

Discussions of Mammography Potential Benefits and Harms Among Patients With Limited Health Literacy and Providers: “Oh there are harms?”

Ariel Maschke, MA¹; Michael K. Paasche-Orlow, MD, MPH²; Nancy R. Kressin, PhD²; Mara Schonberg, MD, MPH³; Tracy A Battaglia, MD, MPH¹; Christine M. Gunn, PhD^{1,4}

A qualitative study suggests that **comprehensive breast cancer risk** and **mammography potential harms** are neither understood by patients with limited health literacy nor consistently addressed by providers.

Patients may glean **unintended messages** from **information materials’ color, detail, and imagery**.

Pre-visit, clinic-based tools may enhance patient understanding and shared decision-making.

RESULTS

PCPs infrequently understood or used comprehensive risk estimators. Patients were often unfamiliar with risk factors beyond family history.

<u>PCP</u>	<u>Patient</u>
<i>“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.” – Adam</i>	<i>“They tell you exercise every day, so now I’m at risk of breast cancer because I go to the gym?” – Denise</i>

Some PCPs, concerned about mammography adherence, avoided potential harms discussions. While patients could describe at least 1 potential benefit, they were typically unaware of potential harms.

<u>PCP</u>	<u>Patient</u>
<i>“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.” – Evette</i>	<i>“There’s harms? Wow, I’m gonna read that first.” – Aliya</i>



Both groups sought tools with plain language, relatable analogies, and simple, whole numbers.

<u>PCP</u>	<u>Patient</u>
<i>“[Y]ou can say... so a woman like you had a 1 in 6 chance of getting breast cancer over the course of the lifetime.’ So trying to use units that are understandable.” – Vanessa (PCP)</i>	<i>“Even though you may have those big words, kind of break it down to simple language so people can understand.” – Carolyn</i>

Both groups preferred clinic-based, pre-visit tools and electronic portals to share information.

<u>PCP</u>	<u>Patient</u>
<i>“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 portal] for the visit and populated beforehand so you have some of that kind of data to work with.” – Dawn</i>	<i>“You can project [data] in the doctor’s office, some people now will be using things mid-screen, hit a button. It’s all happening in front of us. The more data that we receive, the better we have confidence.” – Celeste</i>

INTRODUCTION

- Shared decision-making (SDM) is recommended for women under 50 and may support women under 55 for whom choice about screening intervals remains.
- SDM includes discussion of a woman’s personal risk, potential benefits/harms, and her values.⁵
- Little is known about how limited health literacy (LHL) influences mammography SDM.

OBJECTIVE

To characterize perceptions and discussions of **breast cancer risk and mammography potential benefits/harms** among women with LHL and primary care providers (PCPs).

METHODS

- Women with LHL (HLSI-10 >6), ages 40-54, with no history of breast cancer or mammogram in last 9 months
- PCPs practicing at a local safety-net hospital
- 30 – 60 minute qualitative interviews, including patient review of sample materials
- Grounded content analysis Developed themes around breast cancer risk, mammography benefits/harms, and information delivery preferences

STUDY SAMPLE

Women With LHL (N=25)	
Age (average = 46)	n (%)
40-45	10 (40)
46-50	9 (36)
51-54	6 (24)
Mammogram History	
Prior Mammogram	12 (48)
No Prior Mammogram	13 (52)
Race/Ethnicity	
Black/Not Hispanic	18 (72)
White/Not Hispanic	2 (8)
Not Available/Not Hispanic	2 (8)
Not Available/Hispanic	3 (12)

Primary Care Providers (N = 20)	
Gender	n (%)
Female	15 (75)
Male	5 (25)
Number of Years in Practice	
≤5 years	8 (40)
6-10 years	6 (30)
11-20 years	2 (10)
> 20 years	4 (20)

FUNDING

National Cancer Institute (1K07CA221899)

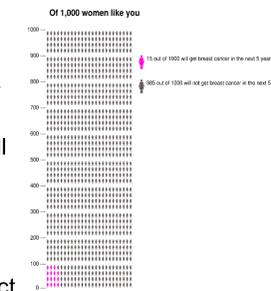


Sample Information Material

You are at low to average risk of breast cancer.

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.

Other factors such as breastfeeding, alcohol intake and exercise may affect your breast cancer risk. How much they affect your risk is uncertain.



Icon Array Image: created by Iconarray.com. Risk Science Center and Center for Bioethics and Social Sciences in Medicine, University of Michigan. Accessed 2020-03-18.

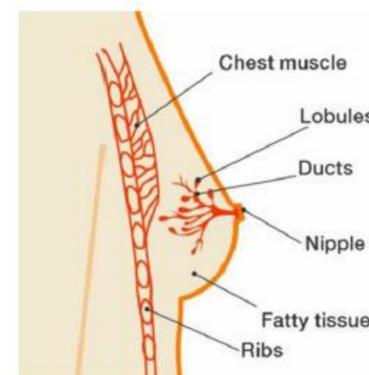
Patient Responses to Sample Information Material

“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].” – Jasmine

“Wow. I don’t know how they really calculated that.” – Tara

“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?” – Nora

Sample Information Material



Patient Responses to Sample Information Material

“I think just maybe the way it’s drawn out. Like [sample image] kind of just looks like a cartoon and what is this and this looks like a tree...if you showed me [sample image] first I would have been like, ‘Is this cancer?’ ... If you used [sample image] like this I wouldn’t know what the hell that was.” – Charlotte

“[Another sample image] looks real. It looks like somebody’s actual picture, but they just printed it out. And [poster sample image] is not bad, but I wish it was more detailed.” – Rosalie

“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.” – Vivienne

“Because it’s red, that’s something dangerous.” – Evelyn

“That color is like blood go all over it. And it’s not flourish.” – Elena

Breast Anatomy Image: <http://ghise-ioan.ro/is-intraductal-papilloma-breast-cancer-932514.php>.

AFFILIATIONS

1. Women’s Health Interdisciplinary Research Center, Boston University School of Medicine 2. Department of Medicine, Section of General Internal Medicine, Boston University School of Medicine 3. Beth Israel Deaconess Medical Center, Harvard Medical School 4. Department of Health, Law, Policy, and Management, Boston University School of Public Health