Published in final edited form as:

J Transcult Nurs. 2015 March ; 26(2): 137–145. doi:10.1177/1043659614523994.

Factors That Influence Mammography Use among Older American Indian and Alaska Native Women

Rosalina D. James, PhD^{1,*}, Dana E. Gold, BA¹, Arlene St John BlackBird, RN BSN², and Susan Brown Trinidad, MA¹

¹University of Washington, Dept Bioethics & Humanities, Seattle, WA, USA

²Cheyenne River Sioux Tribe CDC NBCCEDP, Eagle Butte, SD, USA

Abstract

American Indian and Alaska Native (AIAN) women have relatively high breast-cancer mortality rates despite the availability of free or low-cost screening.

Purpose—This qualitative study explored issues that influence the participation of older AIAN women in mammography screening through tribally directed National Breast and Cervical Cancer Early Detection Programs (NBCCEDP).

Methods—We interviewed staff (n=12) representing five tribal NBCCEDP and conducted four focus groups with AIAN women ages 50 to 80 years (n = 33).

Results—Our analysis identified four main areas of factors that predispose, enable, or reinforce decisions around mammography: *financial* issues and personal investments, *program* characteristics including direct services and education, *access* issues such as transportation, and *comfort zone* topics that include cultural or community-wide norms regarding cancer prevention.

Conclusion—This study has implications for nurse education and training on delivering effective mammography services and preventive cancer outreach and education programs in AIAN communities.

Breast cancer and American Indian and Alaska Native Women

Breast cancer is the second leading cause of cancer-related death among American Indian (AI) and Alaska Native (AN) women (Espey et al., 2007). Overall, breast cancer incidence has been lower for AIANs than non-Hispanic whites (NHW), 76 versus 126 per 100,000 women, respectively (Roubidoux, 2012). However, variability exists nation-wide, with the highest incidence of 134 cases among ANs compared to 50 Southwest AI cases per 100,000 women (Wingo et al., 2008). AIAN women were also diagnosed at a mean age of 57.5 years, nearly six years younger than NHWs (Wingo et al., 2008), and were more likely to be diagnosed at later stages of the disease (Espey et al., 2007). Although mammography has been widely recommended for early cancer detection in women starting at 40 years, AIAN screening rates have historically been low. For instance, a 2006 study reported AI women 50

Corresponding author Rosalina D. James, University of Washington, Department of Bioethics & Humanities, Box 354800, Seattle, WA 98195, USA rdjames@u.washington.edu.

years and older were 62% adherent to annual and 73% to biennial screening compared to NHWs who had greater than 10% higher rates of adherence in both categories (Wampler, 2006). Late stage diagnosis and low screening rates have resulted in disproportionately lower breast cancer survival rates for AIAN women (Espey et al., 2007).

The Centers for Disease Control and Prevention provides screening and treatment to low-income, uninsured, and underinsured women as part of its National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 50 states and, at the time of this study, through 12 AIAN tribal-based organizations (CDC, 2012). Despite availability of free or low-cost mammography, screening has remained low in many tribally-directed compared with state-run programs, particularly for women 50 years and older most likely to benefit from early detection (Kerlikowski, 1997).

Prior studies have identified factors that limit screening outreach to AIAN women, including transportation issues, lack of appropriate education resources, cultural competence concerns with providers, and chronically underfunded healthcare systems that have resulted in lowered community expectations for proper and timely cancer treatment or follow-up (Burhansstipanov, Krebs, Grass, Wanliss, & Saslow, 2005; Canales & Geller, 2004; Orians et al., 2004; Roubidoux, 2012; Sequist et al., 2010). Our study sought to understand why these issues persisted and identify factors that influenced how a subset of older women have responded to outreach and screening opportunities offered by tribal NBCCEDPs. We also explored intergenerational and cultural strengths affecting screening access and use in tribal communities to identify ways in which older women engaged in mammography or why they chose not to screen.

METHODS

We elicited perspectives from tribal NBCCEDP staff and AIAN women 50 years and older. Focus groups were conducted with older women who might have been unresponsive to discussing private and culturally sensitive topics with strangers over the telephone. The group setting allowed women to pick up on threads of conversation where they encountered shared experiences or disagreed on a given viewpoint. However, telephone interviews were an effective way to gather information from NBCCEDP program staff located across the country. Table 1 lists some of the questions asked during interviews with staff and in focus group discussions.

The participatory model has been used extensively to explain health behaviors and the environmental factors that affect them; it has been highlighted by the National Cancer Institute, Community Networks Program as an approach that increases program success (NCI, 2012). Using the PRECEDE-PROCEED framework (Green & Kreuter, 2000, 2005; Green & Lewis, 1986), questions were designed around categories of predisposing factors (forces that influence decisions around health behavior such as knowledge, attitudes, values, experiences, or beliefs); enabling factors (environmental or community factors that promote or inhibit behavior change); and reinforcing factors (incentives that maintain an adopted health behavior, or enforce avoidance of certain behaviors) (Green & Kreuter, 2005). Focus group questions inquired about the influence of personal experiences with cancer, family,

community, the local NBCCEDP, and medical staff on women's beliefs or attitudes towards annual screening. Staff interviews focused on program challenges and strengths for optimal outreach and delivery of mammography.

Study approval process

Study approval took approximately a year and included human subjects review by one university institutional review board (IRB), one Indian Health Board IRB, and by multiple tribal councils and tribal boards. Program directors were asked for guidance on tribal or regional research review protocols, and the level and type of review required for staff interviews varied by NBCCEDP site. For example, some programs required tribal health board review before staff could provide interviews, while others had no prerequisite oversight. Recruitment of Elders required approvals by tribal health boards, IRBs, and councils at both focus group program sites. All review steps were completed prior to interview or focus group recruitment (Figure 1). Tribal approvals for publication also took one year, and were completed before journal submission.

Interviews with tribal NBCCEDP staff

Among participating sites, services were coordinated with local clinics and regional hospitals for a population of women made up largely of enrolled tribal members, but also included low-income non-tribal residents. Most programs were rural, but some served proximal urban tribal members as well. Figure 1a outlines the process for interview recruitment. We identified 13 tribal NBCCEDP directors listed on a publicly available website. One site was not eligible because it no longer received CDC-funding. Directors received an invitational email describing the study and sample interview questions. No interview incentives were provided. Follow-up calls were made to directors whose email addresses failed or who were non-responsive. Seven directors were either unresponsive to follow-up calls or declined to participate for the following reasons: staff too busy with program activities, not interested in supporting research at the time, no time to ferry research protocol through local tribal review and approval process. Directors from the remaining five NBCCEDPs that agreed to participate were first asked if they would be able to interview and then asked for contact information of staff from their site. A total of 12 individual staff members were interviewed. Several staff held two or more of titles and multiple program responsibilities. Most were female with roots in the local communities. Many interviewees had family (e.g., spouse, children) or were enrolled members of federally recognized tribes.

We conducted semi-structured interviews using a written guide. Interviews were conducted in English and lasted 40 – 60 minutes. Program directors and staff discussed factors that influenced access to and use of mammography for women 50 years and older; their views and experiences with regards to potential cultural, attitudinal, structural, or environmental factors that affect breast cancer screening behavior; and to share program strategies to increase screening rates among this population.

Focus groups with AIAN women

Figure 1b summarizes the focus group recruitment process. A total of 33 AIAN women between ages of 50 and 80 years participated in four focus groups about their perceptions

and experiences with regards to breast cancer screening. Participants included women who had received repeat mammograms and women who rarely or never used the local screening services. To ensure respect for local cultures and norms, tribal program directors were consulted throughout the research process. The study team visited participating sites to get feedback on guide questions and to plan study activities. NBCCEDP staff distributed study information packets (invitation letter, flyer, and stamped return postcard) to eligible women and mentioned the study in the course of their scheduled program outreach activities. Although over 40 packets were distributed, no postcards were returned. Instead, recruitment response came from direct interaction with local program staff and word of mouth. The women received a \$35 Wal-Mart gift card for participating.

Focus group participants lived in the vicinity of the tribal NBCCEDPs, and most were familiar with breast cancer outreach and services through the local program. A fifth group was scheduled, but conflicted with a seasonal Elders event and none of the women attended. Focus groups were held between late morning and early evening hours, to make attendance as convenient as possible for participants around their daily activity and work schedules. One site took advantage of a popular luncheon to recruit Elders for a focus group. The other site held focus groups at a community building and staff provided transportation for women as needed. A full meal was provided at the conclusion of these latter focus groups.

Sessions lasted approximately one hour. The guide included open-ended questions about cancer knowledge, beliefs, and attitudes towards mammography, experiences with providers, and healthcare access. Questions were added as needed to ensure themes brought up in earlier discussions were explored in subsequent sessions. For example, when the first group identified environmental factors as important contributors to cancer incidence on their reservation, we revised the discussion guide to include a question addressing this topic.

Data analysis

All discussions were audio-recorded and transcribed for analysis and transcripts were uploaded into Atlas[TI], a qualitative analysis software program. The first and second authors independently reviewed transcripts and identified axial codes and sub-codes that emerged from the data, a technique used in content and grounded theory analysis. Axial codes included (1) *financial*: personal resources and time invested in receiving screening, financial restrictions affecting outreach to AIAN women, and strategies for leveraging funds or resources; (2) *program*: tribal NBCCEDP resources, processes, outreach or education activities, and clinical services; (3) *access*: factors facilitating or inhibiting access to mammography such as physical barriers, availability of services, or competing demands on time or energy; and (4) *comfort zone*: factors such as life experiences, cultural beliefs, or community-wide norms that affect views or prioritization of preventive screening. Coded data was merged to facilitate organization and retrieval during analysis. Table 2 summarizes frequencies of sub-code occurrence across interview and focus group transcripts.

RESULTS

We elicited perspectives of key informants and older AIAN women to identify *predisposing*, *enabling*, and *reinforcing* factors affecting breast-cancer screening behaviors. Table 3 lists axial codes and sub-codes describing factors discussed below.

Predisposing factors

A number of factors predisposed women towards, or away from, mammography screening.

Positive influence—The feeling that cancer was prevalent in the community was a motivator for participating in NBCCEDP early-detection screening. Individuals indicated beliefs that increased disease rates were linked to environmental hazards.

...their houses are built on farmland that had used chemicals...I'm just wondering if that stuff is still in the ground and is it seeping still up into the environment? [FG 4]

Experiences with a family or loved one combined with faith in God mobilized women to get mammograms, or to provide outreach and support to others.

I lost a mother who had cancer...I've had experience with a lady who had a lump on her breast...I don't usually make home visits...I told her 'we have to look up to God everyday, put Him first'...You know, you have to look at positive things...not look back at things that have happened. [FG 3]

Negative influence—Additional expenses and time away from daily responsibilities to keep mammogram appointments made it difficult for women to prioritize preventive cancer screening.

...living is hard...I don't know if they have the time or energy (chuckle) to think about other issues...to spend [travel expenses] to come here for a mammogram, when you could certainly be using it because you have to buy stove oil. [Int 8]

They [IHS] have a van that goes out at seven in the morning and...sometimes they get back after seven [pm]...if they have 10 patients, you have to wait... 'til everybody on that van is done with their doctor's appointments. [Int 4]

Several program staff indicated that women fear a diagnosis coupled with inadequate follow-up, treatment, or support services.

...it's sort of in the back of their heads like, 'Okay, if I get screened, is there going to be something there to help me with any treatments or diagnostic work, if I need it?' [Int 10]

Still others ignored pain or symptoms, fearing bad news and delaying early detection.

...people go into denial. And they'll let it go thinking 'Oh, it'll go away'...there's something growing in there and they don't go in to get it taken care of. [FG1]

Staff reported that some women were not likely to ever accept screening. Indeed, some focus group participants agreed to join a discussion on the grounds that they would not be asked to make an appointment.

I can think of one lady...we tried and tried and tried over the years...and she'll make an appointment, but then she just doesn't come. [Int 12]

Factors that reflected a sense of vulnerability to cancer (e.g., toxic environmental conditions, high cancer incidence in community, watching loved ones cope with the disease) and convenient, local access to screening services seemed to orient women towards mammography. Uncertainty of services or follow-up, negative experiences with the healthcare system, and juggling limited resources, time, and obligations fostered postponement or avoidance of screening. Some described deep faith in God or the Creator among women from their generation and culture. Faith enabled women inclined to screen to respond positively to mammography access. Alternatively, some women were predisposed to non-screening behavior.

Enabling factors

Tribal NBCCEDPs varied in range and geography of their service areas, outreach operations, education, clinical services, staffing, infrastructure, equipment, and systems for assessment and program evaluation. Enabling included individual, programmatic, environmental, community, or cultural factors that promoted or discouraged breast cancer screening.

Positive influence—Several NBCCEDPs relied on mobile mammography units to bring screening and women's health services to rural locations.

...if there was not a way for people to get mammograms in this community that's something that people would just totally blow off. [Int 3]

NBCCEDPs leveraged CDC funds with other resources and identified family support systems to meet basic transportation needs.

We have so-o-o many solutions for transportation, between the clinics themselves, with their transportation dollars and the CHRs [community health representatives], and then our program...has money for gas and transportation [Int 10]

There's usually a family member somewhere that can juggle schedules to get 'em where they need to go. [Int 12]

Programs with long-term outreach described community relations as a driving force in supporting cancer screening across family ties.

We have a lot of women who started with us...it's spread pretty well, from those beginners out to their families. [Int 12]

Tribal staff and focus group participants mentioned the importance of incentives such as food, small gifts, or raffles to ensure adherence to mammogram appointments.

INT: What motivates you to come in for mammogram screening?

RESP: They feed you [group laughter]...They always provide food. [FG1]

Outreach workers or community health representatives facilitated screening recruitment. The ideal individual for this position was described as someone who was dedicated to her community, and of the same generation that shared [traditional] language or cultural background.

Our best outreach worker is [name]...she's a respected Elder... [Int 10]

Typically, workers were tribal members or community residents paid part-time through the NBCCEDP or women's health program. Many were deeply dedicated to reducing cancer deaths among tribal women, contributing a great deal of volunteer time.

The outreach workers don't just work 8 to 5, Monday through Friday...workers have even seen people out at stores (chuckle) and reminded them "Hey, I'm havin' a mammogram day, you're eligible. You turned 40, you need to come in." [Int 11]

Negative influence—Caring for grandchildren or loved ones was common, leaving less time for AIAN women to prioritize self-care, including preventive screening.

I adopted my granddaughter when she was 3. She's eleven now. [FG 1]

Access to timely and reliable transportation was a barrier for eligible AIAN women.

...our contract facility is two and a half hours, one way...[IHS vans] only go certain days of the week and if they are full with already scheduled Indian Health Service appointments...So mine is a tribal program, so she will be made to wait and reschedule her appointment for another day. [Int 1]

I know they get a little income a month and they don't have money for gas.... [FG3]

Sometimes weather, road conditions, or budget issues complicated existing systems for transporting women to appointments or the mobile mammography units to communities.

...wind gusts up to 60 miles per hour, meaning float planes aren't gonna fly...say she had an abnormal screening mammogram, so say she was gonna fly out today for her diagnostic mammogram and ultrasound...So they re-schedule her. She can't get away from work and she may not get it for another three or four months. [Int 2]

...we've had our ferry coverage cut almost in half...So we only get ferry service once a week...And I know we've advocated and sent letters to legislators saying, you know, 'Don't do this.' [Int 2]

I think it'd be beneficial to be able to fly into any of the [communities]...would have to get a plane that could land on these short runways and also carry a mobile mammography unit, which ends up being about 700 pounds. [Int 6]

I'd like to have a really decent road system... [Int 5]

Financial and program strategies that addressed needs for local, convenient, affordable, and timely access to breast cancer outreach, education, and screening enabled AIAN women to adopt mammography practices. Some issues that affected access were beyond the scope of

programs, such as transportation costs or effects of weather conditions on mobile mammography unit schedules. Four of the five NBCCEDP sites where interviews were conducted identified a myriad of tribal resources, grants, and partnerships that they used to leverage support for mammography and other cancer early-detection activities. The multiple funding streams tended to create additional administrative and reporting burdens on the handful of staff (as few as 2 to 4 individuals), in addition to providing the program outreach and services. Whether the enabling factors promoted or discouraged mammography, a few topics seemed to strengthen existing attitudes and behaviors around screening.

Reinforcing factors

Reinforcing factors fostered greater support for mammography behavior or underlined women's belief systems around abstaining from screening.

Positive influence—Women in the focus groups, regardless of whether they believed in screening for themselves, seemed to agree that they wanted cancer early-detection services for their daughters and grandchildren.

[You] set an example for the next generation... the kids are always watching you [FG 4]

Because there's a lotta cancer in my family...So I'm watching out for [adopted granddaughter] and in turn, watching out for her, is taking care of me...I gotta live a long time. She's only eleven. [FG 1]

I **don't** like to go to that mammogram...I think it'd be more acceptable to them [younger generation]. Tell them the seriousness of a sore... different illnesses that now I think they're more open-minded. [FG 2]

Negative influence—Some women lamented the loss of modesty among younger generations, such as dressing in revealing clothing, and perceived this as a loss of respect for the body. This modesty was a value that some women felt was violated by invasive mammography procedures, but may be easier for younger women to accept screening as part of their lives.

...when they're pregnant [they say] 'Hey, feel my belly' ...that was unheard of when we were growing up!...so the younger generation, I think, are gonna' have an easier time going for their check-ups. [FG 2]

Spirituality and belief in a higher power were also repeatedly mentioned as important aspects of life for these women, and these reinforced either their intentions to continue getting mammograms or their decisions to move away from screening.

My mother was diagnosed with cancer and they gave her six months to live...She is 20 years later cancer-free. But by faith, by the love of her children and her family, she's beat it. [FG 2]

Long-term efforts of tribal NBCCEDPs have played a role in making cancer prevention and education a priority among AIAN women in the communities they serve, reinforcing a sense

of self care across generations. Spirituality was central in their lives, helping them face the uncertainty of cancer and draw strength from life events.

DISCUSSION

Qualitative methods provided a means to explain health behaviors from the perspective of key stakeholders (Sofaer, 1999, 2002), including views of underserved AIAN populations. Individuals who participated in this study explained new dimensions to barriers experienced in accessing mammography in their communities. Insights from women who resisted using breast cancer prevention services also helped to illuminate the values and belief systems that drove their personal health decisions. We triangulated focus group responses with those of tribal program staff to describe complex aspects of the interactions between these women, their families, communities, social support systems, providers and the tribal NBCCEDPs. These results provided an opportunity to confirm or expand on theories generated around mammography decision-making among AIANs (Sofaer, 1999). For example, Canales and Geiler (2004) described how decision-making for American Indian women in Vermont on whether to participate in mammography screening existed along a continuum. These decisions, which were based on factors such as “Connecting to Nativeness” and “Taking Care of Self” often changed direction (towards or away from mammography screening) over time. Our study revealed choices women faced that affected the dynamics of their self-care priorities in context of their roles as caretakers of family, community, and culture.

This study explored perspectives of AIAN women 50 years and older regarding mammography screening, and the environmental and organizational systems under which NBCCEDPs operated. Factors that predisposed, enabled, or reinforced women’s decisions and attitudes to use or avoid mammography were organized by recurrent financial, programmatic, access, and comfort zone codes developed from interview and focus group data. In addition to expanding on earlier reports of barriers and facilitators for promoting breast cancer screening among American Indian women, such as the importance of offering incentives (Orians et al., 2004), an intergenerational theme emerged across many of the codes. For instance, family, spouses, and community support all played important roles in motivating women to participate in early breast cancer screening, and enabled adherence to clinical appointments. These findings can be used to promote transcultural nursing training about the importance of working with tribal communities in context of their interconnected relations and social networks (Becker & Foxall, 2006; Haozous, Eschiti, Lauderdale, Hill, & Amos, 2010; Weiner, Burhansstipanov, Krebs, & Restivo, 2005).

Whether or not older AIAN women valued mammograms for themselves, most stressed that it was important for younger women to have access to these services and supported the NBCCEDPs as local systems that responded to the needs of communities. An early study of tribal NBCCEDPs described public education strategies around breast cancer screening as a relatively new role for tribes when some of the programs began in 1990 (Orians, et al., 2004). Over the past two decades, tribal NBCCEDPs have worked to provide a comprehensive package for cancer control that includes support for prevention outreach, education, early detection, local cultural protocol, transportation, continuous and comparable financial support, and access to competent and timely care for follow-up and treatment.

Often through a patchwork of funding mechanisms and leveraged resources, these programs have nurtured a generation of AIAN women to adopt and practice regular mammography screening beginning at age 40. The U.S Preventive Services Task Force revised their mammography guidelines in November 2009, recommending biennial breast cancer screening rather than annual mammograms, and only for women between 50 and 74 years old. Most tribal NBCCEDPs involved in this study promoted screening for AIAN women beginning at age 40, and some perceived a need to have outreach and education for women younger than this. The message of breast cancer screening has been a long-term effort to develop and maintain regular mammography use as a community-wide priority that carries forward to future generations.

Acknowledgments

The authors would like to thank Sharon Fleming and staff at the South Puget Intertribal Planning Agency for their help developing interview questions and conceptualizing this project. We would also like to acknowledge Roberta Cahill and Rita Andrews for taking time to provide honest guidance and feedback on this manuscript.

References

- Becker SA, Foxall M. An analysis of health behavior theories applied to breast-screening behavior for relevance with American Indian women. *Journal of Transcultural Nursing*. 2006; 17(3):272–279. [PubMed: 16757667]
- Burhansstipanov L, Krebs LU, Grass R, Wanliss EJ, Saslow D. A review of effective strategies for native women's breast health outreach and education. *Journal of Cancer Education*. 2005; 20(1):71–79. [PubMed: 15916525]
- Canales MK, Geller BM. Moving in between mammography: Screening decisions of American Indian women in Vermont. *Qualitative Health Research*. 2004; 14(6):836–857. [PubMed: 15200803]
- Centers for Disease Control (CDC). [May 15, 2013] National breast and cervical cancer early detection program (NBCCEDP). Retrieved from <http://www.cdc.gov/cancer/nbccedp>
- Espey DK, Wu X, Swan J, Wiggins C, Jim MA, Ward E, et al. Annual report to the nation on the status of cancer, 1975-2004, featuring cancer in American Indians and Alaska Natives. *Cancer*. 2007; 110(10):2119–2152. [PubMed: 17939129]
- Green LW, Kreuter MW. Commentary on the emerging guide to community preventive services from a health promotion perspective. *American Journal of Preventive Medicine*. 2000; 18(1):7–9. [PubMed: 10806972]
- Green, L.; Kreuter, M. *Health promotion planning: An education and ecological approach*. 4. New York: McGraw-Hill; 2005.
- Green, LW.; Lewis, FM. *Measurement and evaluation in health education and health promotion*. Palo Alto, CA: Mayfield Publishing Company; 1986.
- Haozous EA, Eschiti V, Lauderdale J, Hill C, Amos C. Talking circle for Comanche Women's Breast Health. *Journal of Transcultural Nursing*. 2010; 21(4):377–85. [PubMed: 20601548]
- National Cancer Institute (NCI). [May 15, 2013] Center to Reduce Cancer Health Disparities, Community Networks Program. Retrieved from <http://crchd.cancer.gov/cnp/overview.html>
- Kerlikowski K. Efficacy of screening mammography among women aged 40 to 49 years and 50 to 69 years: Comparison of relative and absolute benefit. *J Ntl Cancer Inst Monogr*. 1997; 22:79–86.
- Orians CE, Erb J, Kenyon KL, Lantz PM, Liebow EB, Joe JR, et al. Public education strategies for delivering breast and cervical cancer screening in american indian and alaska native populations. *Journal of Public Health Management and Practice: JPHMP*. 2004; 10(1):46–53. [PubMed: 15018341]
- Roubidoux M. Breast cancer and screening in American Indian and Alaska Native women. *J Canc Educ*. 2012; 27(Suppl 1):S66–S72.

- Sofaer S. Qualitative methods: What are they and why use them? *Health Services Research*. 1999; 34(5):1101–1118. [PubMed: 10591275]
- Sofaer S. Qualitative research methods. *International Journal for Quality in Health Care*. 2002; 14(4): 329–336. [PubMed: 12201192]
- Sequist TD, Cullen TC, Bernard K, Shaykevich S, Orav EJ, Ayanian JZ. Trends in the quality of care and barriers to improvement in the Indian Health Service. *J Gen Intern Med*. 2010; 26(5):480–6. [PubMed: 21132462]
- Wampler NS, Saba L, Rahman SM, Dignan M, Voeks JH, Strzelczyk J. Factors associated with adherence to recommendations for screening mammography among American Indian women in Colorado. *Ethn Dis*. 2006; 16(4):808–14. [PubMed: 17061731]
- Weiner D, Burhansstipanov L, Krebs LU, Restivo T. From survivorship to thrivership: Native peoples weaving a healthy life from cancer. *Journal of Cancer Education*. 2005; 20(1):28–32. [PubMed: 15916517]
- Wingo PA, King J, Swan J, Coughlin SS, Kaur JS, Erb-Alvarez JA, Jackson-Thompson J, Solomon TGA. Breast cancer incidence among American Indian and Alaska Native women: US 1999–2004. *Cancer*. 2008; 113(S5):1191–1202. [PubMed: 18720389]

Figure 1.**a:** Interview recruitment process**b:** Focus Group (FG) recruitment process

*NBCCEDP staff described multiple roles within the program. Titles (and number of staff/ title) included Director (5), Provider (1), Budget Analyst (2), Data Manager/Analyst (3), Recruitment Coordinator (1), Case Manager (4), and Billing Specialist (1).

Table 1

Sample questions used in the interviews and focus groups

Questions used for interviews with BCCED program staff (n=12)

- In general, do you think that women in the communities you serve are aware of your mammography services?
- Can you tell me about your outreach program, particularly with regards to how you work to encourage older Native women to come in for mammograms?
- Please share your thoughts on what resources you would need to effectively support your program's outreach efforts to this population.
- Are there programmatic issues that make it difficult to reach women age 50 and older about using mammogram services?
- Do you have suggestions on how these issues could be resolved to better serve older Native women?
- What strategies has your program developed that you perceive supports women 50 years and older to use mammography screening services?
- Does your clinic provide education to the community about the benefits of early breast cancer detection? [if yes] Who provides this education - physicians, community representatives, others? [if no] Why do you perceive these women are not receiving education on the benefits of mammogram screening?
- Are there any suggestions you have that would help women in your community use mammography screening services?

Questions used for focus groups with AI/AN women 50 years and older (n=33)

- In your own words, how would you describe cancer?
- What kinds of things might prevent you, or women in your community, from going in for a mammogram?
- Do women in your community receive mammograms outside of the tribal BCCEDP?
- Do you have concerns with communicating your health needs to a provider or nurse? [if yes] Can you describe some of these issues? [if no] What does your provider do to support this communication?
- Do you have a preference for discussing concerns around cancer, breast exams, or screening with a physician, with a nurse, a community health representative, an outreach worker, or some other trusted individual?
- What services does your tribal or health clinic provide that helps motivate you to get a mammogram?
- Do you think that women in your community have access to resources for follow up and treatment should they receive a diagnosis of breast cancer?
- Do you care for grandchildren or other dependents in your home?
- Is transportation to and from the clinic an issue for older women in your community?
- Is cost an issue for women in your community when deciding whether to go in for a mammogram appointment?
- If some of these personal needs were addressed, would you be more likely to receive regular mammograms?

Table 2

Frequency distribution of sub-codes across interview and focus group transcripts

CODE (sub-code)	Interviews (n=12)	Focus groups (n=4)	Total
FINANCIAL			
cost	24	0	24
leverage	51	0	51
outreach/education	5	1	6
Services	39	0	39
PROGRAM			
assessment/evaluation	38	2	40
outreach	71	21	92
education	20	7	27
clinical	82	6	88
ACCESS			
Insurance	40	9	49
Personal	42	18	60
Physical	66	11	77
Services	25	3	28
COMFORT ZONE			
beliefs/attitudes/motivations	4	44	48
cultural/community	45	21	66
personal	33	44	77

Table 3

Factors affecting mammography screening (MS) among American Indian and Alaska Native Women

Factor	CODE (sub-code)	Positive Influences on MS	Negative Influences on MS
PREDISPOSING FACTORS	FINANCIAL cost	<ul style="list-style-type: none"> No data 	<ul style="list-style-type: none"> Investment of personal time & out-of pocket expenses required to make screening appointments
	ACCESS personal, services	<ul style="list-style-type: none"> Family members encourage others to screen. Local, convenient access to mammography services & equipment, including mobile units. 	<ul style="list-style-type: none"> Obligations of caring for dependent children, grandchildren, or spouse. Distance from services. Unreliable transportation.
	COMFORT ZONE beliefs, attitudes, motivations, personal experiences, culture community-wide	<ul style="list-style-type: none"> Perceived high incidence of cancer in community; perceived causes such as familial inheritance of risk, pollution, environmental carcinogens, chemicals in food sources. Availability of female providers. Witnessed loved ones experience cancer diagnosis and/or treatment. 	<ul style="list-style-type: none"> Discomfort with clinical setting or procedure; mistrust of medical or IHS systems; high provider turnover; no female providers; staff or providers insensitive to culture, privacy, or anxieties around cancer risks. Denial; fear of pain due to screening procedure; fear of living with cancer diagnosis; uncertainty of resources for treatment if diagnosed. Spirituality and belief in higher power. Traditional sense of female/body; modesty/respect among older generation.
ENABLING FACTORS	FINANCIAL leverage, outreach & education, services	<ul style="list-style-type: none"> Programs leveraged resources/partnerships; shared personnel, enlisted volunteers, applied for grants. Outreach & education strategies; target clinical staff, AIAN women, community. Incentives such as food, door prizes. 	<ul style="list-style-type: none"> Level of outreach & education resources varied; difficult to sustain activities. Issues with timely & adequate clinical services; high turnover & inconsistent quality of staff.
	PROGRAM assessment & evaluation; outreach & education	<ul style="list-style-type: none"> Some programs had resources for regular program assessment. Outreach & education activities leveraged through parallel 	<ul style="list-style-type: none"> Programs required to cut assessment/evaluation to budget for basic services and staff. Inadequate or inconsistent resources for outreach & education.

Factor	CODE (sub-code)	Positive Influences on MS	Negative Influences on MS
		women's health promotion programs.	
	ACCESS personal, physical, service	<ul style="list-style-type: none"> Women support family to adopt screening practices (i.e., provide childcare, transportation, accompaniment to appointments). Local infrastructure/resources such as mobile units, clinical services/ staff, equipment increased access to mammography. 	<ul style="list-style-type: none"> Physical or geographical barriers to accessing mammography such as road conditions, transportation issues, weather. Limited or no access to screening equipment or specialists. High turnover or culturally insensitive staff, providers, technicians.
	COMFORT ZONE culture, community-wide	<ul style="list-style-type: none"> Enlisted respected women from the community as outreach workers. 	<ul style="list-style-type: none"> Inconsistent access to outreach, education, and cancer information and education in the community.
REINFORCING FACTORS	PROGRAM outreach & education	<ul style="list-style-type: none"> Strategies promoted culturally appropriate, effective engagement of women in screening activities. 	<ul style="list-style-type: none"> No data.
	ACCESS	<ul style="list-style-type: none"> Caring for dependent grandchildren. Role modeling healthy behavior, including mammography adherence. 	<ul style="list-style-type: none"> Distance from services. Unreliable transportation.
	COMFORT ZONE outreach & education, culture, community-wide	<ul style="list-style-type: none"> Consistent, long-term outreach and cancer education. Spirituality & belief in a higher power. 	<ul style="list-style-type: none"> Traditional sense of female/body; modesty/ respect among older generation. Spirituality & belief in a higher power