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TRUST AND MISTRUST IN SHAPING ADAPTATION AND DE-IMPLEMENTATION IN THE CONTEXT OF CHANGING SCREENING GUIDELINES

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Objective: To understand barriers and facilitators to the adaptation of programs reflecting changing scientific guidelines for breast/cervical cancer screening, including factors influencing the de-implementation of messaging, program components, or screening practices no longer recommended due to new scientific evidence.

Design and Methods: We conducted a convergent mixed-methods design in partnership with The National Witness Project (NWP), a nationally implemented evidence-based lay health advisor (LHA) program for breast/cervical cancer screening among African American (AA) women. Surveys were conducted among 201 project directors (PDs) and LHAs representing 14 NWP sites; in-depth interviews were conducted among 14 PDs to provide context to findings. Survey data and qualitative interviews were collected concurrently from January 2019-January 2020.

Setting: National sample of NWP sites from across the United States.

Results: Trust and mistrust were important themes that arose in quantitative and qualitative data. Common concerns about adapting to new guidelines included: 1) perceptions that new guidelines misalign with the personal values and beliefs of AA women; 2) mistrust of guidelines, providers, medical organizations; 3) confusion about inconsistent guidelines and concern they are based on studies that don't reflect the experience of AA women (who experience more aggressive tumors at younger ages); and 4) belief that breast self-exam (BSE) is an empowerment tool for AA women and should be included to promote awareness, given many women discovered lumps/cancer through BSE.

Conclusion: Findings highlight that trust and mistrust are important but understudied social determinants of health among AAs that should be considered in implementation science as they: 1) have critical implications for shaping health inequities; and 2) help explain and contextualize why new screening guidelines may not be fully embraced in the AA community. *Ethn Dis.* 2021;31(1):119-132; doi:10.18865/ed.31.1.119

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INTRODUCTION

Eliminating racial inequities in cancer is a national priority.[1] Breast cancer is responsible for a large proportion of cancer-related morbidity and mortality among African American (AA) women.[1] Markedly, breast cancer death rates are 40% higher in AA women compared with White women, despite similar incidence rates overall.[1] Further, AA women have a higher proportional incidence of aggressive breast cancer at younger ages and less explanatory benefit of BRCA1/2 genes.[1] While many factors contribute to this disparity, including tumor characteristics, comorbidities, and differential access to and response to cancer treatment, later stage at diagnosis is one contributing factor.[1] Only about half of breast cancers among AA women are diagnosed at a local stage compared with 64% in White women[1]; this has been attributed in part to lower frequency of, and longer intervals between, mammograms and delayed diagnostic follow-up.[1] Mammography screening is the most effective method for early detection of breast cancer available, associated with 30%-50% reduction in breast cancer mortality.[2] Increasing participation in, and maintenance of, repeat screening and diagnostic follow-up among AA women is necessary to reduce the excess burden of cancer experienced among this population.

Lay health advisors (LHAs) are

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trained community members who deliver health education, navigation, resources, and social support in community and clinical settings.[3,4] Efficacy and effectiveness trials indicate that LHA programs are effective in improving behavior change for many health issues, including cancer screening, with the strongest evidence from studies among racially/ethnically diverse populations.[5-7] LHA programs have made strong contributions toward the reduction of health disparities and are increasingly being implemented in the prevention and management of many chronic diseases.[3,5] Research is needed to inform how to best implement and sustain such programs over time to maximize their impact on populations experiencing inequities and reduce the burden of breast cancer among AA women. The National Witness Project (NWP) is an exemplar of sustained and effective LHA programs; it has been identified as one of the National Cancer Institute's (NCI) Evidence-Based Cancer Control Programs (compendium of evidence-based programs) for its impact on breast/cervical cancer screening among AA women. NWP was founded by AA breast/cervical cancer survivors to reduce cancer stigma and address inequities in early detection behaviors among AA women who experience greater structural barriers to screening and health care access, including experiences of discrimination and medical mistrust.[8,9] NWP uses a theory-based, culturally appropriate model; during 60-90 minute group-based 'sessions' in communities, LHAs provide resources, support, and education, with follow-up navigation as needed.[8,9] Half of the LHAs are cancer survivors who deliver powerful testimonials. Since 1990, NWP has been disseminated and implemented across 22 states, with more than 400 volunteers, reaching more than 15,000 women annually.[8,9]

> *The goal of this research was to advance understanding of how to support programs to stay evidence-based over time…*

There has been strong growth in the field of dissemination and implementation science (D&I) to address the gap between research and practice.[10] While there has been great focus on context, including the multi-level factors that shape the initial implementation of evidence-based intervention,[11] little work has focused on de-implementation of interventions or program components/messaging over time. De-implementation is the removal or replacement of practices that no longer are (or never were) supported by the best available evidence, because they are unnecessary, costly, harmful, or do not improve health outcomes,[12,13] a priority area for the National Institutes of Health (NIH, NOSI NOT-CA-20-021). Consistent with The Dynamic Sustainability Framework,[14] some changes may be adaptive and appropriate in real-world contexts that are dynamic and change over time. For example, de-implementation may be warranted in the context of changing evidence,[15] as is the case with updates in breast cancer screening guidelines. Current recommendations differ from guidelines that were in place when NWP was developed more than 25 years ago and have changed multiple times in recent years. These changes have caused confusion among community members, related in part to often conflicting screening guidelines across national organizations (eg, age and interval of recommended screening).[16-18] Previous guidelines at the time NWP was developed endorsed mammography screening annually for women aged ≥40 years and clinical breast exams (CBE) and breast self-exams (BSE). As of 2016,[19] the US Preventive Services Task Force (USPSTF) recommends biennial screening mammography for women aged between 50-74 years; as of 2009, they no longer recommend CBE or BSE. The American Cancer Society (ACS) recommends average risk women start annual mammography at aged 45 and women, aged ≥55 years should transition to biennial. CBE is not recommended for breast cancer screening and no BSE statement is provided.[20] Both ACS and USPSTF support breast self-awareness and informed decision-making.

Research is needed to understand barriers and facilitators to adaptation of programs to reflect changing scientific guidelines for cancer screening, including factors influencing the de-implementation of messaging or program components that reflect screening practices no longer recommended or with limited benefit according to new scientific evidence. This is particularly important to understand among AA communities that may experience higher levels of mistrust of providers and medicine, rooted in a system of both historical and ongoing structural discrimination and abuses in the US context (including but not limited to the Tuskegee study).[21,22]

Despite the critical role of social determinants of health (SDOH) and structural factors in shaping health inequities, relatively little work in D&I science has examined the role of SDOHs in shaping implementation and de-implementation of programs, especially in racially diverse community settings experiencing inequities. The goal of this research was to advance understanding of how to support programs to stay evidence-based over time; to do so, we conducted a mixed-methods study in partnership with NWP sites to provide a contextualized understanding of perceptions of and barriers to implementing new guidelines and de-implementing outdated screening guidelines among AA women.

Methods

Participant Recruitment

Our research was approved by the Columbia University institutional review board (IRB) and all procedures followed were in accordance with the ethical standards of the IRB. All NWP sites that were considered as operational at the start of the study (eg, sites conducting at least one educational session in past two years) were invited to participate through letters distributed by mail and email to site project directors (PDs). Of the 16 sites, a total of 14 sites participated.

Data Collection

We used a convergent mixed-methods data collection[23] that leverages the strengths of rigorous qualitative methods (eg, greater depth) and breadth of quantitative survey data. Survey data and qualitative interviews were collected concurrently from January 2019 – January 2020. LHAs learned about the study through in-person meetings or webinars with the principal investigator (PI) and national NWP team. If interested, they completed a participant interest form and were contacted by the research assistant (RA). We sought to recruit as many eligible and active LHAs as the site had. To be eligible, participants had to be an active PD or LHA at participating NWP sites. Informed consent was obtained from all patients being included in the study. Survey data were collected online through Survey Monkey (83%) or by paper surveys that were mailed or securely scanned back to the study team (17%); qualitative interviews were conducted by phone by a trained RA or PI.

Surveys

Surveys involved a combination of open- and closed-ended questions, informed by prior measures piloted with NWP or from the literature. We used an adapted measure from Massatti and colleagues[24] that has demonstrated acceptable reliability in prior work. We used 25 items among PDs and 14 items among LHAs to assess barriers/facilitators to de-implementation across six domains (Decision and planning influences; Organizational support; Implementation enhancement factors; Organizational beliefs/expectations about compatibility; and Implementation processes and progress; Trust/Mistrust)[24] as well as the adaptation sub-scale from the Program Sustainability Assessment Tool.[25] Additional questions assessed knowledge of and attitudes toward guidelines, extent to which the program has been adapted based on new guidelines, and barriers and facilitators to de-implementation of certain screening practices (eg, BSE, CBE, changes in age and interval of mammography and pap tests). Univariate and descriptive analyses were conducted based on survey items.

Interviews

Using semi-structured interviews, the RA or PI (both trained in qualitative methods) interviewed site PDs and asked open-ended questions with neutral, open-ended probes. Interviews were transcribed verbatim from audiotapes. The PI and the RA reviewed all transcriptions using a thematic analytic approach.[26] Analyses followed a systematic, iterative process in which transcripts were read for familiarity with content. Researchers took an inductive approach to analysis to identify codes and general themes, with accompanying quotes reflecting these themes.

Table 1. Lay health advisor (LHA) and project director (PD) sociodemographic characteristics

	PDs, N=14	**LHAs, N=187**	**Overall, N=201**
	n (%)	**n(%)**	**n (%)**
Race			
Hispanic	0 (0%)	5 (3%)	5 (3%)
Non-Hispanic: African American/Black	14 (100%)	179 (97%)	193 (97%)
Age	24-78 (mean=57)	17-88 (mean=55)	17-88 (mean=55)
Education level			
Less than high school	0 (0%)	4 (2%)	4 (2%)
High school graduate or GED	0 (0%)	26 (14%)	26 (13%)
Some college training	1 (7%)	41 (22%)	42 (21%)
Associate's degree	0 (0%)	24 (13%)	24 (12%)
College or university graduate	3 (21%)	44 (24%)	47 (24%)
Graduate or professional degree	10 (71%)	44 (24%)	54 (27%)
Employment status			
Working full-time	7 (50%)	91 (49%)	98 (49%)
Working part-time	1 (7%)	23 (13%)	24 (12%)
Retired	3 (21%)	55 (30%)	58 (29%)
Homemaker	0 (0%)	6 (3%)	6 (3%)
Unable to work	0 (0%)	2 (1%)	2 (1%)
Other	3 (21%)	7 (4%)	10 (5%)
Survivorship			
Cancer survivor	-	53 (29%)	-
Not a cancer survivor	-	130 (71%)	-
Primary care			
Has a primary care physician (PCP)	13 (93%)	178 (97%)	191 (97%)
Does not have a PCP	1 (7%)	5 (3%)	6 (3%)
Health insurance			
Medicaid and/or Medicare	5 (36%)	64 (35%)	69 (35%)
Employer-provided insurance	8 (57%)	87 (48%)	95 (49%)
Pay for insurance out-of-pocket	0 (0%)	9 (5%)	9 (5%)
Affordable Care Act	1 (7%)	4 (2%)	5 (3%)
I do not have health insurance	0 (0%)	6 (3%)	5 (3%)
Other	0 (0%)	11 (6%)	11 (6%)
Health status			
Excellent	2 (14%)	15 (10%)	17 (10%)
Very good	6 (43%)	53 (35%)	59 (36%)
Good	4 (29%)	55 (36%)	59 (36%)
Fair	2 (14%)	29 (19%)	31 (19%)
Poor	0 (0%)	0 (0%)	0 (0%)

RESULTS

Sociodemographic and Site Characteristics

In 2019, surveys and interviews were conducted with 14 PDs and 187 LHAs (total N=201). An average of 14 LHAs were surveyed per site (ranging from 0-29/site). Sites included: Arkansas, Buffalo NY, California, Connecticut, Harlem NY, Houston, Kansas, Las Vegas, Long Island NY, Madison, NE Louisiana, Rochester NY, South Carolina, and Saint Louis. Most sites (71%) were free-standing in the community, 21% were partially or fully supported by an academic or medical organization, and 7% were affiliated with/based in another community-based organization. All but five participants identified as African American or Black women, with an average age of 55 years. Half of the sample was working full-time (49%) and 29% were retired. Nearly 30% were cancer survivors and most had employer-provided insurance (49%). Table 1 displays sociodemographic characteristics for the study population.

Table 2. Implementation of screening guidelines

	PDs	LHAs	Overall
Recommended age to begin mammography screening	(n=13)	(n=161)	(n=174)
Before 40	23%	14%	14%
40	77%	80%	80%
45	0%	4%	3%
50 and later	0%	2%	2%
Recommended mammography screening frequency	(n=13)	(n=181)	(n=194)
Every year	92%	86%	87%
Every other year	8%	7%	7%
I don't know	0%	4%	4%
Other	0%	3%	3%
Screening guidelines used at NWP site	(n=13)	(n=176)	(n=189)
American Cancer Society	54%	39%	40%
US Preventive Services Task Force	8%	2%	2%
Materials and guidelines from local NWP site	23%	13%	13%
Materials and guidelines from NWP national organization	15%	28%	28%
I don't know	0%	14%	13%
Other	0%	4%	4%
Awareness of changing breast/cervical cancer screening guidelines in recent years	(n=13)	(n=180)	(n=193)
Not so aware	0%	10%	9%
Somewhat aware	15%	39%	37%
Very aware	85%	52%	53%
Awareness of changes made to NWP programming to reflect new breast/cervical cancer screening guidelines	(n=14)	(n=181)	(n=195)
Aware	79%	75%	75%
Not aware	21%	25%	25%

PD, project director; LHA, lay health advisor; NWP, National Witness Project.

Attitudes and Beliefs Toward Evidence-based Guidelines and Adaptations

Overall, both LHAs and PDs were supportive of making adaptations to keep the program evidence-based. The majority of those surveyed believed using evidence-based practices and guidelines is important within the NWP program (89%) and that their site delivers education and services that are evidence-based (85%). More than 70% agreed that their site regularly reviews the evidence-base of the program and adapts the program as needed (eg, based on new screening guidelines).

Implementation of Guidelines

Most LHAs and PDs reported their site uses screening guidelines from ACS (40%) or guidelines from the NWP organization (41%), and recommend women begin mammography at age 40 (80%) and get screened annually (87%). Most participants reported being very aware of changes made to breast/cervical cancer screening guidelines in recent years (53% overall; 85% PDs; 52% LHAs). Reflecting this, more than half the participants reported that their site updated messaging about age of initiation or frequency of mammography screening (56%), and reported changes made at their site to program components relating to BSE (38%) and CBE (26%). BSE (86%) and CBE (70%) were commonly reported as educational components in NWP programming (Table 2).

Barriers and Facilitators to Adaptation (Quantitative)

The most commonly reported barriers to adapting programming to reflect new screening guidelines were fairly consistent across LHAs and PDs and included: 1) lack of funding (33% of PDs, 38% of LHAs), 2) insufficient number of trained LHAs/staff (50% of PDs, 20% of LHAs), 3) need for new educational materials/video (33% of PDs, 19% of

Table 3. Barriers and facilitators to implementation and de-implementation in the context of new screening guidelines among lay health advisors and project directors, Part 1

Domain	Construct	Question	PDs, n=13			LHAs, n=178			Overall, n=192		
			Agree	Neutral	Disagree	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Trust/ mistrust	Trust/ mistrust	There is high trust of medical organizations and providers among our community	53%	15%	31%	57%	30%	12%	57%	29%	14%
		I trust the new breast cancer screening guidelines	46%	31%	23%	67%	27%	6%	64%	27%	9%
Decision and planning influences	External support	Other sites are implementing the new screening guidelines	23%	69%	8%	47%	51%	2%	46%	52%	2%
	Scientific evidence	There is evidence that BSE is effective	92%	0%	8%	85%	12%	4%	86%	11%	4%
		Strong evidence informed the changes in mammography guidelines	61%	8%	0%	63%	35%	2%	65%	33%	2%
		There is evidence that CBE is effective	92%	7%	0%	-	-	-	-	-	-
	External group influence	We receive pressure from our partners and funders to use the new guidelines	30%	31%	38%	-	-	-	-	-	-
Organizational support	Staff and community support	Women in the community are supportive in making guideline changes	61%	8%	31%	57%	39%	5%	56%	37%	7%
		LHAs are supportive of making the recommended guideline changes	54%	31%	15%	74%	24%	2%	72%	25%	3%
	Organizational commitment	Organizational leadership is supportive in making recommended guideline changes	84%	15%	0%	85%	13%	2%	85%	14%	2%
	Attitude toward innovation	I think implementing the new guidelines is a very good idea	46%	31%	23%	-	-	-	-	-	-
	Technical assistance	The training we need to use the new guidelines is available	77%	15%	8%	71%	24%	5%	74%	24%	3%
	Knowledge	My site is well-informed about the new guidelines	69%	31%	0%	75%	23%	2%	75%	23%	2%

PDs, project directors; LHAs, lay health advisors; BSE, breast self-exam; CBE, clinical breast exam

Table 4. Barriers and facilitators to implementation and de-implementation in the context of new screening guidelines among lay health advisors and project directors, Part 2

Domain	Construct	Question	PDs, n=13			LHAs, n=178			Overall, n=192		
			Agree	Neutral	Disagree	Agree	Neutral	Disagree	Agree	Neutral	Disagree
Implementation enhancement factors	Ongoing slack resources	We have the resources necessary to support the recommended changes	62%	8%	30%	70%	25%	5%	70%	24%	5%
	Resource availability	Limited funding is a barrier to using the new guidelines	31%	31%	38%	-	-	-	-	-	-
Organizational compatibility	Compatibility	The new guidelines are compatible with my beliefs about breast cancer screening	31%	46%	23%	-	-	-	-	-	-
Implementation process and progress	Ease of use	It is easy to train staff on new screening guidelines	-	-	-	74%	25%	3%	-	-	-
	Assimilation	There has been healthy discussion about changing the program to reflect new guidelines at our site	46%	38%	15%	-	-	-	-	-	-
Adaptation	Adaptation	My site regularly reviews the evidence base of the program	79%	21%	0%	71%	21%	8%	71%	21%	8%
		My site adapts program as needed	79%	7%	14%	83%	13%	4%	83%	12%	6%
		My site makes decisions about which program parts are ineffective	71%	7%	21%	75%	16%	9%	75%	15%	10%

PDs, project directors; LHAs, lay health advisors.

LHAs), and 4) lack of support from the community (25% of PDs, 12% of LHAs). In expanding on these concerns through short-answer, women elaborated on several issues, including: 1) perception that guidelines are confusing for community; 2) concern that guidelines recommending that mammograms occur less frequently may result in AA women not getting screened at all; and 3) concern that removing BSE from programming will not be supported by survivors who found their lump/cancer through BSE or younger AA women who do not have other screening options.

We examined a range of factors that may influence implementation of new guidelines and de-implementation of old guidelines across six key domains (Tables 3 and 4). We found that trust and mistrust were important domains: 1) only 57% of women agreed that there is high trust of medical organizations/providers in their community (53% of PDs; 57% of LHAs); and 2) 64% of women trusted the new breast/cervical cancer guidelines (46% of PDs; 67% of LHAs). Additionally, we found that only 56% of the sample perceived AA women in the community to be supportive of adapting to changes in guidelines (61% of PDs; 57% of LHAs) and 72% perceived LHAs as supportive of making changes (54% of PDs; 74% of LHAs). Furthermore, 31% of PDs perceived the new screening guidelines to be compatible with their beliefs about breast/cervical cancer screening.

PD Perceptions and Concerns Regarding Updating Screening Guidelines (Qualitative)

We conducted qualitative interviews among PDs at 14 sites to provide depth to the quantitative findings. Tables 5 and 6 provide details on

Table 5. Key themes/quotes representing project director concerns about implementing new guidelines and de-implementation of outdated guidelines

Key Concern: Changing guidelines misaligned with African American women's needs and experiences	
1) Perception that AA women may need screening at younger ages due to invasive cancers and strong family history	"We think [BSE] is very important. Because we know several women, especially some of the women that were volunteers in the past. Most of them found their lumps themselves. And we're gonna continue that, because everybody doesn't go out & get a mammogram, even though you really stress it, but they don't do it…So, it's very important that you do the BSE, we're still teaching that...you've got to consider the social economic conditions. Everybody just doesn't go out & get a mammogram… those women that are under age 40, whose doctors don't even recommend getting mammograms until they're 40. If you start teaching them young, to examine your breast every month, you don't know how many lives you can save."
2. Perception that if program keeps changing, women in the community will stop listening and trusting them, and will ultimately be left behind	"[Taking out BSE] has been hard, because that was something that we were taught in the beginning. But I know that as the world changes,…everything else change. They'll tell you that it will be a screening every other year, and then they'll go back the next year and tell you screening every year, but this is my take on it is: if you have family history of cancer, I think that you should be screened yearly. That's just me. But when the guidelines change, we have to go with the guidelines. We use the ACS…the BSE is educational... You get them in the habit of going yearly, and then it changes and they think that it shouldn't change. It shouldn't be every other year. But, if they think every year, instead of them not getting it period, then go every year…I wouldn't want them to say, since y'all keep changing that, just forget it. I'm not doing it…because I know that everything is forever changing, and I just go with the changes."
3) Belief that guidelines don't reflect AA women experiences & BSE is important for those not getting mammograms	"The population of people we're dealing with is quite different from population on a national level where people are going in from mammography, and a physician's exam, a lot of these people don't go to the doctor, period. So we still have to mention both BSE and clinical exams. I think those are critical pieces of information….All that to say that BSE and checking yourself, it still has a place. Right and people in rural communities, they don't have always access to care and there are disparities… a lot of them feel like it is not broken, don't fix it. I'm not hurting and I don't have a problem. I don't need to go to a doctor."
Key concern: Eliminating breast self-exam (BSE)	
4) Many AA LHAs and role models in the program found their own cancers through BSE and importance is ingrained in them	"They're not recommending self-exams anymore, but I know all of my volunteers still educate on self-exams…As a group, we decided that it's still worth giving our shower cards, because a lot of volunteers have been the ones to find their lumps, so that's going to be something that's going to be part of us….so many of them have found their breast cancer on their own while doing their self-examination, so I think that it's just important to continue to educate women on just being able to identify the problems, and being acquainted with their bodies... if a volunteer that has been educating on BSE for 20 years, then I think it's ingrained in them… "We were on top of that stuff..Women were empowered to take control over their breast health and talk to the doctor-- I found something, this is where I found it, we need to see what we need to do about it. A lot of the women had detected their lumps too. And theirs was still age 40, but since so many African American women, well women of color, also had the invasive breast cancers, we started asking younger women to look at their family history…if there was breast cancer in their family, to go and approach their doctors and ask them to get genetic testing done… and insist that they let them start getting mammograms."
5) Belief that BSE is conducive when trained	"Currently, we follow ACS….and then we also actually teach national guidelines so we explain you may or may not get the same answer from your provider…We actually disagree with the suggestion that BSE is actually not conducive. It is, when trained appropriately, and with the right system. At the end of the day, we teach informed decision-making."

key themes (concerns and strategies) that arose related to updating screening guidelines and de-implementing BSE. Key concerns included: 1) Perception that AA women may need screening at younger ages due to invasive cancers and strong family history; 2) Perception that if sites keep changing the program (based on changing guidelines), women in the community will stop listening to and trusting them, and will ultimately be left behind; 3) Many AA LHAs in the program found their own cancers through BSE and its importance is ingrained in them; 4) Confusion due to perceived inconsistency across guidelines and belief that BSE is conducive when trained correctly; and 5) Belief that guidelines don't reflect and weren't informed by the

Table 6. Key themes/quotes representing project director strategies for implementing new guidelines and de-implementation of outdated guidelines

Recommended strategy: reframing breast self-exam (BSE)	
1) Framing BSE as empowerment and awareness tool for AA women	"The struggle I have is it took us a long time to get women to even consider doing BSE that I think it's a shame that we're not recommending that they do it anymore…the history of African American women and treating themselves last, not taking care of the signals that their bodies are sending them… It's just gonna be a pound the pavement, one woman at a time to get people to understand, women to understand that they are valuable. That they are important. They need to listen to their bodies. If it means, touching their breast, doing a self-exam. That's gonna work for them, then that's gonna work for them."
2) Aligning BSE as breast self-awareness (vs screening) in line with funder requirements	"We do the clinical breast exam and then we do breast self-awareness, because our funders won't allow us to do breast self-exam…. We are giving the same information as the breast self-exam, except we're saying breast self-awareness. The women need to be aware of her breast and the breast changes, and that's how we have to do it with this particular grant…there's been no resistance. Our team, they just basically want to make sure that they we're giving out the right information at all times."
3) Leveraging trust in NWP as organizational resource to communicate changes in guidelines.	"We really didn't remove [BSE]. We still teach and we just make sure that they know it's an awareness tool and not a preventative/screening tool. We teach that during the training... Everybody's been really receptive about the new information and they are about to impart into their communities. We're getting good feedback from those ladies about how excited and up to date and how we are always factual and right on time with the new information. Wow, it's so exciting that we've got new information that we're gone be able to share with the community…but I'm not sure if they trust the ACS guidelines. I just know they trust the Witness Project. We have established relationships with those folks, and we're telling them that's what we're using…and rationale on why we're using them."
Recommended strategy: education	
4) Educating about how changes in guidelines impacts AA women who are diagnosed with more aggressive cancer	"We explain the guidelines…we teach people how to do BSE because you're supposed to become familiar with your breast, and you need to do an adequate self-exam to be familiar...But we do talk about the change in guidelines, the change in screening schedule, how that impacts African American women, in particular, since we are diagnosed with more aggressive cancers, and how this needs to be a conversation you have with your doctor...let people know that, a fast growing cancer, you need to be familiar with your breast, because something could happen after your mammogram. And because we are stressed, we are diagnosed with more aggressive cancers. Getting a mammogram every 2 years could be problematic for some women."
Recommended strategy: partnerships	
5) Partnerships with cancer/academic organizations to keep informed about guidelines	" We were active members in the American Cancer Society, so we went to the local American Cancer Society information meetings and networking meetings. So, we got a lot of updated information – brochure, booklets, pamphlets from ACS. I sat on the Institutional Review Board for the local regional, county hospital, so I had an opportunity to find out what was going on that way. And that was really into keeping us updated as to what was actually going on in the industry of breast cancer and breast health…and new research that was out there…and we would follow through to make sure that the information she was giving us was accurate and, especially when they were having that controversial debate over was self-breast exams relevant."

lived experiences of AA women or data that represent AA women (eg, who are diagnosed at younger ages), and that BSE is important for populations not reached by mammograms (younger, low-income, rural). Strategies used or suggested in adapting to guidelines included: 1) Framing BSE as empowerment and awareness tool (not a screening tool) for AA women to be familiar with their breasts/breast changes; 2) Aligning BSE as part of breast self-awareness (vs screening) in line with some external funder requirements; 3) Partnerships with cancer/academic organizations to keep informed about guidelines; 4) Educating about how changes in guidelines impact AA women who are diagnosed with more aggressive cancer and frame as tool for informed decision-making; and 5) Leveraging existing trust in NWP as organizational resource to communicate guideline changes.

> *Medical mistrust has critical implications for contributing to health inequities and should be accounted for within the de-implementation or adaptation process.*

DISCUSSION

The goal of this mixed-methods study was to investigate how community-based programs addressing health inequities adapt over time to changing scientific evidence, and to identify barriers and facilitators to implementing new and de-implementing outdated screening guidelines. Our findings highlight that medical mistrust should be considered a SDOH[27] in that mistrust in health care systems, providers, and/or guidelines is an important social factor that influences health-promoting behaviors (eg, mammography)[22] and has been associated with underuse of preventative screening[28] and health services more generally.[29] As such, medical mistrust has critical implications for contributing to health inequities and should be accounted for within the de-implementation or adaptation process.

Overall, we found most women support adapting the NWP program to reflect evidence-based guidelines and believe their site changes the program as needed to reflect updated screening guidelines. More than half of women reported being very aware of the new guidelines. Much of the broader research on attitudes and knowledge of new screening guidelines suggests most women are unaware of the revised guidelines.[16] Further, while we know that attitudes toward, and knowledge of, guidelines among implementers are important for both implementation and de-implementation of programs,[12,30] we are not aware of any prior studies examining these factors among LHA programs or in community settings that may experience higher levels of medical mistrust. Findings also suggest that positive attitudes and strong knowledge may not translate into adaptation if recommendations are inconsistent with values and lived experiences.

Most LHAs and PDs reported implementing guidelines informed by their local or national NWP organization, indicating strong trust in this specific organization; participants also commonly reported using guidelines from ACS, which recommend mammography screening initiation at a younger age than USPSTF. The majority of women believe mammography screening should begin at aged 40 years (or earlier) and occur annually, and many still include BSE and CBE as part of their educational programming. These findings are very consistent with prior semi-structured survey data we collected in 2017 among a sub-sample of 55 LHAs and 11 PDs from 11 sites nationally,[31] where we found 80% of women supported initiating mammograms at aged 40 years and 91% supported annual screening. We also saw lower delivery of BSE and CBE over time (86% and 70% in 2019 vs 91% and 96% in 2017), possibly due to a new NWP training curriculum disseminated in 2019. As such, it is possible that changes in practice are not fully captured yet or that PDs may have a better sense of program adaptations than LHAs at the time of data collection.

Our data suggest organizational factors are important to overcome barriers to adaptations, including funding and resources to facilitate new messaging/materials and train staff/LHAs. However, the mixed-methods data highlight additional underlying concerns that reflect issues of trust and mistrust as foundational, important concerns. This was reflected by the fact that both PDs and LHAs reported only moderate trust of medical organizational, providers and the new guidelines. Further, LHAs and PDs reported strong concerns that AA women in their community would not be supportive of the new guidelines and did not see the new guidelines as compatible with their personal beliefs/values about screening. In interviews, PDs elaborated upon specific concerns that often related to issues of mistrust, perceptions that the guidelines were not informed by data that represent the experience of or best interests of AA women (eg, who have more aggressive tumors at younger ages), and concerns related to removal of BSE from programming, especially since many in their network discovered their own breast cancer through BSE. It is also important to recognize that the development of guidelines for breast cancer screening has not typically focused on or prioritized scientific or racial equity (eg, guidelines are based on studies that disproportionately represent White women and typically do not include representative samples of AA women or conduct sub-analyses among AAs).[32-35]

Findings are consistent with barriers identified by surveys among LHAs and PDs in 2017,[31] including concerns that: 1) guidelines were based on data that did not include AA women; 2) changing age/frequency would result in delaying/stopping mammograms (eg, "excuse to delay"); 3) mistrust of providers/health systems in the AA community ("don't believe the health care system has your best interest in mind"); 4) confusion about varying ages/intervals for mammogram and concern this would cause conflict in AA community; and 5) concerns about removing BSE. Having these two time points suggests that issues of trust and mistrust are foundational and persistent concerns for this population. Further, data collected among a sample of 76 NWP LHAs eight years prior indicated that medical mistrust was moderate among this group of women.[36]

A growing literature documents medical mistrust or distrust as an important factor that shapes a range of health behaviors and outcomes.[37] Prior work has shown that race-based medical mistrust, related to lack of health care support, experiences of discrimination, and suspicion, is associated with lower screening uptake among AAs.[22,38] Historical events underlie and reinforce this distrust, including structural discrimination and mistreatment by research and medical/public health communities (eg, Tuskegee Syphillis study and Henrietta Lacks), as well as ongoing personal experiences in the health care system and broader societal experiences of discrimination and racism.[22,37,38] Research on changing screening guidelines has found some women are suspicious that guideline changes are a cost-saving measure by insurers or providers.[16,39] An additional component of mistrust that these findings highlight is distrust of data/evidence/guidelines that are not perceived as reflective of their experience (eg, as AA women with poorer cancer outcomes, more aggressive tumors, higher incidence at younger ages)[40] or that invalidate empowering or potentially life-saving experiences that AA women have had (eg, as with removing BSE for cancer survivors who found their own lumps/cancer).

PDs reported strategies they use in light of new screening guidelines. Some successful approaches related to aligning their program components/messaging directly with external funding agency requirements (eg, ACS) and forming partnerships with trusted cancer/academic organizations and funding agencies to stay updated on screening guidelines. Our prior work with NWP indicates organizational partnerships provide an important flow of resources and infrastructure to deliver the program and support adaptations to remain evidence-based.[41] Additionally, given the existing trust within the NWP organization nationally, there is great potential in having them act as a centralized resource and infrastructure for communicating changes in guidelines over time through regular webinars and trainings (as was rolled out in 2019).

One of the biggest tensions in adaptation is related to de-implementing BSE. In communities that experience medical mistrust, when there is no harm caused, and where the community has decisional authority, it may be more useful to think about reframing BSE instead of completely removing program components to reflect updated guidelines. For example, the programs that continued BSE spoke about the importance of keeping this component for many women in their community and cancer survivors, and have adapted their messaging to frame BSE as an empowerment/education/awareness tool (not a screening modality). BSE has been found to be important in the AA community to empower women to be more comfortable with their bodies and gain familiarity with breast changes, which in turn has been associated with mammography use.[42] It is important to recognize that published guidelines from a historically White medical system may carry little weight compared with the struggle against the SDOHs and lived social realities of AA women that reflect patterns of structural racism and interpersonal discrimination within the medical system and limited access to timely, quality healthcare. What may be more prominent to them is the shared body of knowledge and experiences they carry about the realities of breast cancer diagnoses among AA women. This indicates the importance of scientific communities reflecting on what counts as evidence-based, who is at the table when such decisions are made, whose opinion is heard/valued, and who is represented in the data. This includes moving beyond a focus only on considering traditional scientific evidence when decisions are made about what should be de-implemented and adapted.

Strengths and Limitations

Strengths should be recognized. NWP is an ideal program in which to investigate these issues given it has been effective nationally implemented for more than 25 years, during which guidelines have changed. This is the first study to our knowledge that has empirically examined these issues among disparity-focused LHA programs in AA communities. Further, we used mixed-method data collection among a robust national sample. One limitation is our cross-sectional sample, though findings are compared with data conducted in prior years with NWP. While this research provides insight into these understudied issues, research on trust and mistrust are in their infancy in D&I research.[12] Research should examine whether certain strategies are more appropriate and effective for addressing issues of de-implementation, particularly if removing a service may cause harm or further distrust in the healthcare system or patient/provider relationship, or when there may be other unintended negative consequences.

CONCLUSION

We assert that trust and mistrust are important but understudied determinants of equity in implementation science and should be prioritized for studying their impact on various domains along the implementation continuum (adaptation, implementation, sustainability, de-implementation). Further, this work helps contextualize why adaptations in screening guidelines may not be fully embraced in the AA community and illustrates that trust and mistrust are critical but understudied SDOHs that have foundational, multi-layered influences on health behaviors/outcomes and inequities. We also recognize that mistrust and trust are part of a larger embedded system and are themselves influenced and reinforced by historical and ongoing underlying racial and structural discrimination. Making progress toward health equity and racial justice will require recognizing the structural and institutional roles and responsibilities for SDOHs and prioritizing them for action.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Shelton, Johnson, Erwin; Acquisition of data: Shelton, Brotzman, Johnson; Data analysis and interpretation: Shelton, Brotzman, Erwin; Manuscript draft: Shelton, Brotzman; Acquisition of funding: Shelton; Administrative: Brotzman, Johnson, Erwin; Supervision: Shelton

REFERENCES

1. *Cancer Facts & Figures for African Americans 2019-2021*. Atlanta, GA: American Cancer Society; 2019.
2. *Breast Cancer Facts & Figures 2019-2021*. Atlanta, GA: American Cancer Society; 2019.
3. Fisher EB, Coufal MM, Parada H, et al. Peer support in health care and prevention: cultural, organizational, and dissemination issues. *Annu Rev Public Health*. 2014;35(1):363-383. https://doi.org/10.1146/annurev-publhealth-032013-182450 PMID:24387085
4. Earp JAL, Viadro CI, Vincus AA, et al. Lay health advisors: a strategy for getting the word out about breast cancer. *Health Educ Behav*. 1997;24(4):432-451. https://doi.org/10.1177/109019819702400404 PMID:9247823
5. Wells KJ, Luque JS, Miladinovic B, et al. Do community health worker interventions improve rates of screening mammography

in the United States? A systematic review. *Cancer Epidemiology, Biomarkers & Prevention.* 2011:20(8):1580-1598. https://doi.org/10.1158/1055-9965.EPI-11-0276

6. Ayala GX, Vaz L, Earp JA, Elder JP, Cherrington A. Outcome effectiveness of the lay health advisor model among Latinos in the United States: an examination by role. *Health Educ Res*. 2010;25(5):815-840. https://doi.org/10.1093/her/cyq035 PMID:20603384
7. Viswanathan M, Kraschnewski J, Nishikawa B, et al. *Outcomes of Community Health Worker Interventions.* Rockville, MD: Agency for Healthcare Research and Quality; 2009. Evidence Report/Technology Assessment No. 181.
8. Erwin DO, Ivory J, Stayton C, et al. Replication and dissemination of a cancer education model for African American women. *Cancer Control.* 2003;10(5 Suppl):13-21. https://doi.org/10.1177/107327480301005s03
9. Erwin DO, Spatz TS, Stotts RC, Hollenberg JA, Deloney LA. Increasing mammography and breast self-examination in African American women using the Witness Project model. *J Cancer Educ*. 1996;11(4):210-215. PMID:8989634
10. Brownson R, Colditz G, Proctor E. *Dissemination and Implementation Research in Health: Translating Science to Practice*. 2nd ed. New York, NY: Oxford University Press; 2018.
11. Powell BJ, Waltz TJ, Chinman MJ, et al. A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. *Implement Sci*. 2015;10(1):21. https://doi.org/10.1186/s13012-015-0209-1 PMID:25889199
12. Norton WE, Chambers DA. Unpacking the complexities of de-implementing inappropriate health interventions. *Implement Sci*. 2020;15(1):2. https://doi.org/10.1186/s13012-019-0960-9 PMID:31915032
13. Niven DJ, Mrklas KJ, Holodinsky JK, et al. Towards understanding the de-adoption of low-value clinical practices: a scoping review. *BMC Med*. 2015;13(1):255-255. https://doi.org/10.1186/s12916-015-0488-z PMID:26444862
14. Chambers DA, Glasgow RE, Stange KC. The dynamic sustainability framework: addressing the paradox of sustainment amid ongoing change. *Implement Sci*. 2013;8(1):117-117. https://doi.org/10.1186/1748-5908-8-117 PMID:24088228
15. Shelton RC, Chambers DA, Glasgow RE. An Eextension of RE-AIM to enhance sustainability: addressing dynamic context and promoting health equity over time. *Front Public Health*. 2020;8:134. https://doi.org/10.3389/fpubh.2020.00134 PMID:32478025
16. Allen JD, Bluethmann SM, Sheets M, et al. Women's responses to changes in U.S. Preventive Task Force's mammography screening guidelines: results of focus groups with ethnically diverse women. *BMC Public Health*. 2013;13(1):1169. https://doi.org/10.1186/1471-2458-13-1169 PMID:24330527
17. Corbelli J, Borrero S, Bonnema R, et al. Physician adherence to U.S. Preventive Services Task Force mammography guidelines. *Womens Health Issues*. 2014;24(3):e313-e319. https://doi.org/10.1016/j.whi.2014.03.003 PMID:24794545
18. Nagler RH, Fowler EF, Marino NM, Mentzer KM, Gollust SE. The evolution of mammography controversy in the news media: A content analysis of four publicized screening recommendations, 2009 to 2016. *Womens Health Issues*. 2019;29(1):87-95. https://doi.org/10.1016/j.whi.2018.09.005 PMID:30409689
19. US Preventive Services Task Force. *Breast Cancer: Screening*. Last accessed November 30, 2020 from https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/breast-cancer-screening.
20. Meneses K. When should I have a mammogram? Recent changes in ACS mammography guidelines: implications for practice. *J Adv Pract Oncol*. 2016;7(5):567-570. PMID:29282432
21. Shelton RC, Goldman RE, Emmons KM, Sorensen G, Allen JD. An investigation into the social context of low-income, urban Black and Latina women: implications for adherence to recommended health behaviors. *Health Educ Behav*. 2011;38(5):471-481. https://doi.org/10.1177/1090198110382502 PMID:21856885
22. Thompson HS, Valdimarsdottir HB, Winkel G, Jandorf L, Redd W. The Group-Based Medical Mistrust Scale: psychometric properties and association with breast cancer screening. *Prev Med*. 2004;38(2):209-218. https://doi.org/10.1016/j.ypmed.2003.09.041 PMID:14715214
23. Palinkas LA, Aarons GA, Horwitz S, Chamberlain P, Hurlburt M, Landsverk J. Mixed method designs in implementation research. *Adm Policy Ment Health*. 2011;38(1):44-53. https://doi.org/10.1007/s10488-010-0314-z PMID:20967495
24. Massatti RR, Sweeney HA, Panzano PC, Roth D. The de-adoption of innovative mental health practices (IMHP): why organizations choose not to sustain an IMHP. *Adm Policy Ment Health*. 2008;35(1-2):50-65. https://doi.org/10.1007/s10488-007-0141-z PMID:17968652
25. Luke DA, Calhoun A, Robichaux CB, Elliott MB, Moreland-Russell S. The Program Sustainability Assessment Tool: a new instrument for public health programs. *Prev Chronic Dis*. 2014;11:130184. https://doi.org/10.5888/pcd11.130184 PMID:24456645
26. Crabtree BF, Miller WL, eds. *Doing Qualitative Research.* Thousand Oaks, CA: Sage Publishing; 1999.
27. Mohottige D, Boulware LE. Trust in American medicine: A call to action for health care professionals. *Hastings Cent Rep*. 2020;50(1):27-29. https://doi.org/10.1002/hast.1081 PMID:32068276
28. Hammond WP, Matthews D, Mohottige D, Agyemang A, Corbie-Smith G. Masculinity, medical mistrust, and preventive health services delays among community-dwelling African-American men. *J Gen Intern Med*. 2010;25(12):1300-1308. https://doi.org/10.1007/s11606-010-1481-z PMID:20714819
29. LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. *Health Serv Res*. 2009;44(6):2093-2105. https://doi.org/10.1111/j.1475-6773.2009.01017.x PMID:19732170
30. Aarons GA. Measuring provider attitudes toward evidence-based practice: consideration of organizational context and individual differences. *Child Adolesc Psychiatr Clin N Am*. 2005;14(2):255-271, viii. https://doi.org/10.1016/j.chc.2004.04.008 PMID:15694785
31. Shelton RC, Brotzman LE, Johnson D, Erwin D. Perception of new cancer screening guidelines among African American women: Implications for implementation and de-implementation of cancer screening in community settings. Presented at the 40th Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine; 2019; Washington, DC.
32. Haddad DN, Sweeting RS. Black women should NOT change breast cancer screening behaviors based on new guidelines. *Prev Med*. 2017;105(105):95-96. https://doi.org/10.1016/j.ypmed.2017.07.031 PMID:28827073
33. Stapleton SM, Oseni TO, Bababekov YJ, Hung Y-C, Chang DC. Race/ethnicity and age distribution of breast cancer diagnosis in the United States. *JAMA Surg*. 2018;153(6):594-595. https://doi.org/10.1001/jamasurg.2018.0035 PMID:29516087
34. Nelson HD, Cantor A, Humphrey L, et al. Screening for breast cancer: a systematic review to update the 2009 US Preventive Services Task Force Recommendation. Rockville, MD: Agency for Healthcare Research and Quality; 2016 Jan. Report No.: 14-05201-EF-1. PMID: 26889531. Last accessed November 30, 2020 from https://pubmed.ncbi.nlm.nih.gov/26889531/
35. Oeffinger KC, Fontham ET, Etzioni R, et al; American Cancer Society. Breast cancer

screening for women at average risk: 2015 guideline update from the American Cancer Society. *JAMA*. 2015;314(15):1599-1614. https://doi.org/10.1001/jama.2015.12783 PMID:26501536

36. Shelton RC, Dunston SK, Leoce N, Jandorf L, Thompson HS, Erwin DO. Advancing Understanding of the characteristics and capacity of african american women who serve as lay health advisors in community-based settings. *Health Educ Behav*. 2017;44(1):153-164. https://doi.org/10.1177/1090198116646365 PMID:27206465
37. Jaiswal J, Halkitis PN. Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behav Med*. 2019;45(2):79-85. https://doi.org/10.1080/08964289.2019.1619511 PMID:31343962
38. Shelton RC, Winkel G, Davis SN, et al. Validation of the group-based medical mistrust scale among urban black men. *J Gen Intern Med*. 2010;25(6):549-555. https://doi.org/10.1007/s11606-010-1288-y PMID:20195782
39. Coronado GD, Gutierrez JM, Jhingan E, Angulo A, Jimenez R. Patient and clinical perspectives on changes to mammography screening guidelines. *Breast J*. 2014;20(1):105-106. https://doi.org/10.1111/tbj.12219 PMID:24261968
40. Hackshaw AK, Paul EA. Breast self-examination and death from breast cancer: a meta-analysis. *Br J Cancer*. 2003;88(7):1047-1053. https://doi.org/10.1038/sj.bjc.6600847 PMID:12671703
41. Shelton RC, Charles T-A, Dunston SK, Jandorf L, Erwin DO. Advancing understanding of the sustainability of lay health advisor (LHA) programs for African-American women in community settings. *Transl Behav Med*. 2017;7(3):415-426. https://doi.org/10.1007/s13142-017-0491-3 PMID:28337722
42. Bloom JR, Grazier K, Hodge F, Hayes WA. Factors affecting the use of screening mammography among African American women. *Cancer Epidemiol Biomarkers Prev*. 1991;1(1):75-82. PMID:1845174