


Perceptions of Conflicting Breast Cancer Screening Recommendations Among Racially/Ethnically Diverse Women: a Multimethod Study



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BACKGROUND: Conflicting breast cancer screening recommendations have the potential to diminish informed decision making about screening.

OBJECTIVE: We examined the knowledge, attitudes, and intentions related to divergent recommendations for breast cancer screening among racially/ethnically diverse women.

DESIGN: We used a multimethod study design employing focus groups and questionnaires. Focus groups included: (1) two 10-min presentations on the national screening recommendations and the potential benefits and harms of screening and (2) an interactive discussion. Data were collected: 8/3/2017 to 11/19/2019. Analysis occurred from 1/21/2019 to 7/24/2020.

PARTICIPANTS: Participants were (1) women 40–75 years; (2) English or Spanish speaking; (3) self-identified as Latina, Black, or non-Latina White; and (4) no known increased risk for breast cancer.

MAIN MEASURES: Main outcomes were participants' knowledge and perceptions of benefits and harms of screening mammography and their screening intentions. Focus groups were transcribed and analyzed using a qualitative descriptive approach. Quantitative data were summarized using descriptive statistics.

KEY RESULTS: One hundred thirty-four women ($n=52$, 40–49 years; $n=82$, 50–75 years) participated in 28 focus groups. Participants were Latina ($n=44$); Black ($n=51$); and non-Latina White ($n=39$). Approximately one-quarter ($n=32$) had limited health literacy and almost one-fifth ($n=23$) had limited numeracy. In the context of differing national screening recommendations, participants questioned the motives of the recommendation-making agencies, including the role of costs and how costs

were considered when making screening recommendations. Participants expressed concern that they were not represented (e.g., race/ethnicity) in the data informing the recommendations. Immediately following the focus groups, most participants expressed intention to screen within the upcoming year (pre $n=100$ vs. post $n=107$).

CONCLUSIONS: Divergent breast cancer screening recommendations may lead to mistrust and paradoxically reinforce high overall enthusiasm for screening.

KEY WORDS: Cancer; Oncology; Health literacy; Health disparities; Qualitative research; Mammography.

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INTRODUCTION

Breast cancer screening mammography is associated with lower breast cancer-specific mortality.¹ In the United States (US), breast cancer screening recommendations and guidelines differ and discussion around extant guidelines remains contentious.^{2–4} Among women with no known increased breast cancer risk, the National Comprehensive Cancer Network (NCCN), the American Cancer Society (ACS), and the US Preventive Services Task Force (USPSTF) offer, at times, conflicting recommendations about initiation, frequency, and discontinuation of screening mammograms.^{5–7} For example, starting at age 40, initiation of screening is recommended (NCCN) or optional (ACS, USPSTF) either annually (NCCN, ACS) or biennially (USPSTF). Across the three recommendations, there is limited or qualified guidance for discontinuation of screening mammograms based on age or life expectancy (Table 1).^{5–7} While these

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Table 1 Comparison of Breast Cancer Screening Recommendations

Comparison of Breast Cancer Screening Recommendations for Women at Average Risk			
Recommendation	NCCN ⁵	ACS ⁶	USPSTF ⁷
Age to start mammograms	40	45	50
Age to stop mammograms	No recommendation	40–44: screening is optional	40–49: screening is optional
Frequency of Mammograms	Every year	When life expectancy is less than 10 years	No recommendation, but 75 is suggested
		40–44: option for yearly screening	40–49: option for every other year screening
		45–54: yearly screening recommended	50–74: every other year screening recommended
		55 and older: yearly or every other year screening recommended	75 and older: no recommendation

Note: NCCN, National Comprehensive Cancer Network; ACS, American Cancer Society; USPSTF, United States Preventive Services Task Force

recommendations overlap in some aspects, they differ in qualification and strength of recommendations (e.g., “optional” or “recommended” terminology) for specific ages.^{5–7} Differing recommendations may undermine decision making about whether and when to undergo mammography.

There are substantial barriers, such as clinical context, women’s perceptions, and physician views, to increasing patients’ knowledge of breast cancer screening recommendations and helping them weigh the tradeoffs between screening benefits and harms.^{2,6,8–13} In the clinical context, harms are rarely discussed when selecting a breast cancer screening schedule that aligns with patient values.^{14–16} A 2016 survey of US physicians found that most (80%) primary care providers would recommend breast cancer screening to women 40–44 years.^{13,17} Physician recommendations for breast cancer screening have been attributed to perceptions of their patients’ enthusiasm for screening, clinical constraints (e.g., time), and physician uncertainties about the recommendations.^{13,18,19} Moreover, enthusiasm for cancer screening and conflicting recommendations have the potential to leave women uncertain about which sources to use and trust.^{13,18} This could be particularly relevant among women with limited health literacy.²⁰ Patients with limited health literacy experience difficulties navigating the health care system, making health care decisions, and utilizing cancer screening, thus contributing to disparities in cancer care.^{20–22} These contexts, perceptions, and views reinforce enthusiasm for recommendations that align with screening more frequently.^{13,18,19,23}

Evidence is lacking about women’s perceptions of conflicting recommendations and how they might impact screening decisions. In this study, we presented mammography screening recommendations from three leading organizations to racially/ethnically diverse women ages 40–75 years and with varying levels of health literacy. The purpose of this investigation was to examine women’s knowledge, attitudes, and intentions for breast cancer screening mammography in response to divergent screening recommendations.

MATERIALS AND METHODS

Recruitment

Eligible participants included women: (1) 40–75 years of age; (2) English or Spanish speaking; (3) who self-identified as Latina, Black, or non-Latina White; and (4) self-reported no known increased risk for breast cancer (i.e., no personal history of breast cancer; no personal history of atypical hyperplasia; no first-degree family member with history of breast cancer; no known underlying genetic mutation; no self-reported prior thoracic or chest wall radiation therapy). Participants were recruited over the phone and in person using two existing cohorts in Houston, TX: (1) Project CHURCH (Creating a Higher Understanding of Cancer Research and Community Health), a church-based longitudinal cohort study of 2,254 Black adults and (2) MACS (Mexican American Cohort Study), a population-based cohort of over 2,000 Mexican American adults.^{24,25} Participants were also recruited from the Houston, TX area and St. Louis, MO, using community outreach methods (e.g., flyers, social media). Potential participants were given a brief description of the study, provided verbal consent to be screened for eligibility, and answered screening questions over the phone or in person. This study was approved by the University of Texas MD Anderson Cancer Center and Washington University School of Medicine institutional review boards.

Materials

The focus group guide and materials were adapted and modified from Hersch et al.,²⁶ who investigated overdiagnosis in the context of breast cancer screening among women in Australia. Our guide included a discussion of (1) participants’ knowledge and informational needs concerning screening mammography; (2) participants’ considerations when making screening decisions; (3) the influence of others (e.g., health-care providers, family) on decision making; (4) the use of plain language, health literacy, and numeracy strategies in communicating screening benefits and harms; and (5) the evaluation of trade-offs pertaining to benefits and harms when deciding about screening.

Our approach was guided by an integrated model of behavior,²⁷ based on the Ottawa Decision Support Framework,^{28,29} and incorporating theories of Reasoned Action, Planned Behavior, Health Belief Model, and Social Cognitive Theory.²⁷ We used this integrated model to incorporate questions regarding the personal and environmental characteristics of the decision making process.^{30–32} Materials were piloted in English and Spanish, and revised to ensure that they were understandable and relevant (eAppendix). Focus groups included two 10-min presentations on screening mammography, the US screening guidelines/recommendations, and the potential benefits and harms of screening. Recommendation sources were (1) National Comprehensive Cancer Network (NCCN),⁵ (2) American Cancer Society (ACS),⁶ and (3) United States Preventive Services Task Force (USPSTF)⁷ and were identified by a number rather than name to blind participants to the recommendation source (Table 1). We used the term “recommendation” to encompass both guidelines and recommendations, as agencies differed in their terminology. During the focus group discussion, participants were asked to share their reactions, perspectives, and screening intentions.

Measures

Screening Questionnaires. Screening questionnaires (eAppendix) were administered verbally in person or by phone. Screening questions assessed gender, breast cancer history and risk, age, race/ethnicity, education, occupation, income, health literacy, and prior screening mammograms. Health literacy was assessed using the three-item Brief Health Literacy Screen (BHLS), a validated measure available in English and Spanish.³³ Scores range from 3 to 15, and scores ≥ 12 reflect adequate health literacy.

Focus Group Questionnaires. Participants completed pre- and post-focus group questionnaires (eAppendix) with paper and pen. Questionnaires were projected and read aloud. The pre-focus group questionnaire collected sociodemographic characteristics not collected during screening. Participants were also asked if they have a primary care physician, if they have ever had a mammogram, and if they have health insurance.

Numeracy was assessed with the validated 3-item Subjective Numeracy Scale (SNS-3).³⁴ Scores range from 3 to 18, and scores ≥ 10 reflect adequate numeracy. We assessed participants' knowledge of screening recommendations and their perceptions of possible benefits and harms using questions adapted from Hersch et al.^{8,26,35} We used these adapted multiple-choice and open-ended questions to evaluate women's perspectives and knowledge about screening mammography recommendations, benefits and harms, and screening intentions. The 6 multiple-choice knowledge questions assessed breast cancer screening knowledge with higher scores indicating greater breast cancer screening knowledge (score range 1–6).

Focus Groups

Separate focus groups were conducted by (1) age (40–49 years or 50–75 years) due to differing screening recommendations; (2) race/ethnicity (Latina, Black, or non-Latina White) to enhance the culturally relevant perspectives and dialogue; and (3) language (English or Spanish). Each participant was scheduled to participate in one focus group that aligned with their self-identified age, race/ethnicity, and language.

Trained facilitators (AJH and DSH) with almost 20 years of combined qualitative research experience conducted the English language focus groups. For the Spanish language focus groups, AJH and DSH trained and supervised a Spanish-speaking focus group facilitator. Focus groups lasted up to 3 h. Participants were compensated with a \$50 gift card and parking/transportation. After each focus group, participants were provided with a card containing the recommendations discussed (including names of the organizations) and a list of resources.

Analysis

Descriptive statistics were used to summarize sociodemographic characteristics and questionnaires. Focus groups were recorded and transcribed verbatim. Spanish language transcripts were translated into English. We used a qualitative descriptive approach^{36,37} to analyze the rich descriptive content arising from participants' experiences and perspectives.³⁸ With this dynamic approach, we analyzed participant reactions, perspectives, and screening intentions in response to the presentation of the recommendations. Using the focus group guide as an initial outline, we developed a structured codebook. Throughout the iterative coding process, any amendments to the codebook were applied to all transcripts. Coding inquiries were resolved through discussion. Employing a constant comparison method, coders (AJH and MB) compared identified concepts within and across categories to detect patterns, connections, and differences.^{39,40} Conceptual linkages and categories emanating from this analytic process were identified and thematic topics were interpreted by the coding team.

RESULTS

Four hundred seventy-four potential participants agreed to be screened, 268 were screened by phone ($n=262$) or in person ($n=6$), and 134 women participated in 28 focus groups (Houston, TX, $n=26$; St. Louis, MO, $n=2$). Most focus groups were conducted in English ($n=24$). Participants were Latina ($n=44$); Black ($n=51$); and non-Latina White ($n=39$). Of the Latina participants, most requested Spanish language focus groups ($n=26$). Approximately one-quarter ($n=32$) of all participants had limited health literacy and almost one-fifth ($n=23$) had limited numeracy. The majority of Spanish-speaking participants had limited health literacy ($n=16$; Table 2).

Table 2 Sociodemographic Information for Full Sample

Race/ethnicity	AA/Black (N=51)	White (N=39)	Latina-English (N=18)	Latina-Spanish (N=26)	Total (N=134)
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)
Age	Range 54.80 (10.32) 40–73	Range 61.45 (11.38) 40–75	Range 54.06 (10.43) 40–70	Range 52.04 (8.84) 40–73	Range 56.10 (10.88) 40–75
Education	14.61 (1.86) 12–18 Median	15.18 (1.52) 12–18 Median	13.56 (2.45) 6–17 Median	9.15 (3.63) 1–14 Median	13.57 (3.19) 1–18 Median
Income	Range 30–40 1–11 N (%)	Range 60–70 2–11 N (%)	Range 50–60 1–11 N (%)	Range 20–30 1–7 N (%)	Range 40–50 1–11 N (%)
Employment status					
Employed	25 (49.0)	19 (48.7)	11 (61.1)	5 (19.2)	60 (44.8)
Unemployed	4 (7.8)	2 (5.1)	1 (5.6)	0 (0.0)	7 (5.2)
Homemaker	1 (2.0)	2 (5.1)	1 (5.6)	18 (69.2)	22 (16.4)
Retired	15 (29.4)	16 (41.0)	2 (11.1)	3 (11.5)	36 (26.9)
Other	6 (11.8)	0 (0.0)	3 (16.7)	0 (0.0)	9 (6.7)
Marital status					
Single	20 (39.2)	4 (10.3)	5 (27.8)	1 (3.9)	30 (22.4)
Married	11 (21.6)	21 (53.9)	7 (38.9)	20 (76.9)	59 (44.0)
Divorced	11 (21.6)	8 (20.5)	3 (16.7)	0 (0.0)	22 (16.4)
Widowed	6 (11.8)	5 (12.8)	3 (16.7)	2 (7.7)	16 (11.9)
Cohabiting	1 (2.0)	1 (2.6)	0 (0.0)	1 (3.9)	3 (2.2)
Separated	2 (3.9)	0 (0.0)	0 (0.0)	2 (7.7)	4 (3.0)
Generational status					
First	1 (2.0)	5 (12.8)	6 (33.3)	23 (88.5)	35 (26.1)
Second	24 (47.1)	10 (25.6)	6 (33.3)	1 (3.9)	40 (29.9)
Third or higher	26 (51.0)	24 (61.5)	6 (33.3)	2 (7.7)	57 (42.5)
Government insurance (e.g., Medicare, Medicaid)					
Yes	21 (41.2)	21 (53.9)	8 (44.4)	14 (53.9)	64 (47.8)
No	30 (58.8)	16 (41.0)	10 (55.6)	12 (46.2)	68 (50.8)
Unsure	0 (0.0)	1 (2.6)	0 (0.0)	0 (0.0)	1 (0.8)
Private or group insurance					
Yes	35 (68.6)	31 (79.5)	10 (55.6)	7 (26.9)	83 (61.9)
No	15 (29.4)	7 (18.0)	7 (38.9)	18 (69.2)	47 (35.1)
Unsure	1 (2.0)	0 (0.0)	1 (5.6)	1 (3.9)	3 (2.2)
Primary care physician					
Yes	43 (84.3)	37 (94.9)	16 (88.9)	17 (65.4)	113 (84.3)
No	8 (15.7)	1 (2.6)	2 (11.1)	9 (34.6)	20 (14.9)
Self-reported health					
Excellent	5 (9.8)	9 (23.1)	3 (16.7)	0 (0.0)	17 (12.7)
Very good	12 (23.5)	18 (46.2)	6 (33.3)	3 (11.5)	39 (29.1)
Good	21 (41.2)	9 (23.1)	7 (38.9)	7 (26.9)	44 (32.8)
Fair	8 (15.7)	2 (5.1)	2 (11.1)	13 (50.0)	25 (18.7)
Poor	4 (7.8)	1 (2.6)	0 (0.0)	2 (7.7)	7 (5.2)
Health literacy					
Limited	8 (15.7)	4 (10.3)	4 (22.2)	16 (61.5)	32 (23.9)
Adequate	43 (84.3)	35 (89.7)	14 (77.8)	10 (38.5)	102 (76.1)
Numeracy level					
Limited	8 (15.7)	3 (7.7)	5 (27.8)	7 (26.9)	23 (17.2)
Adequate	43 (84.3)	36 (92.3)	13 (72.2)	19 (73.1)	111 (82.8)
Mammogram ever					
Yes	47 (92.2)	37 (94.9)	17 (94.4)	18 (69.2)	119 (88.8)
No	4 (7.8)	2 (5.1)	1 (5.6)	7 (26.9)	14 (10.5)
Unsure	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.9)	1 (0.8)

Note: Percentages may not total to 100.0 due to rounding and/or missing data. Age is presented in years and represents the age at which women were screened for eligibility. Education is presented in approximate years (e.g., high school graduate = 12 years). Income was assessed using \$10,000 intervals and is presented as thousands of US dollars (e.g., 40 = 40,000 USD per annum); N=13 refused to report income. Employment "Other" category includes student, unable to work/disabled, and other. Mammogram ever is whether women ever had a breast cancer screening mammogram. Generational status refers to the number of familial generations living in the US

Overall, mean knowledge scores increased by almost 1 point out of 6 points on pre- to post-focus group questionnaires (pre=3.52 vs. post= 4.49; Table 3). The majority (n=107) supported annual screening beginning at 40 years but were unsure about when to discontinue screening (eTable 1). Most participants described physical benefits of screening (pre n=120 vs. post n=124). For downsides, 22.4% (n=30) of participants responded

that there were no downsides pre-focus group compared to 4.6% (n=6) post-focus group.

Quantitative and qualitative data are presented narratively below and in eTables 3.⁴¹ The quotations included provide illustrative examples of participants' perspectives. Participant number, race/ethnicity, and age are included to demonstrate similarities and differences across sociodemographic characteristics.

Table 3 Breast Cancer Screening Mammogram Knowledge by Health Literacy and Numeracy

	Limited HL (N=32)	Adequate HL (N=102)	Limited HN (N=23)	Adequate HN (N=111)	Total Sample (N=134)
Pre-questionnaire	N (%)	N (%)	N (%)	N (%)	N (%)
When to start					
40 years old	26 (81.3)	81 (79.4)	18 (78.3)	89 (80.2)	107 (79.9)
45 years old	0 (0.0)	4 (3.9)	1 (4.4)	3 (2.7)	4 (3.0)
50 years old	1 (3.1)	7 (6.9)	2 (8.7)	6 (5.4)	8 (6.0)
Unsure	5 (15.6)	10 (9.8)	2 (8.7)	13 (11.7)	15 (11.2)
How often					
Every year	26 (81.3)	79 (77.5)	19 (82.6)	86 (77.5)	105 (78.4)
Every other year	2 (6.3)	11 (10.8)	2 (8.7)	11 (9.9)	13 (9.7)
Every 5 years	2 (6.3)	5 (4.9)	2 (8.7)	5 (4.5)	7 (5.2)
Unsure	2 (6.3)	7 (6.9)	0 (0.0)	9 (8.1)	9 (6.7)
When to stop					
65 years old	1 (3.2)	1 (1.0)	0 (0.0)	2 (1.8)	2 (1.5)
70 years old	2 (6.5)	8 (7.9)	1 (4.4)	9 (8.3)	10 (7.6)
75 years old	7 (22.6)	16 (15.8)	5 (21.7)	18 (16.5)	23 (17.4)
<10-year life expectancy	3 (9.7)	3 (3.0)	1 (4.4)	5 (4.6)	6 (4.6)
<5-year life expectancy	1 (3.2)	21 (20.8)	2 (8.7)	20 (18.4)	22 (16.7)
Unsure	17 (54.8)	52 (51.5)	14 (60.9)	55 (50.5)	69 (52.3)
Pre- and post-questionnaires	M (SD) Range	M (SD) Range	M (SD) Range	M (SD) Range	M (SD) Range
Breast cancer knowledge (score range 0–6)					
Pre-focus group	2.90 (1.63) 0–5	3.70 (1.37) 0–6	2.61 (1.64) 0–5	3.71 (1.35) 0–6	3.52 (1.46) 0–6
Post-focus group	4.13 (1.43) 0–6	4.60 (1.09) 1–6	3.73 (1.52) 0–6	4.64 (1.05) 1–6	4.49 (1.19) 0–6

Participant Reactions and Perspectives About the Recommendations

Theme: Questioning the Data and Evidence for Multiple Recommendations. Following the focus group presentation of the three national screening recommendations, participants questioned the data upon which the recommendations were based. Some participants suggested that the recommendation-making organizations lacked high-quality data, resulting in the development of multiple recommendations. Participants also questioned the methods and statistics used to develop and inform the recommendations.

So they don't really have good information... (P1043, Black, 40-49 years)

...they may have a different number[s] of participants in those studies that could yield different results... (P1060, White, 50-75)

...Where, when, how was that information gathered and I know that these are major big organizations, and they probably have good data, but at the end of the day what is good data? (P1122, Latina English, 40-49)

... they're saying, okay, we're guessing, but here is this time frame. (P1022, Black, 50-75)

Black and Latina participants expressed concern that they were not represented in the data (i.e., the data was not racially/ethnically heterogeneous) informing the

recommendations. This concern initiated a line of questioning about the purpose of differing recommendations.

It depends on the data that they've gathered and in the dataset and do you have enough diversity of participants. (P1046, Black, 40-49)

... maybe their group wasn't as diverse as another group. Maybe they just targeted a certain group ... And they got the survey from that group, not the whole population... And that's possibly why they have the difference in their recommendations. (P1030, Black, 50-75)

... women... where there is so much poverty who never probably have access to good healthcare, maybe like that was a group that was studied on... I wonder... why we didn't hear anything about breast cancer detection in the Hispanic population. (P1097, Latina English, 50-75)

As participants described how they questioned the differing recommendations, they suggested that a streamlined screening guideline could help avoid confusion and would allow for a universal message.

I would love for the organizations to get together and come up with one based on data, and I think that that would be helpful to all of us in the public. Because as it is, we are already questioning... And I think that that creates confusion... (P1104, Latina English, 40-49)

... Health organizations need to get together and come up with one national screening [recommendation], because I think that that creates a problem for how people address getting screenings, because you're getting mixed signals, mixed information. One says this, the other one says that... you all need to be universal. (P1029, Black, 50-75)

Why aren't the organizations... collaborating? Instead of having three separate ones stating these facts and this data... why aren't the three of them working together as a group and collaborating?... (P1412, White, 40-49)

Theme: Questioning the Recommendation-Making Organizations. Participants questioned the purpose of multiple recommendations. In particular, they questioned financial motives and how that could lead to differing screening recommendations. Skepticism arose as participants questioned how insurance companies and government stakeholders considered cost.

If you want to do a mammogram at age 30, your insurance will not pay for it. You have to be 40 or else the insurance will not pay. So, do you recommend that age group because they know their insurance will pay...? (P1068, Latina, English, 50-75)

I think looking at the recommendations, and especially, knowing that there's three different organizations with different opinions on when you need it, when you start, when you stop, how often. I think that makes me want to research more and keep an eye on what's happening with insurance companies and the government when it comes to these kinds of screenings... (P1411, White, 40-49)

... I'm sure politics and money is one thing... some states are like, "oh, man, we don't want to pay for these things for our Medicaid patients," ... I understand that those large stakeholders probably prefer to massage their data in one way versus another way to kind of push toward the answers that they might want to see... (P1124, Latina, English, 40-49)

Furthermore, participants expressed concern regarding the make-up of the recommendation-making organizations and the inclusion of women, suggesting that the recommendation for earlier and more frequent screening is more "woman-driven".

It used to be that there were a lot of men on those boards, so they [were] a little bit insensitive to our wellbeing. I wonder... are there any more women on boards, so they can make better decisions?... we probably are a little bit more sensitive than a man ... Because sometimes they devalue a woman... (P1004, Black, 50-75)

... I am thinking that some of those organizations are more women-driven than like, maybe option Organization 1 is more women-driven than [Organization] 2 and 3. (P1064, Latina, English, 50-75)

... who's really in charge...? Are women equally represented in these organizations at the top levels? (P1410, White, 40-49)

Theme: Attending to Recommendations with More Frequent and Continued Screening. Participants described their comfort and familiarity with more frequent screening schedules. This preference often aligned with NCCN recommendations (i.e., Organization 1). Compared to the other two organizations (Organization 2: ACS; Organization 3: USPSTF), NCCN provides the strongest recommendation for starting annual screening at age 40 years and does not provide a discontinuation recommendation.

I'll stick with those recommendations of Organization Number 1 [NCCN]. That's what I'm most comfortable with, and that's what I'm most familiar with... I definitely would disagree with Organization 3 [USPSTF], so I would probably consider Organization 2 [ACS], but my thought process is more along with Organization 1 [NCCN]. (P1073, Black, 40-49)

I thought that you should start getting the breast cancer screening earlier than 40... And... it says, when you hit a certain age, you can skip one year and do it... every other year... I wouldn't be comfortable with that,

and it doesn't matter... how old I am; I would like it every year. (P1070, Latina, English, 50-75)

Expressing surprise, participants pushed back against the idea of discontinuing screening. They supported the idea of continuing screening as women age.

I didn't realize the age was 75 when they start saying okay, you don't have to do it annually... I thought they just always continued forever. (P1010, Black, 50-75)

I think that, if we are still strong, and everything, then we have to do it, right? Why not? Why not? (P1133, Latina, Spanish, 40-49)

... They look at a woman who is of a certain age, and they say, "Okay.... you're not worth that to us." There's no benefit to us to treat you ... I think that's disgusting. (P1018, White, 50-75)

Some participants demonstrated openness to discontinuation of screening, particularly when considering quality of life. They described the importance of personal choice and offered varying ages for when to consider discontinuing screening.

... I'm not as upset about them saying no recommendation, 75 is suggested because personally, I don't think I would want to undergo a mastectomy if I had it after 75... (P1408, White, 40-49)

... why are you going to go through so much suffering if you're aware or you don't want to live a life, even though you're too old, low quality... (P1106, Latina, Spanish, 50-75)

Women in their 40s appeared open to considering discontinuation around 75, while those 50 and over expressed openness to discontinuation in the future more generally or at an age older than 75.

Because it just seems like the correct thing to do... like as far as when to stop like, when you are 75, you are getting to a point where these people are getting older. I don't know what their life expectancy is. I think they have already been through enough... I think it should be your choice regardless if you want to do this or not, it's up to you... (P1105, Latina, English, 40-49)

I can speak for my grandmother. She was 97 and had a small cancer, and they said, "Don't bother." Well, yeah, 97, a pea-sized cancer. So, that to me is a cutoff point I guess. (P1094, White, 50-75)

Screening Attitudes and Intentions: Continued Enthusiasm for Screening

On the post-focus group questionnaire, participants shared their renewed intention to screen within the upcoming year (pre $n=100$ vs. post $n=107$). Participants were interested in annual screening and encouraging those around them to be screened, for example, "... I will continue to keep going. Every year now... (P1022, Black, 50-75)," and, "... make sure other women in your life are getting it [mammograms] also, advocate for each other. (P1410, White, 40-49)" Those who had skipped a past mammogram described embarrassment and the need to be "better" or to "get back on track" by undergoing regular screening in future for example, "... despite that I'm not doing it [mammograms], I need to get better, on top of it. It's one of these things where... it looks like it's worth it in the long run... (P1047, Black, 40-49)" However, while motivated to screen, some participants described barriers to their screening intentions, including insurance coverage, financial strain, and competing financial priorities.

I'm not going to probably change my mind; I'll do it every year... my insurance will pay for it... (P1082, White, 50-75)

... as soon as I find a clinic that is not that expensive, I am ready to get the exam done. I have never had a mammogram and I am about to turn 41... my priority is getting the exam done. (P1118, Latina, Spanish, 40-49)

...sometimes you have to wait a couple of months before there's an opening that it's free or half price... Because there are a lot of women out there that don't have insurance, so can't afford it... (P1070, Latina, English, 50-75)

... we're immigrants... a lot of times we don't take care of our health in order to send money to our family who is in our country, and we forget about ourselves.... (P1121, Latina, Spanish, 40-49)

DISCUSSION

In this study of racially/ethnically diverse women eligible for breast cancer screening in the US who varied by health literacy and numeracy, the presentation and discussion of multiple inconsistent screening recommendations appeared to enhance enthusiasm for earlier, more frequent, and continued screening. Concerns and questioning toward recommendation-making organizations heightened the uncertainty surrounding how recommendations are developed and whose interests they represent. Financial, racial, and gender-related questioning drove the discussion regarding the development of the recommendations.

Our findings suggest that at the population level, pro-screening messaging for breast cancer has been so impactful¹³ that even when reviewing divergent recommendations and increasing awareness of potential downsides, women's overall interest in frequent screening appears to remain high. Participants were skeptical of the data supporting the recommendations and members of the recommendation-making organizations. Differing recommendations were viewed as a reflection of limitations in the data and as representing the interests of dominant versus racially/ethnically marginalized groups. To address these concerns, efforts should be made to increase transparency in guideline development. Participants also suggested that a consistent set of recommendations from one collaborative group would be clearer than the multiple conflicting recommendations.

Cancer screening enthusiasm has been well documented.^{42–45} Breast cancer screening decision aids for women ≤ 50 years have been found to improve knowledge, informed decision-making, and reduce the intention to screening, yet show mixed results for decisional confidence and decisional conflict.^{46,47} Schapira and colleagues found that even when presenting screening recommendations side-by-side and including individualized risk estimates, women did not initiate breast cancer screening based on their individual risk. In addition, Hersch et al.⁴⁸ described testing their breast cancer screening decision aid among women 48–50 years and found no change in screening participation. Reviewing divergent recommendations and objective risk and increasing awareness of potential downsides do not appear to have an impact on screening behaviors.^{48,49} We add to this body of evidence by elucidating women's unease about not adhering to annual screening recommendations. The focus group format allowed participants to discuss and grapple with the differing recommendations, providing insight into participant perspectives and social dynamics. Participants who were not adherent to annual screening were encouraged by other participants to "take care" of themselves and participants suggested that they would encourage their friends and family to be screened annually. This illustrates the pressures of decision making in a social context and the challenges associated with deciding a screening schedule that differs from the expected annual screening. These findings emphasize the importance of supporting the social and emotional factors associated with selecting a

recommendation-informed screening schedule. As we move toward risk-stratified screening schedules which will result in reduced screening frequency for some women based on their personal risk estimates, there is a need to address social and emotional factors in an environment of screening enthusiasm.⁵⁰ Destigmatizing the option of screening less, and providing more transparency about the evidence, can help support women as they make screening decisions that align with evidence and their values and preferences.

Black and Latina participants questioned how adequately minority women were included in the data supporting recommendations. These concerns are well-founded. Although breast cancer screening recommendations are often based on a combination of retrospective data, modeling, and expert opinions, inclusion of racial/ethnic minorities in research cohorts⁵¹ and clinical trials is lacking and racism in the health care system is well documented.^{52,53} Furthermore, there is limited evidence on the specific physical, psychological, and financial impacts of screening among racial/ethnic minorities.⁵⁴ Black and Latina women also experience distinct and overlapping racism and discrimination as they consider breast cancer screening mammography.⁵⁵ As we move toward personalized risk-based screening recommendations, consideration surrounding racism in clinical algorithms and how these estimates are perceived is essential.⁵⁶

LIMITATIONS

Participants were motivated to attend a breast cancer screening focus group and this selection may have attracted those who were already enthusiastic about screening. In addition, our aim was to recruit a balanced number of participants with limited and adequate health literacy and numeracy. While we targeted our recruitment to community-based sites serving those at increased risk for limited health literacy, most participants had adequate health literacy and numeracy. Additionally, it is unclear how women's stated attitudes and intentions regarding breast cancer screening mammography might translate to screening behaviors.

CONCLUSION

In general, women questioned divergent breast cancer screening recommendations. Their concerns appeared to renew their focus on screening earlier, later in life, and more frequently. Providing divergent breast cancer screening recommendations at the population level may inadvertently undermine trust in screening recommendations and reinforce overall enthusiasm for screening.

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