Research Article

American Indian Women and Screening Mammography: Findings from a Qualitative Study in Oklahoma

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ABSTRACT

Background: *Breast cancer is an important public health issue within the American Indian (AI) community in Oklahoma; however, there is limited information to explain the low screening mammography rates among AI women.* ***Purpose:*** *To identify the motivational factors affecting an AI woman's decision to obtain a mammogram.* ***Methods:*** *Through the use of the Theory of Planned Behavior, 24 elicitation interviews were conducted with eligible for mammography AI women obtaining services at an Oklahoma-based tribal clinic.* ***Results:*** *Most women had mixed attitudes toward screening mammography. Environmental-related factors also were cited as barriers in getting a screening mammogram and women recommended improved accessibility to mammography screening. Participants identified family members, friends and their personal physician as critical social referents. No specific culturally related beliefs or taboos were noted.* ***Discussion:*** *This study provides new theoretically guided insights into the motivation of AI women to obtain screening mammography. Future interventions to promote mammography screening among AI women may yield more effective results if key social referents are included in the decision-making process.* ***Translation to Health Education Practice:*** *Public health practitioners need to incorporate a socio-ecological approach to the design of a related intervention, and acknowledge the diversity in terms of cultural affiliation and beliefs within the AI population they serve.*

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BACKGROUND

Mammography is the single most effective method of early breast cancer detection because it can identify cancer several years before physical symptoms develop.[1,2] American Indian/Alaska Native (AI/AN) women have the lowest up-to-date mammography screening rates (70. 4%)[3] and are dying disproportionately due to advanced breast cancer disease compared to Caucasian women.[4] Despite efforts to promote breast cancer screening, the number of Oklahoman women who died from breast cancer during the last two decades did not change substantially,[5] and women of ethnic minorities and low socioeconomic status (SES) remained disproportionally under-screened.[6] Among AI women residing in the Potawatomi county (the study location), between 1997 and 2006 almost half (43%) of American Indians with breast cancer were diagnosed at an advanced regional stage, compared to only 25% of white women.[7]

Moreover, at the Citizen Potawatomi Nation Health Services (CPNHS), a tribal clinic that serves AI women in the CPN jurisdictional area, mammography screening

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rates for women of ages 52 to 64 have been declining during the last four years; 81.1% in 2005, 74.5% in 2006, 66.9% in 2007 and 35.3% in 2008. These findings indicate under-screening among the AI women in Oklahoma and the need for culturally appropriate mammography-related health promotion interventions.

To plan better and develop interventions to increase screening mammography rates among AI women, it is critical to understand the factors that contribute to the screening decision-making processes. According to the literature on AI women and mammography screening, reasons for not seeking mammography commonly are either personal or environmental. Personal reasons and beliefs include: (1) embarrassment;[8-10] (2) fatalistic beliefs;[8] (3) fears;[8,11] (4) family needs placed before a woman's needs;[12] (5) radiation from mammography causes cancer; [13] (6) breast cancer is a white woman's disease; [13] and (7) mammography is painful.[13] Environmental factors include: (1) mistrust of medical providers and conventional health care;[14-16] (2) long appointment waiting times; [15] (3) lack of transportation; [12,15] (4) lack of culturally sensitive care; [15] and (5e) lack of access to mammography screening.[14,15]

Physician recommendation has been established as woman's primary motivating factor to get a screening mammogram.[17, 18] However, within the AI population, only one study by Risendal et al[10] showed that physician referral was positively associated with recent mammography experience. Besides the physician's encouragement, other social factors include encouragement by significant others, such as family members, friends, and elderly.[19]

The role of the AI culture in mammography screening is not clear. Some studies show that women who participate in rituals and traditional ceremonies or who speak their native language are more likely to get a screening mammogram. [20,21] Others, like Canales and Geller,[14] show that women who were more connected to their AI identity were more likely to do Breast Self Examination, and so felt there was no need to get a screening mammography. In a more recent study by Canales et al, [22] it was found that the degree of traditionality was an important factor in the planning of a future mammogram. In fact, planning to have a mammogram was higher among AI women who tended to describe themselves as similar to non-Indians in most ways. This may be a more prevalent issue as more AI women move to urban areas coupled with the increased possibility that their acculturation within the dominant white culture might change their degree of affiliation within the AI culture.

Theoretical Framework

The Theory of Planned Behavior (TPB), an expectancy-value theory, was the conceptual model upon which we developed the interview guide and the methods for conducting the interviews. The TPB posits that intention is the immediate antecedent of the behavior and assumes it captures the motivation to behave in a particular way. In turn, intention is determined by three factors: attitude toward the behavior, subjective norms and perceived behavioral control. The TPB is a useful model in predicting intention and behavior and has not been applied in behavioral settings among the AI population. [23,24]

Several studies have utilized the TPB as the theoretical framework to study screening mammography.[25-29] However, one of the critiques of the theory was that it lacks the ability to capture the socio-cultural or environmental factors that are relevant to the beliefs that predict intention and make it less adaptable to minority populations.[30] One way to overcome this weakness is to incorporate qualitative research that addresses the socio-cultural context of the behavior. In response to this recommendation, our study also incorporated additional interview questions regarding the role of the AI culture in the decision making process of screening mammography as well as how AI women view the current health care services provided to them through the tribal clinic.

In addition to the TPB and its constructs, the study's theoretical framework also employed the construct of self-efficacy, a component of the Social Cognitive Theory (Figure1). Self-efficacy is defined as personal beliefs about how capable one is performing the behavior that leads to specific outcomes.[31] A few studies have examined the construct of self-efficacy in relation to mammography screening behavior or intention.[32-36] In all of these studies, self-efficacy seemed to be an important predictor of intention to get a screening mammogram. In addition, one study has shown that a breast cancer intervention that promoted self-efficacy was successful in promoting mammography screening within an AI community.[37]

PURPOSE

The overall aim of this study is to identify the motivational (psychosocial and cultural) factors affecting an AI woman's decision to obtain or not obtain a screening mammogram at a tribal clinic in Oklahoma. This will be accomplished through a series of individual interviews with women of the priority population. The results of the qualitative research will be used to develop an assessment survey that will measure the prevalence and relative importance of these motivational beliefs. Through convergence analysis the results of both qualitative and subsequent quantitative research will be used to inform program planners how to better design a culturally sensitive intervention promoting screening mammography based on a sound theoretical framework, such as the TPB as described earlier. Two research questions guide this study: (1) what motivates AI women to get screening mammograms; and (2)what is the role of the AI culture in the decision making process to get a screening mammogram?

As stated earlier the participation in screening mammography at the CPNHS is low and little research examined the reasons for such limited participation. Despite the plethora of beliefs associated with no regular mammography screening among AI women, no local research was ever conducted to find out why AI women in this geographical area do not get screening mammograms. The importance of conducting research at a local level due to the diversity of AI populations in terms of culture, history and

health behaviors across regions and tribes has already been documented.[38] Moreover, there are still important research questions to be answered based on the existing literature, such as what the physician's role is in mammography screening, to what degree culturally-associated beliefs influence a woman's decision to get a mammogram, and what the role of the environment is in making that decision. For these reasons, it is imperative to examine more fully the influences upon AI women's decisions to get a screening mammogram within a specific geographical location in Oklahoma.

METHODS

This study took place at a tribal clinic in Oklahoma, among a population of AI women who visited the CPNHS clinic during the fall of 2005 to obtain health-related services. The study focused on women who were at least 40 years of age, per the American Cancer Society guidelines that state that annual screening mammography begins once a woman reaches the age of 40.[39] Women 65 years of age and older were excluded, since past research has shown women aged 65 and older have different intentions and beliefs regarding screening mammography than women aged 50-64.[40] An advisory committee to the researchers was formed which was comprised of the directors, (administrative and medical) of the clinic, clinic staff and a breast cancer survivor. The advisory committee met monthly. During the meetings the lead researcher of the study informed the committee members about its progress and sought their advice as to how to better design the study, enhance the quality of data collection and interpret the results.

Measures, Materials and Procedures

The TPB guided the conduct of the interviewing process. The theory suggests conducting elicitation interviews with at least 20 individuals, about half of whom have performed or intend to perform the behavior under investigation and half of whom have not performed the behavior or do not intend to perform it.[41] Elicitation interviews are open-ended, semi-structured interviews with women in the priority population. We used a semi-structured format, with the interviewer asking specific questions to elicit information relevant to the TPB model constructs. For instance, to identify attitudes related to mammography, women were asked about perceived advantages regarding screening mammography. Formative research through elicitation interviews is recommended within special populations in order to identify specific, salient beliefs which may extend the explanatory power of the TPB constructs.[42]

The development of the questions assessing self-efficacy was based on a guide for constructing self-efficacy scales.[43] The guide suggests asking participants in open-ended interviews to describe the things that make it hard for them to regularly seek mammography. We also asked each woman to describe the steps that they usually go through to get a mammogram and the degree of difficulty they experience in achieving these tasks. Table 1 summarizes the seventeen lead questions and their corresponding constructs of the TPB and self-efficacy. Additional questions were asked to respond to some of the advisory committee's research questions, such as what are the women's beliefs on breast cancer and how the women perceived the quality of care they receive at the clinic. The discussion guide was pilot tested with three women who were members of the priority population, and then revised accordingly.

Eligible women for elicitation interviews were identified from the participating clinic's computerized list of women eligible for mammography. The women were then stratified- through the creation of cells or subgroups- according to the following criteria: (1) their status of past mammography experience (i.e., women who have been participating in mammography screening regularly vs. women who never had a mammogram or have not had a mammogram within the last three years); (2) whether they had private health insurance, and (3) by age (40-49, 50-59 and 60-64). This stratification ensured that we had a diverse group of interviewees to provide a variety of ideas. Two to five women were randomly selected from each cell and invited to be interviewed. The purpose of random selection was to promote credibility and reduce suspicion about why certain women were selected for the study.[44]

In a letter signed by the clinic director, women were invited to participate in the study, then invited by telephone to set up an interview. All study participants completed an informed consent form which was approved by the University of Oklahoma Health Science Center Institutional Review Board office, and were offered financial reimbursement ($20) for their time. The interviews were conducted by an AI research graduate student trained in qualitative research methods. Each interview was performed at the clinic, lasted on average for about 50 minutes, and was audio-tape recorded while the interviewer took notes. The tapes were transcribed by the research graduate student to facilitate content analysis.

Once each interview was transcribed, the PI listened to the tape while reading the transcript to verify that the transcript represented the discussion. If needed, the PI edited the transcription. The PI also provided feedback to the research graduate student, especially at the beginning of the interviewing process, on how to improve her interviewing skills, for instance, by identifying gaps in the information received and prompting for more follow-up questioning. Once the transcription of all interviews was done, four transcripts were randomly chosen and the PI and a graduate student coded the transcripts independently. Coding refers to the process of assigning labels to text so that the researchers can group and compare similar pieces of information. Once the coding was completed, each coder developed a code-book. Later the two coders met to compare results and finalize the coding book, which was used to guide the rest of the coding of the transcripts by the research graduate student. All coded transcripts were then imported into a software program (QSR N*Vivo 2.0) to facilitate management and retrieval of the qualitative data. Content analysis was based on the coded qualita-

Table 1. Women's Elicitation Interview Leading Questions

1. Please tell me a little bit about yourself: where you grew up, where you currently live, if you have any family, etc.
2. What does being healthy mean to you?
3. When I say the word breast cancer, what does this mean to you?
4. What do you do to protect yourself from breast cancer?
5. How much of a threat do you consider breast cancer to be for you?
6. Do you talk with other people about breast cancer?
7. One way to detect breast cancer early is having a mammogram. Please tell me everything you know about mammography.
8. Describe to me any important experience that you had related to mammography.
9. Do you talk with other people about mammography?
10. Now I would like you to take a minute and think of the next time that you will get a screening mammogram, maybe in six months or 10 years. Just tell me the first 5-10 things that come to your mind as quickly as possible when you think of getting a mammogram.
11. Based on the things you've said, in what ways do you think mammography affects your life? What are the advantages of mammography screening? What are the disadvantages of mammography screening? (Attitude)
12. When I asked you to think about things related to mammography, did you any people, groups, or organizations come to mind as you thought about having a mammogram? If so, tell me those people/organizations by their role or relationship to you rather than by name. In what ways do these people/ groups/ organizations influence your decision to get a mammogram? (Subjective norms)
13. Now, assume you have decided to get a screening mammogram sometime in the near future. I would like you to think for a minute and write down all the steps that you go through from the time you make the decision until the time you actually receive the results of the mammogram. After you do that, I want you to rate on a scale of 1-10 (10 being the most difficult) how difficult it is to accomplish each step. (Self-efficacy)
14. According to the latest recommendation guidelines, women are supposed to get a mammogram every one to two years. Now what makes it difficult for you to get a mammogram on a regular basis? (Perceived behavioral control)
15. We've talked so far about things that make it difficult for you (or other women) to get a mammogram. Now, I want you to think for a minute and tell me things that might make it easier for you to get a mammogram on a regular basis. (Perceived behavioral control)
16. Now, we will change the subject of our discussion and we will talk about you and particularly being a Native American woman. Based on the demographic information you have filled out, you belong to the … tribe. What does being a member of this particular tribe mean to you? Describe your tribe.
17. According to our records, you have been/ have not been getting a mammogram on a regular basis. What makes you come back/ or not come back and get a mammogram? (Self-efficacy/Perceived behavioral control)

tive data.[45] A table for the data analysis was developed, which included constructs and their definitions, and the main nodes (or codes) that were combined to retrieve the content related to the construct. The analysis was first done within each subgroup (i.e., women with or without recent mammography experience). The results from the two subgroups were then merged to identify themes that were important to all women. Common themes were identified through the analysis done via QSR N*Vivo 2.0 and verified by the researchers' visual inspection of the data. Themes were said to be related and important if they were mentioned more than once by at least half of all the participants. Key ideas were defined as those ideas mentioned not as frequently as the thematic ideas, but were viewed as important.

To ensure that we reached data saturation, we conducted two additional focus groups (N=6) at the end of the elicitation interview series with additional women. No new information was obtained in the focus group research, and therefore we are confident that we reached data saturation.

RESULTS

Participant Demographics

Twenty-four women were interviewed. Fourteen had a regular mammogram within the last three years, and the rest had not obtained a mammogram within the last three years. Eight tribes were represented in the sample. The participants' mean age was 52 years (SD=1.5), with 38 % between 40-49 years of age and 62% between 50-64 years of age. The majority of the participants (30%) belonged to the Citizen Potawatomi Tribe. Almost half of the women were married and had children. Most stated they had at least a high school education and 58% had education beyond high school, including some with graduate education. The gross annual income for half of the women fell below $20,000. Please note that even though we did not specify whether the annual income referred to household or personal income, based on the fact that the majority of the women (55%) were not married, one can assume that the majority of the income

reported was personal income. Table 2 summarizes the information on participants' demographics and the tribal affiliation.

Themes

Several themes across participants and key ideas emerged from the analysis of text segments regarding women's perceptions of breast cancer and mammography. The data gathered in this study consistently identified the following themes and key ideas- according to the TPB- as major factors influencing AI women's decision to get a screening mammogram: (1) mixed attitudes toward mammography; (2) subjective norms; (3) perceived behavioral control barriers toward mammography screening; (4) perceived behavioral control-facilitators toward mammography screening; (5) self-efficacy (i.e., decision-making steps toward mammography screening) ; (6) negative attitude toward breast cancer; (7) communication with personal physician on mammography screening; (8) positive attitude toward the health care services women receive at the clinic; and (9) cultural related factors toward mammography screening. Each theme, discussed below, has been arranged to reflect the appropriate TPB construct.

Attitude toward the behavior: Mixed Attitudes toward mammography screening

Women were asked to tell us some of the first things that came on their mind when they thought of mammography. Women, overall, expressed more negative attitudinal beliefs than positive ones toward mammography. The women talked about embarrassment associated with exposing one's private parts, pain and discomfort as well as fear of finding one if she has breast cancer. In fact, pain and fear were identified as prevailing beliefs among most women regardless of their previous mammography history.

On the other hand, most of the women expressed a positive attitude toward mammography as they had expected that mammography would result in early detection of breast cancer and possibly better clinical outcomes. A few women mentioned that mammography helps them live longer and continue caring for their families especially their children and grandchildren. Moreover, some women expressed the idea that mammography would make them feel good about themselves because it is an act of taking care of themselves; it may result in relief finding out whether they have breast cancer or not instead of wondering about it.

Subjective Norms

The subjective norm or social influence refers to persons, groups of people, or organizations that might encourage women, either through their own behavior, verbally, or in some other way, to get a mammogram on a regular basis. Whereas no themes emerged, we identified a few key ideas.

For instance, women who regularly obtain mammograms know other women who also have mammograms. These other women could be family members (e.g., daughters), friends, coworkers, or members of their extended social network, and they often discussed their mammography experience with them.

When asked about the specific role that family plays in their decision whether to get a mammogram or not, the women said family members (including husbands, sons and daughters) encourage and even remind the women to get a mammogram. On the other hand, a few women without recent mammography experience said that their family plays no role in their decision to get or not get a screening mammogram and that it is primarily up to them to decide.

Perceived Behavioral Control-Barriers toward mammography screening

In terms of barriers, no themes were identified. However, some key ideas were uncovered. For instance, most women with recent mammography experience considered scheduling to be a significant barrier for themselves and others. Scheduling referred to problems of taking time off work, coordinating personal schedules or simply setting up appointments. Another issue was lack of transportation to the mammography site. Language barriers, especially among older American Indians who may not have received a high school education or speak English fluently, were mentioned as barriers to fully understanding the information regarding mammography received in pamphlets or orally from their physicians. Another important idea, identified primarily among women without recent mammography experience was procrastination, which was cited as an excuse for not having a regular mammogram.

Perceived Behavioral Control-Facilitators toward mammography screening

Regarding facilitators toward screening mammography, no themes were identified in at least 50% of the transcripts. Key ideas mentioned include having female staff involved in screening and/or making scheduling procedures easier for the women. Many women stated that a more accessible mammography site would make it easier for them to get a mammogram. These women suggested several ways to increase accessibility to mammography screening, such as the use of a local mammography facility, the use of a mobile screening mammography unit, or the provision of mammograms at local tribal clinics. Another interesting idea mentioned was providing women a step-by- step description of the mammography procedure, as well as training the staff to use a more personable approach to alleviate some of the fear and anxiety women experience during the mammography procedure.

Moreover, many women without recent mammography experience felt that changing the way in which mammograms are scheduled would make it easier for them to receive a mammogram. They referred to the flexibility, the time and day when appointments are offered and the reminders to them for scheduling the mammogram.

As said earlier, apart from the TPB constructs, we have also included the self-efficacy construct as well as some additional questions that seemed to be important to the advisory committee members. The following are the results pertaining to these questions.

Self-Efficacy: Decision-making steps toward mammography screening

Participants were asked to describe the steps that they would take from the time they decided to get a mammogram until the time they received their mammography

Table 2. Demographic Characteristics of Participants

	Recent Mammography Experience (*N* = 14)		Without Mammography Experience (*N* = 10)		Overall (*N* = 24)	
	N	%	*N*	%	*N*	%
Age						
40-50	6	42.9	4	40	10	41.7
51-65	8	57.1	6	60	14	58.3
Marital Status						
Single	1	7.1	2	20	3	12.5
Married	6	42.9	5	50	11	45.8
Divorced	5	35.7	1	10	6	25
Separated	0	0	1	10	1	4.2
Widowed	2	14.3	1	10	3	12.5
Education						
Some High School (HS)	3	21.4	2	20	5	20.8
HS Diploma or GED	4	28.6	1	10	5	20.8
Some College	6	42.8	4	40	10	41.7
Bachelor's Degree	1	7.1	2	20	3	12.5
Some Graduate School	1	7.1	0	0	1	4.2
Income ($)						
0-9,999	4	28.6	6	60	10	41.7
10-19,999	3	21.4	0	0	3	12.5
20-29,999	5	35.7	1	10	6	25
30-39,999	1	7.15	2	20	3	12.5
40-49,999	1	7.15	1	10	2	8.3
Type of Residence						
Rural	4	28.6	5	50	9	37.5
Town	9	64.3	4	40	13	54.2
Urban	0	0	1	10	1	4.15
Metropolitan	1	7.1	0	0	1	4.15
Tribal affiliation						
Citizen Potawatomi	5		2		7	29.2
Choctaw	2		0		2	8.3
Creek	2		1		3	12.5
Chickasaw	2		1		3	12.5
Cherokee	2		2		4	16.7
Seminole	0		1		1	4.2
Sac& Fox	0		2		2	8.3
Seminole-Creek	1		1		2	8.3

results. They were also told to rate on a scale of 1-10, with 10 being the most difficult, how difficult each step would be.

Upon reviewing all the steps that women mentioned during the interviews, we created the following set of decision steps, with the average perceived degree of difficulty shown in parentheses; the higher the number in the parentheses the higher the degree of difficulty.

Women with recent mammography experience indicated the following: (1) decide to get a mammogram (Difficulty=3); (2) talk to doctor about referral (Difficulty=2); (3) make appointment through contract health (Difficulty=2); (4) make arrangements with place of employment (Difficulty=2); (5) go to appointment (Difficulty=2); (6) get undressed (Difficulty=4); (7) put on gown (Difficulty=1); (8) go to the room where the mammogram is performed (Difficulty=5); (9) have the mammogram done (Difficulty=7); (10) get dressed (Difficulty=4); (11) wait for results (Difficulty=7); and (12) talk to doctor (Difficulty unrated).

Women without recent mammography experience were far less vocal on this question. When looking at their results the following steps were established: (1) decide to do it (Difficulty unrated); (2) schedule annual exam (Difficulty=5); (3) have annual exam (Difficulty=7); (4) get referral for a mammogram (Difficulty=5); (5) schedule mammogram (Difficulty=5); (6) take off work (Difficulty=7); (7) have the mammogram done (Difficulty=7); (8) go home (Difficulty unrated), (9) forget about it (Difficulty unrated); and (10) wait for results (Difficulty=3).

Negative attitude toward breast cancer

Before we started our discussions on mammography with the participants, the interview team elicited information on how women perceived breast cancer, which served as a framework for the discussion to follow. Most women revealed negative feelings toward breast cancer. In fact, several women associated breast cancer with death, pain and suffering as the following comment illustrates:

> "Illness, pain, suffering it's not only hard on the person that has breast cancer but it's hard on the family as well. It can cause a lot of problems emotionally as well as physically." [Woman with recent mammography experience, 50-64 years old, with no insurance]

Moreover, an overwhelming number of women did not feel that breast cancer was a white woman's disease. Most women felt that it could happen to any woman regardless of their race/ethnicity, as shown in the following statement:

> "No it's not racial. It could be any race. That's a myth. I think probably a lot of Indian women have had it at one time but a lot of them didn't go to the doctor back then. So they probably thought it was another health issue that caused their death." [Woman without recent mammography experience, 40-49 years old, with insurance]

Communication with personal physician about mammography

Women who had regular mammograms were for the most part satisfied with communication between themselves and their physicians. In other words, most women did not suggest anything that would improve this communication or anything that hindered their communication. In addition, most of the women in this group said that it was their physician who initiated any discussions they had about mammography and breast cancer. When women were asked what were some of the topics they talked about, these included scheduling and referral issues as well as perceived risk of developing breast cancer.

On the other hand, women without recent mammography experience, reported that they do not discuss mammography screening with their personal physician despite the fact that a few of them (two in fact) admitted that their physician attempted to broach the subject. When women were asked what would make it easier for them to talk with their physician about mammography and breast cancer they provided a variety of answers. These included: (1) physician broaching the subject because it is a subject they don't usually think about; (2) the provider they were dealing with were female; (3) having a good repartee with the physician.

Positive attitude toward the health care services women receive at the clinic

As a theme, women were satisfied with the health care they receive through the local clinic. The majority of the women described the clinic staff as supportive, helpful and caring.

Despite the overall positive perception of the health care system, a few women, primarily those without recent mammography experience, expressed negative attitudes. Some of the participants commented on problems with communication with the physician and the lack of a holistic approach toward treatment. In addition, women mentioned that the health care system was too business-oriented and not as personalized as it was in the past. Moreover, there was a perception of substandard health care provided at tribal and Indian Health System care facilities. Some representative comments are shown below:

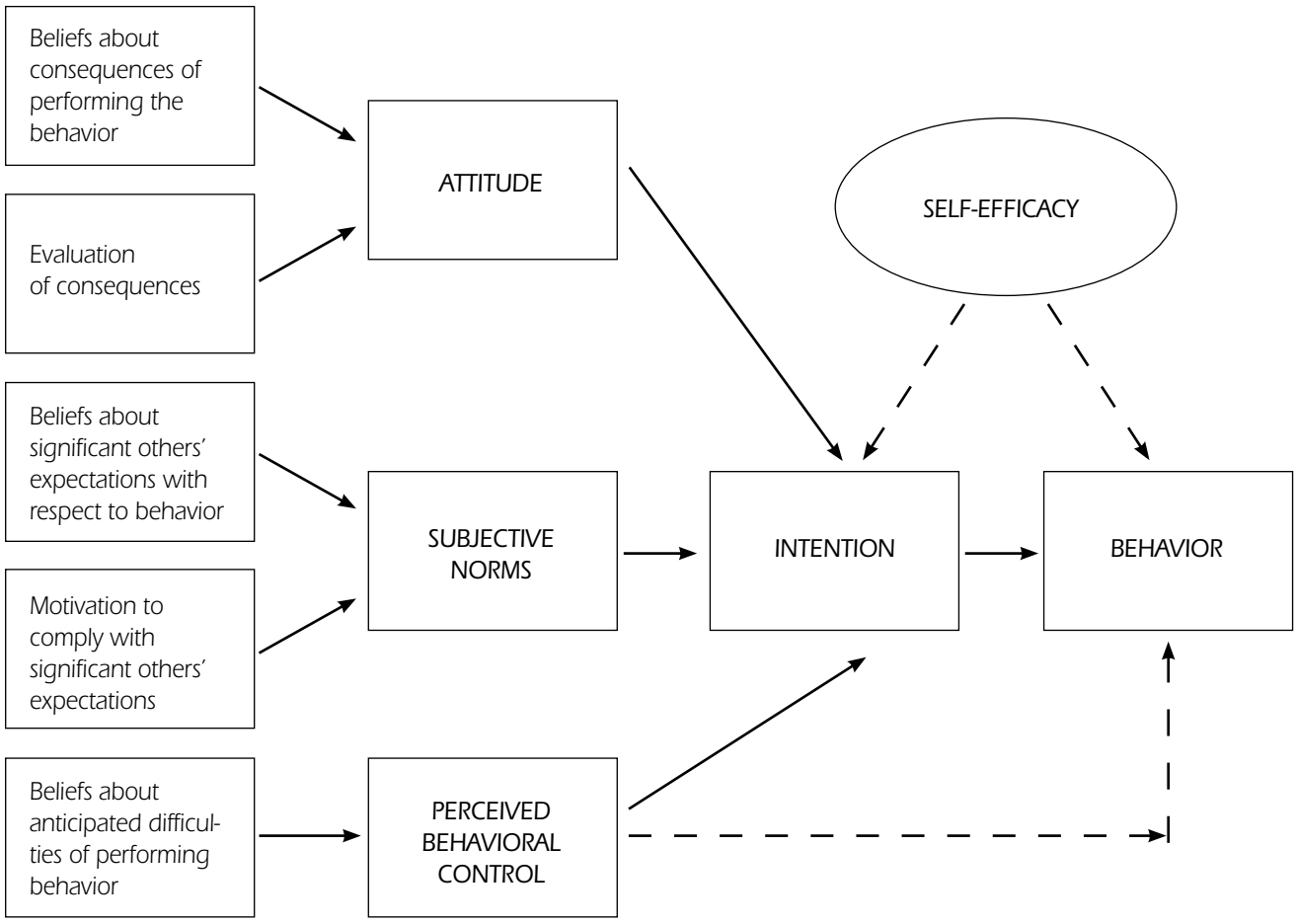
> "I think it needs to be improved in the way that doctors talk to you, to explain things in simple terms and thoroughly with you. Sometimes they use big words you don't understand and you're confused about what they're talking about, and sometimes reluctant to pinpoint down things you don't understand." [Woman with recent mammography behavior, 50-64 years old, with insurance]

> "I don't have anything against the doctors they do a good job, but mostly I feel they treat symptoms and prescribe medication. Medication and surgery is their only answer and there are other ways I feel." [Woman without recent mammography experience, 50-64 years old, no insurance]

Culturally related factors toward mammography screening

During the interviews, it was difficult to

Figure 1. The Expanded Framework of the Theory of Planned Behavior with the Construct of Self-efficacy



Note. The solid lines refer to a definite direct link between two components, whereas the dotted lines to a possible direct link between two components.

elicit specific cultural beliefs on mammography screening. In order to overcome this difficulty, we used the funnel approach of interviewing by starting out a conversation with asking women to describe the rituals associated with the tribe they belonged to, then move the topic of our conversation toward specific beliefs on life, death, family, society, traditional medicine, overall health, cancer and mammography screening.[46] In this section we will only describe the highlights of our conversations.

> Many participants talked about the use of traditional medicine as a way of healing various diseases. Participants mentioned either of knowing someone (e.g., a grandmother, an uncle) who uses traditional medicine or themselves learning to use traditional medicine. They also mentioned personal experiences with traditional medicine, primarily during their childhood. One interesting idea was that Indian people are more susceptible than people from other ethnic and racial groups to diseases. As one woman said "We are more susceptible because of the Indian in us." [Woman with recent mammography experience, 50-64 years old, no insurance].

The discussion on culture also centered on the woman's role in the AI society. Among a variety of opinions, the overall sense was that the woman's role is changing from a more traditional (e.g., taking care of family particularly children) to a more modern one, such as being part of family and tribal decision-making. One interesting traditional practice mentioned was that women in some families are separated from their family during their menstrual cycle. For instance, they are not allowed to eat at the table with the family, they are separated from the men, and they cannot participate in tribal activities. In regards to the woman's position in relation to the man's position in the family, the participants' views ranged from the woman's position as equal to the men to subordinate to them.

However, many women mentioned that women are the leaders in the family. Women are considered to be the ones

who care for and hold the family together. They are responsible for their children and often take the responsibility of raising their grandchildren also. Women were seen as the "pillar" of the family unit. Finally, a few women discussed being active in their churches and a strong belief in Christianity was apparent among some of the women. A few women mentioned changing from traditional beliefs to Christianity and seemed doubtful that the two could be practiced simultaneously. Here is an illustrative comment regarding the role of women in the AI society:

> The woman's role in our traditional way is to be submissive. To do things that were traditionally done by women I think of all races. To care for the family to take care of the husband's needs. The women in our tribe are very strong women. Even the ones that are still into our traditional ways either at church or at the stomp dances, they are not vocal. They don't need to be vocal, but they're very strong in general. I have to say they lead their families. [Woman with recent mammography experience, 50-64 years old, with insurance]

To summarize, our qualitative research revealed some interesting findings regarding AI women's beliefs toward mammography screening using the TPB as the framework for the elicitation of these beliefs. The careful sampling procedure of recruiting women from various SES backgrounds and most importantly past mammographic experiences, revealed a plethora of rich insights regarding mammography screening. Some of the highlights include the mixed attitudes toward mammography with more prominent the beliefs about fear and pain associated with mammography, the inclusion of family (e.g., husbands and daughters), friends and personal physicians as social referents toward mammography screening, the description of various environmental factors such as scheduling procedures that impede regular mammography screening, and finally the description of culturally related beliefs that are centered on the use of traditional medicine and the role of AI woman in the broader AI community.

DISCUSSION

The purpose of this study was to identify the theoretically-based motivational factors affecting an AI woman's decision to obtain a mammogram and the role that American Indian culture plays in mammography utilization.

In general, this study found mixed attitudes toward screening mammography. Women noted that mammograms are useful for the early detection of breast cancer and to help them stay healthy enough to take care of their children and loved ones. These beliefs are in line with existing research findings among AI women and other minority populations.[12,47] Women also expressed concerns about embarrassment resulting from exposing their breasts to other people and concerns about discomfort and pain they believe are associated with mammograms. The existence of these beliefs is also supported by the relevant literature.[8,13]

An additional resounding finding was that fear strongly regulates an American Indian woman's decision to get breast cancer screening. This finding raises concerns regarding how to motivate women to get a mammogram, since fear is deeply rooted in the consciousness of the women, and is hard to uproot merely by providing information about screening guidelines. One must wonder if women citing procrastination as one reason for not getting a screening mammogram is an example of "avoidance behavior," or a more pervasive underlying fear.[48] Another finding that underscores the existence of fear is the fact that many women associate breast cancer with death. Perhaps AI women have been more likely to witness other women dying from breast cancer once they are diagnosed with the disease, even though it is well known that women can survive breast cancer. Previous research also supports the presence of fear of death associated with breast cancer.[11,19] AI women have noted that they are less likely to get breast cancer but when they do, it is deadly.[13,49]

This study revealed another interesting finding as most women indicated that breast cancer does not abide by racial boundaries and that it can affect all women, regardless of their race and ethnicity. This is in contrast with existing literature in which American Indian women stated that breast cancer is a white woman's disease.[13] This finding shows that there is a growing awareness among the AI women who participated in this study about the prevalence of breast cancer across racial/ethnic groups. This could be attributed to the fact that they live close to a metropolitan area; they come in contact with women from other racial and ethnic groups and therefore observe other women, not only American Indians and Caucasians, who also develop breast cancer.

In terms of subjective norms or social influence, women did not identify a predominant person or entity as influential in their decision-making. Nonetheless, family encouragement, particularly the influence by daughters, as well as physician recommendation were a few key ideas mentioned as supported by the literature.[10] Our research shed some more light on this aspect by providing specific recommendations by women who are less likely to get a mammogram, on how to improve their communication with the physician in regards to mammography screening. Moreover, this is the first time that adult daughters are mentioned as social referents for breast cancer screening. Adult-daughters have been mentioned previously as social referents among Filipina and Latina women.[50]

Women also said that they know other women who get screening mammograms—family members, friends and coworkers—and that they discuss mammography with them. Social modeling has been used in the past to promote mammography screening among AI women;[37] and therefore, we anticipated that social modeling could be an important motivating factor for screening mammography among AI women of this study as well. Interestingly enough, elders were not mentioned as possible sources of influence regarding screening mammography, despite the fact that the literature suggests the opposite.[19] One possible expla-

nation is that the elders who reside among this study population are more likely to use traditional healing methods to deal with health issues in general and are relatively unfamiliar with mammography screening. Another possible explanation is that breast health is a sensitive topic of discussion and not openly discussed among elder AI women. More qualitative research is needed to explore this aspect of social influence.

Related to the construct of social modeling is self-efficacy.[31] The results pertaining to self-efficacy lead to the following observations. First, more decision-making steps were cited by women with recent mammography experience than those without (perhaps because they were more likely to be familiar with the mammography process). Second, women without a recent mammography experience, in general, indicated more difficulty in accomplishing the tasks that lead to mammography screening than those with a recent mammogram. This could be an early indication that lack of self-efficacy in obtaining a regular screening mammogram plays a role in the decision-making process.

Most of the barriers mentioned were contextual factors such as scheduling (e.g., taking time off work) or obtaining transportation to the mammography site. Moreover, based on the self-efficacy question results one can observe that women without a recent mammography experience cited more difficulty in achieving tasks such as scheduling a mammogram or taking time off work to get a mammogram. This further underscores the importance of these contextual barriers. Becker and Foxall [16] showed that women in some areas of the country perceive cancer-screening services as prescribed procedures leaving few options for women's choices and preferences. Physicians in some areas may expect women to conform to demands that do not permit a woman to receive a mammogram until a clinical breast examination has been scheduled and completed.[16]

In terms of facilitators, women made specific suggestions on how to facilitate decision-making. A few suggestions related to contextual issues such as making scheduling easier for women, providing greater access to mammography screening through better time offerings, provision of transportation to the clinic, use of a mammography site at a local facility, or use of a mobile mammography unit. Women suggested that staff employ a more personable approach by providing step by step descriptions on what women can expect during the mammography screening.

Women's emphasis on improving environmental factors is not surprising as literature has shown that contextual or environmental factors play important roles in promoting mammography screening.[15,51] In addition, these findings emphasize the importance of a socio-ecological approach toward prevention of breast cancer as also supported by the literature.[49] The social ecological model suggests that, to achieve the desired health outcomes, changes need to occur at the personal, interpersonal, community, organizational and policy levels. [52] An example of change at an organizational level may be the enactment of policies conducive to mammography screening. An example at a community level includes the use of existing social networks to promote mammography screening. Currently, there is limited emphasis on designing and implementing interventions using this broader ecological approach among AI populations.[49] Most of the interventions address either the intrapersonal level (e.g. lack of knowledge) or inter-personal level (e.g., social modeling) through the provision of social support, outreach and educational activities.[53]

Women's attitudes were generally positive toward the services they receive from the tribal clinic and toward their communication with clinic physicians. These findings contrast with those found in the literature which are lack of culturally sensitive care, or mistrust toward the medical care providers.[15] The positive attitudes expressed in this study could be attributed to the fact that it took place at a tribal clinic where many of the medical personnel are of AI descent. Moreover, all the clinic's patients are American Indians, and therefore there is some degree of cultural sensitivity.

On the other hand, women without recent mammography experience voiced dissatisfaction with the health care services they currently receive, with the lack of a holistic approach toward treatment, and with communication issues with physicians, all barriers that previous literature has documented.[14,15]

Regarding the second research question, we did not identify any cultural beliefs or taboos specific to mammography screening or breast cancer despite earlier research that has shown the opposite.[49,54] This could be attributed to the fact that women in this study lived close to a metropolitan area, and therefore were more likely to come in contact with non-native women, and may be more acculturated to the dominant white culture.

However, AI women noted culturally related beliefs on the subject of health, and specifically on the use of traditional medicine, as well as on the role they play in the AI society. Women stated that their role is changing from a traditional to a more modern one where women contribute to family and even tribal decision-making. We are unsure how the women's changing roles might impact their decisions to seek screening mammography, but one can speculate that, as more women become leaders in their families and in tribes, they become more empowered and thus more likely to take an active role in seeking health care and preventive measures toward diseases.

On the other hand, AI women consider themselves as their families' main caregivers. This belief might relate to two other findings of this research. First, AI women are less likely to get a mammogram because they have no time to do that, as they are busy taking care of their family members. Second, mammography is an important screening test to them because it enables them to live longer and take care of their children and extended family.

As with all qualitative studies, the results of this study cannot be generalized beyond the small number of AI women who participated in it. Nevertheless, the results provide great insights as to why AI women in Okla-

homa, despite the fact that they have *free access* to screening mammography, still do not get regular mammograms. Specifically, the results suggested that women have mixed attitudes toward mammography with some indication that fear of cancer and its association with death can be a deterrent for regular mammography. Nonetheless, no specific culturally related beliefs or taboos were associated with breast cancer. Moreover, family, friends and physician recommendation can be also important motivating factors. Environmental factors such as scheduling issues may also be additional key factors to consider in the promotion of mammography screening among AI women.

TRANSLATION TO HEALTH PROMOTION PRACTICE

Upon identifying the salient beliefs on mammography screening, the salient beliefs were then transformed into item-statements which comprised specific scales part of a larger survey that we used to quantitatively measure the association of each belief to the intention to get a future screening mammogram. Through reliability assessment and factor analysis, nine sub-scales were developed reflecting the four major constructs of the expanded TPB consisting of 46 items. The names of the subscales, the number of items used to measure them, and the corresponding Cronbach's alpha are shown below: (1) positive attitude, 14 items, 0.96; (2) negative attitude, 6 items, 0.81; (3) attitude-mistrust toward mammography, 2, 0.81; (4) perceived behavioral control-facilitators, 5 items, 0.75; (5) perceived behavioral control-barriers, 5 items, 0.89; (6) subjective norms-family/friends, 5 items, 0.90; (7) subjective norms-physician, 2 items, 0.75; (8) self-efficacy-scheduling, 4 items, 0.71; and (9) self-efficacy-procrastination, 3 items, 0.79. One can observe that all subscales as they emerged through factor analysis corresponded to the theoretical framework. Moreover, they were reliable with reliability coefficients ranging from 0.71 to 0.96. This is an important finding that shows how useful the TPB was in providing a framework for eliciting salient beliefs in this special population by utilizing contrasting (in terms of past behavior) sub-populations. This approach generated a plethora of *unique* positive and negative beliefs associated with mammography screening for this population. However, it is premature to state which of the above beliefs will be most important to focus on in the design of health promotion programs. Moreover, it is unclear what role cultural affiliation plays for all American Indian women (rural/reservation and urban) in the decision making process of getting a mammogram. Future quantitative research will facilitate the determination of the relationship between beliefs, cultural affiliation, and intention to get a mammogram.

Furthermore, the use of semi-structured individual interviews as suggested by the TPB, rather than focusing primarily on group research as it has been done in the past among AI populations, has provided a broader understanding of the belief system regarding mammography screening among AI women.[11,19,49] One can argue that conducting interviews regarding mammography screening at a clinic setting could introduce bias to the study. However, there are numerous studies that have used successfully this approach.[55,56] In addition, as the TPB suggests we made sure that we interviewed women who did not get regular mammograms in order to have as much balance as possible on mammography screening perspectives and the quality of care the patients receive from the clinic. The fact that we have received both negative and positive beliefs showed that the interviewers probed in depth and attempted to elicit both perspectives. In addition, this is the first study of its kind conducted within this specific AI population. From a health promotion perspective, according to the Theory of Diffusion of Innovation (Rogers, 1995), a new program, or an innovation that will be designed based on the results of this study will be better diffused within the broader AI population when it is launched among women who already have some access to services (i.e., early majority), rather than among women who do not use the clinic services at all (i.e., laggards).[57] These are the women who interact frequently with their peers, are somewhat resourceful and are not very educated. Educational innovations promoting screening mammography could become more effective by first influencing the interpersonal networks of the early majority along with making the success of the innovation more visible.

To conclude, the results of this study point into two major considerations: (1) The use of a socio-ecological approach toward the design of a related intervention by addressing all levels of intervention (i.e., intrapersonal, interpersonal, community, organizational, and policy levels); and (2) The understanding that there is diversity among the AI tribes in terms of their behavioral, normative, control, and cultural beliefs their members hold as well as the practice of health-related behaviors.[38] Therefore, it is important that practitioners consider the degree of traditionality or connection to the Native American identity of the population they serve, as well as the existence of unique salient beliefs during the planning of a related intervention.

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