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Community Based Participatory development, implementation and evaluation of a cancer screening educational intervention among American Indians in the Northern Plains

Krishnan Subrahmanian, MPhil, **Daniel Petereit, MD**, **Shalini Kanekar, PhD**, **Linda Burhansstipanov**, **Sarah Esmond**, **Raylene Miner**, **Caroline Spotted-Tail**, and **B. Ashleigh Guadagnolo, MD, MPH**

Abstract

Objectives—The study describes the creation and implementation of a culturally appropriate cancer education intervention, and assesses its efficacy among Native Americans in a community with documented cancer-related disparities.

Methods—Education workshops were developed and conducted on three reservations in Western South Dakota and Rapid City by trained community representatives. Over four-hundred individuals participated in the two-hour workshops. Participants answered demographic questions, questions about previous cancer screening (to establish baseline screening rates), and completed a pre and post workshop quiz to assess learning.

Results—Participants demonstrated significant increases in cancer screening-related knowledge levels. Surveys reveal that participants found the information of high quality, great value and would recommend the program to friends. Pre-workshop data reveals cancer screening rates well below the national average.

Conclusions—Workshop participants increased their knowledge about cancer etiology and screening. This intervention may represent an effective tool for increasing cancer screening utilization among Native Americans.

INTRODUCTION

A recent report by the Centers for Disease Control and Prevention on the status of cancer in the US revealed that death rates from cancer from 1975-2004 were declining except among American Indian/Alaska Native populations, for whom death rates had remained level. [8] Other population-based studies have suggested higher cancer-related death rates among American Indians [30,4,17]. These data suggest that advances in cancer prevention and care are not reaching this vulnerable population. Stage at presentation of cancer is associated with cancer survival outcomes and research has shown that American Indian cancer patients present with more advanced stage disease than other racial/ethnic groups in the United States. [25,22,17,4,30,14]. For cancers for which a screening test is available, advanced-stage at presentation is preventable; and American Indian (AI) populations have consistently been shown to have relatively low screening utilization rates [12,29,5,24,13,8,30]. Also possibly contributing to these disparities, studies have shown the interval from diagnosis to treatment is significantly longer for AIs. [31,30,25]

There is evidence that there are especially high cancer incidence and cancer mortality rates among AIs in the Northern Plains when rates are compared to white populations and AI

Corresponding Author: Daniel Petereit, MD.

populations residing in other regions [9]. For example, AIs in the Northern Plains (North and South Dakota, Nebraska and Iowa), served by the Aberdeen Area Indian Health Service (IHS), have cancer mortality rates that are 30% higher as compared to that of the overall US population. [16] The root causes for these cancer disparities are multi-factorial and includes patient, physician and health system related factors. Both real and perceived barriers complicate access to cancer screening and cancer treatments for the AIs.[32,23]

Culturally competent interventions are those that tailor “delivery to meet patients’ social, cultural and linguistic needs.” [2] These interventions in the AI community respect the cultural and spiritual practices that are the norm in Indian country, are developed by and with community members, are taught by community members and emphasize the data and facts applicable to Indian people.

Culturally-competent interventions for AIs have been successful at improving cancer-related health care utilization and education in this vulnerable population in communities where the cancer incidence is not nearly as high as in the Northern Plains [6,18,3,34,35,36,26]. However, none have specifically targeted AIs in this region of the country, where the outcomes data are most sobering. Table 1 shows incidence rates, as published recently in a Centers for Disease Control report,[8] both nationally and for the Northern Plains region for whites and American Indians for prostate cancer, colo-rectal cancer, breast cancer and cervical cancer and shows that American Indians in the Northern Plains have higher rates of prostate cancer than other AI/AN groups. They also have higher rates of colon cancer and cervical cancer than other AI/AN groups, the nationwide rate or the rate amongst whites living in the Northern Plains.

The Cancer Care Institute (CCI) in Rapid City serves approximately 70,000 adult AIs from three reservations and the urban Rapid City area. Prior studies conducted in this region have found persistent stage disparities for screen-detectable cancer among American Indian patients presenting to this facility. [14,15]Furthermore, an analysis of the Rapid City CCI-based Walking Forward community survey by Pandhi and colleagues found that only 44% of a sample drawn from 975 Native Americans living in the service region of the Rapid City Regional Hospital reported ever receiving cancer screening. [21] Participants in the Walking Forward community survey reported receiving site-specific cancer screening at proportions much lower than those reported in the general United States population. Based on these data as well as other quantitative and qualitative data from these community-based surveys, a cancer education intervention was developed and implemented in this population. Our investigation seeks to determine if a one-day culturally-appropriate cancer education intervention results in improved cancer screening knowledge and cancer etiology knowledge.

METHODS

Preliminary data to identify potential barriers

Targeted community and cancer patient surveys and data from the patient navigation program identified three critical barriers to cancer treatment. These are: a) the *lack of awareness* of cancer screening and treatment options due to an absence of sustained community education programs [14]; b) delay in initiation of physician-patient dialogue pre and post cancer diagnosis; and c) discontinuity of cancer care upon return to the reservation.

Study Design

This study is an interventional study employing an educational intervention. Pre- and post-workshop surveys and quizzes were utilized to determine whether participants amassed a greater knowledge of cancer etiology, prevention and treatment.

Participants & Recruitment Strategies

The Walking Forward Program relied on their Community Research Representatives (CRRs), tribal community members who serve as liaisons between the Walking Forward program and reservation communities, to recruit participants for this project. CRRs coordinated and implemented workshops on three reservations (Pine Ridge, Cheyenne River, Rosebud) and among the American Indian community of Rapid City. The primary target population of the workshops was adult (> 18 years of age) American Indians. Promotional information about workshops and/or one-on-one sessions occured via:

- Informational flyers
- Distribution through Community Health Representatives, health educators, pubic heath nursing and county nursing.
- Newspaper announcements
- Public Service Announcements
- Public housing, Community Action Programs
- Public Schools
- Community Programs

Specifics of the Walking Forward patient navigation and community research representative program have been described in detail in prior publications [23,25] A ten-dollar incentive was paid to workshop participants to defray the cost of childcare, gas or other incidental expenses. Table 2 indicates the number of participants at each site.

Inclusion/Exclusion Criteria

Workshops were developed for adult men and women over 18 years of age and who self-identified as American Indian. Participants were consented for workshop participation as well as for pre- and post-workshop data collection. In the preliminary workshops, 66 people participated in the breast cancer workshops, 111 participated in cervical cancer workshops, 70 individuals participated in prostate cancer workshops and 163 participated in colo-rectal cancer workshops. In total 410 individuals participated in cancer screening workshops.

In order to assess and analyze participant knowledge accurately, a project participant was required to respond to fifty percent of the pre-workshop questions and fifty percent of post workshop questions. Of the 66 participants in breast cancer workshops, 64 were eligible for knowledge item analysis. Of the 163 who participated in colo-rectal workshops, 145 were eligible for analysis. Of the 70 who participated in prostate cancer workshops, 51 were eligible for knowledge item analysis. Of the 111 who participated in cervical cancer, 99 were eligible. In total, 359 individuals had assessments that were eligible for knowledge item analysis.

Intervention

CRRs coordinated and evaluated cancer workshops in order to increase knowledge and recruitment to appropriate breast, cervix, colon and prostate screenings. Workshops were developed by the Walking Forward Program using both internally and externally created materials, such as those from Walking Forward cancer education material and the Cancer Information Service's ”What You Need to Know...” series. Cancer Information Service is a free service of the National Cancer Institute that provides educational materials about Cancer. This material was combined with the Native American Cancer Research group's “Get on the Path” series which has completed extensive intertribal testing for cultural and scientific appropriateness”. The strategy of a short educational intervention is not a new one.

Other interventions have utilized short educational workshops, in a group or one-on one setting when attempting to drive a specific change in behavior related to cancer screening. [2,18,6] The decision to do a two-hour work-shop (rather than a lengthier intervention) was made after consultation with community members. The primary reason for a 2-hour intervention was logistics, in that some individuals needed to travel long distances to get to the workshop, take off of work, or did not have childcare and needed to bring their children with them to attend. This length of an intervention was chosen to maximize community member participation. After the workshops were developed, the workshop content materials and plans were submitted to focus group testing and vetting. In June of 2008, 39 American Indian participants on the three reservations participated in provided comment on the pilot workshop content, length, quality and structure. After recommended modifications of the program were completed, 27 additional American Indian community members participated in a focus group in Rapid City. CRRs were trained to use the curriculum by the workshop development team at Rapid City Regional Hospital in August of 2008.

The workshop content included the following components. Workshop materials are available for review by interested parties:

- Opening Prayer
- Welcome of the participants
- Introduction and Agenda
- An explanation to participants about the ARS (Audience Response System—described below) and how to use it.
- A survey of demographic information using the Audience Response System
- Information about local community health resources
- Information on screening methods are available for different types of cancer
- Barriers to Screening
- A presentation of the film Cancer in the Great Land
- Risk Factors Related to Cancer
- Symptoms of Cancer

After this introduction to the program and cancer generally, participants were given cancer-site specific information. The cancer types covered by these workshops included breast, cervical, colo-rectal or prostate cancer. Appendix A-D includes the topics covered in each of the individual workshops.

During the implementation phase of the education workshops, CRRs/Navigators used different formats to determine which are more acceptable and effective with their respective local communities. For example, the CRRs sometimes held workshops that may or may not have been gender specific depending on the subject material. Prostate Cancer workshops were often conducted with only men and cervical and breast cancer workshops were often held with only female participants. When requested, CRRs conducted workshops in one-on-one with participants.

Outcomes measurement

Pre- and post-test measures were administered to assess increase in cancer knowledge of participants through the use of an Audience Response System. At the conclusion of each cancer screening education workshop, participants were invited to participate in a

subsequent study intended to track the screening rates of workshop participants to assess whether or not the workshops led to increased screening rates among participants.

Data recording and statistical analyses

The Audience Response System is a computer assisted-tool consisting of hand-held keypads linked wirelessly to a computer system and an audiovisual display. Keypads allow participants to respond anonymously and in real time questions or statements posed by a moderator or instructor. The ARS software then stores the data in a database, tallies the results and produces an answer frequency bar graph that the presenter may display to the audience. For data consistency participants use the same keypad throughout the workshop. Matched paired t-tests were conducted using SPSS 17.0 and paired t-test post hoc power analysis was conducted using G Power software. [10,33]

RESULTS

Evaluation of the intervention

Table 3 summarizes the demographic information of the workshop participants.

Table 4 shows the summary data from the workshop pre- and post-tests for the cancer knowledge quiz by cancer site. Matched pair t-test analysis of response data indicated that workshop participants scored significantly higher on the cancer knowledge quiz after as compared to before the workshop.

Participant Evaluation of the Workshop

Participant Survey Evaluation of the Workshop content is shown in Table 5. 77.8% of participants found the workshops very understandable, 70.5% of participants strongly agreed that the workshops provided useful information, 66.9% of participants rated the information as “high” quality and 90.1% of participants would recommend the workshops to their friends. Chi squared analysis reveals that prostate cancer workshop participants were more likely to “maybe” recommend the workshop than participants in other workshops (chi-square p=.038). All other chi-square analysis showed no distinction between workshop type.

Assessment of potential role of online/electronic media to enhance intervention

Participants were asked if the workshops were available as a free download from the internet whether they would be able to access the slides.

While there was no significant difference across age groups (p=.498) individuals on Cheyenne River Indian Reservation reported with greater frequency than those from other reservations that the Internet is not really an option for them. Fully 51% of participants from Cheyenne River said that the internet was not really an option for them (p=<0.001).

Baseline Screening Rates prior to workshops

In order to determine the baseline screening rates of workshop participants, each was invited to respond to questions regarding how recently they had received a pap smear, mammogram, prostate exam, fecal occult blood test and colonoscopy. American Cancer Society guidelines were then used to construct variables for specific screening sites as follows: cervix – women age 21 years or older; breast – women 41 or older; prostate – men 51 or older; and colon – either gender 51 or older. This data is summarized in Table 7.

Discussion

This intervention represents the first reported community-based cancer screening intervention in Northern Plains American Indian communities. Participants in a one-day culturally appropriate cancer-screening workshop increased their knowledge about cancer etiology and screening. Survey data collected showed that the workshop was favorably received by individuals in these communities where cancer-related health disparities have been documented. Furthermore, pre-intervention data collected further reinforced the need for educational programs in this region as evidenced by the relatively low rates of cancer screening utilization among our participants. For example, of our participants 51 or older, only 21% had received a colonoscopy or sigmoidoscopy. This is lower than the national colonoscopy rate of 52% for same-age individuals.[27] Similarly, only 67% of women over the age of 21 in the workshops had undergone a pap smear in the past three years, which is markedly lower than the 79-85 % national average. [28] These findings corroborate previous studies showing low screening utilization among American Indians in the Northern Plains. This is particularly pronounced given that those who choose to participate in such a workshop are a self-selected group of individuals motivated to learn more about disease prevention. [25,22,17,4,30,14].

While this effort as part of a larger community-based program (the Walking Forward Program) is not the first community based cancer intervention amongst Native American communities, it is the first to be implemented in the Northern Plains area. This is an important distinction because of the high rates of cancer in the Northern Plains.[16] Some investigators have conducted other interventions in other AI communities showing the importance of cancer screening programs among urban AIs,[18,19] and lay health advisors in the Denver metropolitan area were successful in recruiting AI women for mammography. [3] Another program implemented among the Lumbee Indian community, participants in one on one lay educator workshops knew significantly more about pap smear tests than counterparts who had not undergone the workshop.[6] Women of the eastern-band Cherokee of North Carolina who participated in a one on one workshop were more likely to answer all questions regarding cervical cancer correctly and subsequently be screened for cervical cancer.[7] While these interventional studies found success, authors also acknowledged that in the respective communities, cancer incidence was no higher in the AI population than in the US general population. It is important then, to build on the success of these previous studies and implement similar workshops in the Northern Plains where cancer incidence remains higher among AIs compared to that of the non- American Indian population. [9]

Potential Limitations

There are several limitations to this study. First, selection bias could have resulted in higher gain-in-knowledge measurements in post-workshops, given the possibility that participants who found the workshop less helpful may have left the workshop early (prior to post-test administration). In fact, 48 (12%) participants who started the workshop left at some point before completing the evaluation. Future workshops will need to address strategies to increase participation and subsequent retention of participants throughout the workshop. Practically, workshops are time-intensive and human capital-intensive enterprises. CRRs coordinated 64 workshops between December 2008 and November of 2009. Recruiting and retaining participants was challenging. During the winter, ensuring that workshops took place and that participants were able to attend was particularly challenging due to the occurrence of inclement weather. While there was no significant variation amongst sites in terms of learning or satisfaction outcomes, ensuring uniformity of implementation, even with a standardized curriculum, is a concern.

Viewing the educational materials available through the National Cancer Institute and the Native American Cancer Research and listening to the feedback from community members regarding the logistical feasibility surrounding transportation, we chose to do a one-day intervention. Furthermore community members remarked that one two to three hour session was most likely to attract an individual to attend.

While educational workshops are a good first step, a one time two-hour intervention is unable to unilaterally get people educated, screened, and fully informed on treatment options. In future iterations, immediately after an educational workshop, we would spend more time consenting individuals for screening if it is indicated and actually having health care providers on site who are ready and willing to perform screening services.

Furthermore it is important to consider an educational workshop as the first step in a series of interventions to teach people about screening and subsequently more about cancer and their health. Walking Forward hopes to use the screening workshops as an introduction to have people screened and should they need it, introduce them to the range of services Walking Forward provides for those diagnosed with cancer. In this way the two-hour module is a beginning with positive educational value, rather than an end in itself.

Regardless, these workshops hold potential as a preventative intervention amongst American Indians in this region, and such workshops may be an effective tool at increasing screening rates.

Implications for Future Implementation

The identified challenges offer opportunities for improvement as the next generation of workshops begins. In the new iteration of workshops, it would be helpful to establish consistent permanent schedules so that health care workers at IHS and in the community know when and where the workshops will be and thus can refer patients to the workshops on a routine basis.

While Community Research Representatives are excellent recruiters and advocates, utilizing the network of survivors and American Indian cancer patients who have participated in the Walking Forward patient navigation program may also facilitate recruitment and retention. For example, these survivors and previous patients may be interested in organizing workshops at their home or in the community, inviting friends and families to learn more about cancer. This model of organizing has long been used by political, union and community organizers and Walking Forward is taking nascent steps to utilize this model to organize around cancer education [20] [11] Furthermore, learning from the experience of survivors and inviting their wisdom and stories to be included in the workshops will be a valuable part of workshop content revisions. Organizations tackling other diseases in other parts of the world that have used this model of survivors teaching others have found great success and we hope to build on this success in the area of cancer education and screening. [1]

The method of disseminating workshop content offers a potential focus for improvement. Weather, distance and marketing were all challenges in terms of recruiting and retaining participants. Perhaps, distributing the information via the internet is a possibility, e.g., 56% of respondents said that either they could download and implement and disseminate or knew someone who could do the same if given workshops via the internet. This is encouraging and the use of internet as a viable tool for health education in these communities should be explored.

Conclusion

It is our experience that involvement of AI community members in every step of development and implementation of the intervention was critical to the success of this endeavor. Follow up screening data from workshop participants will reveal whether such workshops actually increased screening rates and ultimately mitigated high cancer mortality rates observed amongst American Indians in the Northern Plains. At the end of these workshops individuals were consented for a follow up study to determine whether participation in the workshops actually prompted screening. The ultimate goal of this study will be to decrease the observed high cancer mortality in this population.

Appendix A: Contents of Colorectal Cancer Workshop

- What is the intestinal tract?
- What is the colon?
- What is the rectum?
- Why are the colon and rectum important
- Risk factors associated with colon cancer
- Statistics about cancer incidence in Indian Country
- Common colorectal risk factors
- Healthy Lifestyle and Protective Factors
- Survival Rate Statistics
- Screening Recommendations specific to colorectal cancer
- Screening Methods specific to colorectal cancer
- A presentation on colonoscopy, sigmoidoscopy and removal of polyps.

Appendix B: Contents of Breast Cancer Workshop

- Breast Anatomy
- Breast Cancer Incidence Rates
- Breast Cancer Risks Factors
- Breast Cancer Protective Factors
- Common Symptoms for Breast Cancer
- Screening for Breast Cancer
- Self- Exam
- Clinical Breast Exam
- Mammogram
- Mammogram Results
- Concerns about Mammograms
- Tips to Help you Prepare for Your Mammogram

Appendix C: Contents of Prostate Cancer Workshop

- Anatomy of the Prostate Gland
- What is the Prostate Gland
- Prostate Cancer in Indian Country
- Prostate Cancer Incidence Rates from 1999-2004
- Prostate Cancer Mortality Rates
- Prostate Cancer Risk Factors
- Prostate Cancer Protective Factors
- Screening for Prostate Cancer
- Digital Rectal Exam
- Prostate Specific Antigen Test
- What is the Prostate Specific Antigen Test?
- What Besides Prostate Cancer Can Cause High PSA Levels?
- Where is Prostate Cancer Screening Available in the Northern Plains?
- Where Can I get a PSA Blood Test?
- Prostate Cancer Screening Results
- Prostate Cancer Symptoms

Appendix D: Contents of Cervical Cancer Workshop

- Anatomy of the Cervix
- Female Reproductive System
- Cervical Cancer in Indian Country
- Cervical Cancer Incidence Rates 1999-2004
- Cervical Cancer Mortality Rates
- Cervical Cancer Risk Factors
- How Can you Protect Yourself?
- How Can I help Myself?
- Symptoms or Signs Related to Cervical Cancer
- Cervical Cancer Diagnosis in Indian Country
- Who Needs to get A Pap Test?
- Screening for Cervical Cancer
- Women Who Had a Hysterectomy
- Pap Smear Results
- Human Papillomavirus
- What is HPV?

- Genital Types of HPV
- HPV and Cervical Cancer
- How can people prevent HPV related disease?
- Learn More About HPV-Resources

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Table 1

Cancer Specific Incidence in the Northern Plains [8]

Cancer	All Race/Ethnicity Nationwide Rate	AI/AN Nationwide Incidence Rate	Northern Plains Non Hispanic White Incidence Rate	Northern Plains AI/AN Incidence Rate
Prostate	160.8	77.5	160.0	160.3
Colon/Rectum in males	62.9	36.8	62.0	79.8
Colon/Rectum in Females	45.8	29.7	45.3	60.4
Breast	125.3	62.9	130.5	112.2
Cervical	8.8	6.6	7.5	11.3

Incidence Rates for 200-2004 per 100,000 persons and are age adjusted

Table 2

Workshop Location

	N	Percent
Rapid City	107	26.5
Pine Ridge Reservation	41	10.1
Cheyenne River Reservation	184	45.5
Rosebud Reservation	72	17.8
Total	404	

Table 3

Demographic Information

Gender	**Number**	**Percent**
Male	104	26.8%
Female	284	73.2%
Race		
American Indian	373	97%
African America	2	0.5%
Caucasian	5	1%
Hispanic Latino Chicano	1	0.2%
Prefer Not to Answer/No response	3	0.6%
Age		
81 +	11	2.7%
65-80	49	12.1%
50-64	90	22.2%
41-49	78	19.3%
31-40	66	16.3%
21-30	53	13.1%
13-20	29	7.2%
Prefer not to answer/Missing info	28	6.9%
Education Status		
Did not graduate from High School	93	24.8%
High School Graduate	130	34.7%
Some College no Degree	80	21.3%
College	43	12.3%
Graduate School	14	3.7%
Prefer not to Answer	15	4%
Total	375	

Table 4

Knowledge Assessment Pre and Post-Test Results

Workshop	N (participants who were eligible for knowledge item assessment)	Pre-workshop mean score	Standard Deviation	Post-workshop mean score	Standard deviation	T	P-value (2-tailed)
Cervical	99	57% (8 questions)	25%	77%	20%	-9.9	< 0.001
Breast	64	45% (9 questions)	20%	69%	26%	-9.7	<0.001
Prostate	51	42% (9 questions)	23.2%	62%	21%	-6.7	<0.001
Colorectal	145	33% (10 questions)	20%	55%	24%	-10.4	<0.001

Note: a higher score indicates a higher level of cancer-related knowledge.

Table 5

Evaluation of the One-Day Workshop

Overall how understandable was the workshop?	**N**	**Percentage**
Very Understandable	280	77.8%
Fairly Understandable	74	20.6%
Not Understandable	6	1.7%
Total	360	
No response	44	
This workshop Provided useful information to me		
I strongly agree	251	70.5%
I agree	103	28.9%
I don't agree	2	0.5%
Total Responses	356	
No response	43	
How would you rate the overall quality of information in the presentation?		
High	238	66.9%
Average	113	31.7%
Low	5	1.4%
Total Responses	356	
No response	48	
Would you recommend to a friend?		
Yes	319	90.1%
Maybe	34	9.6%
No	1	0.2%
Total	354	
No response	50	
How would you evaluate the Session Length?		
Too Long	62	17.5%
Appropriate Length	263	74.1%
Too short	30	8.5%
Total	355	
No Response	49	
How did the ARS keypad system affect your learning?		
It made no difference	150	44.9%
It improved my learning	163	48.8%
It reduced my learning	7	2.1%
Not sure	14	4.2%
Total	334	

Table 6

If workshops were available as a free download, participants would be able to access the slides.

Yes I have the skills	101	28.5%
I know someone with the skills	96	27.1%
The internet is not really an option in my community	105	29.7%
I would need to ask around	35	9.9%
Don't know/Not sure	17	4.8%
Total	354	

Table 7

Baseline Screening Data

	Age appropriate Candidates	Age appropriate screening rate in our study	Age appropriate screening rate Nationally
Colonoscopy (greater than age 50)	150	21%	52%
Pap smear (greater than age 21)	242	67% (with a pap smear in the last three years)	79-85%
Mammogram (women greater than age 40)	271	67% (with a mammogram in the last three years)	81.1%
PSA test (males greater than age 5)	37	16% (ever received a PSA test)	49%-71%