. Furthermore, there is evidence that probability-based Web panels elicit more accurate data than nonprobability samples and traditional self-report via random-digit dial.<sup>28</sup> We were not able to verify self-reported MDBs, which limits inferences of analyses in women self-identified as having MDBs. We were also not able to verify that the increased BD awareness among women with prior diagnostic imaging was a direct result of the diagnostic imaging. Because BD awareness and knowledge were not assessed in Connecticut before legislation enactment, we cannot verify that knowledge increased after legislation; however, the inference that the greater knowledge of the masking effect of BD in Connecticut versus other states was a result of the legislation as opposed to other Connecticut-related factors is strengthened by our

finding that this association persisted in multivariable analysis and when comparing Connecticut with other northeastern states, thus eliminating potential confounding advantages that could be conferred by its northeastern location.

Strengths of the survey include its large geographic scope, 65% cooperation rate, adequate sample size, oversampling strategy, and our effort to examine multiple domains of BD understanding.

Almost half of women age eligible for mammography screening had not heard of BD, and approximately half did not know the impact of BD on breast cancer detection and risk. An important implication of these findings is that many US women lack the information necessary to participate fully in decisions regarding mammography screening, supplemental screening, and hormone therapy. Tailoring education for particular groups at risk of lower exposure to health information and greater risk of aggressive forms of breast cancer (eg, those with less formal education and minorities, respectively) will be critically important to mitigate additional disparities in knowledge and participation in health care decision making. This study also examined the impact of BD legislation on women's awareness and knowledge of BD. Our findings suggest a positive impact of legislation

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on women's BD knowledge and support continued and targeted efforts to improve BD awareness and knowledge among US women eligible for screening mammography.

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at www.jco.org.

### **AUTHOR CONTRIBUTIONS**

Conception and design: Deborah J. Rhodes, Carmen Radecki Breitkopf, Jeanette Y. Ziegenfuss, Celine M. Vachon Collection and assembly of data: Deborah J. Rhodes, Carmen Radecki Breitkopf, Jeanette Y. Ziegenfuss Data analysis and interpretation: All authors Manuscript writing: All authors Final approval of manuscript: All authors

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## **AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

### Awareness of Breast Density and Its Impact on Breast Cancer Detection and Risk

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# Appendix

Table A1. Association of Respondent Characteristics and BD Awareness (multivariable analysis*)					
Independent Variable	OR	95% CI	Р		
Age (1-year increase)	1.02	1.00 to 1.04	.10		
Race					
White non-Hispanic (referent)	1.0		Referent		
Black non-Hispanic	0.55	0.32 to 0.95	.03		
Hispanic	0.25	0.14 to 0.45	< .001		
Other/multiple races	0.67	0.28 to 1.65	.38		
Household income (one-category increase)†	1.04	0.99 to 1.08	.09		
Educational attainment (one-category increase)‡	1.18	1.07 to 1.29	< .001		
Insurance					
No insurance noted (referent)	1.0		Referent		
Employer/private coverage	2.00	1.08 to 3.72	.03		
Public coverage (Medicare/Medicaid)	1.44	0.77 to 2.68	.25		
Overall health (one-level increase; excellent, 1; poor, 5)	0.92	0.77 to 1.10	.34		
Metropolitan statistical area (metropolitan v nonmetropolitan)	1.03	0.69 to 1.54	.89		
Legislation status (Connecticut v non-Connecticut)	1.94	0.85 to 4.39	.11		
Most recent routine health care visit (within past 24 $v > 24$ months ago)	1.08	0.71 to 1.65	.71		
Total mammograms					
Never had mammogram (referent)	1.0		Referent		
< 5	1.53	0.90 to 2.60	.12		
$\geq 5$	1.51	0.82 to 2.80	.19		
Ever recalled for diagnostic evaluation after any mammogram (yes v never/NA)	2.25	1.58 to 3.21	< .001		
Ever had breast biopsy (yes v never/NA)	1.11	0.69 to 1.76	.67		
Hormonal therapy (ever v never/nonmenopausal)	1.56	1.06 to 2.27	.02		
Positive history of breast cancer (self; yes v no)	1.35	0.55 to 3.31	.51		
Positive history of breast cancer (relative; yes v no)	1.02	0.73 to 1.42	.92		

Abbreviations: BD, breast density; NA, not applicable; OR, odds ratio.

\*Single multivariable logistic regression model that includes all predictors in table. †Income categories: < \$5,000, \$5,000 to \$7,499, \$7,500 to \$9,999, \$10,000 to \$12,499, \$12,500 to \$14,999, \$15,000 to \$19,999, \$20,000 to \$24,999, \$25,000 to \$29,999, \$30,000 to \$34,999, \$35,000 to \$39,999, \$40,000 to \$49,999, \$50,000 to \$59,999, \$60,000 to \$74,999, \$75,000 to \$84,999, \$85,000 to \$99,999, \$100,000 to \$124,999, \$125,000 to \$149,999, \$150,000 to \$174,999, or ≥ \$175,000.

#Education categories: no formal education, 1st/2nd/3rd/4th grade, 5th/6th grade, 7th/8th grade, 9th grade, 10th grade, 11th grade, 12th/no diploma, high school graduate or equivalent, some college/no degree, Associate's degree, Bachelor's degree, Master's degree, or professional/doctoral degree.

Independent Variable	Correct Knowledge of BD Masking Effect			Correct Knowledge of BD As Breast Cancer Risk Factor		
	OR	95% CI	Р	OR	95% CI	P
Age (1-year increase)	0.97	0.94 to 1.00	.07	0.97	0.94 to 0.99	.02
Race						
White non-Hispanic (referent)	1.0		Referent	1.0		Referent
Black non-Hispanic	0.56	0.25 to 1.26	.16	1.26	0.63 to 2.54	.51
Hispanic	1.34	0.47 to 3.83	.58	1.55	0.59 to 4.05	.37
Other/multiple races	0.61	0.21 to 1.74	.35	0.66	0.25 to 1.73	.40
Household income (one-category increase)†	1.10	1.04 to 1.16	.001	0.99	0.94 to 1.04	.60
Educational attainment (one-category increase)‡	1.18	1.00 to 1.39	.05	0.91	0.81 to 1.02	.10
Insurance						
No insurance noted (referent)	1.0		Referent	1.0		Referent
Employer/private coverage	0.65	0.27 to 1.56	.33	1.37	0.59 to 3.18	.46
Public coverage (Medicare/Medicaid)	0.75	0.30 to 1.89	.54	1.94	0.81 to 4.64	.13
Overall health (one-level increase; excellent, 1; poor, 5)	1.04	0.82 to 1.32	.73	0.94	0.76 to 1.16	.58
Metropolitan statistical area (metropolitan v nonmetropolitan)	1.29	0.77 to 2.15	.34	1.80	1.09 to 2.97	.02
Legislation status (Connecticut v non-Connecticut)	3.49	1.44 to 8.43	.006	0.56	0.30 to 1.06	.08
Most recent routine healthcare visit (within past 24 $v > 24$ months ago)	1.04	0.56 to 1.93	.91	0.90	0.54 to 1.53	.71
Total mammograms						
Never had mammogram (referent)	1.0		Referent	1.0		Referent
< 5	0.97	0.41 to 2.32	.95	0.79	0.36 to 1.70	.54
≥ 5	1.60	0.67 to 3.81	.29	1.29	0.58 to 2.91	.53
Ever recalled for diagnostic evaluation after any mammogram (yes v never/NA)	1.24	0.79 to 1.95	.35	0.82	0.55 to 1.23	.34
Ever had a breast biopsy (yes v never/NA)	1.86	1.08 to 3.19	.03	1.71	1.08 to 2.71	.02
Hormonal therapy (ever v never/nonmenopausal)	0.92	0.58 to 1.45	.72	0.91	0.61 to 1.37	.66
Positive history of breast cancer (self; yes v no)	0.88	0.32 to 2.41	.81	0.90	0.38 to 2.10	.80
Positive history of broast concer (relative; yes y no)	1 55	1 00 to 2 40	05	1 20	$0.90 \pm 0.100$	10

Abbreviations: BD, breast density; NA, not applicable; OR, odds ratio. "Single multivariable logistic regression model for each outcome that includes all predictors in table. †Income categories: < \$5,000, \$5,000 to \$7,499, \$7,500 to \$9,999, \$10,000 to \$12,499, \$12,500 to \$14,999, \$15,000 to \$19,999, \$20,000 to \$24,999, \$25,000 to \$29,999, \$30,000 to \$34,999, \$35,000 to \$39,999, \$40,000 to \$49,999, \$50,000 to \$59,999, \$60,000 to \$74,999, \$75,000 to \$84,999, \$85,000 to \$99,999, \$100,000 to \$124,999, \$125,000 to \$149,999, \$150,000 to \$174,999, or ≥ \$175,000.

Education categories: no formal education, 1st/2nd/3rd/4th grade, 5th/6th grade, 7th/8th grade, 9th grade, 10th grade, 11th grade, 12th/no diploma, high school graduate or equivalent, some college/no degree, Associate's degree, Bachelor's degree, Master's degree, or professional/doctoral degree.