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Discussions of Potential Mammography Benefits and Harms among Patients with Limited Health Literacy and Providers: “Oh, There are Harms?”

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Abstract

Starting breast cancer screening at age 40 versus 50 may increase potential harms frequency with a small mortality benefit. Younger women’s screening decisions, therefore, may be complex. Shared decision-making (SDM) is recommended for women under 50 and may support women under 55 for whom guidelines vary. How women with limited health literacy (LHL) approach breast cancer screening decision-making is less understood, and most SDM tools are not designed with their input. This phenomenological study sought to characterize mammography counseling experiences among women with LHL and primary care providers (PCPs). Women ages 40–54 with LHL who had no history of breast cancer or mammogram within 9 months were approached before a primary care visit at a safety-net hospital. PCPs at this site were invited to participate. Qualitative interviews explored mammography counseling experiences. Patients also reviewed sample information materials. A constant comparison technique generated four themes salient to 25 patients and 20 PCPs: addressing family history versus comprehensive risk assessment; potential mammography harms discussions; information delivery preferences; and integrating pre-visit information tools. Findings suggest that current counseling techniques may not be responsive to patient-identified needs. Opportunities exist to improve how mammography information is shared and increase accessibility across the health literacy spectrum.

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Among women in the United States, breast cancer remains one of the most commonly diagnosed cancers and the second leading cause of cancer death (Centers for Disease Control and Prevention, 2020). Breast cancer screening aims to detect breast cancer before symptoms arise, when cancer is more treatable, but involves tradeoffs, particularly for younger women. Potential screening benefits include improved survival and avoiding intensive, costly treatments, while potential screening harms include overdiagnosis, overtreatment, false positives, radiation exposure, and costs associated with additional testing (Mandelblatt et al., 2015; 2016; Siu, 2016). Though guidelines agree that women should initiate breast cancer screening by age 50, the balance of potential mammography benefits/harms for women in their forties is less clear (Gøtzsche & Jørgensen, 2013; Howlander et al., 2019; Tonelli, Connor Gorber, & Joffres, 2011). Recent estimates indicate that, for an average-risk woman, the difference between initiating mammography at age 40 versus 50 is one fewer death from breast cancer per 1,000 women, while annual screening from ages 40 to 69 yields almost double the number of false-positive results compared to biennial screening (Mandelblatt et al., 2009). However, uncertainty persists about the benefits and harms of different breast cancer screening protocols (Myers et al., 2015). Potentially small or uncertain mortality benefits, when considered alongside additional years of potential screening harms, may alter the balance of people's preferences. As such, professional guidelines about mammography initiation and spacing vary for women in their forties, and spacing recommendations for women up to age 55 remain contested (Siu, 2016).

Subsequently, shared decision-making for breast cancer screening decisions is recommended for women under 50 and may support women under 55 for whom varied guidelines leave room for choice (Oeffinger et al., 2015; Siu, 2016). Shared decision-making (SDM) is a consultation model that promotes collaborative decision-making between patients and clinicians (Durand et al., 2014), and is most useful when multiple healthcare choices and/or varied evidence are available. Optimally, for breast cancer screening, SDM includes discussing a woman's personal breast cancer risk, available screening options and their evidence bases, potential screening benefits and harms, and a woman's values and preferences (Croes et al., 2020; DuBenske et al., 2018).

Among patients, understanding of breast cancer risk varies. While patients often define breast cancer risk primarily as a function of family history (Buxton et al., 2003; Davis, Stewart, & Bloom, 2004; Haber, Ahmed, & Pekovic, 2012; McCaul & O'Donnell, 1998), other dimensions such as physical symptoms (e.g. breast pain) and how personal risk compares to others' influence perceptions of breast cancer risk (Gillespie, 2012; Gunn et al., 2019). Women often inaccurately assess their breast cancer risk, with studies demonstrating over- and underestimation for various patient groups (Costanza et al., 1992; Davis et al., 2004; Evans et al., 1993; Smith et al., 1996; Woloshin et al., 1999), and identifying challenges patients have interpreting numeric information commonly used to characterize risk (Davis et al., 2004; Gillespie, 2012). Women are typically more aware of potential mammography benefits than harms (Hoffmann & Del Mar, 2015; Shi et al., 2019; Yu et al., 2017). Among potential harms, women are more likely to be aware of false positives than overdiagnosis or overtreatment (DeFrank et al., 2012; Nagler, Franklin Fowler, & Gollust, 2017). Data also show positive associations between awareness of potential harms,

confusion about screening recommendations, and ambivalence about mammography completion (DeFrank et al., 2012).

Recent research exploring SDM for women considering breast cancer screening endorsed the importance of PCPs counseling about risk factors, including patients' personal risk, as well as potential mammography benefits/harms (Croes et al., 2020). Evidence suggests, however, that PCPs often demonstrate limited engagement in comprehensive breast cancer risk assessments and discussions of potential mammography benefits/harms with patients. One study indicates that less than half of PCPs report usually or always asking patients about risk factors beyond family history, 76% report never calculating risk, and only 9% feel confident or very confident utilizing a risk calculator (Sabatino et al., 2007). PCPs' limited knowledge of certain risk factors, like breast density, and time-constrained clinic visits may also curb robust breast cancer risk discussions (Brown et al., 2019; DuBenske et al., 2017; Haas et al., 2016; Martinez et al., 2017). Additionally, PCPs often underestimate mammography's potential harms (Hoffmann & Del Mar, 2017; Martinez et al., 2017; Shi et al., 2019), and both patients and clinicians report few discussions of potential harms during mammography counseling (Haas et al., 2016; Hoffman et al., 2010; Wegwarth & Gigerenzer, 2011).

Another relevant dimension of mammography counseling is health literacy. Health literacy is defined traditionally as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine, 2004). Paasche-Orlow and Wolf (2007) expanded this definition to include how healthcare system attributes to influence individuals' ability to understand and act upon information. As such, health literacy may directly and indirectly influence women's understanding of relevant health information and participation in SDM (Berkman et al., 2011; Gaglio, Glasgow, & Bull, 2012; Golbeck et al., 2005; Stacey et al., 2017).

To date, breast cancer screening SDM research has been conducted predominantly among college educated and white populations (DuBenske et al., 2018; Elkin et al., 2017; Han et al., 2018). One recent systematic review documents racial and ethnic minority groups' general SDM preferences, challenges, and facilitators (Jolles, Richmond, & Thomas, 2019). Other research highlights the specific need for culturally appropriate cancer screening SDM tools and reports that older African American women are interested in breast cancer screening SDM and find related decision aids helpful (Hawley & Morris, 2016; Salzman et al., 2020). Less research, however, has examined whether this approach is responsive to women with limited health literacy, a salient concern given that concepts covered during mammography screening decision-making are complex. Patients with limited health literacy (LHL) may identify the purpose of cancer screenings with less accuracy (Morris et al., 2013), possess insufficient understanding of breast cancer risk and potential mammography benefits/harms (Brewer et al., 2008; Davis et al., 2002), and ask fewer questions during counseling (Katz et al., 2007). Visual aids may clarify nuanced concepts, but further research can identify relevant informational needs and delivery formats (Brewer et al., 2008; Mazor et al., 2016). PCPs may struggle with the types and amount of breast cancer screening information to share, fearing confusion, mammography deterrence, and patient-

provider relationship ruptures among patients with LHL (Gunn et al., 2020). However, the extent to which perceptions of breast cancer risk and potential mammography benefits/harms influence mammography decision-making among women with LHL is less known.

This phenomenological study, therefore, sought to characterize the lived experience of mammography counseling among women ages 40–54 with LHL and PCPs. Additionally, it collected formative patient feedback on the content and format of sample mammography informational materials. Results may clarify mammography information needs and delivery preferences among patients with LHL and PCPs, and inform development of interventions that enhance mammography counseling specifically for women with LHL.

Methods

From November 2018 to May 2019, we conducted a qualitative, interview-based study in six outpatient primary care practices located at a safety-net hospital to explore patient and PCP mammography counseling experiences. Paasche-Orlow and Wolf's conceptual model provided theoretical grounding for the study design. The model outlines how health literacy, through access to care, patient-provider communication, and self-care, influences health outcomes (Paasche-Orlow & Wolf, 2007). The framework's patient-provider communication domain, emphasizing knowledge, beliefs, and decision-making participation, informed literature searches that prioritized perceptions and discussions of breast cancer risk and mammography's potential benefits/harms among patients and PCPs, and shaped interview guides for both groups. The Boston University Medical Center Institutional Review Board approved all activities and materials.

Patient Interviews

We sought 25 eligible patients among women ages 40–54 with no mammogram in the prior 9 months and no history of breast cancer. The age range for eligibility was chosen based on professional guidelines, which vary in mammography initiation and spacing until age 55, rendering the review of potential benefits and harms particularly salient. We identified women with upcoming primary care visits at a Boston-based academic, safety-net practice. If present and interested, women completed the Health Literacy Skills Instrument-10, a 10-item validated measure of health literacy focused on decision-making skills (Bann et al., 2012). We invited women who scored less than 7, suggesting limited health literacy, to complete a qualitative interview. Interviews occurred immediately after primary care visits or at participants' convenience. We purposively sampled at least 10 participants with and 10 without prior mammograms.

Patient interview guides were pilot tested with five women with LHL. Topics included knowledge of and experiences with mammography and mammography discussions with providers, familiarity with breast cancer risk and potential mammography benefits/harms, and information delivery preferences. Seeking formative evaluations of information materials to guide development of a decision aid for LHL women, patient interviews also included the presentation and guided discussion of four images representing common elements of mammography counseling and three screenshots from an online mammography decision aid. One displayed a woman getting a mammogram; two others showed breast

anatomy in detailed and simplified forms, and the final was a set of mammogram images displaying breast density levels. The decision-aid pages were from Breast Screening Decisions (Weill Cornell Medicine, 2016) and covered mammogram definitions, a sample risk assessment results page, and a review of mammogram benefits and potential harms. A trained research assistant (AM) conducted 45–60 minute patient interviews in a private space. Patients received 40 USD as an incentive.

Primary Care Provider Interviews

Eligible PCPs included physicians and nurse practitioners who practiced in family medicine or outpatient general internal medicine clinics. Approximately 150 PCPs were invited via e-mail and through in-person invitation at a practice-wide meeting. PCPs who participated were entered into a raffle to receive 200 USD, which occurred after recruitment completion.

Clinician input informed development of PCP interview guides, which were pilot tested with clinical study team members before enrollment commenced. PCP interview topics included general counseling practices, familiarity with and use of risk estimates, patient preference elicitation, experiences implementing SDM for mammography, and recommendations for facilitating SDM. An investigator (CG) conducted 30-min PCP interviews via phone or in-person in a private location.

Data Analysis

Interviews were audio-recorded and professionally transcribed verbatim. Transcripts were verified against the audio files to ensure accuracy, de-identified, assigned pseudonyms to protect confidentiality, and uploaded into NVivo 12.1.0 qualitative data management software. Codebooks included deductive codes based on our guiding conceptual framework (Paasche-Orlow & Wolf, 2007), interview guides, and relevant literature, plus inductive codes sourced from interview responses. We linked patients' responses to sample materials in NVivo to facilitate content analysis of images (QSRInternational, 2020). Two investigators (CG, AM) independently coded three patients and three PCP interviews, compared coding results, and achieved consensus in coding definitions and applications. One investigator (AM) coded remaining transcripts, and another investigator (CG) reviewed six randomly selected coded interviews to ensure quality.

Utilizing a content analysis approach, codes were compared within and across patient and PCP interview groups to generate themes. For patient interviews, CG and AM created summary maps that represented content from key themes for each participant (Miles, Huberman, & Saldana, 2020). These, along with post-interview memos, established that theoretical saturation had been achieved within 23 patient and 17 PCP interviews. Two more patient interviews and three PCP interviews were completed to confirm that no new thematic variations arose in either group. A constant comparison technique was used to refine final themes and identify representative quotes (Charmaz, 2006).

Results

Figure 1 displays the patient recruitment process. Two hundred and thirteen potentially eligible women with upcoming appointments were identified. Of the 65 women who

completed screening, 10 were ineligible due to HLSI-10 > 6, and 13 self-reported mammograms in the prior 9 months or spoke limited English; 14 women were eligible but declined enrollment, were unable to be re-contacted, or did not complete interviews before sample size was reached; 25 women enrolled in the study. Of the 150 invited PCPs, 26 responded, 20 of whom completed interviews. Table 1 presents the demographics of the 25 enrolled patients and 20 PCPs. Four themes related to mammography counseling were identified as salient for women and PCPs: 1. Addressing family history versus comprehensive risk assessment; 2. Discussion of potential harms associated with mammography; 3. Preferences for information delivery; and, 4. Integration of tools to facilitate mammography discussion.

Addressing Family History versus Comprehensive Risk Assessments

PCP Responses—Though some PCPs discussed a range of breast cancer risk factors, such as smoking and exercise, most PCPs prioritized family history.

“I think providers don’t do a great job of conveying risks for breast cancer. I think family history is pretty well understood, but otherwise, not as much.”

– PCP 1

“So, I think family history in my mind drives so much more than any model, whether that’s right or wrong, but in my mind family history just drives the bus.”

– PCP 2

Infrequent use of comprehensive risk assessment was attributed by some PCPs, in part, to limited familiarity with breast cancer risk estimators. Of the 20 PCPs interviewed, only two described regularly using risk calculators. Nine PCPs never used them, while eight PCPs incorporated calculators only when they highly suspected patients’ increased risk, triggered most often by family history of breast cancer. Among those who used risk calculators, some reported struggling to interpret results, and others described results as being difficult to explain to patients. This led a few PCPs to refer patients elsewhere to receive support.

“The percentage is very hard to explain to the patient. Maybe it’s because of my own lack of understanding fully, but it comes up a lot when we try to do the risk evaluations.”

– PCP 3

“In the last years, maybe I’ve used [a risk calculator] one or three times ... But it took me so long to figure out how to use it ... it’s like, okay, I’m not going to spend time on this. I’m just going to send them somewhere else.”

– PCP 4

Patient Responses—Aligned with PCPs reporting limited comprehensive risk assessment use, most patients, regardless of mammogram history, did not recall discussing personal risk with their PCPs. Most patients cited family history as the primary source of breast cancer risk, often characterizing personal risk as a function of family history alone. Prior mammogram experience did not necessarily translate into awareness of risk factors or personal risk, as Patient 1 and Patient 2 (prior mammograms), respectively, asked “*What are*

the risks besides what you hear on TV?” and *“What would put me at risk?”* When reviewing a sample risk assessment results page from a decision-aid (Figure 2), most patients described limited awareness of and confusion about risk factors other than family history. They desired risk information that not only named additional risk factors, but also explained how they impacted their individual risk. Many patients also demonstrated challenges interpreting percentages and sought clarity about how percentages were calculated.

Discussion of Potential Harms Associated with Mammography

PCP Responses—Most PCPs addressed potential mammography benefits and harms during counseling. Among the 13 PCPs who discussed potential harms, the most cited potential harms were false positives, psychological stress or anxiety, logistical inconvenience of additional testing, and pain associated with mammogram machines. A minority of providers actively avoided potential harms discussions. These PCPs, seeking mammography adherence among patients, worried that describing potential harms or uncertainty about benefits would deter patients from care.

“I don’t tend to get into those [potential harms] details because I feel like it gets us off track and then people are less likely to be willing to do it.”

– PCP 2

“[Spending] a lot of time going into all the negatives of mammogram I don’t feel like is helpful. Because ultimately, we want to promote everybody to get it. That’s still the message. And the confusing message is when we say, ‘Oh well they say different and they say don’t get a mammogram and they say you have dense breasts so don’t ... ‘ that’s when people get confused.”

– PCP 3

Patient Responses—Most patients described at least one mammography benefit, typically early detection when breast cancer is treatable. Though two patients (both no prior mammograms) described pain from the mammogram machine as a potential harm, most patients with and without mammogram experience were unable to report potential mammography harms. Patient 3 said, *“There wouldn’t be a downside.”* Patient 4 likewise added, *“I don’t think there’s any risk of you letting your breasts up there. I don’t think nothing’s going to hurt you.”* Upon reviewing a decision aid page about potential mammography harms, many patients like Patient 5 expressed surprise when learning about harms: *“There’s harms? Wow, I’m gonna read that first.”*

False positives were a challenging topic for patients and PCPs. Only one patient, who had prior mammogram experience, named false positives as a potential mammography harm, but was unsure why they occur. When reading false-positive information provided via the sample decision aid, some patients struggled to articulate what the result meant, sometimes misinterpreting “positive” as a good outcome.

“False positive, let me see if I’m right ... Me, I understand false positive means that they did a test but the test came like not sure if it was positive ... like if you do the test, but you’re not sure, you’re not 100 percent sure if it’s false or if it’s contagious

or whatever, true or false or whatever, how do say it, positive I mean. So that's why they do it."

– Patient 6

Though PCPs believed that patients should have false-positive information, many struggled to address this issue, and others, adequately during brief clinic visits.

"When you're in the room 20 minutes and you're trying to discuss about a test ... that sounds great but then how do you describe the false positive result and what kind of anxiety that can bring ... how do you explain that to them or show it to them visually ... I don't have a great aid that does that."

– PCP 5

Preferences for Information Delivery

PCP Responses—Most PCPs preferred describing risk with smaller numeric units and whole numbers, which they believed were easier for patients to digest. A few PCPs found analogies rooted in patients' everyday experience, like lottery tickets or traffic navigation, effectively conveyed breast cancer risk information.

"[Y]ou can say, 'So 1 in 12 women, on average, will be diagnosed with breast cancer over the course of their life. Your risk is double that ... so a woman like you had a 1 in 6 chance of getting breast cancer over the course of the life-time.' So trying to use units that are understandable."

– PCP 6

"When I talk about medications, it's like yeah it's not going to make it zero, but talking about playing in the street, you can get hit by a car, but it's much worse if you're on the highway. Just take me from the highway to a side street. People seem to like that ... 'I understand. I can still get hit by a car but it's less risky.'"

– PCP 5

Patient Responses—Aligned with PCPs, many patients preferred simpler data visualizations like pie charts, rather than icon arrays.

"A pie chart, graphs, I'm more so that kind of person, but [the icon array] doesn't do nothing for me."

– Patient 5

When reviewing sample images, patients called out visual detail, imagery, and color as informational cues. Patients compared a black-and-white, detailed, front and side medical illustration of a breast against a color, simplified, side-only drawing of a breast (Figure 3). Associating red coloring with sickness/danger and branch-like renderings of lobules and ducts with damage, many patients suggested that the colored, simplified image represented an unhealthy breast, perceptions potentially misaligned with the visual aid's intended messaging. Some patients noted that detail made illustrations feel realistic and thus led to better associations with their own bodies.

Integration of Tools to Facilitate Mammography Discussion

PCP Responses—Several PCPs noted that patients arrive to appointments unable to recall or unaware of their families' cancer histories. These PCPs desired mammography tools that elicited patients' family histories prior to counseling.

“I think very often when we do family history in the moment, we hear, ‘I had a relative with cancer, I don’t remember what type,’ or ‘I don’t remember what side of the it was on’ ... There might be an opportunity for patients to come in prepared to share that history, which would be really helpful.”

– PCP 1

For some PCPs, the waiting room setting was discussed as an ideal intervention space because it allowed sufficient time for information exposure and would be immediately followed by an in-person conversation. Thus, if patients experienced concern or identified questions, PCPs could respond expeditiously.

“I think the ideal thing is [patients] would do this in the waiting room and kind of come with their little printout of the information ... and had a way to interact with that information before the visit with the provider.”

– PCP 7

Patient Responses—Some patients similarly suggested that multi-media information tools available in clinical spaces prior to encounters could set them up for successful mammography conversations.

“[T]he computer is just amazing ... so if you can even project [graphics] in the office, the doctor’s office, some people now will be using things just mid-screen, hit a button, and it’s all happening in front of us. So it’s quick data ... and I think the more data that we receive, the better we have confidence.”

– Patient 7

Both groups also recommended using electronic patient-provider portals to relay information to patients and equip PCPs with relevant information to optimize discussions. In reference to the patient portal, Patient 8 stated, “*It’s helpful. I mean, even if they just put in information for patients and materials to read on what you should be doing, next steps, preventive care.*” PCP 8 further suggested:

“I think it would be good if there was an opportunity after the patient has seen a video, read something, to ask questions online, so that could actually be incorporated into [the electronic patient portal] for the visit and populated beforehand so you actually have some of that kind of data to work with.”

Discussion

This study explored breast cancer risk and potential mammography benefits/harms perceptions and discussions among women with LHL and PCPs, and elicited patient feedback on sample mammography information formats. We found that family history was the primary risk factor that PCPs discussed and that patients associated with breast cancer

risk, consistent with other studies (Buxton et al., 2003; Collins et al., 2014; Davis et al., 2004; Haber et al., 2012; McCaul & O'Donnell, 1998; Sabatino et al., 2007). Quantitative risk assessment was infrequently used by PCPs, with patients, regardless of mammogram history, similarly lacking knowledge of their own risk. Potential mammography harms were unfamiliar to most patients, and proved challenging for PCPs to address. Both PCPs and patients preferred mammography information materials with plain, relatable language and simple numeric values. Patients highlighted the importance of illustration detail, imagery, and color in aiding understanding. PCPs and patients recommended utilizing pre-visit settings, such as waiting rooms, to elicit family history and provide mammography information.

Supports that address PCPs' discomfort with elements of breast cancer risk assessment and potential mammography benefits/harms discussions may enhance counseling efforts. In our study, many PCPs stated that they felt limited comfort using risk calculators, as others have found (Collins et al., 2014; Martinez et al., 2017; Petrova, Garcia-Retamero, & Cokely, 2015; Sabatino et al., 2007). Some avoided potential harms discussions, also aligned with prior work (Haas et al., 2016; Hoffman et al., 2010; Wegwarth & Gigerenzer, 2011). In addition to concerns about mammography deterrence cited by PCPs in our study, uncertainty about the evidence supporting potential mammography harms may challenge individual counseling efforts (Siedlikowski, Ells, & Bartlett, 2018). Though professional guidance suggests providing balanced information, current cancer screening guidelines present potential benefits/harms in unbalanced and non-quantified ways (Caverly et al., 2016). Reformulating guidelines may be one way to model balanced presentation of ambiguous evidence for PCPs. Integrating user-friendly guidelines and promoting use of systems-level tools, such as electronic medical record reminders and performance reports, may reinforce provider uptake of SDM- and guideline- concordant activities (Schapira et al., 2016). Additional research may explore the provider motivations, provider knowledge, tools, and environmental conditions necessary to support PCP-initiated risk and potential benefits/harms discussions. These efforts may be particularly salient to safety-net settings, where PCPs often serve patient populations with higher rates of LHL and fewer personal resources to access to mammography information beyond healthcare encounters.

Our study contributes to existing literature exploring which counseling elements are best conveyed by specific information formats (e.g., numbers, narratives), particularly how women with LHL respond to visual aids describing risk assessment results, potential benefits and harms, and breast anatomy. Generally, simple graphical formats like single line or pie charts may enhance patient understanding, and packaging graphs together may improve accuracy of patient risk perception (Brown et al., 2011). Additionally, international decision-aid standards recommend presenting information in a side-by-side format to visually signal balance and enhance probabilistic understanding (Abhyankar et al., 2013). However, further efforts may parse the unique influences of health literacy, numeracy, and graphicacy on visual format comprehension. A small body of research indicates that pictographs accompanied by plain language explanations may enhance knowledge acquisition among individuals with LHL (Fagerlin, Zikmund-Fisher, & Ubel, 2011; Tait et al., 2012) and pictographs alone may enhance knowledge and acceptability across varied numeracy levels (Hawley et al., 2008; Tait et al., 2010). Information presented in numeric,

versus graphical, terms, may better serve individuals with limited graphicacy (Gaismaier et al., 2012). Though our study did not assess the numeracy and graphicacy of patients, findings suggest that our cohort of women with LHL may ascribe unanticipated meaning to visual aids based on design features such as color, detail, and imagery. Referencing our conceptual framework's patient-provider communication domain, these preliminary findings may suggest that, absent information-sharing from providers, responses to materials' design features may influence patients' beliefs, behaviors, and health outcomes in unintended ways. Additional research may explore the relationship between limited health literacy, numeracy, and graphicacy; characterize the availability heuristics of women with LHL when reviewing visual formats; consider the extent to which such associations influence understanding, acceptability, and impact of materials; and pilot test materials to adequately address patient needs.

Despite evidence that patients with LHL may require tailored support, most available patient decision aids were developed without input from this population. A recent review indicates that only 3 of 97 patient decision aid trials either included individuals with limited education or health literacy or used tools explicitly designed to meet the needs of these patient groups (McCaffery et al., 2013). Additionally, only a few cancer screening and prevention interventions report effects by health literacy (Han et al., 2017; Heckel et al., 2018). Two interventions assessing decision aids in colorectal cancer screening contexts found that a patient decision aid/video combination improved screening knowledge, and a web-based decision aid increased readiness to receive screening and identify screening preferences (Miller et al., 2011; Smith et al., 2014; 2010). While a subset of studies demonstrate improvements in knowledge (Volk et al., 2008) and recall (Freed et al., 2013; Meppelink, Smit et al., 2015; Meppelink, van Weert et al., 2015) for LHL groups, most investigations observe improvements in individuals with adequate, rather than limited, health literacy. This raises concern that efforts may be widening health literacy disparities and underscores the need for interventions designed for and tested with LHL groups of varied backgrounds, including race, ethnicity, and gender identity.

As a qualitative study conducted at a single institution, findings may be context-specific and have limited generalizability. Patients' demographics and experiences with processes of care at a safety-net institution are indicative, respectively, of the socio-demographic characteristics of the patients that this specific institution serves and this institution's processes of care. Furthermore, providers' shared processes of care experiences may be related to characteristics of the institution. These experiences may not be reflective of other hospitals' patient populations and processes. Patients and PCPs were not clinical dyads, and we were unable to compare patient and provider data directly. Additionally, some topics may not be comprehensively represented in the data. For example, while interview guides asked patients about breast cancer information sources, we did not ask where or from whom specific breast cancer risk or potential harm or benefit information was acquired. Sample size also limited intersectional analysis of patients' literacy status and other factors that may also influence SDM. Finally, this is an observational study conducted at a single point in time, which relied upon patient and provider accounts and recall bias remains a potential threat.

Conclusion

This exploratory study sought to characterize breast cancer risk and potential mammography benefits/harms perceptions and discussions among women with LHL and PCPs to inform development of decision tools for LHL populations. PCPs infrequently used risk assessment tools, and some PCPs avoided potential harms discussions. Patients, regardless of mammogram history, generally were unaware of breast cancer risk beyond family history and had limited knowledge of potential mammography harms. Visual aids may better relay specific concepts to patients with LHL, but should be piloted tested with this population to optimize understanding. Integrating informational tools into clinical settings prior to PCP counseling may enhance SDM.

Ultimately, this study identified discordance between the potential screening benefits/harms information that patients with LHL desired and PCPs' described approaches to mammography counseling. It also identified information delivery preferences shared by both groups, but not readily feasible in clinical contexts. These findings reveal that current forms of breast cancer screening counseling may not be responsive to patient or PCP needs. The experiences captured offer worth-while foci for future interventions that explicitly address breast cancer screening SDM, for example decision-aid testing with LHL groups, and provide opportunities to enhance SDM across the health literacy spectrum.

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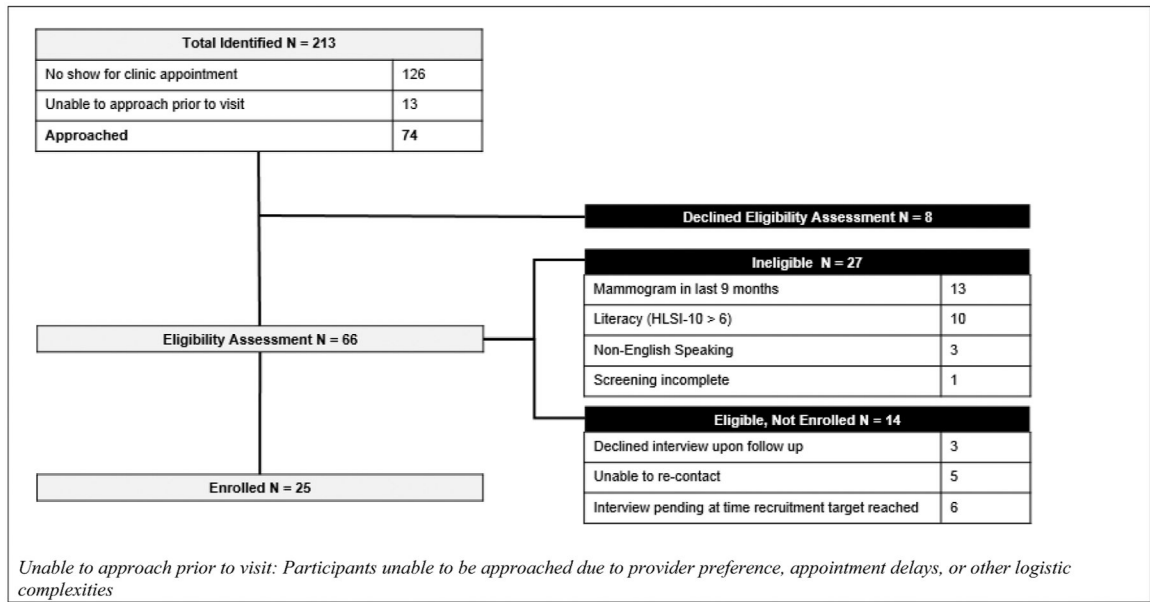


Figure 1.
Patient recruitment.

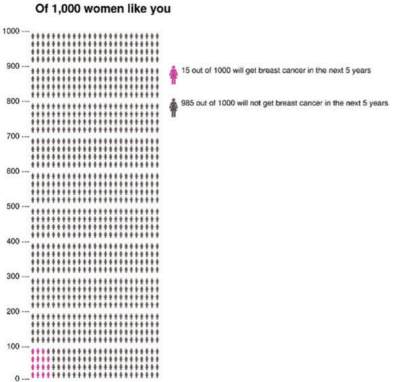
<p style="text-align: center;">Icon Array</p> <p><i>The below icon array is a generic representation of a copyrighted icon array presented to patients.</i></p>	<p style="text-align: center;">Patient Responses</p>
<p>You are at low to average risk of breast cancer.</p> <p>Based on your responses, your chances of developing breast cancer in the next 5 years is 1.5%. Out of 1,000 women like you, 15 of them will develop breast cancer in the next 5 years.</p>  <p style="text-align: center;">Of 1,000 women like you</p> <p style="text-align: center;">15 out of 1000 will get breast cancer in the next 5 years</p> <p style="text-align: center;">985 out of 1000 will not get breast cancer in the next 5 years</p> <p>Other factors such as breastfeeding and exercise may affect your breast cancer risk. How much they affect your risk is uncertain. Click here to learn about how you can reduce your breast cancer risk.</p> <p><small>Image created by Iconarray.com, Risk Science Center and Center for Bioethics and Social Sciences in Medicine, University of Michigan. Accessed 2020-03-18.</small></p>	<p>“Because if you think about it, out of a thousand women, 15 of you are going to develop it, you know – so that’s a little concerning, you know, very concerning. But at the same time, I don’t want to worry about it either. I could be in the 85 percent that do it get, you know ... so that’s like a 50/50 chance basically ... half and half ... You will or you won’t [get breast cancer].” – Patient 9</p> <p>“Wow. I don’t know how they really calculated that.” – Patient 8</p> <p>“They tell you exercise every day, so now I’m at risk of breast cancer because I go to the gym?” – Patient 10</p> <p>“So I mean what are they saying? Is it that breastfeeding can put you at risk for breast cancer? ... It says that it may affect your breast cancer risk. Affect it in what way?” – Patient 2</p>

Figure 2.
Patient responses to sample breast cancer risk assessment.

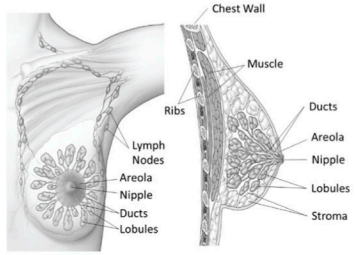
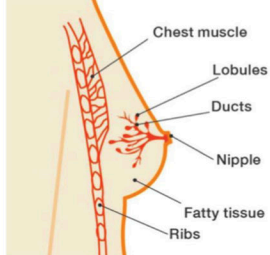
Breast Anatomy Illustrations	
Image A	Image B
 <p>Source: Illustration by Samuel K. Collins ©. Labels added by authors</p>	 <p>Source: http://ghise-ioan.ro/is-intraductal-papilloma-breast-cancer-932514.php</p>
Patient Responses	
Detail	
<p>"Detail is important. It's more detailed, looks more real and human. [Image B] does not look like a human body. It looks like a line and a slope and a little pathway right here, maybe this is a tree. [Image A] looks real." – Patient 1</p> <p>"[Image A] you get a better view of it. It's almost like they did it in 3D so you can get a better look at what the breasts look like, what the lobes and all this stuff inside. They even put the little chest behind the breast...I mean it's done in black and white, but it just, it gives you a little bit more than [Image B]." – Patient 11</p>	<p>"I think just maybe the way it's drawn out. Like [Image B] kind of just looks like a cartoon and what is this and this looks like a tree...if you showed me [Image B] first I would have been like, 'Is this cancer?' ... If you used [Image B] like this I wouldn't know what the hell that was." – Patient 14</p> <p>"[Image A] looks real. It looks like somebody's actual picture, but they just printed it out. And [Image B] is not bad, but I wish it was more detailed. They're both good, but I wish that there was more definition and stuff and [Image B components] right here were named and everything." – Patient 15</p>
Imagery	
<p>"[Image A] looks kind of like flowers. [Image B] looks like, more like dead branches or dried up. It looks different, totally different." – Patient 12</p> <p>"I just thought [lobules] were like baby stretch marks. That's how they look on my boobies at least. But just [lobules] look more clearer in [Image A]." – Patient 13</p>	<p>"It looks kind of scary to me, like something could be wrong, because it's just – I'm not a doctor or anything – it just looks like branches, like dried up unhealthy something." – Patient 12</p> <p>"Yeah, when it's into all those branches go down. Now it's summertime. Now it's winter...Winter. It's like something is there's something in it, like something is damaging." – Patient 16</p> <p>"The ducts in here looks like a tree. This looks like a plant with like baby peas." – Patient 13</p> <p>"My first look at it is it looks like a ladder leaning up against a wall." – Patient 2</p>
Color	
<p>"[Image B] needs color, but in fact it just looks like an area with a pond and a driveway and, like I said, but [Image A] is more detailed. [Image A] doesn't have to have color, because it's so detailed." – Patient 1</p>	<p>"Because it's red, that's something dangerous." – Patient 17</p> <p>"That color is like blood going all over. And it's not flourish." – Patient 16</p>

Figure 3.
Patient responses to breast anatomy illustrations.

Table 1.

Participant characteristics

Women with Limited Health Literacy (N = 25)	
Age (average = 46)	n (%)
40–45	10 (40)
46–50	9 (36)
51–54	6 (24)
HLSI-10 Score	n (%)
0	1 (4)
1	2 (8)
2	1 (4)
3	6 (24)
4	3 (12)
5	6 (24)
6	6 (24)
Mammography History	n (%)
Prior Mammogram	12 (48)
No Prior Mammogram	13 (52)
Race	n (%)
Black/African American	18 (72)
White	2 (8)
Not Available	5 (20)
Ethnicity	n (%)
Hispanic/Latina	3 (12)
Non-Hispanic/Latina	22 (88)
Primary Care Providers (N = 20)	
Gender	n (%)
Female	15 (75)
Male	5 (25)
Number of Years in Practice	n (%)
5 years	8 (40)
6–10 years	6 (30)
11–20 years	2 (10)
> 20 years	4 (20)
Educational Materials Provided to Patients	n(%)
None	17 (85)
In office handouts	2 (10)
Out of office referrals	1 (5)