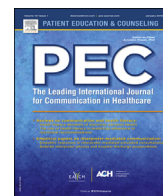




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Women's perceptions of dense breast notifications in a Massachusetts safety net hospital: "So what is that supposed to mean?"

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ABSTRACT

Objective: Currently, 30 US states mandate that radiologists notify women when dense breast tissue is found on mammography. Little is understood about how notifications are perceived by recipients. This qualitative study sought to understand how dense breast notifications (DBNs) impact women's perceptions and their participation in follow-up care.

Methods: We assessed rates of DBN recall and conducted semi-structured telephone interviews with 30 English-speaking women ages 40 to 74 after receiving a DBN from a Massachusetts hospital. Content coding characterized women's recall of the notification content, perceptions of breast density, and planned or actual participation in follow-up care.

Results: Most women (81%) recalled receiving a DBN, but few could recall specific content. Women described struggling to understand the meaning of breast density and created their own explanatory models of dense breasts that differed from medical explanations. Many women planned to or did talk with their doctors about breast density as a result of receiving the notification.

Conclusions: Women receiving DBNs have limited knowledge and many misperceptions about the implications of having dense breasts.

Practice implications: Educational support is needed to promote informed decision-making about breast cancer screening that incorporates personal risk in the setting of dense breast legislation.

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1. Introduction

Since 2009, 30 states have adopted legislation requiring mammography providers to provide written notification to women with dense breast tissue seen on a mammogram [1]. Approximately 40–50% of women receiving mammograms have dense breasts, representing over 27 million women ages 40–74 in the United States [2]. While the content of state notifications differs slightly, 28/30 (93%) explicitly state that having dense breasts increases cancer risk and all mention that having dense breasts

makes it more difficult to detect cancer on a mammogram (see [3] for details on state legislation). Information about these risks is often accompanied by the suggestion that women speak with their doctors and/or pursue supplemental screening with ultrasound or magnetic resonance imaging (MRI).

Dense breast notifications have the potential to alter women's perceptions of their breast cancer risk or change screening behaviors. While these laws aim to empower women [4], the impact of notifications remains uncertain. Survey research indicates that legislation may increase awareness of breast density and knowledge about its impact on cancer risk and mammography sensitivity [5]. However, awareness varies by patient factors (race/ethnicity, income, health beliefs) [7] and setting (academic vs. county hospitals) [6]. The legislation is also associated with greater use of supplemental MRI and ultrasound [8,9]. These studies have quantitatively examined the anticipated changes in specific knowledge and attitudes resulting from dense

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breast notifications, but there are potential emotional, social, and behavioral responses that have yet to be characterized. Previously we found that the notifications were written at a high literacy level (mean Flesch-Kincaid score of grade 10.5 across 24 states; range: 7–19.4) [3]. Given the generally high literacy level of these notifications, there is a significant potential for misinterpretation that may impact patient beliefs, attitudes, knowledge and participation in follow-up care. To explore a fuller range of women's perceptions of receiving a dense breast notification and their intentions for follow-up care beyond what is possible with survey research, we conducted a qualitative study of women receiving mammograms in one Massachusetts safety-net hospital to elicit their experience after receiving a dense breast notification.

2. Methods

This qualitative interview study assessed women's awareness regarding notification of breast density, understanding of the notification's content, and planned or actual follow-up care. Massachusetts' notification law requires that specific information be communicated to patients, including: 1) Whether and to what degree dense breast tissue was identified on their mammogram; 2) The fact that dense breast tissue is common and not abnormal; 3) Direction to informational resources; 4) The fact that dense breasts may increase breast cancer risk and mask breast cancer on a mammogram; 5) The fact that women with dense breasts may need supplemental screening with ultrasound or MRI; and 6) that they should discuss results with their physician (see online supplement for sample) [10]. While exact language is not legislated as in some other states, the distributed notifications are consistent with other states' mandated text in terms of content [3]. Study activities were approved by the Boston University Medical Center Institutional Review Board.

2.1. Sampling and recruitment

English speaking women aged 40–75, who had a routine screening mammogram at Boston Medical Center (BMC) with a normal result, received a dense breast notification after January 1, 2015, and who recalled receiving this notification were potentially eligible. A normal finding was defined using the Breast Imaging Reporting and Data System criteria, 4th edition [11]. Those who had a mammogram done concurrently with a visit in a breast specialty clinic were excluded, as these women's clinical experiences may influence perceptions about breast density in relation to cancer risk.

After we obtained a Health Insurance Portability and Accountability Act waiver to allow us to contact women about the study, the radiology department generated a list of potential women who met initial inclusion criteria. A letter from the Chief of Breast Imaging was sent to potentially eligible women, informing them of the study and indicating they may be contacted. The letter included a phone number and email where women could opt out of further contact. After one week passed without receiving an opt-out response, a research assistant called patients for screening. The screening call reviewed inclusion criteria and assessed women's recall of the breast density notification to determine eligibility. Those who recalled the notification were invited for an interview, while those who did not recall the notification were asked only about their demographic information.

2.2. Data collection

Eligible and willing women participated in one 20–45 min interview via phone after providing verbal informed consent. All

interviews were conducted by one of two trained research assistants using a semi-structured interview guide. The interview guide incorporated concepts represented in the Health Belief Model [12,13], assessing breast density notification as a *cue to action* and its impact on *perception of an illness threat* (breast cancer risk), and subsequent *health behaviors* (intended/actual follow-up care). Interviews included a series of questions about how women first learned they had dense breasts, what they recalled about the notification and their understanding of its meaning, perceptions of breast cancer risk, and planned or actual follow-up care. Interviews were recorded and transcribed verbatim to facilitate data analysis by study investigators.

2.3. Analysis

Among those screened, we explored notification recall by reporting the proportion of women who recalled receiving the breast density notification relative to all eligible women screened. Chi Square and Fisher's exact tests assessed whether socio-demographics (race, insurance status, or age) contributed to differences in recall.

We conducted a manifest content analysis to identify women's perceptions and actions taken after receiving the notification, ensuring that themes remained grounded in the words of participants, so as to accurately represent their experiences [14,15]. This technique is a systematic approach for compressing a large amount of qualitative data into fewer content categories based on explicit rules [16]. The primary author and a research assistant independently reviewed audio files and transcripts for the first eight interviews and created a preliminary list of codes. Then, we compared coding and reconciled differences to create a refined code book with explicit definitions and examples. A third investigator reviewed the codebook for completeness prior to proceeding. Using the refined list, two coders independently coded the remaining interview materials. To establish reliability between coders and ensure rigor, a modification of Cohen's kappa was calculated [17]. Ten percent of cases ($n=3$) were randomly selected for agreement analysis. Within each case, six random paragraphs were selected and agreement statistics were based on the proportional overlap of coding for the same content within these 18 segments [17]. This established moderate reliability between coders ($\kappa=0.56$), so the codebook was revised once more and reviewed for calibration ($\kappa=0.78$) before the remainder of transcripts were coded. Content codes were grouped to build broader themes around perceptions and actions described by women who had received dense breast notifications. At each stage, an additional reader met with coders to ensure transparency in the coding and theme-building process. The final themes were reviewed by the entire research team and transcripts were made available for review.

To graphically display a participant-level summary of recall for specific notification elements, content codes were used to generate a spectrum graph (Fig. 2). The spectrum graph displays which of four main content elements (i.e., increased risk of cancer, masking bias, talking to a doctor, and supplemental screening) each participant recalled. Participant identification numbers are arrayed on the outside of the graph, with each row representing a recalled aspect of the notification content. Circles denote those who recalled each content domain during the interview. We divided the spectrum into two categories: those who had spoken with a doctor prior to the interview, versus those who had not, as we expected that a clinical interaction involving dense breasts would enhance message recall. This allowed us to visually examine the graph for patterns along this dimension.

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