



American Indian Men's Perceptions of Breast Cancer Screening for American Indian Women

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Abstract

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Keywords

American Indian; breast cancer; breast cancer screening; community-based participatory research; social support

Cover Page Footnote

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ABSTRACT

Screening, especially screening mammography, is vital for decreasing breast cancer incidence and mortality. Screening rates in American Indian women are low compared to other racial/ethnic groups. In addition, American Indian women are diagnosed at more advanced stages and have lower 5-year survival rate than others. To better address the screening rates of American Indian women, focus groups (N=8) were conducted with American Indian men (N=42) to explore their perceptions of breast cancer screening for American Indian women. Our intent was to understand men's support level toward screening. Using a community-based participatory approach, focus groups were audio-taped, transcribed verbatim, and analyzed using a text analysis approach developed by our team. Topics discussed included breast cancer and screening knowledge, barriers to screening, and suggestions to improve screening rates. These findings can guide strategies to improve knowledge and awareness, communication among families and health care providers, and screening rates in American Indian communities.

Keywords: American Indian, breast cancer, breast cancer screening, community-based participatory research, social support

INTRODUCTION

Breast cancer is one of the most frequently diagnosed cancers in women (Kohler et al., 2011) and is the second leading cause of cancer mortality among American Indian and Alaska Native (AI/AN) women (Indian Health Service & Department of Health and Human Services, 2002-2003; Kohler et al., 2011). Past studies have shown that breast cancer incidence is lower among AI/AN than other racial/ethnic groups in the United States (American Cancer Society, 2004; Daley et al., 2011; Eberth, Huber, & Rene, 2010; Wingo et al., 2008). AI/AN have some of the lowest screening rates for major cancers and the poorest 5-year cancer survival rates of any racial/ethnic group (American Cancer Society, 2004; English et al., 2008). The 5-year breast cancer survival rate is only 50% for AI/AN compared to an average 62% for other racial/ethnic groups (non-Hispanic white, Hispanic, African American, Asian American, Hawaiian Native) (Clegg et al., 2002). For mammography, only 37% of eligible AI/AN women reported having a mammogram within the last year, and only 52% reported having a mammogram within the last two years (American Cancer Society, 2004). This is compared to 57% and 72% respectively among non-Hispanic white women (American Cancer Society, 2011).

Since 1980, breast cancer mortality has significantly decreased among all racial/ethnic groups with the exception of AI/AN (Stewart et al., 2004). Several factors that contribute to AI/AN women's poor mortality rates are limited access to screening, lack of cancer prevention education and lack of knowledge about breast cancer screening (Daley et al., 2011). Without preventive care there is an increased risk of detecting breast cancer at later stages (English et al., 2008; Li, Malone, & Daling, 2003; Ooi, Martinez, & Li, 2011; Wingo et al., 2008). Studies have found that AI/AN women have a 1.7 to 2.0 fold increased risk of being diagnosed with late stage breast cancer when compared to non-Hispanic whites (English et al., 2008; Li, Malone, & Daling, 2003).

Mammograms can detect breast cancer in its early stages when tumors may be too small to be felt (American Cancer Society, 2011). Early detection of breast cancer allows for increased treatment options and a better 5-year survival rate (Venkatramana, Sreedharan, Muttappallymyalil, & Thomas, 2011). Having access and overcoming barriers to this type of preventive screening are important for AI/AN populations (Daley et al., 2011). Because AI communities tend to be community-centered, social support is very important (English et al., 2008). Families play a key role in providing social support; therefore, understanding AI men's perspectives on breast cancer may enhance understanding of men's social roles in health decisions, particularly when it comes to breast cancer screening of AI women. As part of a larger study, we asked AI men about their perceptions of breast cancer and breast cancer screening among AI women, as well as what they perceived their role to be in helping decrease breast cancer disparities among AI women. Our overarching goal was two-fold: (1) To gain an understanding of what AI men know and want to know about breast cancer; and (2) To get AI men talking about breast cancer and what they might be able to do to help. To our knowledge, no previous studies report on men's social roles in health decisions on this topic. Pessimism among elder AI/AN has been reported as being detrimental to health outcomes of elder AI/AN women (Ruthig & Allery, 2008). This study used focus groups to assess perspectives of AI men toward breast cancer screening among AI women.

METHODS

We conducted a series of 8 focus groups with men aged 25 and older, stratified by age, to identify their knowledge and beliefs concerning women's breast cancer screening. Four groups were conducted with men 25 to 39 years of age and four with men 40 years of age and older in Kansas and Missouri. Demographic surveys were administered after participants provided consent and prior to the start of focus groups. Participant characteristics are listed in Table I. The focus groups were part of a larger study funded by Susan G. Komen for the Cure (POP0600430, PI: Daley) that took place from 2006-2008. All focus groups were moderated by men from the local AI community; moderators were trained prior to conducting groups. All focus groups were conducted in English. 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 men frequent, e-mail listservs from community organizations, and direct recruitment through our community advisory board. Participants received a \$25 gift card and a meal for their time and effort. Study protocols were approved by the University of Kansas Medical Center's Human Subjects Committee and local tribal councils, as appropriate.

Table I. Characteristics of American Indian Men \geq 20 Years of Age

Characteristic	Males aged \geq 20 years (n=42)
Median age (in years)	44
Age collapsed into 2 groups (in years): N (percent)	
20-40 years	12 (36.36)
\geq 40 years	21 (63.64)
Current living situation: N (percent)	
Married/Partner	22 (66.67)
Divorced/Widowed	7 (21.21)
Never Married	4 (12.12)
Highest grade/year of school completed: N (percent)	
Some high school	2 (6.06)
HS graduate/GED	6 (18.18)
Post HS certification	2 (6.06)
Some college	11 (33.33)
AA degree	4 (12.12)
BA/BS or more	8 (24.24)
Currently have health insurance outside of IHS: N (percent)	
No	9 (27.27)
Yes	24 (72.73)
Place most healthcare received: N (percent)	
IHS	13 (39.39)
KU Medical Center	5 (15.15)
Other healthcare facility	15 (45.45)
Have been diagnosed with cancer (other than breast cancer) by a doctor or other healthcare	

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professional: N (percent)	
No	31 (93.94)
Yes	1 (3.03)
Not sure	1 (3.03)
Self, spouse, or any blood relative diagnosed with breast cancer: N (percent)	
No	21 (62.50)
Yes	10 (31.25)
Not sure	2 (6.25)
Length of breast cancer for self, spouse, or family (in years): N (percent)	
< 1 year	1 (10.00)
1-5 years	3 (30.00)
6-10 years	3 (30.00)
11-15 years	1 (10.00)
16-20 years	1 (10.00)
> 21 years	1 (10.00)
No answer	23
Self, spouse, or family member received treatment for breast cancer: N (percent)	
No	1 (10.00)
Yes	8 (80.00)
Not sure	1 (10.00)
No answer	23

*Missing 9 surveys

Focus group moderator's guides were developed in conjunction with our community advisory board, based on prior interviews with community leaders and providers (Daley et al., 2011). Focus groups were held in both urban areas and on reservations during both days and evenings to accommodate participants with various work schedules. Group sessions lasted between 60 and 90 minutes and were audio-taped and transcribed verbatim. No additional groups were interviewed after data saturation was achieved on major themes. Focus group moderators and assistant moderators met with the study team to discuss whether or not saturation was achieved on major themes after completing three groups in each stratum. Moderators and assistant moderators took notes during all groups, which were discussed with the team. Based on these notes, the team decided to complete one more group per stratum to ensure saturation had occurred, after which they met again and agreed that saturation was reached on major themes. Saturation occurs when participants no longer mention major new ideas for each topic area (Bernard, 2006). Transcripts were coded by hand by three members of the research team using a codebook developed by both academic and community member researchers. The codebook was developed by coders who were members of the research team, including both emic and etic representatives. Once transcripts were read, an initial list of codes was identified inductively by all of the coders and the PI.

The research team identified topic areas covered in the focus groups and assigned them codes that could be used to organize the data for analysis, which were organized into a codebook.

After the codebook was drafted, the initial code list was reviewed by the coding team and a consensus was sought for the primary, secondary, and tertiary codes. Both academic and community members on the research team identified potential topic areas and codes based on the transcripts. Meetings to develop the codebook lasted approximately three months. The final codebook was agreed upon by consensus. Coders included both academic and community members of the research team, following a community-based participatory research protocol developed by the team (Daley et al., 2010). Throughout the coding process, the team met bi-weekly to ensure coding was being done in a similar way by all coders. Any discrepancies were thus able to be modified during the coding process. To ensure final inter-coder reliability, approximately 10% of the codes were cross-checked by the principal investigator (PI); 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. All exemplary quotes were identified by community members to ensure fair representation of the culture. Full details of the analytic process are described elsewhere (Daley et al., 2010).

RESULTS

Focus group themes clustered into 3 major topic areas: breast cancer and screening knowledge, screening barriers, and suggestions to encourage screening and awareness.

Breast Cancer and Screening Knowledge

Men aged 25 to 39 were unaware of breast cancer incidence and mortality rates and how these compare to other cancers. Their relative lack of knowledge led them to believe that breast cancer awareness is not a priority in Native communities. For example, a participant stated,

"I don't know that I could rank [various cancers]. I just look at cancer as bad. I don't know."

An absence of breast cancer facts and details was also found in the men aged 40 and over groups. In general, the older men had little knowledge about breast cancer, though some participants had learned about symptoms, causes, risks, and prevention due to family members who have had breast cancer. Older men related personal experiences of loved ones,

"I understood it's lumps. That's about all I know."

Another participant stated,

"Well the fact that she lost one breast... from a female standpoint I'm sure that's pretty threatening."

These statements exemplify some of their understanding through sympathy and concern. Some participants of the aged 40 and over group pondered why they had witnessed an increase in breast cancer in their communities over the years.

"You know, our great-grandparents, that generation, there weren't very many old people. But there are a lot more people in my parent's and grandparent's generation and my generation now because we're not dying from so many other things [as] before. We're old enough to get cancer."

Men aged 25 to 39 emphasized that breast cancer is a hereditary disease and is a concern for men and their families. The discussion of biology and transmission of genes was absent in the focus groups aged 40 and over.

Generally, younger participants did not have direct experience with breast cancer.

"Well this is a rather morbid way to look at it, but neither one of us know anyone that has had breast cancer. A presumption would be if we knew someone that had breast cancer a

whole lot of things would change in our world in the context of how we perceive that illness."

Due to limited experiences, younger men did not share the same sense of attention or consideration for breast cancer risks, symptoms, or prevention. In contrast, men aged 40 and older often knew that mammograms are used to detect breast cancer, but did not know further specifics. Those who had women close to them who have had breast cancer explained the importance of mammography.

"In today's time there's a good chance of catching it early. Preventative medicine, the mammograms... can be offered pretty frequently and regularly in an urban area, at least, at no cost, free screens and things of that nature, yes, I think it is."

Some men preferred to be on the periphery and did not desire a more central role in learning about breast cancer and screening.

"I think females are more familiar with it than men are and I think that's the more important issue."

Other men shared the common complaints women give of mammograms, such as

"I know a lot of women equate them to torture devices. Put their breast out on the table and smash it out flat, take an x-ray of it. They're not real happy about having it done."

Participants believed that women have more knowledge about breast cancer than men. This is in part due to the fact that men and women do not talk about women's body parts or mammography. Statements such as,

"... and I learned a long time ago, never say anything about a woman's body, it's really none of my business what happens there," and,

"My grandma, she had to get one [breast] removed, but that was all that was said that she has breast cancer and had to get one removed and that was end of subject," demonstrated common attitudes.

Screening Barriers

All groups agreed that certain factors inhibit mammogram use. These barriers include cost, lack of insurance, accessibility, and competing priorities (family and work).

"And I think that's what a lot of them probably do, again the availability, the money, no insurance, they're not going to get it because, you know, if it involves their kids. They'll send their kids [to the doctor], they'll probably break their backs to send them, not themselves."

The group aged 40 and over also mentioned embarrassment and privacy as factors that inhibit women from getting mammograms. Statements such as,

"I think Native women have a tendency to be a little bit more personal about this issue than other women outside of the Native community," and,

"I mean I know that most people tend to be more comfortable around a medical professional of their own sex. And I mean especially with the Natives tending to be a little bit more private, I'm sure that's more magnified with wanting to be with another woman during that type of testing,"

portrayed how men view the personal health issues of women.

The men aged 25 to 39 discussed the operation of hospitals and health centers as a reason women do not get mammograms. Younger men discussed their frustration with how the Indian Health Service (IHS) works.

"I think the Indian Health Service here sucks. So I think not as many people get mammograms because they go through the system you always get harassed; you don't have enough money, we can't fund that, why don't you wait about two, three, four, six months, you know."

Other comments were not specific to mammograms, rather the care provided by IHS and the difficulties navigating through the system.

"Just like when you get a referral down here... they gotta hold a meeting. They decide who's going to get what. Who's going to get the money to do this and do that for that? A person needs to have an operation, they gotta decide down here if they can... if they're going to give them the money or not."

Another barrier that came up in both strata revolved around communication. The men aged 25 to 39 thought that risk and prevention for breast cancer and other diseases are not discussed enough among Natives, including in family discussions. The group containing men aged 50 and older diverged from the younger men's group in attitudes toward promotion of screening of family members. Though most participants felt uncomfortable and embarrassed discussing breast cancer and mammograms, some have discussed them with their wives or family members if someone in their family has had breast cancer. These family conversations focused on how breast cancer and screening have evolved overtime,

"Now you see my mom never talked about it, my sisters never talked about it, but my wife and my daughters do, so yes, I think it's changing."

Other men not only sensed a change in communication dynamics, but also a change in approaches to health awareness.

"But men always stay to one group, women always stay in the other, but now the generation is starting to get to where the men can (be) involve(d) or do get involved."

Many men aged 40 and older believed that senior generations and people living on reservations may have trouble trusting Western medicine.

"I mean unless it was a downright emergency, we didn't go. Dad didn't trust doctors."

The participants did not go into detail to explain why they or their families did not trust Western medicine. Some mentioned past experiences where people were slighted. Others talked about the lack of trust in terms of a systems-level issue. And some based opinions on word-of-mouth,

"I didn't trust in doctors, I always went to grandma, take care of this or that and it was usually home remedies with us. I didn't trust a lot of the doctors... all you hear, 25 people hear the bad things and only five people hear the good things."

Suggestions

Participants aged 25 to 39 believed education about breast cancer should include culturally-tailored print media or other resources explaining breast cancer in simple terms with direct data.

"I have to be real honest, that yeah, when there's [sic] brown people on the front cover, I tend to look at it a little closer than if there were blonde-haired, blue-eyed people."

The information distributed to communities should not only look Native, but the details should include specific facts and figures that would help Native populations.

"The data that I want would be found in a pamphlet. What is the percentage, at what age, potential risk factors, potential positive things you can do, [and] treatment opportunities."

Participants aged 40 and older had many suggestions for improving mammography rates, but none are overwhelmingly supported. The comments reflected an array of activities, yet none of these was agreed upon in the focus group sessions. For example, one participant suggested exchanging ideas at a community gathering,

"We need to have an open forum, you know. We need to say, cards on the table, you know."

Other participants believed a possible solution is found in the training of Native health care workers,

"[name of a tribal university] as potential doctors, nurses, techs, because this is the future. These are the ones that are going to have to go back to the reservation, go back to wherever and educate and inform."

DISCUSSION

The purpose of this study was to understand AI men's perspectives about women's breast cancer screening. AI men had a basic knowledge of breast cancer and were familiar with many of the barriers that women experience when trying to access a mammogram. While many of these barriers are shared with other underserved populations, i.e., cost, lack of insurance, and competing priorities, some barriers may be more explicit to AI men and their families. While embarrassment and privacy are factors associated with other groups, they may be of particular importance among AIs. In comparison to AI men aged 25 to 39, men aged 40 and older described breast cancer within the context of women's experiences and stated that Native women tend to be more private than women in the general population. Men aged 40 and over were also more familiar with risks, symptoms, and treatments for breast cancer. Embarrassment and privacy issues may need to be addressed through family based education. Enhanced knowledge may lead to more support for women to get screened.

Other barriers mentioned were those related to trust. Young men (aged 25 to 39) viewed the IHS as a barrier to care. Even though local IHS facilities offer screening mammography through contract health services, the perceptions and prior experiences of many Natives were described as negative.

Participants in our study seemed receptive to and supportive of enhancing breast cancer screening among AI women. The suggestions from men aged 25 to 39 were for more culturally-tailored media that was simple, easy to access, and contained direct data. Men aged 40 and over gave no specific preference for future actions, but agreed that something needs to be done to raise awareness among AI/AN. Neither stratum offered suggestions that incorporate men or family-based support to promote breast cancer screening. This is somewhat surprising, because the data indicated that communication dynamics are changing within families. Gender relations in reference to breast cancer awareness and promotion are an important topic for future research.

This study contained two primary limitations. First, the number of participants was small in comparison to the number of AI men in the area. Second, this study was conducted in a limited geographic region, which included northeast Kansas and the Kansas City metropolitan area. Therefore, the generalizability of study results is limited. However, multi-tribal representation in our heterogeneous population derives from different parts of the country. Our research team identified behaviors upon which we can intervene to encourage education and screening throughout AI communities.

Overall, the implications of the results are two-fold. Both strata agreed that opportunities exist to enhance awareness and support for men's role in breast cancer education and screening decisions. By listening to our focus group participants, our research team is in the process of developing culturally-tailored breast cancer educational materials that promote awareness, screening, and resources designed specifically for the local community. In addition, we may better identify enhanced involvement of men in health decision making if researchers use study models that emphasize gender and household dynamics. Creating or using models that stress gender and household dynamics may be better suited to capture the changing positions and nuances of AI men's support roles in relation to health decisions that pertain to women's health, including breast cancer.

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