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Assessment of Mammography Experiences and Satisfaction among American Indian/Alaska Native Women

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Abstract

BACKGROUND—American Indian/Alaska Native (AI/AN) women have lower breast cancer (BCA) screening and 5-year survival rates than non-Hispanic Whites. Understanding reasons for low screening rates is important to combat later stage diagnoses. The purpose of this study was to assess mammography experiences and satisfaction among AI/AN women.

METHODS—Nine focus groups were held with rural (N=15) and urban (N=38) AI/AN women 40 years and older in Kansas and Kansas City, Missouri, living both near and far from Indian Health Service (IHS) and tribal facilities, to examine experiences and satisfaction with mammography. Transcripts were coded and themes identified using a community-based participatory research approach.

FINDINGS—Themes were classified under knowledge, communication, and awareness of breast cancer, barriers to mammography, mammogram facility size, impressions of mammogram technologist, motivations to getting a mammogram, and how to improve the mammogram experience. Participants had knowledge of prevention, but described cultural reasons for not discussing it and described better experiences in smaller facilities. Participants indicated having a mammogram technologist who was friendly, knowledgeable, respectful, competent, and explained the test was a determining factor in satisfaction. Other factors included family history, physician recommendation, and financial incentives. Barriers included transportation, cost, perceptions of prejudice, and time constraints. Participants on reservations or near IHS facilities preferred IHS over mainstream providers. Suggestions for improvement included caring technologists, better machines with less discomfort, and education.

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CONCLUSIONS—Interventions to enhance the professionalism, empathy, and cultural awareness of mammogram technologists, reduce barriers, and provide positive expectations and incentives could improve satisfaction and compliance with screening mammography.

Introduction

It is known widely that early detection of breast cancer (BCA) is key to survival. However, American Indian/Alaska Native (AI/AN) women have some of the lowest screening rates and the rates have been declining since 2005 while screening rates have remained the same or increased among women from other ethnic groups (Centers for Disease Control and Prevention, 2012). Data from the 2003 California Health Interview Survey also showed that mammogram screening rates among AI/AN women aged 40 years and older were significantly lower than for Whites, African Americans and other races combined (Eberth, Huber, & Rene, 2010). These lower screening rates likely contribute to the higher mortality (Harper et al., 2009).

Socio-economic, cultural and health-system barriers have been shown to contribute to the low screening rates of American Indian (AI) women (Becker, Affonso, & Beard, 2006; Daley et al., 2012; Watson-Johnson et al., 2011). Barriers to routine mammography that have been identified in studies with AIs include lack of access to mammography due to cost and lack of transportation, fear of being diagnosed with breast cancer, mistrust of mainstream healthcare establishments and the feeling of embarrassment during the mammogram test (Daley et al., 2012; Watson-Johnson et al., 2011). Practice-based mammography interventions such as sending reminders or telephone counseling have not been effective with the AI population because of migratory patterns and cultural factors (Becker & Foxall, 2006). To improve screening rates for AIs, interventions should be culturally tailored, and factors such as facility barriers within healthcare systems, tribal-specific information, role of family, and women's opinions about screening tests should be considered when planning breast screening interventions with AI communities (Becker & Foxall, 2006). It is important to consider some of these factors as screening rates among AIs have been shown to vary with tribal affiliation and geographical location (Roubidoux, 2012).

A longitudinal study of 6,898 women found that unpleasant mammography experiences, such as enduring more pain than anticipated or being dissatisfied with the technique of the screening staff, was negatively correlated with return for future mammography (Scaf-Klomp, van Sonderen, Stewart, van Dijck, & van den Heuvel, 1995). In addition, a body of information has formed regarding patient preferences for learning about the results of their mammograms. These studies have found that women prefer to be told about abnormal results by their primary care physician (Lind, Kopans, & Good, 1992) and that satisfaction increases if results are directly interpreted so that further diagnostic studies can be performed while they are still at the facility (Hulka et al., 1997; Wilson et al., 1998). However, these studies were conducted using instruments whose psychometric properties were not tested.

The present study is part of a larger project to understand the mammography experiences and satisfaction of AI/AN women and to develop and test a Patient Assessment of Mammography Services tool for American Indians (PAMS-AI). The purpose of this study was to assess mammography experiences and satisfaction among AI/AN women. The overall hypothesis was that the experiences and satisfaction with mammography for AI/AN women will be influenced by individual, community and cultural factors, and the use of Indian Health Service (IHS). The results of this formative work will inform the development of the PAMS-AI.

Methods

Participant Recruitment

Various strategies were used to recruit participants for this study, including: 1) collaborating with members of AI/AN communities, institutions and organizations to distribute flyers and inform community members about the focus groups, 2) partnering with the pastor of a church attended predominantly by AI/AN community members to invite members of the congregation to participate in the focus group study and to utilize the church as a location for a focus group, 3) posting flyers at a local Indian Center, 4) working with community leaders of three tribes represented in Kansas to spread the word within the reservations, and 5) attending and volunteering at pow wows and health fairs on various reservations. In addition, focus groups were advertised through flyers, emails, and word-of-mouth. Interested individuals were recruited after completion of an eligibility survey. American Indian/Alaska Natives were recruited throughout the Kansas City area, including Kansas City, Kansas and Kansas City, Missouri.

To be eligible, the individual had to be an AI/AN woman 40 years or older with no history of breast cancer, lumpectomy, mastectomy, or radiation and should have had a mammogram within the past five years. Eligible individuals were invited to one of the upcoming scheduled focus groups and provided with a reminder card indicating the date, time and location of the focus group. When recruited over the phone, a reminder card was mailed to the individual's address. If not eligible, the individual was thanked for her time and interest. Each scheduled participant was called or sent an email two days prior to their assigned focus group as another reminder. To participate in a focus group, each participant was required to sign an informed consent form and complete an eligibility questionnaire and a demographic survey.

This study was carried out in accordance with the University of Kansas Medical Center's (KUMC) policies and procedures relating to Human Subjects, as written in accordance with the Code of Federal Regulations (45 CFR 46). Approval to conduct the study was obtained from KUMC's Institutional Review Board (IRB) and from the review boards of participating tribes.

Focus Groups

A total of nine focus groups were held at three geographically disperse locations in the state of Kansas and in Kansas City, Missouri between November 2010 and March 2011 with AI/AN women; focus groups were held with AI/AN women living in an urban area far from an IHS facility, an urban area close to an IHS clinic, and reservation areas with tribal clinics. The groups were stratified by location (rural or urban) of where the participants lived (see Table 1). Women self-identified as AI/AN from various tribes were screened using an eligibility criteria form. Of the 120 AI/AN women contacted and screened, 96 met the eligibility criteria to participate in the focus groups and 53 of the 96 of eligible women (55.2%) participated in the focus groups. Reasons for not participating included: distance to focus group location was too far, time was not convenient - could not take the time off work to attend, not interested at the time because of other health issues, and lack of transportation.

There were 4 – 12 women per focus group and each group discussion lasted about two hours. In general, focus groups were very interactive with no single participant dominating the discussions. Participants were identified by first names and arranged around a round table or U-shaped seating to help them feel at ease and comfortable to share their mammography experiences. A meal was served first and each session began with introductions followed by an icebreaker.

Focus groups were conducted by a moderator and an assistant moderator who followed discussion points in a prepared moderator's guide. The moderator's guide was developed with input from community advisory board members and was based, in part, on information from prior mammography focus groups with Non-Hispanic White, Hispanic and Black women conducted by our research team (Engelman, Cizik, & Ellerbeck, 2005; Engelman, Cizik, Ellerbeck, & Rempusheski, 2012). The moderator encouraged every participant to contribute to the discussions and told participants that there were no wrong answers, just different opinions. To be maximally effective and to follow the principles of community based participatory approach (Daley, James, Ulrey, & al, 2010; Daley et al., 2012), an AI moderator who was part of the study team facilitated the sessions and elicited responses from participants. The moderator took steps to create a nonthreatening, nonjudgmental, supportive climate conducive to open exchange and expression, ensured that the session direction remained relevant to the study, that all group members were allowed to contribute, and that responses were not inhibited or shaped by one or two dominant members. Focus group discussions focused on barriers to obtaining mammograms, motivating factors to obtain mammograms, past mammography experiences, and areas of mammography satisfaction and dissatisfaction. More specifically, the discussions explored reasons why AI/AN women do not get mammograms regularly, characteristics of mammography facilities, participants' impressions about the mammography test, health care systems and how those could influence a woman's decision to get a mammogram. Discussions also included participants' ideas of the perfect mammogram experience.

Focus group discussions were audio-taped and video-taped and information collected was kept confidential and in a locked file cabinet in a locked office. Basic demographics, contact information, and survey responses were the only personal information collected about participants. This information was kept in a locked file cabinet and/or on a secure password-protected computer server and only people who oversaw this research were able to access the information. Participants received a \$25 gift card as compensation for their time and effort.

Qualitative Data Analysis

A stringent systematic qualitative analysis of the focus group transcripts was conducted (see **Figure 1**). Focus group audio-tapes were transcribed verbatim and transcripts were reviewed and revised by two separate individuals for accuracy by listening to the tapes. All the transcripts were read by the principal investigator and two other team members who collectively came up with a list of codes. A codebook was developed based on the suggested code list. The codebook was continuously revised with additional codes during the process of coding. Initially, a coding trial run was done where two transcripts were coded by hand by three individual team members; the primary (etic), secondary (emic) and tertiary coder (etic).

Coders met periodically to compare coding styles and ensure that coding was done in a systematic and consistent manner. An etic coder is a member of the research team formally trained in qualitative methods, but is not a community member. An emic coder is a member of the research team formally trained in qualitative methods who is also a community member (Daley, James, Ulrey, Joseph, et al., 2010). After agreeing on coding style, all transcripts were coded by hand and the coding process was led by the primary research team coder – the primary coder was not an AI/AN community member and is, therefore, considered an etic coder. The secondary coder was an American Indian community member (emic coder). The principal investigator of the research team served as the tertiary coder (also an etic coder) and was not a community member. This approach ensured that we obtained insider community perspective (emic) that could have been missed by the outsider

(etic), and conversely ensured that we got outsider perspective that could have been overlooked by an insider immersed in the AI/AN culture (Daley, James, Ulrey, & al, 2010; Daley et al., 2012). Coding was based on a combination of qualitative analytic approaches (Daley, James, Ulrey, & al, 2010; Daley et al., 2012).

There were several stages of the coding process; initially transcripts were open-coded; identifying within the text key words, themes and descriptions of behavior. Subsequently, codes were assigned to code families or categories growing out of the data. Finalized coded transcripts were reviewed systematically by the coders, who independently formulated short summary statements or themes about AI/AN women's mammography experiences. The themes were developed separately for each stratum by each coder. Themes were reviewed and similar themes across coders were combined.

Developed themes were reviewed by additional emic and etic reviewers. Reviewers were individuals who were not involved in the focus groups or participated in coding. The etic reviewer reviewed coded transcripts and summary statements and cross-checked 10% of the codes for inter-coder reliability; few to no differences were found. The etic coder compiled summary statements into thematic statements. The etic reviewer reviewed the prepared thematic statements with coders and then combined them into more comprehensive statements. The emic reviewer assessed the condensed themes for cultural appropriateness after which the etic reviewer would revise the themes again based on comments from the emic reviewer. The research team reviewed the revised themes, agreed on and finalized them, and came to a consensus on what the themes meant.

Themes were grouped into coding categories that allowed the categorization and retrieval of text related to patient satisfaction, barriers to obtaining mammograms, mammogram preferences, and culturally-specific issues related to obtaining mammograms. Key ideas, words, phrases, and recommendations were used to formulate summary statements and conclusions. Data analysis was used to identify key components of the AI/AN experience to include in a Patient Assessment of Mammography Services for American Indian (PAMS-AI) instrument - to be developed subsequently and validated for use with AI/AN women.

Results

Participant Demographics

Participants were women aged 40 or older who self-identified as AI/AN (N=53). Our study participants were highly educated, as 96.2% had attained at least a high school diploma and 52.8% had a bachelor's degree or higher. This percentage is high compared to the national and state averages. Nationally, 12-13% of self-reported AI/ANs (alone or mixed) aged 25+ have bachelor's degrees or higher. In Kansas and Missouri, 15.0-19.9% of self-reported AI/ANs (alone or mixed) aged 25+ have a bachelor's degree or higher. All participants could read and speak English and over 75% had some college education or higher.

Participants indicated an affiliation to over 30 different tribes. Participant demographic information is shown in Table 2. About two-thirds of the participants had private health insurance, yet more than half of them used IHS or tribal clinics as their primary source of health care. Most (83%) had had a mammogram within the last two years primarily for routine screening purposes and about two-thirds got a mammogram every year.

Themes that Arose from Focus Groups

The focus group transcripts revealed both similar and unique themes across different focus groups and locations. These discussion points were summarized into statements (themes) and classified under the following categories: knowledge, communication, and awareness of

breast cancer, barriers to getting a mammogram, mammogram facility size, impressions of mammogram technologist, motivations to get a mammogram, and suggestions on how to improve on the mammogram experience.

Knowledge, Communication, and Awareness of Breast Cancer—Across all focus groups within each stratum, women had some knowledge of breast cancer symptoms and risk factors. They acknowledged the importance of education and awareness in the prevention of breast cancer but highlighted the fact that AI/AN women, especially the older generation, do not discuss breast cancer and/or mammograms with family members or friends. However, AI/AN women who had a family member or close friend diagnosed with the disease were more likely to talk about mammograms or breast cancer. As a result, strategies to encourage communication among AI/AN women, particularly using women with a personal or family history of BCA, could be important in educational efforts in this population. Participants indicated that AI/AN women do not talk about mammograms and breast cancer because, for cultural reasons, some AI/AN women do not like to talk about their bodies. Also, they find the topic embarrassing and some are afraid to talk about the disease. As two women noted:

“Well I've always found, I bet you have too, in our culture our older people are not ready to talk about their private parts. I mean they're real modest”.

“I think prior to my mother being diagnosed with breast cancer, I hadn't worried about it. No one had ever talked to us about...you know, she's a nurse, she never talked to us about breast self exams or...but until it happened in our family and now we talk about it with like my girls and even our sons”.

Barriers to Getting a Mammogram—Participants shared various reasons why they and other AI/AN women do not get mammograms. Reasons mentioned included cost - “Well if you don't have insurance it's a big barrier because I don't think that most women will make an appointment if they know that it's going to cost money. You know, what do they charge, \$70/\$80, to that person that's not insured that's grocery money for a week or gas money for a week. And then I think some of the programs that are low income those don't count either sometimes because it's so hard to get through the process”; lack of transportation - “Get gas to go there and back. And it could be an all-day thing and if you've got to watch kids, you've got to take your kids along with you and then you've got to make sure they get something to eat. It involves a lot of stuff. Cause like with our family we're still extended, you know, living, with transportation, cars, you know, sharing rides. It just involves a lot of people”; and embarrassment and conflicting priorities - “And the tests for cancer, they're so invasive, you know, they're personally invasive. So it's...I don't want to say you dread it, but, you know, it's something that's very easy to put off, you don't have the time”.

The distance from mammography facilities, lack of mammogram equipment at Indian Health Service facilities, not knowing what to expect, pain or discomfort during the test, trust, and worry about being diagnosed with breast cancer also were given as reasons for not getting mammograms. Participants furthermore expressed that as AI/AN women, they consider the mammography experience to be embarrassing; “I'm going to go over here and have my clothes off with these people and sometimes people I think that they think...and I can't speak for other Indian people, but this Indian woman is not an immodest person and to be having to stand around in a room cold with paper clothes on for the convenience of some other people that I'm a pound of ground beef and they know nothing about, you know, I think that's a negative way of delivering healthcare. ...”. Similarly, the importance of modesty was an important viewpoint that is exemplified by the following: “Modesty's a big thing. It's a value that we usually, if you're brought up traditionally you hold that to try to be modest, so that would be embarrassing”.

Participants also repeatedly indicated that the mammography experience would be more satisfactory without the discomfort and embarrassment they felt during the mammogram test itself.

Mammogram Facility Size—Women indicated they had a better experience in smaller facilities than in larger facilities. They believed that small mammogram facilities provided better services than large facilities as explained by one participant;

“I think it kind of goes back to, you know, what kind of facility you go to. If you go to, you know, a smaller, you know, like the hospital where they don't see as many, but if you go to like [XXXXXXX], I mean, you know, like I said, it's like a cattle call in there...”.

Impressions of Mammogram Technologist—The experience with specific mammogram technologists impacted whether women had a positive or negative mammogram experience;

“Yeah, I didn't like mine. The lady that I had was a little old lady and she was just pretty much blunt and, you know, just...I didn't like it and I didn't want to go back. I ain't doing this again. My sister's like, nope, you've got to do it every year, you've got to do it every year. Oh my God, I'm going to somebody else, that one was too much”.

Women prefer a technologist who is friendly, knowledgeable and respectful and who will explain the steps of the mammogram test;

“I think it depends on the tech cause I know... my first experience she didn't explain anything, the next time I went it was better. And then I had the one lady that made fun of me because I had small breasts, but the other experiences have been okay. I think it depends a lot on who you get”.

Motivations to Get a Mammogram—Even though mammograms are recommended, the literature shows that AI/AN women often do not get screened (Centers for Disease Control and Prevention, 2012). Motivation to be screened in the absence of symptoms is an important aspect of routine mammography utilization. Participants noted a variety of interpersonal motivating factors including early detection, personal family history of cancer, and a sense of responsibility to take care of oneself so that one can be around to care for family members. External motivating factors included physician recommendations and financial incentives to obtain screening. Some participants expressed their personal motivations for getting mammograms;

“To be safe. To make sure you don't have cancer. If you do have it, I mean hopefully you found it early”.

“I'd say mine is probably higher because there's history of cancer in my family”.

“Something to encourage them that they're doing this for others rather than it's all about you. Because if you're not there then who's going to take care of the family”?

For other women, not having to pay for mammography out-of-pocket motivated them to get the test.

“I go to IHS because they ... pay the copay too. One thing about the copay, sometimes I have it, sometimes...most of the times, I don't”.

“But then when we[an organization of which participant was a member] started offering those incentives where if you get a breast exam and you can show

verification... and they can get up to \$25 in XXXXXX gift cards. And I mean I've seen more women that will go and get it..."

Several women indicated that their primary care provider did not talk to them about breast cancer or getting mammograms. Women informed about breast cancer and the importance of getting breast cancer testing are more likely to get mammograms than those who are not informed, as exemplified by this participant:

"...it wasn't until my doctor was reviewing my chart and then he was like oh, you know, you're at that age when we need to, you know, get a mammogram. So I think that, you know, with having a female doctor that she is proactive and she really encourages the women to get mammograms and, you know, pap smears".

Women mentioned that reducing the discomfort and pain during the mammogram test will positively affect the experience and increase compliance to screening mammography;

"I have horrible experiences with it. I dread it. If I could just go like maybe every two/three years I would be happy. The machine is cold. I had it done in the hospital and the people were distant and maybe they thought I didn't speak English".

Suggestions for Improving the Mammogram Experience—Participants made several suggestions when asked what their ideal mammogram experience would look like, including: having caring and competent mammogram technologists who explain the procedure; having education about breast cancer using oral tradition by local elder women, and educational materials; using warm rooms, warmed technician hands, and heated blanket instead of paper gowns; creating better machines that cause less discomfort; and providing a "one stop shop" of multiple screenings in one day, with same day results.

Discussion

In this study, AI/AN women shared their mammogram experiences from scheduling to results reporting and how their experiences affected their satisfaction with mammography. Focus groups were held with AI/AN women living in an urban area far from an IHS facility, an urban area close to an IHS clinic, and reservation areas with tribal clinics to determine how experiences would vary with service locations. Similar to reports by Daley et al. (Daley et al., 2012), AI/AN women, in general, were knowledgeable about mammograms and why getting mammograms is important and the risk factors for breast cancer. However, this knowledge is not shared among friends and family because culturally, AI/AN women do not feel comfortable talking about their bodies, especially women of older generations.

When participants were asked what percentage of AI women they thought got regular mammograms, they thought that only about half of AI women got regular mammograms. However, data from the demographic survey by our study participants showed that 64% of participants had obtained annual mammograms. Therefore, the perception of women in our study was lower than the actual screening rate, which approaches the 70% goal set by Healthy People 2020 (US Department of Health and Human Services, 2009, 2012), though still falls short. Similar mammography rates have been reported for women in this region previously (Greater Kansas City Affiliate of Susan G Komen for the Cure, 2011; Wingo et al., 2008). The rates in this study are slightly lower than the national average (67.1%) for women 40+ who reported to have had a mammogram within the past 2 years (National Center for Health Statistics, 2013). Discussions from our focus groups highlighted several of the same barriers to mammography reported by others (Daley et al., 2012; Engelman et al., 2005; Watson-Johnson et al., 2011; Wingo et al., 2008) including transportation, distance to mammogram facilities, lack of insurance, cost, no time, and conflicting priorities. However, the discussions also examined factors contributing to how AI/AN women perceived the

mammography experience and satisfaction, such as culture, location of mammography facility, type of healthcare system (IHS or others), competence and attitude of facility staff. One major observation was that AI/AN women in this study indicated that they preferred IHS or tribal clinic services over other providers. Many of the tribal clinics in our region contract with the IHS and often share providers. Twenty (20) of the 53 (37.7%) participants indicated that they got most of their health care from the IHS. However, none of the tribal or IHS clinics in our study area provides mammograms; the IHS clinics do not provide mammography services so women have to go to other facilities to get the mammogram test. However, most of the events that contribute to the mammography experience (women's interactions with their provider, referral, scheduling, payment, and getting results of mammograms) are handled by the IHS. Thus, the stated experiences for women in our study who used IHS and their satisfaction with IHS services may have been influenced by their experiences at IHS and based on their satisfaction with IHS, in general, or IHS in their mammography-referral role.

Although 64% of our study participants had private health insurance, more than half of those with private insurance indicated that they used the IHS or tribal clinics as their primary source of healthcare. Participants indicated that they were more comfortable with and trusted providers of the IHS and tribal clinics more than providers from mainstream facilities. This phenomenon was particularly obvious in focus groups held at locations close to an IHS or tribal clinic. Study participants at these locations were very satisfied with the referral system for mammograms and were more likely to get annual mammograms than the women living further from an IHS or tribal clinic. This could be because some study participants indicated experiencing prejudice from staff at mainstream mammography facilities, especially those in border towns around reservations. The most common standard applied for eligibility for health services from the Indian Health Service is being enrolled as a member of a federally recognized Tribe (Indian Health Service, 1967). For this study, participants self-identified as AI or AN. We did not ask participants to present proof of tribal membership. Because participants using IHS services did not get mammograms at these IHS facilities, it is unknown directly from this study if the stated experiences with the mammogram test itself noted by participants were based on their satisfaction with IHS in general.

Patient satisfaction with mammography services is an important facet of mammography utilization. In a survey of 255 women, Fine and others (Fine, Rimer, & Watts, 1993; Ware & Davies, 1983) found that more than 30% reported that their first mammogram experience affected their decision to have subsequent mammograms. Satisfaction especially is important in screening mammography where participants have no symptoms and are not motivated by ill-health to comply. Published mammography patient satisfaction studies include self-reports on the discomfort experienced during mammography (Kornguth et al., 1993; Rutter, Calnan, Vaile, Field, & Wade, 1992), the efforts of health care personnel to ensure privacy, encouragement to ask questions, and the provision of information (Bakker, Lightfoot, Steggles, & Jackson, 1998). Reports on women's satisfaction with mammography primarily have been outside the United States (Brett & Austoker, 2004; Cockburn et al., 1991; Jeon et al., 2011; Loken, Steine, & Laerum, 1998). To our knowledge, the present study is the first to examine mammography satisfaction among AI/AN women. A patient's satisfaction with mammography could be influenced by aspects of the practice and personal factors such as the woman's characteristics, mammogram experience, attitude and expectations (Loken et al., 1998). Thus, we expected AI/AN women's mammography satisfaction to be different from those of women from other ethnic groups given the unique history and culture of this population. It is noteworthy that women in this study regarded the technical competence and attitude of the mammography technologist as the determining factor for a positive or negative mammogram experience and satisfaction. In all focus groups and across all strata, AI/AN women in our study suggested that they had better

experiences in smaller facilities, and indicated that having mammogram technologists who were friendly, knowledgeable, respectful, and explained the test procedure and what to expect were primary factors in mammography satisfaction. Participants also described internal and external motivating factors that were also important, including family history, physician recommendation, and financial incentives.

Women's expectations about the mammogram test have been shown to affect their perception of pain and satisfaction with mammography. Participants in this study indicated that the mammography experience would be more satisfactory without the discomfort and embarrassment they felt during the mammogram test itself. Rutter et al. (1992) showed that a woman's expectation of pain was the most important measure for predicting discomfort or pain during mammography. In a study by Kornguth et al. (1993), women perceived significantly less pain and greater overall satisfaction with the mammogram test when the compression was controlled by the women than when the compression was technologist-controlled. For women getting mammograms for the first time, these expectations could be based on information from friends and relatives who have had mammograms. Thus, mammogram technologists may serve as an important point of intervention to increase women's satisfaction with mammography; by having a respectful and positive attitude (as indicated by participants in this study) and by providing women with accurate information and positive expectations that would dispel the myths about mammograms and reduce women's fears and concerns about mammography.

Implications for Practice and/or Policy

These results suggest that an intervention at the mammogram technologist level to enhance professionalism, improve competence and increase cultural awareness may increase AI/AN women's satisfaction with mammography, and may, thus, increase their use of it. Other suggestions made by participants to improve overall mammography rates in AI/ANs included providing incentives, more education about breast cancer culturally tailored to AI/AN, sending reminders for mammogram appointments, use of a buddy system, and combining mammography with other health screenings. Follow-up studies will develop and test a Patient Assessment of Mammography Services for American Indian women (PAMS-AI) survey instrument based on results of the present study. The PAMS-AI will be designed as a patient satisfaction instrument that may be used by mammography facilities that serve AI/AN women (IHS and non-IHS, alike). The PAMS-AI instrument purpose will be to identify opportunities for mammography service satisfaction improvement and areas of particular service excellence. It is hoped that feedback to facilities via PAMS-AI results will drive service improvements. With widespread and collaborative use, the PAMS-AI also has the potential to monitor trends in mammography satisfaction among AI/AN women.

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* Each of these steps completed by: Lead Coder= team leader; Emic Coder= from population; and Etic Coder= from outside of population

Figure 1.
Systematic Qualitative Analytic Process

Table 1

Focus Group Sampling Frame

AI/AN women (> 40 years)			
Urban (7 focus groups)		Rural (2 focus groups)	
Kansas City Metroplex	Lawrence, KS	Reservation #1	Reservation #2
4 groups	3 groups	1 group	1 group
20 participants	18 participants	8 participants	6 participants

Table 2

Demographic information of focus group participants

Characteristic	N	Percent
Age (in years, mean, SD)	52	(53.3 ± 9.21; mean age)
Where grew up		
On a reservation	17	32.7
On a tribal trust land	3	
In a rural area (off reservation)	7	13.5
In an urban area (off reservation)	18	34.6
In a suburban area (off reservation)	6	11.5
Other	1	1.9
Living situation		
Married/living with a partner	20	37.7
Divorced/separated/widowed	22	41.5
Never married	9	17.0
Other	2	3.8
Education		
Elementary/Grade school	1	1.9
Some high school/ High school graduate/ GED	10	18.9
Post high school certification/ Some college	14	26.4
2 or 4-year college graduate (AA/BA/BS degree)	17	32.0
Graduate degree	11	20.8
Health insurance		
No insurance	7	13.2
Private insurance	34	64.2
IHS or Tribal insurance	8	15.1
Medicare or Medicaid	4	7.5
Primary source of health care		
IHS	20	37.7
Tribal clinic	11	20.8
Traditional healer	0	0
Other	18	34.0
No response	4	7.5
Last mammogram		
Two years ago or less	44	83.0
More than 2 but not more than 5 yrs ago	7	13.2
More than 5 yrs ago	1	1.9
Not sure/Don't know	1	1.9
Reason for last mammogram		
Part of a routine exam or checkup	48	90.5
Because of a symptom or health problem	2	3.8
Follow-up from an earlier abnormal test	1	1.9

Characteristic	N	Percent
Not sure/Don't know	1	1.9
No response	1	1.9
Screening mammogram history		
Every year	34	64.2
Every other year	5	9.4
Irregularly	12	22.6
Only had one mammogram	2	3.8