# Awareness of and reactions to mammography controversy among immigrant women 

Rebekah H. Nagler PhD ${ }^{1,2} \mid$ Jennifer A. Lueck PhD ${ }^{3}$ | Lauren S. Gray MA ${ }^{1}$

${ }^{1}$ School of Journalism and Mass Communication, University of Minnesota, Minneapolis, MN, USA
${ }^{2}$ School of Public Health, University of Minnesota, Minneapolis, MN, USA
${ }^{3}$ Department of Communication, Texas A\&M University, College Station, TX, USA

## Correspondence

Rebekah H. Nagler, PhD, School of Journalism and Mass Communication, University of Minnesota, Minneapolis, MN, USA.
Email: nagle026@umn.edu


#### Abstract

Background: There is substantial expert disagreement about the use of mammography to screen for breast cancer, and this disagreement routinely plays out in the media. Evidence suggests that some women are aware of the controversy over mammography, but less is known about whether immigrant and other underserved women have heard about it and, if so, how they react to it. Objective: To explore immigrant women's awareness of and reactions to mammography controversy. Design: Community-engaged qualitative study: we conducted six focus groups with 53 women aged 35-55 from three immigrant communities (Somali, Latina and Hmong) in a major US metropolitan area. A grounded theory approach was used to identify themes; NVivo 10 was used to enhance analyses.

Results: Several themes emerged: (i) low awareness of mammography controversy across groups, despite self-reported attention to health information; (ii) high intentions to be screened, even after being told about the controversy; (iii) few reported discussions of mammography's risks and benefits with clinicians; (iv) substantial interest in learning more about mammography and breast cancer, but some low selfefficacy to obtain such information; and (v) questions about whether health recommendations matter and what qualifies as evidence. Conclusion: Given on-going expert disagreement about mammography screening, it is important for clinicians to help women understand mammography's risks and benefits so they can make an informed choice. This is particularly critical for immigrant and other underserved women, who may be less able to access, attend to, process, retain and act on health information (a phenomenon known as communication inequality).


## KEYWORDS

awareness, community-engaged research, controversy, immigrant women, mammography

## 1 | INTRODUCTION

For more than two decades, there has been substantial expert disagreement about the use of mammography to screen for breast cancer. In 1993 and 1997, experts debated the age at and frequency with which screening should occur, ${ }^{1,2}$ and in 2001, a Cochrane meta-analysis questioned whether women should be screened at all. ${ }^{3}$ Controversy
erupted again in November 2009, when the US Preventive Services Task Force (USPSTF) downgraded mammography screening for women aged 40-49 to a C rating (recommendation against routine screening). ${ }^{4}$ This move not only conflicted with prior USPSTF recommendations but also encountered resistance from the American Cancer Society (ACS) and American College of Radiology (ACR), who stipulated that screening should begin at age $40 .{ }^{5,6}$ Most recently, debate resumed in

[^0]

FIGURE 1 Conceptual model: effects of media exposure to mammography controversy ${ }^{14}$

Potential for communication inequalities: Negative effects of mammography controversy could be more pronounced among immigrant and other underserved women

October 2015, when ACS changed its long-standing recommendation that average-risk women begin screening at age $40 .{ }^{7}$ The organization now recommends annual screening beginning at age 45 and biennial screening once a woman turns 55. The new ACS guidelines still conflict with those of the USPSTF, which continues to recommend routine biennial screening starting at age $50 .{ }^{8}$

Importantly, such scientific debate routinely plays out in the media. Following the 2001 Cochrane review, news coverage by high-profile outlets such as the New York Times prompted widespread attention, placing mammography controversy on the public agenda. ${ }^{9}$ Additionally, content analyses of the 2009 USPSTF announcement showed that coverage can be dramatic and sometimes misleading. One study found that $33 \%$ of news stories were politicized and controversial in tone, ${ }^{10}$ and another found that coverage was unbalanced, with the majority of news stories and social media posts unsupportive of the recommendations. ${ }^{11}$ Parties who were highly motivated to respond-professional organizations as well as breast cancer survivors and advocates-issued statements and rebuttals, which also received coverage. ${ }^{12,13}$ Ultimately, with each new set of recommendations, and each new study on breast cancer screening and mortality, journalists often invoke a controversy frame. ${ }^{14}$ News stories will remind readers about the disagreement among experts, or refer to prior research that conflicts with the latest study. In so doing, they underscore the on-going debate for the public. For example, in 2014, several studies were published that questioned the value of screening. ${ }^{15,16}$ Not only did these studies receive substantial coverage, but journalists frequently contextualized research findings by referencing prior expert disagreement (e.g. "Doctors have debated the value of mammograms for years"). ${ }^{17}$

Given the breadth and intensity of media coverage, a central question is whether the public is aware of the controversy over mammography and, if so, how it reacts to it. Overall, there is evidence that some women do perceive such conflict and controversy, with estimates ranging from approximately one-third to one-half of general population women. ${ }^{11,18-20}$ Nearly one-third have reported being confused about screening recommendations, ${ }^{11}$ and one study on mammography utilization rates post-2009 found a pattern consistent with such confusion (i.e. initial drop in screening followed by an upswing). ${ }^{21}$ There is also some evidence of backlash, with women reporting negative attitudes toward screening recommendations. ${ }^{20,22}$

Less is known, however, about whether women from underserved populations are exposed to mammography controversy. ${ }^{23}$ This is a
pressing concern, because vulnerable populations may be particularly unable to reconcile conflicting and controversial health messages in the media. ${ }^{14}$ Research on communication inequalities ${ }^{24}$-defined as differences in social groups' ability to access, attend to, process, retain and act on information-suggests not only that lower levels of health literacy could influence processing of conflicting screening messages, but that underserved women may have fewer opportunities and/or feel less able to discuss confusion with clinicians. Additionally, cultural beliefs about the nature and value of science could vary across population subgroups, and thus may influence how some women interpret and understand screening messages. Ultimately, greater confusion about screening recommendations and less trust in guidelines could influence women's intentions to schedule or keep a screening appointment. Figure 1 depicts the possible cognitive and behavioural effects of media exposure to mammography controversy, which could be exacerbated by communication inequalities.

The potential for such differential message effects among underserved women is worrisome, given persistent cancer disparities, particularly among immigrant women. ${ }^{25}$ Later stage at diagnosis, due in part to lack of screening, is one factor contributing to higher mortality rates in immigrant communities. ${ }^{25}$ Indeed, data show that women who are recent immigrants have some of the lowest rates of mammography screening, and this is true for women aged 40-49 and $50-74 .^{26,27}$ These patterns have prompted increased efforts to promote breast cancer prevention and screening among immigrant women, ${ }^{28-33}$ yet media exposure to mammography controversy could undermine these efforts-particularly absent informed decision-making conversations with clinicians.

Given cancer disparities among immigrant women, coupled with the potential for communication inequalities, the current study asks two questions: (i) To what extent are immigrant women aware of controversy about mammography and (ii) how do they react to this controversy? Potential reactions include cognitive (controversy perceptions), behavioural intentional (screening intentions) and communication (screening discussions, information seeking) outcomes. To our knowledge, only one study has examined these questions with women from diverse backgrounds, using a sample that consisted predominantly of English-speaking Caucasian and African-American women. ${ }^{23}$ To address our research questions focusing on immigrant women, we conducted a community-engaged qualitative study with women from three immigrant communities (Somali, Latina and Hmong) in the Minneapolis-St. Paul, Minnesota (Twin Cities) metropolitan area.

## 2 | METHODS

## 2.1 | Participants

The Twin Cities metro has the largest Hmong and Somali populations of any US metro, ${ }^{34,35}$ as well as a growing Latino population from countries including Mexico, El Salvador and Guatemala. ${ }^{36} \mathrm{We}$ therefore chose to sample women from these three prominent immigrant communities, which are sufficiently diverse to allow us to explore perceptions of mammography controversy across communities. Because the goal of this research was to explore immigrant women's awareness of and reactions to controversy-rather than to compare and contrast the perceptions of women from different immigrant communities-our analysis focused on identifying themes that emerged across all three communities. This qualitative study used focus groups, a valuable methodology for exploring people's perceptions, experiences and reactions. ${ }^{37}$ Krueger and Casey ${ }^{38}$ suggest that we would have needed to conduct at least three to four groups per community if our goal had been to make such comparisons; that said, it is worth noting that, across groups and communities, women were remarkably consistent in their awareness of and reactions to controversy.

Participants were recruited in collaboration with the Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo), a community-driven research arm of St. Paul, Minnesota-based West Side Community Health Services, Inc. The SoLaHmo partnershipcomprising Somali, Latino and Hmong community members and health professionals-works with academic researchers to conduct community-engaged research, ${ }^{39}$ with the goal of improving community health by building upon the unique cultural strengths of these communities. For this project, SoLaHmo researchers recruited participants from their respective communities. To be eligible, participants had to self-identify as Somali, Latina or Hmong; be female; and be between ages 35 and 55 to maximize relevance of the mammography controversy, as a key debate is whether women should begin screening in their 40 s or 50 s . Six focus groups were held in the Twin Cities metro between September and November 2014 ( $N=53$; group range=6-12). Two groups were held per community: $34.0 \%$ ( $n=18$ ) of participants were Somali, $41.5 \% ~(~ n=22)$ were Latina and $24.5 \% ~(n=13)$ were Hmong. This within-group homogeneity enabled groups to be held in women's native language, as noted below, and encouraged sharing and open discussion among participants. ${ }^{38}$ Sociodemographic and health history characteristics of participants are provided in Table 1.

## 2.2 | Procedure

All groups were held in community settings and facilitated in Somali, Spanish or Hmong by trained SoLaHmo researchers using a semistructured question guide. The academic-community research team developed this guide during Summer 2014 using an iterative process. During weekly team meetings, SoLaHmo researchers (at least two per community) would weigh in on question scripting and flow, revising language to maximize the likelihood of understandability. The guide's five key domains and sample questions are listed in Table 2. There
were two community researchers at each group, with one serving as facilitator and the other as note taker; academic researchers provided administrative support. Before the start of each group, participants provided informed consent and completed a translated intake survey that included sociodemographic and health history questions. Group discussions lasted approximately 90 min ; sessions were recorded and professionally translated and transcribed by SoLaHmo researchers. After the group discussion, participants received a $\$ 40$ gift card for their time. The study protocol was approved by the University of Minnesota Institutional Review Board and the Masonic Cancer Center Cancer Protocol Review Committee.

## 2.3 | Analysis

Grounded theory principles guided data analysis and interpretation. ${ }^{40}$ This inductive approach allows themes and concepts to emerge from the data. Academic team members (RHN, JAL, and LSG) read the focus group transcripts, analysed and coded data using the constant comparative method. ${ }^{41}$ This technique requires researchers to be "constantly alert to the similarities and differences which exist between instances, cases and concepts, and to ensure that the full diversity and complexity of the data is explored." ${ }^{42}$ (pp. 261-262) As themes emerged, coders reread and recoded transcripts, ensuring that themes were grounded in data, and resolved any disagreement through discussion. This iterative process continued until no new information emerged. ${ }^{41}$ One team member (LSG) used NVivo 10, the computer-assisted qualitative data analysis system from QSR International, to enhance these analyses by extracting and organizing themes and example quotes, which corresponded to those identified through hand coding. All themes and illustrative quotes were member checked with a SoLaHmo partner (SP).

## 3 | RESULTS

Given the current study's research questions, our analysis focused on domains 3-5 of the question guide (Table 2). Within each domain, several dominant themes emerged.

## 3.1 | Awareness of and reactions to mammography controversy

### 3.1.1 | Low awareness of mammography controversy across groups, despite self-reported attention to health information

Awareness of mammography controversy was virtually non-existent; across groups, only one woman had heard about such controversy, and only after the facilitator's prompting (see Table 2, Domain 3 for a sample question prompt). Importantly, this lack of awareness cannot be entirely explained by insufficient opportunities for exposure: the 2014 mammography studies that garnered national attention were widely covered by local media, ${ }^{43,44}$ and, across groups, women reported engaging with health information. Frequently used sources included

TABLE 1 Focus group sociodemographic and health history characteristics $(N=53)^{a}$

| Characteristic | $n^{\text {b }}$ | $\%^{\text {b }}$ |
| :---: | :---: | :---: |
| Ethnicity |  |  |
| Somali | 18 | 34.0 |
| Latina | 22 | 41.5 |
| Hmong | 13 | 24.5 |
| Religion |  |  |
| Christianity | 20 | 42.6 |
| Hmong Animism/Shamanism | 6 | 12.8 |
| Islam | 18 | 38.3 |
| Other | 3 | 6.4 |
| Nativity (country of birth) |  |  |
| Somalia | 17 | 33.3 |
| Mexico | 17 | 33.3 |
| Ecuador | 4 | 7.8 |
| Laos | 10 | 19.6 |
| Thailand | 2 | 3.9 |
| Years in United States |  |  |
| <10 | 10 | 19.6 |
| 10-14 | 13 | 25.5 |
| 15-19 | 15 | 29.4 |
| 20-25 | 6 | 11.8 |
| >25 | 7 | 13.7 |
| Age (years) |  |  |
| <40 | 19 | 43.2 |
| 40-49 | 20 | 45.5 |
| >49 | 5 | 11.4 |
| Education |  |  |
| No formal schooling | 7 | 14.0 |
| English as second language (ESL) | 2 | 4.0 |
| Elementary/middle school (grades 1-8) | 14 | 28.0 |
| Some high school (grades 9-12) | 8 | 16.0 |
| High school graduate or GED | 3 | 6.0 |
| Some college | 11 | 22.0 |
| College graduate or more | 5 | 10.0 |
| Health insurance coverage |  |  |
| Yes | 37 | 75.5 |
| No | 10 | 20.4 |
| Don't know | 2 | 4.1 |
| Regular health-care provider |  |  |
| Yes | 37 | 75.5 |
| No | 12 | 24.5 |
| Don't know | 0 | 0.0 |
| Health-care provider visits in past year |  |  |
| 0 | 9 | 18.0 |
| 1 | 9 | 18.0 |

Table 1 (Continues)

| Characteristic | $\mathbf{n}^{\mathbf{b}}$ | $\%^{\mathbf{b}}$ |
| :---: | ---: | :---: |
| 2 | 10 | 20.0 |
| $3-4$ | 9 | 18.0 |
| $>5$ | 12 | 24.0 |
| Don't know | 1 | 2.0 |

Ever had mammogram (among n=25 who are age 40+)

| Yes | 14 | 58.3 |
| :--- | ---: | ---: |
| No | 9 | 37.5 |
| Don't know | 1 | 4.2 |


| Most recent mammogram (among n=14 who ever had) |  |  |
| :--- | :---: | :---: |
| <1 year ago | 5 | 35.7 |
| More than 1 but not more than 2 years ago | 5 | 35.7 |
| More than 2 but not more than 5 years ago | 2 | 14.3 |
| >5 years ago | 2 | 14.3 |
| Don't know | 0 | 0.0 |


| Ever had breast cancer |  |  |
| :--- | ---: | ---: |
| Yes | 0 | 0.0 |
| No | 48 | 94.1 |
| Don't know | 3 | 5.9 |


| Family/close friend ever had breast cancer |  |  |
| :--- | ---: | ---: |
| Yes | 6 | 12.0 |
| No | 42 | 84.0 |
| Don't know | 2 | 4.0 |

${ }^{\text {a }}$ Total of six groups conducted (group range=6-12).
${ }^{\mathrm{b}}$ Ns vary across items due to missing or refusals. Percentages may not sum to 100 due to rounding.
medical (e.g. physicians, other providers), mainstream traditional and digital media (e.g. broadcast news, Internet, social media), ethnic media (e.g. Hmong Radio) and interpersonal sources (e.g. friends, family).

After being told that experts disagree on the age of screening onset, many women still found the message that mammograms begin at age 40 to be highly salient. One woman noted, "Because I'm almost 40, it's time to get checked" [L1; In the focus group identifier, the letter refers to the immigrant community (Somali, Latina or Hmong) and the number refers to the group (first or second) held in that community. For example, "L1" refers to the first Latina group.]. Others felt that 50 was too late, a concern that often appeared in media coverage following the 2009 USPSTF announcement:

Facilitator: So you said that you have never heard of this disagreement before...what do you think of doctors and experts not agreeing on the age?

P7: I think-I think I'll agree more with the 40.

Facilitator: With the 40?

P7: Starting at 40. Because it seems like-for myself as
how I see it-that the women, when they have breast cancer, most when they are 40...so I think I agree with the 40 rather than waiting for the 50. (H1)

The precise source(s) of the mammograms-begin-at-age-40 message was not clear. Some women did refer to the "pinking" of society, pointing to the breast cancer lay community's (and corporate sponsors') aggressive promotion of prevention and, more specifically, screening beginning at age $40 .{ }^{45}$

### 3.1.2 | High intentions to be screened in the future, even after being told about the controversy

Given the salience of the age 40 message, perhaps it is not surprising that women were undeterred after learning about the controversy: most reported intending to begin or continue screening in the future. This finding was consistent across groups-for example, "I'm going to be turning 40 soon...so l'll start getting checked" (L1); "In a few months I will be going [to get a mammogram]" (H1); and "Yes, [I will go get a mammogram], Insha'Allah, if I reach next year!" (S2).

Interestingly, these high intentions contrasted with comments from some women, who seemed to question the value of prevention and screening. For example, one woman suggested that mammography was only important if someone was experiencing pain: when asked whether women in the Somali community are getting checked for breast cancer, she said, "No, only if the individual is experiencing pain. That's the only time when we seek doctors. Most of the time we don't expect to get breast cancer" (S1). In addition, a Hmong participant felt that screening is only necessary if one has a family history:

> Sometimes, you know, because I'm going out a lot with my husband with those older women, you know? I heard [them] talking about, "okay, you know, I don't have a history of that, it will not come to me. I don't think I need to pay attention." I hear that most of the time. (H2)

Another woman suggested that a single mammogram might be sufficient: "Go once and if there [is] nothing, then you shouldn't go again" (H2). These comments might reflect some women's ambivalence about screening. Alternatively, it is possible that some women provided socially desirable responses to questions about screening intentions; this possibility is consistent with previous research, which has found that women from vulnerable communities overreport mammography use. ${ }^{46}$

## 3.2 | Mammography information acquisition

### 3.2.1 | Few reported discussions of mammography's risks and benefits with clinicians

Across groups, few women reported that their clinicians described the risks and benefits of screening during well-woman visits-discussions that are recommended by the ACS, USPSTF and other organizations to promote informed decision making. As one woman explained:

P1: They will just ask, "we are going to check your breast for breast cancer." And then they exam[ine] to see if there is a tumor and you allow them to; after they are done and there is nothing, they say there is no tumor.

Facilitator: Well, do they talk about the benefits from the mammogram or the risks?

P1: That, they have not talked [to] me about it before, so I don't know. (H1)

Several women suggested that being taught to trust one's clinician could in fact deter one from questioning his/her recommendations:

P10: No, I've never talked to [the] doctor about if there's a risk or not. They just say...l accept everything...

Facilitator: So you just go, you get your exam done...you don't ask questions, you don't talk about the risks?

P10: No, exactly, I don't ask questions. I should though, right? I should ask what the risks are if I do something. With the trust that's there...

Facilitator: Is this question weird for you to ask them?

P2: I don't think we've been taught to confide in our doctors...whatever the doctor says, that's what we should do. We don't ask why or if there's another way to do it... we've been taught to trust doctors...that what they say is right. (L1)

Despite this and other potential barriers (e.g. language challenges), several women recognized that they would likely need to be the ones to initiate the risks/benefits conversation. One woman said, "Me? I will ask. Ask questions and get more information. If there really is a risk that's very constant or something with my mammogram, I will ask" (L1). Another woman indicated that, in the past, her clinician never discussed the risks/ benefits of screening, but "now I will get checked up and consult with my doctor" (S1).

### 3.2.2 | Substantial interest in learning more about mammography and breast cancer, but some evidence of low self-efficacy to obtain such information

Several women expressed interest in learning more about mammography controversy. The one woman who indicated she had heard about the controversy said that, as she approaches age 40 , she will seek information from multiple sources, including her clinician:

Um...I guess I would probably access the different sources
out there and see why one feels it's 40 and why one would

TABLE 2 Focus group semi-structured question guide: key domains and sample questions

| Key topical domain | Sample question |
| :--- | :--- |
| 1. Sources of health information | Think about the last time you learned something about health. Where <br> did you get this information? What was the topic you learned about? <br> You've just identified a source that you used recently. What are some <br> other sources that you have used to get information about health? <br> (Probe for media, interpersonal and medical sources) |
| 2. Information about and perceptions of breast cancer prevention and | Of the sources you mentioned, which is the most important source of <br> health information for you? In other words, what source do you trust <br> the most and why? | | Now we'd like to talk about information about a specific health topic: |
| :--- |
| breast cancer. What have you heard about breast cancer? From what |
| sources have you heard or received this information (e.g. radio, family |
| member and doctor)? |

${ }^{\text {a }}$ Under Domain 2, if participants did not mention the mammography controversy unprompted, then under Domain 3 the facilitator would describe the controversy and ask whether participants had heard about it and, if so, from what sources. The facilitator would describe the controversy in several ways to maximize the likelihood of understanding (e.g. "disagreement," "debate" or "differences" between doctors or experts about the age and frequency with which women should get mammograms).
${ }^{\text {b }}$ As of October 2015, ACS recommends that average-risk women begin annual mammography screening at age 45 . At the time of focus group data collection, however, the disagreement among major US professional organizations was whether women should begin screening at age 40 or 50 .
feel 50 is better. And then just weigh it out that way...and I guess I would have to talk to my doctor, too, to [assess] their professional opinion on it.... (H2)

Others were interested in learning more about breast cancer more generally. When asked what information she might seek, one woman said, "What age you should check for breast cancer? How you should go
about making [an] appointment? What are the risk factors? Treatments and so on" (S2). Another woman was similarly interested in such information, having recognized a knowledge deficit:

With this conversation that we've had, I don't think I'm very informed, but at least I know about the agreements and disagreements and what...calls my attention to start to get a checkup and learn a little more about this...about cancer. What are the symptoms? I'm interested to find out. It awoke my curiosity. (L1)

While some felt well equipped to seek more information-whether from clinicians, the Internet or other sources-others felt lower self-efficacy to acquire information (a phenomenon that has been described as information efficacy). ${ }^{47}$ For instance, some looked to the facilitator for guidance:

Facilitator: Does hearing about this disagreement [make] you want to look for more information?

P6: Yes.

Facilitator: Yea? So if you want to find more information on this, where would you look?

## P6: I don't know-

P5: I don't know-do they have a place? You're the one who tells [us]? (H1)

Others called for greater health communication efforts in community settings:
"[You need to] promote more information, in health centers, send flyers ... because a lot of us don't know ... we don't inform ourselves ... the information-where it is, when, at what time..." (L2).

## 3.3 | Perceptions of health recommendations and research

### 3.3.1 | Questioning whether population-based recommendations matter

In discussing mammography controversy, some women questioned the value of guidelines like the ACS or USPSTF recommendations. Rather than relying on population-based recommendations and the professional organizations that issue them, several women felt decisions should be made on an individual basis: "I think they [clinicians and experts] should treat people as individuals. Like saying...it could be a familial thing, it could be a dietary aspect or maybe due to being overweight" (L2). One woman also emphasized the role of autonomy in screening decisions and added that one's personal clinician (rather than an impersonal organization or task force) should make
recommendations: "I think it's a personal choice and also-I honestly think it should be your own personal doctor and it's going to depend on your relationship with your doctor" (H2). To this end, one woman suggested, "Maybe there shouldn't be any [recommendations]" (H2).

### 3.3.2 | Questioning what qualifies as evidence and who should determine what is right in cases of expert disagreement

Discussions of recommendations also raised questions about what constitutes valid data or evidence. Anecdotal accounts-for example, a woman's experience with breast cancer before 50-resonated with some women. Referencing the controversy, one Hmong participant felt that women (i.e. laypersons), rather than experts, should determine what is best in cases of disagreement:


#### Abstract

I just feel um...like if [experts] don't agree, then why don't [they] do an open discussion to invite a group of womenlike this-to ask the women their opinion about the current issue, what age do they see is the one that mob [get sick/ breast cancer] the most. (H1)


## 4 | DISCUSSION

To date, most research on women's awareness of and reactions to mammography controversy has focused on the general population. These studies have found that some women perceive conflict and controversy about mammography, and some report adverse reactions including confusion about screening recommendations. ${ }^{11,18-20}$ Yet it is equally if not more important to assess perceptions of controversy among underserved women-who, facing communication inequalities, might be particularly unable to reconcile conflicting and controversial screening messages, experience even greater confusion and possess fewer opportunities to discuss such confusion (and, more broadly, the risks/benefits of screening) with clinicians (see Fig. 1). We are aware of only one study (by Allen and colleagues) that has explored this issue among diverse women. ${ }^{23}$

The current study focused on immigrant women in particular, and in our Somali, Latina and Hmong sample, we found that women were largely unaware of expert disagreement about mammography. This finding was consistent with Allen et al.'s results, and awareness was lower than in general population studies. ${ }^{11,20}$ This low exposure cannot be entirely explained by a lack of opportunity: there was coverage of the mammography controversy in local media, and women reported paying attention to health information in media and other sources. That said, low awareness could be explained, at least in part, by differences in how immigrant women in our sample understood or interpreted mammography controversy. Although this concern is somewhat mitigated by responses that reflect shared understanding [e.g. "No (I haven't heard about the disagreement), but in the past I heard women should get checked every year" (S2)], further research is needed to explore how immigrant and other underserved women interpret controversy.

When women were made aware of the controversy, there was little evidence of confusion and negative attitudes were rare. These findings contrasted with the Allen et al. study, which found that women were both confused about mammography recommendations and suspicious of changes, questioning whether insurers and providers were trying to reduce health-care costs. ${ }^{23}$ In our study, participants reported that screening at age 40 made sense to them-often noting that age 50 seemed too late-and many reported intentions to screen in the future.

The fact that most women in our sample remained committed to screening after learning of the mammography controversy is consistent with recent studies on overscreening and overdiagnosis. US society has long been enthusiastic about cancer screening, ${ }^{48}$ and recent recommendations-which brought the risks of overdiagnosis to the fore-do not appear to be shaking women's confidence in screening. ${ }^{22}$ Similar enthusiasm has been seen in the United Kingdom ${ }^{49,50}$ and Australia. ${ }^{51}$ In addition, while evidence suggests that overuse of care may be more common among whites, ${ }^{52}$ for historically underserved women, relinquishing screening might be seen as losing hard-fought access to preventive care. ${ }^{23}$ That said, some immigrant women did seem to question the value of screening. It is not known whether their comments reflect ambivalence toward screening or overreporting of screening intentions, ${ }^{46}$ but it suggests that clinicians and public health practitioners must proceed with caution-encouraging prevention and screening to reduce inequalities, while also promoting informed decision making and understanding of screening's risks and benefits.

The question of informed decision making is at the heart of the mammography controversy. For example, when in 2009 the USPSTF recommended against routine screening for women aged 40-49, "routine" was often overlooked by the media, survivors, advocates and clinicians. The task force amended its recommendations to clarify this point, stating that the decision to screen before age 50 "should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms." ${ }^{n 4}$ (p. 716) Unfortunately, our results suggest that, at least for some immigrant women, patient-clinician discussions of mammography's risks and benefits remain infrequent. There could be any number of potential reasons for this-including clinicians' commitment to screening ${ }^{53}$ and lack of awareness of new recommendations ${ }^{54}$-but it is important to encourage informed decision making around screening. This is particularly critical for immigrant and other underserved women, who may be less able to access, attend to, process, retain and act on health information. ${ }^{24}$ The current study found some evidence of these communication inequalities: although immigrant women in our sample were engaged with and interested in learning more about mammography and breast cancer, many felt unsure about where and how to seek such information. Some women also questioned the value of evidencebased recommendations and what qualifies as evidence-patterns that have been observed in the general population as well. ${ }^{55}$ Clinicians are well advised not only to discuss the risks/benefits of screening with immigrant women, but to point women towards reliable and accessible information sources. Health information is not often tailored and/or targeted for immigrant communities, so identifying appropriate information sources is essential.

Results must be interpreted in the light of several limitations. First, as previously noted, our goal was to explore immigrant women's awareness of and reactions to mammography controversy, rather than to compare and contrast the perceptions of women from different immigrant communities. We therefore report themes that emerged across all three communities, and we cannot generalize about each community based on these data. Larger studies with Somali, Latina and Hmong women are necessary to identify community-specific patterns and examine potential subgroup differences (e.g. educational differences in reactions to controversy within communities). Second, a majority of the sample was insured and saw a health provider within the last year; findings might differ among immigrant women with less healthcare access. However, given women's frequency of medical interaction, it is particularly noteworthy that risks/benefits discussion with clinicians was so infrequent. Third, a majority (80.4\%) of participants have lived in the United States for more than 10 years; results might differ among women who have recently immigrated and are likely less acculturated. Fourth, although one community partner did member check themes and illustrative quotes, budget constraints prevented additional community researchers from participating in data analysis. These constraints also precluded formative research (e.g. cognitive interviews) to ensure that participants understood the interview guide, including what was meant by controversy or disagreement; the fact that SoLaHmo researchers worked closely with the academic team to develop the guide allays some, but not all, of these concerns. Last, this study has a broader scope than prior research: previous studies with general population and diverse women have focused on a specific controversy (e.g. the 2009 USPSTF recommendations), while the current study with immigrant women explores broader expert disagreement about mammography. Future research that takes this broader perspective should be conducted with non-immigrant women to enable stronger comparisons.

It is likely that breast cancer screening recommendations will continue to evolve, as the evidence base grows and medical technology advances, and they are likely to remain high on the media agenda. In time, awareness of mammography controversy may become more widespread. It is therefore critical for clinicians to help women to negotiate mammography's risks and benefits so they can make an informed choice-a particular challenge in today's complex information environment. There also may be a role for communication campaigns and other public health interventions designed to reduce cancer disparities. For example, instead of using ethnic media to promote screening at age 40, it may be important to promote talking to one's clinician about when to start screening. Clinical interactions may not always afford the time or opportunity for risks/benefits discussion. Arming women with information via other channels may be necessary if we are to support informed decision making and, ultimately, prevent widening cancer disparities.

## ACKNOWLEDGMENTS

We thank the following community researchers from the Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo) for their assistance with development of research tools and data
collection: Maira Rosas-Lee, MA; Naima Dhore; Mai See Thao, PhD Candidate; Mariam Egal, MPH; Xai Gao Sheng Chang; Laura Serrano; Maria Arboleda; Amran Ahmed, MN; Nira Ly, JD; Natalia Calixto; and Shannon Pergament, MPH, MSW. We also thank K. Vish Viswanath, PhD, Marco Yzer, PhD, Alexander Rothman, PhD, and John Finnegan, PhD for their helpful feedback during earlier stages of this research.

## SOURCE OF FUNDING

This work was supported by a Grant-in-Aid of Research, Artistry and Scholarship from the Office of the Vice President for Research at the University of Minnesota (Minneapolis, MN, USA). R.H.N. acknowledges support from the Building Interdisciplinary Research Careers in Women's Health Grant (2K12-HD055887) from the Eunice Kennedy Shriver National Institutes of Child Health and Human Development, the Office of Research on Women's Health, and the National Institute on Aging, administered by the University of Minnesota Deborah E. Powell Center for Women's Health (Minneapolis, MN, USA). This content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

## CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

## REFERENCES

1. Fletcher SW, Black W, Harris R, et al. Report of the international workshop on screening for breast cancer. J Natl Cancer Inst. 1993;85:1644-1656.
2. NIH Consensus Development Panel. National Institutes of Health Consensus Development Conference Statement: breast cancer screening for women ages 40-49, January 21-23, 1997. J Natl Cancer Inst. 1997;89:1015-1026.
3. Olsen O , Gotzsche PC. Cochrane review on screening for breast cancer with mammography. Lancet. 2001;358:1340-1342.
4. Preventive US. Services Task Force. Screening for breast cancer: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2009;151:716-726. w-236.
5. American Cancer Society. American Cancer Society responds to changes to USPSTF mammography guidelines. American Cancer Society, 2009. Available at http://pressroom.cancer.org/index. php?s=43\&item=201. Accessed 23 May 2016.
6. American College of Radiology. New SBI and ACR recommendations suggest breast cancer screening should begin at age 40 . American College of Radiology, 2010. Available at http://www.acr.org/ About-Us/Media-Center/Position-Statements/Position-Statements-Folder/New-SBI-and-ACR-Recommendations-Suggest-Breast-Cancer-Screening-Should-Begin-at-Age-40. Accessed May 23, 2016.
7. Oeffinger KC, Fontham EH, Etzioni R, et al. Breast cancer screening for women at average risk: 2015 guideline update from the American cancer society. J Am Med Assoc. 2015;314:1599-1614.
8. U.S. Preventive Services Task Force. Final recommendation statement: breast cancer: screening. U.S. Preventive Services Task Force, February 2016. Available at http://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/ breast-cancer-screening1. Accessed May 23, 2016.
9. Steele WR, Mebane F, Viswanath K, et al. News media coverage of a women's health controversy: how newspapers and TV outlets
covered a recent debate over screening mammography. Women Health. 2005;41:83-97.
10. Fowler EF , Gollust SE . The content and effect of politicized health controversies. Ann Am Acad Polit Social Sci. 2015;658:155-171.
11. Squiers LB, Holden DJ, Dolina SE, et al. The public's response to the US Preventive Services Task Force's 2009 recommendations on mammography screening. Am J Prev Med. 2011;40:497-504.
12. Rabin RC. New guidelines on breast cancer draw opposition. New York Times. 16 Nov 2009.
13. Drossman SR, Port ER, Sonnenblick EB. Why the annual mammogram matters. New York Times. 28 Oct 2015.
14. Nagler RH, Fowler EF, Gollust SE. Covering controversy: What are the implications for women's health? Women's Health Issues. 2015;25:318-321.
15. Pace LE, Keating NL. A systematic assessment of benefits and risks to guide breast cancer screening decisions. J Am Med Assoc. 2014;311:1327-1335.
16. Miller $A B$, Wall $C$, Baines $C J$, et al. Twenty five year follow-up for breast cancer incidence and mortality of the Canadian National Breast Screening Study: randomised screening trial. Br Med J. 2014;348:9366.
17. Szabo L. Study raises awareness of risks of mammograms. USA Today. 11 Feb 2014.
18. Taplin SH, Urban N, Taylor VM, et al. Conflicting national recommendations and the use of screening mammography: Does the physician's recommendation matter? J Am Board Fam Med. 1997;10:88-95.
19. Meissner HI, Rimer BK, Davis WW, et al. Another round in the mammography controversy. J Women's Health. 2003;12:261-276.
20. Kiviniemi MT, Hay JL. Awareness of the 2009 US Preventive Services Task Force recommended changes in mammography screening guidelines, accuracy of awareness, sources of knowledge about recommendations, and attitudes about updated screening guidelines in women ages 40-49 and 50+. BMC Public Health. 2012;12:899.
21. Wang AT, Fan JQ, Van Houten HK, et al. Impact of the 2009 US Preventive Services Task Force guidelines on screening mammography rates on women in their 40s. PLoS ONE. 2014;9:e91399.
22. Davidson AS, Liao X, Magee D. Attitudes of women in their forties toward the 2009 USPSTF mammogram guidelines: a randomized trial on the effects of media exposure. Am J Obstet Gynecol. 2011;205:e1-e7.
23. Allen JD, Bluethmann SM, Sheets M, et al. Women's responses to changes in US Preventive Task Force's mammography screening guidelines: results of focus groups with ethnically diverse women. BMC Public Health. 2013;13:1169.
24. Viswanath K. Public communications and its role in reducing and eliminating health disparities. In: Thomson GE, Mitchell F, Williams MB, eds. Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business. Washington, DC: National Academies Press; 2006:215-253.
25. Gany FM, Shah SM, Changrani J. New York City's immigrant minorities. Reducing cancer health disparities. Cancer. 2006;107(8 Suppl):2071-2081.
26. American Cancer Society. Breast cancer facts \& figures 2013-2014. Atlanta: American Cancer Society, 2013. Available at http://www. cancer.org/acs/groups/content/@research/documents/document/ acspc-042725.pdf. Accessed May 23, 2016.
27. Centers for Disease Control and Prevention. Cancer screeningUnited States, 2010. MMWR Morb Mortal Wkly Rep. 2012;61:41-45.
28. Harcourt N, Ghebre RG, Whembolua GL, et al. Factors associated with breast and cervical cancer screening behavior among African immigrant women in Minnesota. J Immigr Minor Health. 2014;16:450-456.
29. Lor M, Bowers B. Evaluating teaching techniques in the among breast and cervical cancer health awareness project. J Cancer Educ. 2014;29:358-365.
30. Raymond NC, Osman W, O'Brien JM, et al. Culturally informed views on cancer screening: a qualitative research study of the differences
between older and younger Somali immigrant women. BMC Public Health. 2014;14:1188.
31. Shelton RC, Jandorf $L$, Thelemaque $L$, et al. Sociocultural determinants of breast and cervical cancer screening adherence: an examination of variation among immigrant Latinas by country of origin. J Health Care Poor Underserved. 2012;23:1768-1792.
32. Thorburn S, Kue J, Keon KL, et al. "We don't talk about it" and other interpersonal influences on Hmong women's breast and cervical cancer screening decisions. Health Educ Res. 2013;28:760-771.
33. Torres E, Erwin DO, Trevino M, et al. Understanding factors influencing Latina women's screening behavior: a qualitative approach. Health Educ Res. 2013;28:772-783.
34. U.S. Census Bureau. BO2006: Asian alone by selected groups. 20092013 5-Year American Community Survey. U.S. Census Bureau, 2013. Available at http://factfinder2.census.gov. Accessed May 23, 2016.
35. U.S. Census Bureau. BO4001: First ancestry reported. 2009-2013 5-year American Community Survey. U.S. Census Bureau, 2013. Available at http://factfinder2.census.gov. Accessed May 23, 2016.
36. Minnesota Compass. Immigration: population trends: foreign born population by birthplace, 1870-2014. Available at http://www. mncompass.org/immigration/population-trends\#1-5581-g. Accessed May 23, 2016.
37. Sofaer S. Qualitative methods: What are they and why use them? Health Serv Res. 1999;34(5 Pt 2):1101-1118.
38. Krueger RA, Casey MA. Focus Groups: A Practical Guide for Applied Research, 4th edn. Thousand Oaks, CA: Sage Publications Inc; 2009.
39. University of Minnesota Clinical and Translational Science Institute Performance of community-based research: guidance statement. Available at http://www.ctsi.umn.edu/sites/default/files/ Performance\%20of\%20Community-Based\%20Research.pdf. Accessed July 25, 2016.
40. Glaser B, Strauss A. The Discovery of Grounded Theory; Strategies for Qualitative Research. Chicago: Aldine; 1967.
41. Strauss A, Corbin JM. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park, London: Sage Publications Inc; 1990.
42. Pidgeon NF, Henwood K. Using grounded theory in psychological research. In: Hayes N, ed. Doing Qualitative Analysis in Psychology. Hove, UK: Psychology Press; 1997:245-273.
43. Stoxen C. Research raises more mammogram doubts. Minneapolis StarTribune. 2 Apr 2014.
44. Perry S. Mammography screening doesn't change overall death rates, study update finds. MinnPost. 13 Feb 2014.
45. Orenstein P. Our feel-good war on breast cancer. New York Times. 25 Apr 2013.
46. Allgood KL, Rauscher GH, Whitman S, et al. Validating self-reported mammography use in vulnerable communities: findings and recommendations. Cancer Epidemiol Biomark Prev. 2014;23:1649-1658.
47. Basu A, Dutta MJ. The relationship between health information seeking and community participation: the roles of health information orientation and efficacy. Health Commun. 2008;23:70-79.
48. Schwartz LM, Woloshin S, Fowler FJ, et al. Enthusiasm for cancer screening in the United States. J Am Med Assoc. 2004;291:71-78.
49. Waller J, Douglas E, Whitaker KL, et al. Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study. BMJ Open. 2013;3:e002703.
50. Waller J, Osborne K, Wardle J. Enthusiasm for cancer screening in Great Britain: a general population survey. Br J Cancer. 2015;112:562-566.
51. Hersch J, Jansen J, Barratt A, et al. Women's views on overdiagnosis in breast cancer screening: a qualitative study. Br Med J. 2013;346:f158.
52. Kressin NR, Groeneveld PW. Race/ethnicity and overuse of care: a systematic review. Milbank Q. 2015;93:112-138.
53. Yasmeen S, Romano PS, Tancredi DJ, et al. Screening mammography beliefs and recommendations: a web-based survey of primary care physicians. BMC Health Serv Res. 2012;12:32
54. Hinz EK, Kudesia R, Rolston R, et al. Physician knowledge of and adherence to the revised breast cancer screening guidelines by the United States Preventive Services Task Force. Am J Obstet Gynecol. 2011;205:e1-e5.
55. Carman KL, Maurer M, Yegian JM, et al. Evidence that consumers are skeptical about evidence-based health care. Health Aff. 2010;29:1400-1406.

[^0]:    This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

