ORIGINAL RESEARCH

A Qualitative Study of Spanish-Speakers' Experience with Dense Breast Notifications in a Massachusetts Safety-Net Hospital

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BACKGROUND: Legislation requiring mammography facilities to notify women if they have dense breast tissue found on mammography has been enacted in 34 US states. The impact of dense breast notifications (DBNs) on women with limited English proficiency (LEP) is unknown.

OBJECTIVE: This study sought to understand Spanish-speaking women's experience receiving DBNs in a Massachusetts safety-net hospital.

DESIGN: Eligible women completed one audio-recorded, semi-structured interview via telephone with a native Spanish-speaking research assistant trained in qualitative methods. Interviews were professionally transcribed verbatim and translated. The translation was verified by a third reviewer to ensure fidelity with audio recordings.

PARTICIPANTS: Nineteen Spanish-speaking women ages 40–74 who received mammography with a normal result and recalled receiving a DBN.

APPROACH: Using the verified English transcripts, we conducted a content analysis to identify women's perceptions and actions related to receiving the notification. A structured codebook was developed. Transcripts were independently coded and assessed for agreement with a modification of Cohen's kappa. Content codes were grouped to build themes related to women's perceptions and actions after receiving a DBN.

KEY RESULTS: Nineteen Spanish-speaking women completed interviews. Nine reported not receiving the notification in their native language. Four key themes emerged: (1) The novelty of breast density contributed to notification-induced confusion; (2) women misinterpreted key messages in the notification; (3) varied actions were taken to seek further information; and (4) women held unrealized expectations and preferences for follow-up.

CONCLUSIONS: Not having previous knowledge of breast density and receiving notifications in English contributed to confusion about its meaning and inaccurate interpretations of key messages by Spanish speakers. Tools that promote understanding should be leveraged in seeking equity in risk-based breast cancer screening for women with dense breasts.

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INTRODUCTION

Providing health information to those with limited English proficiency (LEP) has challenged the health system for decades. There are 25.1 million people in the USA who have LEP, 64% of whom speak Spanish.[1] The importance of accommodating linguistic needs in health care is apparent from the body of research identifying associations between language barriers and misconceptions about disease,[2] poor understanding of recommendations,[3] and worse health outcomes.[4–6] While implementation of the Culturally and Linguistically Appropriate Services (CLAS) Standards aims to improve quality and eliminate disparities by providing culturally competent care,[7] few organizations have met these expectations. For example, most health systems do not provide adequate linguistic access including interpreter services, multilingual signage, and written translation services.[6,8,9]

In the context of these LEP-related barriers, there simultaneously exists a trend towards engaging patients in decision-making. This is exemplified in the proliferation of state legislation mandating that women receive written notification if their mammogram indicates they have dense breast tissue. These laws, enacted in 34 states,[10] aim to empower women to become active in decisions about supplemental breast cancer screening and prevention. Participation in decision-making in this setting is important, as there are few data to suggest clinical benefit from supplemental screening based on breast density alone, despite some notifications suggesting that this is the case.[11,12] Instead, understanding a woman's risk for developing breast cancer, including breast density, can guide future screening.[13,14] Effectively engaging women in decision-making relies on patients having knowledge of relevant information and choices, identifying preferences and values, and understanding that their decisions will be respected by physicians.[15]

It is not clear that LEP women are prepared to receive these messages regarding breast density. Mammography result letters are often written at levels too difficult for many patients to understand, language aside.[16] Women with LEP are known to have difficulty understanding mammography information[17] and receive fewer preventive services.[18] Hispanic/Latina women with LEP are less likely than white women to correctly identify that they have received an abnormal result,[19] although verbal notification improves comprehension.[19] Research on English speakers' understanding of breast density notifications have revealed high anxiety, poor understanding of the association with breast cancer risk, and confusion about what to do.[20,21] Intuitively, we expect these phenomena to be amplified when language barriers exist. Difficulty understanding results can impact downstream care: Non-English speakers are twice as likely to have a delay in follow-up to an abnormal mammogram compared to English speakers, which can contribute to disparities in health outcomes.[4] Thus, we sought to explore the impact of breast density legislation on women with LEP by conducting a qualitative study of Spanish-speaking women receiving dense breast notifications in a Massachusetts safety-net hospital.

METHODS

We used qualitative interviews to assess women's awareness of breast density notification, understanding of the notification's content, and planned/actual follow-up care after the enactment of the Massachusetts legislation in January 2015. The radiology department of an urban Massachusetts safety-net hospital identified patients who met the inclusion criteria, after obtaining a HIPAA waiver. Eligible women were aged 40–74, identified as Spanish-speaking in the medical record, had a mammogram with a normal result between January and August 2016, and received a dense breast notification (see Supplement for sample notifications in English and Spanish). Those whose mammograms occurred with a visit in a breast specialty clinic were excluded, as these women's clinical interactions may have influenced their perceptions and course of care. Study activities were approved by the Boston University Medical Center Institutional Review Board.

Potentially eligible women received a letter in Spanish that informed them of the study, indicated they may be contacted, and offered an opt-out phone number and email. If no opt-out was received within 7 days, a trained, a native Spanish-speaking research assistant initiated contact. The screening call reviewed the inclusion criteria and assessed women's recall of the breast density notification to determine eligibility.

After providing verbal informed consent, women participated in one 30-min audio-recorded phone interview. A semi-structured interview guide based on the Health Belief Model[22,23] covered how women learned they had dense breasts, what they recalled about the notification, their understanding of its meaning, perceptions of breast cancer risk, and planned/actual follow-up care. Women were asked to describe the notification content in a non-directive manner, although the language the notification was written in was elicited, if unspecified.

Interviews were transcribed in Spanish, then translated to English by a professional transcriptionist. The translations were verified by the interviewer, and any substantial discrepancies were resolved by a third outside native Spanish-speaking reviewer. English transcripts were uploaded to MaxQDA qualitative analysis software to facilitate analysis.[24] Sampling continued until thematic saturation, where no new themes were identified.[25] This occurred at 16 interviews; three interviews that had been previously arranged were completed and included in the analysis.

Data Analysis

Using the English transcripts, a content analysis identified women's perceptions and actions related to receiving the notification.[26] We structured a codebook around the interview guide domains. The primary author and a research assistant independently reviewed five interview transcripts and created a preliminary list of codes grounded in the data. Then, we compared coding and reconciled differences to create a codebook with explicit definitions and examples. Using the codebook, two coders independently coded the remaining materials. To assess agreement and ensure transparency, a kappa was calculated on the next five interviews.[27] Any discrepancies in coding generated a review of the interviews with the team, examining the context of the coded passage and its relevance to the research questions. Once good reliability was established ($\kappa > 0.7$), the remaining interviews were coded. Content codes were grouped and compared to build broader themes around perceptions and actions described by the women.

To further ensure transparency and promote analytic rigor, preliminary findings were presented in partnership with a community-organization, *La Alianza Hispana*, at a Science Café. We discussed preliminary themes in an informal setting with a group of local Spanish-speaking women via a translator from the organization. Women's feedback emphasized the importance of receiving medical communications in Spanish, anxiety about breast density, and lack of knowledge women have about breast density. This was incorporated into the final presentation of themes.

RESULTS

The study team conducted 133 screening calls, identifying 21 eligible women. Of note, 10 women (7.5%) were ineligible due to language misclassification (i.e., they did not speak

Spanish). Nineteen women completed interviews between January and September 2016. Interviews were conducted within 2 months of the mammogram, on average. The mean interview length was 27 min. The average age of participants was 48.3 (SD = 7.7). As seen in Table 1, all identified as Hispanic, representing several countries of origin. Almost all (18 of 19, 95%) reported having public insurance. Ten women reported having received the letter in Spanish, while nine received the notification in English. The majority of women (n = 13, 68%) had annual mammograms, four received mammograms every 2 years, and two reported that this was their first mammogram. Most had never heard about dense breasts until the notification (n = 15, 79%), and women spoke to a range of healthcare and social contacts about receiving the notification (Table 1).

Four themes emerged: (1) The novelty of breast density contributed to confusion about the notification; (2) women misinterpreted key messages contained in the notification; (3) varied actions were taken to seek further information; and (4) women held unrealized expectations and preferences for follow-up. Below, we describe each theme using representative quotes. Participants are identified by age and the language in which they received the notification.

Theme 1: The Novelty of Breast Density Information Contributed to Confusion—"It may provide an explanation, but I read it and I read it but I don't understand it"

Women acknowledged that the purpose of the notification was to provide information, "I believe the purpose is for us to know what we have or whether or not we have something. That's a good thing." (age 42, Spanish notification)

Table 1 Participant Characteristics in the Context of Dense Breast Notification

	N (*N* = 19)	Percent
Country of origin		
Dominican Republic	9	47
Puerto Rico	3	16
El Salvador	2	11
Guatemala	2	11
Other	3	16
Insurance		
Public	18	95
Commercial/private	1	5
Mammography use		
Annual	13	68
Every 2 years	4	21
First mammogram	2	11
Notification language		
Spanish	10	53
English	9	47
Notification's first mention of dense breasts		
Yes	15	79
No	4	21
Post-notification communication		
Talked to doctor prior to interview	6	32
Planned to speak to a doctor in the future	12	63
Talked to family	11	58
Talked to friend	4	21
Talked to other healthcare providers	4	21

Yet most (79%) participants had never heard of breast density until receiving a dense breast notification. As a frontline communication tool, women found the content, and especially the lack of explanation about breast density, to be confusing:

> Perhaps better explanation about the meaning of breast density because not everybody has the same ability to understand things…I think it needs a little more explanation. (age 42, Spanish notification)

Although women who received the notification in both English and Spanish described confusion, this was compounded with frustration when participants received the notification in English:

> Honestly, I should have received this letter in Spanish because that is my primary language and it is noted in my medical records. Anything related to my health and any actions I should take regarding my health, I should get an appointment or any written explanation should be in Spanish so that I know what course to take. I feel that I have not received much information. That is why I am looking for someone to explain it to me, in Spanish, because the letter is in English and I understand very little. (age 68, English notification)

> Here, it says [*patient tries to read medical terms in English*] it's in English and I can't even pronounce them in English. Fibroglondular densis-, heterogeneous densi-… I thought I had all four. (age 46, English notification)

Receiving the letter in English required women find someone who could provide a translation, thus creating delay in their understanding of the notification. This delay prolonged worry related to questioning what the letter said:

> As soon as I received it, the first thing I think about is that they're going to tell me something bad. And it's even worse because it's not in my native language. You don't have someone to read it for you immediately. Until you find someone to read the letter for you, it's a little bit hard. (age 42, English notification)

While receiving the notification in English contributed to delays in comprehension, all women described struggling to understand what it meant to have dense breasts, leading to initial reactions dominated by fear and anxiety. The receipt of a letter in the mail put women on alert, evoking reactions of concern about their health: "I got scared thinking I had cancer or something like that." (age 49, English notification)

Theme 2: Women Misinterpreted Key Messages Contained in the Notification—"If they were totally normal, they wouldn't have density"

Despite not fully understanding the content of the notification, women sought to interpret its meaning. Women struggled with the interpretation of three specific components of the notification content: (1) dense breasts are considered normal; (2) dense breasts increase your future risk for developing breast cancer; and (3) dense breasts reduce the sensitivity of mammography to detect a cancer (masking bias).

Most women (12 of 19) reported understanding that dense breasts are relatively common. For example, "Between 40 and 50% of patients suffer from this condition. Meaning it's normal within 40 to 50% of women to have this condition." (age 49, English notification) Yet for the other seven women, interpreting whether or not dense breasts were normal proved difficult. One woman explains how prior experience with mammography communication was used as a benchmark, leading her to conclude that dense breasts are not normal: "It says here that you must pay attention when you have dense breasts. So, I think it's not normal. Other letters I have received never contained those explanations; they never came like that." (age 42, Spanish notification)

The legislation seeks to provide women with information about the increased risk of cancer associated with dense breasts, yet only one woman reported an understanding of this association. In fact, several women reported the notification either informed them otherwise or a normal result was interpreted as a lack of cancer risk: "It said there was no risk of cancer and that made you feel more at ease." (age 45, Spanish notification)

Finally, women reported widespread confusion about the idea of masking bias introduced in the letter; that is, when dense breast tissue makes it more difficult to detect cancer on mammography. Some women who received the notification in Spanish interpreted dense breasts as the physical presence of "masses": "It kind of explains that it's a mass that grown inside the breasts that sometimes it doesn't allow for the breast to be seen entirely." (age 43, Spanish notification) Conceptualizing dense breasts as an obstructing mass was accompanied by the idea that mammograms were completely ineffective, heightening some women's concerns about density. As the woman above described: "I feel very worried because when the breasts are dense, there is *no* possibility to detect breast cancer." Many women struggled with what this meant for future testing:

> I don't understand because if they can't see it clearly, if I have something and they couldn't see it clearly, I think they should refer me for another exam where they can see things clearly. Otherwise, why dense breasts? What causes it? (age 42, Spanish notification)

Theme 3: Women took varied actions to seek further information—"You have to know what's going on"

To draw meaningful conclusions from notification content amidst feeling confused, women described their efforts to seek additional information. Women placed great importance on deciphering the meaning of the notification through information seeking. One woman summarizes this sentiment:

> It's important to always be informed of your health… When you know what you have, what can happen, and what you're up against, you feel better when you know what to do. When something happens to you, you should know who to turn to and what questions you need to ask so you are informed and are current in what's going on. (age 42, English notification)

Women sought information and assistance from a variety of contacts, including the internet, friends, and family, as well as medical providers. We found that initial information-seeking differed based on the language in which they received the notification. Four women who received the notification in English sought clarification from the internet, while only one woman receiving a Spanish notification did so.

> I immediately went to the internet because I didn't understand what density meant. I started reading a lot on dense breasts; that it's like a mass of fat…I cleared some of my questions and doubts on the internet, really, not from what the hospital sent me, no, no, no. (age 46, English notification)

There were limitations in using the internet, particularly the lack of personalized information. This same woman stated, "There are four types of dense breasts. I didn't know which of the four I had because it only talked about dense breasts, and that was it."

Women who used the internet also reported discussing breast density with friends and non-physician care providers: "So, when I had the mammogram done again this year, that's when I worried more [about my dense breasts] and a neighbor of mine said 'Oh, I have the same thing. Don't worry.'" (age 42, English notification) While initial information-seeking strategies differed, women across groups discussed the importance of contacting physicians to clarify their interpretation, gather additional information, and seek advice:

> A doctor can clear your ideas and tell you what's going on because…he knows what he's talking about… I'm going to the doctor so he can tell me because there are various websites and people talking. They're having conversations on the internet and you read it but you don't know how accurate the information is. It's better to talk directly, face-to-face with a doctor so he can tell

you; he's going to talk to you clearly. (age 42, English notification)

The notification's message about speaking with one's doctor was understood and acted upon by many women in the sample. The majority had either already spoken with their doctor ($n = 6$) and/or had intentions to do so in the future ($n = 12$).

Theme 4: Unrealized Expectations and Preferences for Follow-up—"It's as if the mammogram wasn't enough"

Many women interpreted the receipt of a letter to indicate that additional tests or visits were forthcoming. More than just a desire for future testing, women expected doctors to initiate follow-up: "I thought I was going to get another letter or I was going to get a phone call with an appointment to see a doctor. But, to date, I haven't received anything." (age 41, English notification) Others interpreted the lack of action to mean that everything was normal: "If it were something of serious concern, they would have called me. So it must not be too serious because they haven't called me." (age 49, English notification)

In addition to expressing the ways in which expectations were not met, many of the women interviewed shared their preferences for follow-up communication. Two aspects of communication appeared most salient to these women: (1) timely, understandable information; and (2) verbal communication with a physician to allow questions to be answered. Examples are presented in Table 2.

In suggesting alternative follow-up or communication strategies, one woman indicated that these written notifications felt impersonal, emphasizing the importance of personalized messaging:

> It made me feel like it wasn't important. As if they just decided to send me that and that's it… I felt like they treated my problem as something unimportant… It looks like it was taken from a book. Honestly, I think what I found on the internet is better than what they sent me here. (age 46, English notification)

This woman's comment underscores the importance of the topic to her and the impact of the mode of communication on her understanding and emotional response.

DISCUSSION

We learned, among 19 Spanish-speaking women receiving dense breast notifications in Massachusetts, that while women appreciated the intention to provide them with information, not having previous knowledge of breast density contributed to confusion about its meaning and did not result in accurate interpretations of the notification's key messages. Further, almost half did not receive the notification in their native language, contributing to delays in understanding. The notifications did motivate women to seek further information, and all women valued timely, understandable, and in-person communication about breast density. These findings indicate areas for improvement in the implementation of breast density legislation from both health systems and interpersonal perspectives.

From a health system perspective, nine of the women received a notification in English despite being identified in the medical record as Spanish-speaking, stressing the challenges in developing automated notifications that rely on such data. Across settings, the collection of race, ethnicity, and language data in health records is far from reliable.[28,29] Missing data and misclassification are common, despite acknowledgement that these data can improve care and achieve equity if used well.[30] Communications based on poor data collection may perpetuate disparities when they favor particular groups such as native English speakers. With 47% of sampled women receiving a notification in their non-native language, our findings mirror others demonstrating unmet translation needs from 41 to 69%,[17,31] although Massachusetts has been a leader in

Table 2 Sub-Themes Relating to Women's Preferences for Dense Breast Communications

Sub-theme	Quote	Participant
Timely and understandable communication	Whether it be via letter, or in person, whichever way it is, they just have to work with me as soon as possible after giving me the information.	Age 41, Spanish notification
	I think that number one, you can explain something like: Dense breast means this and this. If it's nothing to worry about, then let them know. Then, you explain you have breast... you are one among people who have dense breasts…	Age 64, Spanish notification
	I would like a pamphlet or something like that, containing images and a detailed explanation.	Age 47, Spanish notification
Verbal communication	I think it would be better for someone to give you that information in person; this way, if we have any concern or question, we can ask right there what does dense mean?	Age 45, Spanish notification
	I think it would be better if a doctor met with you after the mammogram, even if just for five minutes – just for the doctor to say, 'look, your mammogram shows everything is normal. You can wait until next year'... a doctor should be available to explain it to you without you having to make an appointment. If a doctor would have explained this to me, even if through an interpreter, I would have felt more at ease.	Age 41, English notification

obtaining such data.[32] Even with extensive training and rigorous documentation processes, our data indicate that patients still do not always receive health communications in their preferred language. Interventions that improve the accuracy of medical record language documentation and its use, particularly those that elicit preferred language, together with robust interpretation services can improve the care experience for LEP patients.[31]

We found that there were several misconceptions about breast density. Similar to findings here, in a study among English-speaking women, we documented barriers to understanding the content of breast density notification.[33] In both studies, women did not have a clear explanation for the term dense breasts, struggled to understand what it meant for their health, and had reactions of worry and anxiety related to receiving the written notification. Spanish-speaking women receiving the notification in English expressed additional stress around receiving the letter in English and may have experienced heighted anxiety that was less easily resolved.

In a readability analysis of dense breast notifications across the USA, we noted the high literacy level at which notifications were written.[34] Thus, there is a clear need to amend the content related to literacy level, but cultural tailoring is equally important. For example, women reported that dense breasts represented some type of "tumor" or "mass" when the notification was received in Spanish, a description not found in our English sample,[33] nor among women receiving the English version. This may suggest a need to adjust the translation to maintain fidelity with the message's meaning, provide accurate explanations for medical terminology, and establish clear expectations for recipients.[8] Amendments for literacy and cultural meaning are supported by tools like the Agency for Healthcare Research and Quality's Universal Precautions Toolkit.[35] This tool aids professionals in simplifying messages to minimize miscommunication and can guide the development of communications such as those under study here.

From an interpersonal perspective, providing a written notification of breast density did not align with women's communication values. Women expressed a desire for timely and in-person health communication. This is consistent with other studies in LEP populations, where the ability to ask clarifying questions is of paramount importance.[2,36,37] Our study also documented that women receiving the notification in English experienced delays in resolving concerns, as they had to first access an informal translator before contacting a healthcare professional for clarification. Delays and lack of access to timely language-concordant information are known to impact participation in care.[4] The goal of this legislation is to promote engagement in decision-making about possibly beneficial supplemental screening. While there remains significant controversy and relatively little data on the clinical benefit of supplemental screening with MRI or ultrasound based on breast density alone, there is more consensus on using breast density as an opportunity to assess breast cancer risk and inform screening. Some state organizations have provided guidance for clinicians in this regard.[13,14] Yet, we know that minority and underserved populations are less often aware of their breast cancer risk[38,39] and breast density,[21,40,41] and fewer receive breast cancer risk assessment.[42] This suggests that equitable care downstream of learning one's breast density has not yet been achieved. Achieving timely access to these services for non-English speakers is an important step in promoting equity in evidence-based breast cancer screening. Given the widespread uptake of these notification laws, further research and resources should be invested in improving communication with primary care providers who order mammograms. This can be achieved by building the capacity and systems that enable primary care to counsel women about breast density, conduct risk assessment, and develop evidence-based tools to support risk-based screening for all women.[43, 44]

Limitations

While the qualitative design of the study allowed for an open exploration of experiences, understanding the optimal course of care for these women was beyond the study scope. Sampling women close to the time of the notification did not allow for an analysis of subsequent healthcare interactions on this topic, as not all women had yet received such care. Data on the direct impact of breast density notification on health service use and population health is needed.[45] As a single-site study of Spanish-speaking women, women's experiences were influenced by the implementation of the legislation within this health system and established clinical processes. Perceptions and behaviors may be different across characteristics that we were unable to differentiate between, including Hispanic cultures, levels of acculturation beyond language, prior experience with mammography and abnormal results, language supports that may have facilitated care, or among other languages or care settings. As no known research has elicited the perspective of patients with LEP related to dense breast notifications, this study is an important contribution to the literature.

Conclusion

Spanish-speaking women receiving a breast density notification acknowledged the importance of being informed about their own breast density. Misperceptions about the meaning of breast density, its impact on health, and language-related barriers to achieving a clear understanding of breast density mitigated the impact of raising awareness. Future efforts should consider the effects of health system and interpersonal factors that differentially affect the receipt of health

communications for patients with LEP. Standards and tools that promote universal understanding of health information should be leveraged in seeking equity in risk-based breast cancer screening for women with dense breasts.

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Compliance with Ethical Standards:

Study activities were approved by the Boston University Medical Center Institutional Review Board.

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