RESEARCH

Community Cancer Screening: Reducing Health Disparities among Native Americans in Rural, Tribal Communities

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ABSTRACT

Native Americans have higher cancer morbidity and mortality rates than non-Native Americans and cancer screening rates are lower. This qualitative case study used community-based participatory research principles to identify individual, family, community, and environmental factors that positively influenced screening rates in a rural, Native American community. Over a two-year period, 90 people participated in 11 focus groups to inform the evaluation of the Standing Rock Reservation Men's and Women's Health Days Program. Focus group interviews were digitally recorded, transcribed, and saved into NVivo for analysis. Categories and themes were developed using a modified grounded theory approach, leading to a comprehensive model that allowed coding of all comments. The evaluation confirmed that many components of the screening were valuable, such as the advantages of holistic, culturally appropriate approaches within a social setting. Individual experience with cancer and other chronic diseases, family experience with cancer and family support, and friends and exposure to toxins in the community influenced participation in cancer screening. Collaboration between organizations, intensive outreach and recruitment, multiple services provided in one location, consistency of staff, incentives, and the opportunity to socialize and share a meal increased participation. Barriers to screening, such as transportation, changing funding and criteria for screenings, reductions in other services, and unpleasant screening procedures, have required ongoing patience and problem solving on the part of the community team to ensure that high rate of screenings continue. These findings led to recommendations for program development in the target community and other similar communities nationally.

KEYWORDS: Cancer screening; Health disparities; Native Americans; community health

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INTRODUCTION

Native Americans in North Dakota and nationally have higher cancer morbidity and mortality rates than non-American Indians (White et al., 2014; North Dakota Department of Health, 2012). Cancer screening rates are also low. One community increased cancer screening numbers and the number of screening days annually through the Standing Rock Reservation Health Days Program. This intersectoral approach (Rantala, 2014) to community health screening included diverse partners: Custer Health, the local public health organization; Standing Rock Tribal Health; Indian Health Service (IHS); the North Dakota Breast and Cervical Cancer Early Detection Program; Avon Foundation; Susan G. Komen affiliates; North Dakota Department of Health (ND DoH); and the Great Plains Tribal Chairman's Health Board. It had two components: Women's Health Days which began in 1997 and Men's Health Days, introduced in 2003. Standing Rock Sioux Tribe, located in south central North Dakota and north central South Dakota, has 6,171 residents. The sparsely populated reservation spans Mountain and Central time zones. To resolve complications resulting from differences in legislation across the two states, North and South Dakota formally agreed that the entire Standing Rock community would be served by the ND Women's Way Program. Initially, Custer Health used screening resources available through the Women's Way Program to implement the program; IHS provided clinic space and staff for screening; community health representatives (CHRs) recruited participants. Other organizations joined to increase community participation in screening days; for instance, the casino provided food; community providers set up diabetes, dental, and nutrition education stations.

The Men's and Women's Screening Days program has been recognized regionally and nationally as a successful screening program (http://archived.naccho.org/topics/modelpractices/database/practice.cfm?practiceID=63). This paper describes driving forces that motivated tribal members to participate in screening initially and to return in future years, as well as individual, family, community, and environmental supports for and challenges to screening. Two evaluation questions guided interviews with community members to identify those factors that contributed to successful programming and increased rates of cancer screening:

1. How do individual, family, and community factors influence screening for chronic diseases, including cancer, diabetes and heart disease?
2. How do characteristics of the screening program and other health care programs influence screening for chronic diseases?

MATERIALS AND METHODS

Interviews with Community Members and Providers

This qualitative case study (Yin, 2017) was guided by community based participatory action (CBPR) research principles; CBPR principles guided planning and implementation of the Enhanced Evaluation of Standing Rock Men's and Women's Health Days Programs, ensuring that data collection and dissemination of results occurred in a manner appropriate for this community (Minkler et al., 2008; Israel et al. 1998). Representatives from organizations engaged in the screening program formed an evaluation workgroup overseeing planning, implementation, analysis, and dissemination of information. A tribal resolution; IRB approval through Sitting Bull College, Aberdeen Area IHS, and Essentia Health; and approval by the ND DoH were obtained.

Sample and data collection process

Standing Rock tribal members who were 40 years of age and older were recruited to participate in focus groups. Tribal members representing people who screen regularly, those who rarely participated in cancer screening, and members

who had never participated in the Men's and Women's Health Days screenings were invited to participate. CHRs, in consultation with Custer Health, identified participants, reminded them about the focus groups, and arranged transportation for those with no means to travel independently. Ninety people participated in 11 focus groups in five of the eight Standing Rock Communities. Men's and women's groups were held separately, which the workgroup determined was culturally appropriate in this community. Focus groups were conducted at the casino and in public buildings in each community, to ensure greater access for community members. Data collection occurred over a two-year period. After review of initial evaluation results, the workgroup identified a gap resulting from lack of data collection in one community; therefore, additional focus groups were conducted.

Members of the workgroup participated in focus group training prior to conducting the focus groups. When participants arrived for each focus group, a workgroup member asked them to sign in; at the conclusion, that person provided each participant with incentives, thanking them for participating. Each focus group was managed by a facilitator who led the focus group; a co-facilitator who was available for support in the group and to assist any member who needed to leave the meeting during the interviews. A note taker typed verbatim comments. Each focus group began with a prayer and the facilitator's explanation about the purpose of the meeting and a review of the informed consent form. Members who wished to participate signed the informed consent form and received a copy of the form. Interviews were guided by a semi-structured interview schedule which was created by the evaluation work team and revised following the first two focus groups.

Data analysis

Interviews was digitally recorded and transcribed for analysis. Transcripts were then saved into NVivo for development of categories and themes using a modified grounded theory approach. The categories were created through an iterative process, where two researchers working independently coded a sample of comments, compared their results, revised the categories, and presented the categories to the evaluation team for further revisions. Existing theory and research also guided the development of categories, especially the ecological perspective (Markus, 2012). This led to a comprehensive model that allowed coding of all comments. Individual interviews were also conducted with individuals representing organizations who participated in the screening days, to augment understanding about the program.

RESULTS

Evaluation Question 1. How do individual, family, and community factors influence screening for chronic diseases, including cancer, diabetes and heart disease? Men's and women's comments fell into four categories: 1. Individual factors that influence participation in screening, 2. Family factors that influence participation in screening, 3. Community factors that influence participation in screening, and 4. Characteristics of Health Screening Days that influence participation in screening (See Table 1 for all categories and frequencies.)

Table 1. *Individual, Family, Community and Health Screening Days Factors Influencing Screening.*

Factors Influencing Screening	Categories	Number: Phrases
Individual Factors	Age of individual	5
	Experience with Cancer and knowing whether have cancer	43
	Currently screening yes or no	36
	Health other than cancer	13
	Lack of time	5
	Stubborn	2
	Risk factors for cancer	5
Family Factors	Family member experience with cancer	39
	Knowledgeable about screening and supports person in participating	15
Community Factors	Environmental risk factors	4
	Friend supports	12
	Gossip	4
	Interventions to increase awareness about screening	4
	Referral to screening program by health care provider	1
Health Screening Days	Funding	11
	Criteria for eligibility for screening	32
	Health care provider	9
	Incentives, such as knives, beads, meal, and socialization	49
	Other activities, providers at the screening, ie diabetes, eye, heart, mental health, nutrition.	22
	Process flow of activities during health screening day	6
	Recruitment	35
	Transportation	32
	Location	9
	Scheduling	18
	The screening itself, screening results, and screening days overall	39

Individual Factors That Influence Participation in Screening. Fear of having cancer was both a motivator and barrier to screening. Having had cancer motivated some to continue screening and to encourage others to screen; on the other hand, some were fearful of learning that they had cancer. Having other health issues such as diabetes and risk factors such as obesity and smoking motivated some to participate.

When they found out I did have cancer, I went through the procedures and everything else. Because I am cancer free, I thought I'd try to be an advocate for anyone with cancer or refer anybody [for screening]. I contacted my nephews, anybody,

my three sons, anyone that was over forty and I encouraged them to go to the men's clinic and they did.

"I just don't want to hear the bad news. If I have cancer I don't know; how I would deal with it?"

Lack of time and other responsibilities were a common barrier. "*I know, I always tell my daughters; you better get over there. She says, 'Well I can't, Mom, I got no leave or whose going to watch my kids?'"*

Family Factors. The most commonly mentioned reason for participating in screening was having experience with a family member with cancer.

The first cancer that my mom had was colon cancer; I had to have that colonoscopy done.

It was my grandmother, my mother, and my sisters that I lost to cancer.

I don't know how many cards I filled out with a lot of my friends and relatives on them; but I just had one go to the last women's day in September. She hit me in the arm and she said, "Oh, I'm really glad you signed me up." I said why and she has cervical cancer.

Family members frequently encouraged other members to participate in screening.

Community Factors. Community factors influencing participation in screening included friends in the community, and environmental factors. "My coworker, she goes every year too and she said, "I went to Women's Way. "I said, "good for you, we got to go every year." "Yes we do," she said. On the other hand, fear of gossip kept some from participating in health screening events. "Gossip is one of the biggest things on the reservation, so there's another fear there. They think someone's going to say, so and so went to Women's Way, I wonder what's wrong with her?." Exposure to environmental risk factors, such as Agent Orange, asbestos, and carbon monoxide, were identified as community factors that might influence the decision to be screened for cancer.

Evaluation Question 2. How do characteristics of the screening program and other health care programs influence screening for chronic diseases? A combination of factors regarding the program influenced participation in screening, including:

1. Policies and procedures for funding and the criteria for eligibility for screening,
2. Access to health screening days (scheduling, transportation),
3. Incentives (food, gifts such as multifunction tools, other activities such as Diabetes counseling and nutrition),
4. Characteristics of the screening itself, including the provider, workflow, and the screening itself.

Policies and Procedures. A common barrier for participating in screening by tribal members was complexity of funding, with multiple payors such as Women's Way, insurance, the VA, IHS, co-pays, and out of pocket costs.

"*When I got that billing, that's why I didn't go back. I know they called me and said, "are you coming to the next Women's Way?" And I was kind of hesitant. My husband said, "well, you've been going all this time. Why are you going to stop?" I said, "look at this bill, I can't pay this."*

Cancer screening criteria. Confusion about criteria for cancer screening at the national and local level impeded participation;

A question that comes to mind: is there different age brackets for different cancers? Do you know what I mean? Like what he said for the prostate; is that 30s, pancreatic cancer is that like in the 50s?

Access to health screening days. Multiple methods of outreach, including flyers, word of mouth from family and friends, the local radio and newspaper,

a phone call inviting one to participate, district meetings, posters at the store, post office and district building, CHRs, letters with an appointment time, stories by survivors of cancer, increased knowledge about and participation in screening. "*I keep hearing about this maybe I should go check it out.*" Existing transportation is available and has additional benefits; "*I get a big kick out of the men because around the first, here comes the shuttle picking them up and out they go and I think it's fun for them because they get to visit in their own language.*" It is problematic, though, in terms of flexibility, availability, and scheduling, and may not be appropriate for someone who has compromised health issues. Access is enhanced by extending screening to several locations.

Incentives. "Offering meals" was the most common incentive. "*Maybe a small meal. That small meal doesn't see much to everybody but those of us who can't afford a meal at lunch…I'm here I'm getting a free meal.*" Gifts such as tools and gas cards were appreciated. Holding other activities during the day also increased participation: breast self-exam, dental care, diabetes, domestic violence, eyes, heart, mental health, and nutrition.

They also check your blood pressure, check your blood, make sure you have your doctor's appointment and they have the new jelly things now where you can actually feel one of those things. Yeah, a breast with a bead in it and you has to like put it on and try to find it. And the diabetic and the eye, if you need to go to the eye clinic and the dental if you need to go to the dental.

I think as you go into the different departments, you go into this one. They check your cholesterol, you go into this one they check your diabetes and so forth. What I feel about that is that it gives me a chance to sit down there, not only to be checked but to ask questions or make comments and so forth and that's the only way you learn.

The screening itself. The flow of activities, screening staff, the screening itself, and screening results influenced participation. Participants described the process in a matter-of-fact way and as positive.

You just go there and you sit down with one individual and they talk about this and that and then you sign a form or you do this and then you go onto the next one which maybe takes care of the cholesterol and maybe the other one takes care of diabetes and finally you get to the doctor and then he checks you out and that's the important part.

Having consistent screening staff who were engaged in the community positively influenced screening. The rapid turnover among physicians was a barrier to participation.

But when they are in town they remember us. You know they know our names, they call us and ask how are you doing and everything like that. And a lot of the doctors are even friendly.

If you have a certain doctor, mine's [Nurse practitioner with? years' service in the community], because he's always been there. I'd rather go to him.

Doctors are so hard to recruit and keep on the reservation, because we don't have nothing that attracts them here and they have to travel 90 miles to Bismarck and so many miles to Rapid City. So it's hard to recruit them and retain them. I know that's a problem that we have. They don't like our school; they don't like their kids in our schools so that's a big problem that we have.

The most common reason to avoid the screening itself was because it was unpleasant, especially rectal exams, colonoscopies, prostate exams, and mammograms.

Fear of the glove (laugh), the exam part of it. I think a lot of people fear that the most, the exam part.

I think the problem with that kit is it has to be private. Because people see you with that and they say oh, you're playing with your poop. My brother was very ashamed of doing one of those, my

youngest brother, and I got very upset with him and I told him you have to do it there's a lot of things that they can find out with that screening that may save your life so just do it.

DISCUSSION

The Standing Rock Men's and Women's health screening days, guided by an active workgroup of community members, health care providers, and other community organizations, have increased men's and women's screening rates for colorectal, prostate, breast, and cervical cancer. Individual experience with cancer and other chronic diseases, family experience with cancer and family support, and friends and exposure to toxins in the community influenced individuals to participate in cancer screening. Characteristics of the screening that increased screening rates were collaboration between organizations, intensive outreach and recruitment, multiple services provided in one location, consistency of staff, incentives, and the opportunity to socialize and share a meal.

Barriers to screening, such as transportation, changing funding and criteria for screenings, reductions in other services, and unpleasantness of some screening procedures, have required ongoing patience and problem solving on the part of the community team to ensure that the high rate of screenings is maintained. Following the evaluation, the number of field clinics was increased to increase access in remote regions of the reservation. Education regarding screening recommendations has increased. Where possible, screenings have been integrated into IHS clinics' regular routine, with providers recommending screening. Screening tools have changed to reduce unpleasantness. Referrals and post card notices of annual screening dates and locations are managed centrally to ensure that no one falls through the cracks.

The evaluation confirmed that many components of the screening were valuable, such as the advantages of a holistic, culturally appropriate approach to health screenings within a social setting. Overall, community members expressed strong support: *They take interest, "Come in here and sit down and we'll work with you." I can sit down and talk face to face with an individual that has expertise in this area and it gives me a chance to interact with them and get my questions answered.* An unintended consequence of the evaluation was increased commitment to continue the process, unifying community organizations. Collaboration between partners continues, to address some ongoing issues such as differences of opinions about screening criteria and fear surrounding cancer screening and treatment; and new issues arise.

Recommendations for Implementation in Other Communities

Recommendations to increase cancer screening rates, especially in rural, tribal communities, include:

1. Develop and nurture robust community partnerships and trusting relationships with community members through transparency, patience, persistence, and flexibility as demonstrated by adapting programs to fit diverse communities.
2. Create cancer screening events that provide opportunities for other screenings, health education, and socialization.
3. Support independence for health clinics with already established culture and procedures.
4. Seek funding to support local programs, adding resources.
5. Recognize that cancer screening might not be a community's first priority. Family and community events take priority. For instance, if a funeral occurs on a screening day, the screening event will not be successful.

6. Use feedback to develop, implement, and adapt programs to accommodate constantly changing environments.
7. Advocate for increased funding from local, state and national sources that support cancer screening and prevention activities across organizations.

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Conflict of interest statement

The author has declared that no competing or conflict of interests exists. The funders had no role in study design, writing of the manuscript and decision to publish.

Authors' contributions

PC conceived, planned and executed the study; JB, CB, JF, MG and DMW participated in planning, data collection, analysis and writing; PC, JT, JS participated in planning, execution and writing.

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