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Breast Cancer Screening Perceptions among American Indian Women under Age 40

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Introduction

Breast cancer is the second-leading cause of cancer death in women in the United States [1, 8–10], and the second leading cause of mortality among American Indian (AI) and Alaska Native (AN) women [3, 23]. Although breast cancer incidence and mortality rates declined significantly each year from 1999 to 2008 among women in the United States in general, and white women in particular, incidence and mortality rates remained unchanged for AI women [7]. Breast cancer incidence is lower for AI/AN than other ethnic groups (58.0/100,000 women versus 89.8 to 140.8/100,000 women), but 26% of AI/AN women

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with breast cancer will die from it. AI women are twice as likely to die of breast cancer as non-Hispanic white women [12].

For average risk women, the National Cancer Institute recommends annual or biennial screening mammography to begin at age 40 [11], while the US Preventive Services Task Force suggests that screening mammography should start at age 50 and end at age 74 [20]. Screening rates in AI/AN women have been declining since 2005 and AI/AN women have some of the lowest screening rates [2]. In 2008, 62.7% of AI/AN women aged 40 and older had a mammogram within the past 2 years - compared to 67.9% for white women [2]. Clinical screening rate data reported by the Indian Health Service (IHS) indicates that the percentages of AI/AN women who were up to date with their biennial mammogram screening, were even lower [18]. According to IHS data, in 2002, 42% of AI/AN women aged 52–64 had a mammogram at least once over a two year period; this rate increased in 2009 to 45% [18]. Also, between 2000 and 2008, screening mammography rates among AI/AN women were among the lowest compared to women of other ethnic/racial groups [16]. As a result of these low screening rates, AI/AN women are diagnosed with breast cancer at later stages of the disease and have poorer disease outcomes [23]. Five-year breast cancer survival rates for AI/AN women are among the lowest of all racial/ethnic groups. Several factors have been identified or suggested as reasons for late stage diagnosis of breast cancer, including low compliance to breast cancer screening, less education, socio-economic factors (poverty, lack of access to healthcare, lack of healthcare insurance), cultural considerations, and institutional factors.

Also, there may be a generational divide in the way that AI women perceive breast cancer and breast cancer screening. Women from an older generation perceived screening mammography as embarrassing and humiliating because their bodies are exposed and being touched by someone they do not know [4]. There are indications that the perceptions of younger AI women toward breast cancer screening may be different from those of elders. The present study examines the perspectives of young AI women toward breast cancer screening to determine if attitudes and beliefs are changing within this population. This is important because in a study with young AI ages 20–44 years, breast cancer was the leading cancer diagnosed and it accounted for about 30% of all cancers diagnosed in young adult AI/AN women across various IHS regions [22]. With the recommended age for getting a mammogram being 40 or 50, women below these ages may not see the need to educate themselves about breast cancer and could perceive themselves as at low risk for the disease. Understanding attitudes of AI women not of recommended screening age may help shed light on low screening rates among AI women; and, this information may be used in the development of outreach strategies to improve current rates and screening for future generations.

Methods

To understand breast cancer screening beliefs and behaviors among AI women in Kansas and Missouri who have not yet reached the age at which screening mammography is recommended, we conducted a series of five focus groups with women 25–39 years of age (n=44). Four scheduled groups had low attendance due to weather and an upcoming holiday; interviews were conducted with participants who attended using the focus group questions (n=4) and groups were rescheduled. AI women were trained to serve as focus group moderators and conducted all groups and interviews. Participants were recruited primarily through word-of-mouth at local pow wows and other cultural events. Additional recruitment was done through posters and flyers at locations AI women frequent, e-mail listservs from community organizations, and direct recruitment through our community advisory board.

Study protocols were approved by the university institutional review board and local tribal councils, as appropriate.

Focus group moderator's guides were developed in conjunction with a community advisory board, based on prior interviews with community leaders and providers [4]. Focus groups were held in both urban areas and on reservations during both days and evenings to accommodate women with various work schedules. Groups lasted between 60 and 90 minutes and were audio-taped and transcribed verbatim. Transcripts were coded by hand by three members of the research team using a codebook developed by both academic and community member researchers, following a community-based participatory research protocol developed by the team. Approximately 10% of the codes were cross-checked by the study's principal investigator (CMD) to ensure inter-coder reliability; few to no differences were found. Coders identified preliminary themes that were then combined into thematic statements by the PI and checked by a community member researcher. Full details of the analytic process are described elsewhere [6]. Results from this study have been previously presented at multiple community presentations.

Results

Forty-four AI women participated in five focus groups and four additional participants were interviewed (total n=48). Women age 40 and under were recruited; participants ranged in age from 28 to 38 years. The majority of participants had some type of health insurance (62.5%) for coverage outside of the IHS, but almost half (49.0%) used the IHS for the majority of their medical care (see Table 1). It is important to note that the IHS is not an insurance carrier, but rather a provider of health care. Often mammography is done through contract health services in the IHS and when fiscal year funds are depleted, mammography and other contract services cannot be offered [19]. Refer to Table 1 for demographic information including age, marital status, education level, health insurance, and healthcare.

Most participants had personal experience with breast cancer and/or mammography or have known someone who has had breast cancer. Even though participants were not of recommended screening age, the majority had some connection to mammography or breast cancer. Women discussed a range of experiences from their own mammograms to family members and friends passing away from breast cancer to stories of survivorship. Participants spoke of their lives being affected by others' experiences living with breast cancer.

Those women who had been screened talked about their experiences in relation to their own body or family history. Women who had been screened previously saw screening as a necessity to living healthy and an important part of well-being.

Most participants had a general understanding of breast cancer risk factors (particularly age and family history), symptoms, and screenings, but were unsure how to correctly conduct breast self-examination (BSE). Women discussed age and family history as risk factors. Some women spoke of family history as the main reason for getting a mammogram, even though they had not reached the recommended screening age. The participants identified symptoms (e.g., pain, lumps, and discharge) and had a general understanding of risk factors and screening methods but did not feel confident in self-examinations. Women who had received BSE instruction (refer to Table 2) from providers did not care for the models used because they were not comparable to the shape, texture, and size of their own breasts. The models also did not seem to help women learn how to properly perform the technique.

Factors, such as differences in model shape and not knowing how to discriminate between fat tissue and abnormalities, impaired the correct conduct of BSE. Some women did not feel confident in their skills and second-guessed the outcome. Women believed that their

confidence would improve and indicated they would trust their results if these ideas were implemented in BSE education and training.

Participants wanted breast cancer information and screening procedures explained in simple language. Women desired a simplified approach for breast cancer information and screening and wanted to understand breast cancer screening, treatment, and risk at an in-depth level, but voiced their concerns over language use. The majority of women preferred to have explanations from health care providers and other sources of care in straightforward, easy-to-grasp terms. In addition, some participants yearned for simple, yet direct information to be included in educational materials, e.g., brochures and pamphlets.

Women discussed their sources of breast cancer information including family and friends, the media, brochures and pamphlets, pink ribbons, and awareness walks. Some women had discussed breast cancer with their health care providers, but were not given information about mammograms or were told to wait until they are closer to age 40. Participants provided a variety of responses for breast cancer knowledge and screening sources. Some participants sought out specific sources, e.g., Race for the Cure events. Other participants recognized educational efforts via signs and symbols associated with breast cancer awareness, such as pink ribbons. However, the most agreed upon sources of information included family and friends, and the media. The media's efforts in promoting breast cancer awareness cannot be underestimated, but participants recognized that more things could be done to promote screening among Native women. Participants asserted that the information received through various media sources lacked AI details. Lastly, friends and family were noted as great sources of information. Many of the participants knew friends and family with breast cancer and many of these individuals had undergone screening and treatment. Their personal experience with breast cancer and screening provided a rich source of knowledge from which others could learn. Focus group participants indicated that they believed the experiences of family and friends would likely influence screening behaviors.

Because the focus group participants were not of the recommended screening age, some had not discussed screening with their health care providers. However, family history, confusing technical terms, and unanswered questions prompted some women to discuss breast cancer and breast cancer screening with their health care providers.

Participants believed there is a lack of education about the specifics of mammograms, including why they are important, what to expect, the procedure itself, and current guidelines for screening. According to our focus group sample, younger women felt that they were not being exposed to appropriate educational materials on breast cancer screening. Women did not think that health care providers were supplying appropriate information to encourage future screening.

Some respondents also had uncertainties about mammograms and what they entail. Not knowing what to expect made women uncomfortable with the idea of future screenings. While the actual screening process intimidated some women, others focused on the results. A common notion found throughout the focus groups was the uncertainty of the screening procedure and outcome.

Women listed and described the barriers to mammography: competing priorities, cost, lack of insurance, transportation, location, and fear of mammography or possible results. The participants agreed that several factors may hinder a woman's ability to get a mammogram. Some respondents shared how their current financial situation prevented them from being screened; a mammogram is too expensive. Although some Native women have insurance through the IHS, obtaining a mammogram can be difficult if they have to travel a long distance to a facility or if the facility does not have the proper screening equipment. This

topic was of particular relevance to participants because they lived in a variety of places: rural areas, reservations, and urban centers. For women who lack health insurance, spending money on a mammogram may seem less of a priority when considering household bills and other financial responsibilities.

Financial issues were not the only hindering factor; simply finding a moment to get screened also made it harder for some women to make their health a priority. Work schedules, childcare duties, and family obligations may impede a planned screening. For women who have little or no support system, finding babysitters is more of a hassle than skipping doctor's visits. And when faced with an issue involving another family member, some women are likely to ignore their health concerns in order to provide for others. The lack of self-attention keeps women from maintaining their own health and keeping up with preventive measures.

Those participants who have had mammograms were referred to mobile vans, local hospitals and clinics, health fairs, imaging clinics, and specialists. Women described positive and negative experiences associated with these outlets. Some women appreciated the mammograms brought to them, via mobile vans, or their availability at local health fairs. However, these experiences also had problems. For example, a number of women who have undergone mammograms found the referral system frustrating as it often provided them with inconvenient appointment times at unfamiliar sites. Other women spoke of insensitivities of hospital and clinic staff toward Native women. However, not all experiences were negative. For the women who sought out a mammogram, typically, they reported that they had received one and several were satisfied with their experience.

Participants believed that Native people do not talk about breast cancer or mammography due to embarrassment and that women do not view annual mammography as a priority unless they have a family history of breast cancer. Women believed that embarrassment was an issue for many community members. Participants stated that some women do not want others knowing their business or that they may have a potential health issue. Because screening is not the norm, it raises curiosity or concern for those who want to get screened.

Women agreed that screening mammography is vital to the health of their community. Generally, breast cancer screening (BSE or mammography) was referred to as not coming up in casual conversation unless there was a particular reason that caused that conversation to happen—someone experiencing problems. Most participants agreed that current attitudes and behaviors concerning breast cancer needed to change to increase awareness and screening.

Participants believed a social component must be built into any campaign to encourage mammography and that programs should be Native-specific. Other suggestions included free screenings, mobile vans, health fairs, drive-through mammograms, and using the “buddy system” to alleviate fear and access issues. Overall, women felt that breast cancer outreach efforts and educational programs should contain information specific to Native people. Women desired culturally-tailored information so that it would be more relevant to them and more breast cancer screening would result. In addition, attendees stated that the Native women they know who have received a screening, did so through their social support networks. Women agreed that potential screening recipients would be more apt to go if they were not alone. Participants described women that they knew who had been screened, were accompanied by friends or relatives to their mammogram appointment. They believed that women going with others alleviated some of the stress associated with screening.

Participants offered additional suggestions to bolster screening rates. They discussed different venues for free screenings. Another factor women believed would positively impact screening rates is the cost—they need to be free of charge.

Discussion

The purpose of this study was to identify knowledge and beliefs of AI women under 40 years of age toward breast cancer screening, with an emphasis on mammography. We found that the majority of participants had a general understanding of breast cancer, and almost all knew a woman who had dealt with the disease or had their own experiences with mammography. But outside of symptoms, many women lacked knowledge of details about screenings and their risks for getting breast cancer.

Many of the women noted cost as a primary factor that would deter them from being screened. With lower rates of insurance and higher poverty rates compared to other ethnic groups [13, 15], AI women face more difficulty obtaining access to providers and regular care [14], and other financial liabilities such as bills and groceries take precedence over health [5]. An increase in future mammograms is reliant on affordable screenings, so interventions will need to address the issue of cost and access.

All of the women wanted additional education about breast cancer. They believed medical providers would be their best source of information, especially regarding BSE [5]. BSE is no longer recommended by many agencies, e.g., Susan G. Komen for the Cure and US Preventive Services Task Force. BSE has not been shown to improve mortality rates and some women feel anxious performing the technique, causing additional stress. Other organizations, such as the American Cancer Society and the Centers for Disease Control and Prevention, state that BSE is an option but it should not replace a screening mammogram. Instead of focusing on BSE, most organizations promote awareness of one's body to know what is normal for the individual. Yet, patient-provider dialogue seemed to be a need that some of the women were missing. Many women lacked confidence about their ability to identify a lump, so physicians and other medical professionals need to take the time to ensure that patients fully grasp the steps for noticing abnormalities. In addition to better instruction, respondents also voiced the importance of having education materials with simple language and breast models that were similar to their own figures. It is also important to improve breast cancer screening materials that are available for AI. It has been shown that a holistic approach to health education designed by AI/AN women was effective in motivating AI/AN women 40 years and older to get mammograms [21]. In addition to educational materials, awareness walks appeared to resonate with many younger women as educational outreach turned into community action. Therefore, it is imperative to include educational materials alongside community activities.

While some shared feelings of embarrassment about conversations surrounding breast health, others were comfortable with talking about the topic [5]. There was a consensus that breast cancer and mammography were not something women discussed with each other unless someone was having health issues or had been diagnosed with a malignancy. Finding a way to converse about such a personal issue will help AI women learn why early detection is so important and encourage their female relatives and friends to get screened.

Some participants acknowledged that their health care providers played a role in the knowledge they do possess. This is appropriate because the majority of participants had been immediately affected by breast cancer in some fashion and providers are more likely to talk with women who have relatives with the disease. While this skewed sample is a

limitation to the study, it also allows us to talk with women about discussions with their doctors that may not otherwise occur.

The limited number of potential participants was the major limitation to our study. This study was conducted in a small geographic portion of the Midwest. However, multi-tribal representation in our heterogeneous population derives from different sections of the country. Our team is able to shed light on barriers to breast cancer screening that may exist in different Native communities in the United States.

Very little research has been done regarding young women's perceptions on breast cancer and screening for the disease, and to our knowledge, no other study describes young AI women's viewpoints. Existing studies have found that young women from other minority populations share similar concerns with our participants about breast cancer screening: finances, time, family history, and lack of confidence in performing BSE [17]. Although our focus group participants may share similar worries to other women, differences in culture and beliefs of AI women require an alternate approach to creating initiatives that will increase screening and promote awareness [5]. By talking with AI women before they reach screening age, we have a better understanding of their needs and can provide services that will increase their likelihood of being screened.

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Table 1

Demographics (n=48)

Age (in years, mean, SD)	33, $\pm$ 5.1, range 28–38
Marital status	
Married living with a partner	38.3%
Divorced/Separated/Widowed	29.8%
Never married	31.9%
Education	
High school graduate/GED	20.8%
Post high school certification	2.1%
Some college	50.0%
2-year graduate (AA degree)	12.5%
4-year college graduate (BA/BS degree) or more	14.6%
Health insurance (not including access to care through the IHS)	
Yes	62.5%
No	37.5%
Majority of healthcare	
Indian Health Service	49.0%
Other	51.1%

* Percentages may not add up to 100% because participants could answer multiple options or leave the question blank.

Table 2

Screening Behaviors (n=48)

Screening experiences	
Ever talked with a doctor about breast cancer screening	41.7%
Ever been taught to do a breast self exam (BSE)	83.3%
Ever done a breast self exam	66.7%
Ever had a clinical breast exam	85.4%
Ever had a mammogram	25.0%
Ever had a mammogram, other than routine	33.3%
Timing of mammograms	
A year ago or less	16.7%
More than 1 but not more than 2 years ago	16.7%
More than 2 but not more than 5 years ago	25.0%
More than 5 years ago	41.7%

* Percentages may not add up to 100% because participants could answer multiple options or leave the question blank.