

What Do Women Know About Breast Density? Results From a Population Survey of Virginia Women

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Abstract

Purpose: Breast density reduces the sensitivity of mammography and is a moderate independent risk factor for breast cancer. Virginia is one of 24 states that currently require notification of patients when they have dense breasts. However, little is known about what women in the general population know about breast density. This survey study assessed knowledge about breast density and about its impact on mammography and breast cancer risk.

Methods: A random sample of 1024 Virginia women between ages 35 and 70 years without breast cancer, reached by landline and cell phone, who completed a 24-minute interview. Bivariate and multivariate analysis was performed.

Results: Thirty-six percent of respondents had been informed about their breast density. These women were more likely to be familiar with the term “breast density.” Seventy-five percent of respondents reported being either somewhat or very familiar with risk factors for breast cancer, but <1% spontaneously listed breast density as a risk factor. About half of women who had a mammogram in the last year were aware of their breast density. Overall, only one in five women were aware that density reduces the sensitivity of mammography and only one in eight were aware that density increases breast cancer risk. Very few respondents (5.3%) were able to correctly answer three density knowledge questions. Lower-education, African-American, and Jewish women were less knowledgeable about breast density.

Conclusions: Although women are becoming aware of the term “breast density,” they may not understand its relationship to cancer detection on mammography and, especially, its relationship to breast cancer risk.

Key Words: Breast density, mammography, breast cancer knowledge, breast cancer risk, population studies

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INTRODUCTION

Breast density is a moderate independent risk factor for breast cancer [1] and reduces the sensitivity of mammography [2], yet women may not know or understand the implications of their personal breast density on cancer risk or detection. Women in at least 27 states are subject to “breast density notification laws” that require radiologists to inform women of their

mammographic breast density, and federal bills have been proposed in the last three congressional sessions that would set a minimum federal standard for dense breast tissue notification [3]. The assumption underlying these laws is that women will use this information to inform and guide decisions about breast cancer screening they make with their health care providers. Specifically, women with dense breast tissue

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may benefit from additional screening with ultrasound or other modalities owing to the reduced sensitivity for breast cancer for women with dense breast tissue [4,5].

Breast density is currently classified by the radiologist into one of four categories: almost entirely fatty, scattered fibroglandular densities, heterogeneously dense, or extremely dense [6,7]. Approximately half of all women screened will fall into one of the two high-density categories [8,9]. In the United States, this means that approximately 19 million women will be notified that they have dense breasts this year [10]. But many, if not most, will be unclear about its meaning for their personal breast health [11,12].

The current body of research on women's knowledge of breast density is limited. Smaller studies have found that when women were provided with information on breast density, they were able to identify density as a risk factor for breast cancer, but knowing that information did not alter their screening behaviors [11]. One large-scale study [13] surveyed participants in a prerecruited, online access panel and did not directly survey the general population.

The Virginia "Breast Density" notification law went into effect on July 1, 2012, and was the third breast density notification law in the United States, after Connecticut and Texas. Our study sought to explore what women in Virginia know about breast density and its risks for cancer detection, diagnosis, and recommendations.

METHODS

This study was reviewed and approved by the University of Virginia Institutional Review Board for Social and Behavioral Sciences.

The Virginia "Breast Density" notification law went into effect on July 1, 2012. The law requires that patients be informed if they have heterogeneous or extremely dense breast tissue on mammography by inclusion of a specific statement in their result letter [14] (Appendix 1). A second law updated the language to specifically state that women with dense tissue may benefit from additional screening and was effective July 1, 2013 (Appendix 1). The Virginia Survey on Breast Cancer Screening was conducted via telephone by the University of Virginia Center for Survey Research during the summer and early fall of 2013.

Questionnaire Development

Before the questionnaire was drafted, a total of four focus groups were conducted. The first focus group included

breast cancer survivors and the second included women who had never had breast cancer. Two breast cancer advocates, who were active members of the study team, helped to conduct the focus group sessions. Results from these focus group sessions assisted in development of the language and content of the survey.

A second set of two focus group sessions were then assembled: one in Charlottesville, Virginia, and a second in Richmond, Virginia, an area with a more racially and ethnically diverse population. These second focus group sessions were designed as group self-administered surveys followed by a group debriefing, after which the survey was modified based on feedback. A live telephone pretest of the survey was conducted in May 2013, yielding 26 completed interviews. This allowed final revisions to the survey instrument to clarify questions.

The survey questionnaire included questions about breast cancer screening adapted from the Mayo Clinic Long Term Follow-up Study [15] as well as a number of new questions developed expressly for this study. The final questionnaire, in English and Spanish, covered a number of topics in sequence: the respondent's family experience with breast cancer, her current breast cancer screening practices, her assessment of her own risk for breast cancer, understanding of breast density, understanding of current screening guidelines, willingness to change screening practices, sources of information about breast cancer screening, and demographics.

Sample

The survey used a triple-frame telephone sample of Virginia phone numbers, combining a conventional random-digit landline telephone sample, a sample of directory-listed landline telephone numbers, and a random-digit cell phone sample with active numbers identified. The survey instrument included an initial screen that asked for women aged 35 to 70 and screened out women with a prior diagnosis of breast cancer and those not residing in Virginia. For households reached via landline, respondents were asked to say how many women in the household met the eligibility criteria, and then a random selection procedure [16] was used to select one of these women as the respondent. For cell phone interviews, the person answering the phone was simply screened for eligibility.

Interviewing

All interviews were conducted by trained, female interviewers from June through October 2013. Spanish speakers who preferred native language were called back

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