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How can an Education Workshop Serve as an Intervention for American Indian Screening Participation

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Abstract American Indians (AIs) continue to have elevated cancer incidence and mortality, and most have issues accessing cancer screening services. During 2013–2014, Mayo and its partners created Native Cancer 101 Module 10 "Prevention and Early Cancer Detection" education workshop. A community-based AI organization implemented nine of these workshops during 2014–2015 via diverse venues. Nearly all participants eligible for at least one type of cancer screening participated in a workshop and consented to follow-up within 3 to 6 months to determine if screenings had been completed or scheduled. Native Cancer 101 Module 10 workshops were conducted with 150 community members of whom 6 had recently completed cancer screening (n = 144). The workshops had a 25.20% increase in knowledge, and 97.1% of subjects responded that they would recommend the workshop to their friends and family. Most (136 of 144) submitted a consent form to be contacted 3 to 6 months following the workshop. Patient navigators reached 86 (63.2%) of the consented participants in the follow-up calls after the workshop, and 63 (46.3%) self-reported that they had completed at least one cancer screening test for which they were eligible. The single implementation of the workshop influenced community participants' completion of cancer screening.

Keywords American Indian · Cancer education · Patient navigators · Evaluation · Modules

Background

There are 567 federally recognized tribal nations [1], and of them, approximately 70% of American Indians and Alaska Natives (AIs/ANs) live in urban areas [2]. American Indians (AIs) have long experienced lower health status in contrast with other US populations. AIs have a life expectancy of 73.7 years compared to 78.1 years for non-AIs [3, 4]. More than one quarter (26.6%) of AI/AN lived in poverty in 2015, representing a poverty level nearly twice that of the overall population (15.3% for the overall US population and 28.4% for AIs) [5, 6]. The median household income of single-race AI/AN households in 2015 was $38,530 compared to $55,775 for the nation as a whole [7]. Slightly more than half (53.1%) of AI/AN own their own home compared to 63% of the overall population [8]. Adequate sanitation facilities are lacking in about 36% of AI/AN homes [9], and approximately 12% of AI/AN housing lacks waste disposal facilities and adequate safe water supplies [10, 11]. Further, the injury rate for AIs/

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ANs is higher than the general population because they statistically take on more dangerous jobs [12]. About one out of five (20.7%) AIs/ANs lacked health insurance coverage in 2015 compared to an overall 9.4% of the Americans across all racial demographics [13]. These data illustrate AI/AN disparities that have important health implications.

The socioeconomic conditions (i.e., where people live and work) have a substantial influence on health with cumulative lifetime effects [14]. When contrasted with other populations, AIs are more likely to have a lower socioeconomic status, lack health insurance, and live in poverty, leading to less access to cancer prevention and screening services [15]. Additionally, 20% have not completed high school; incomplete high school education has been associated with unhealthy and risk taking behaviors [16]. Adult AIs have daily behaviors and comorbidities that increase risks for cancer, including obesity, commercial tobacco use, diabetes, and high blood pressure. The Indian Health Service (IHS) reported AI cancer screening rates were significantly lower in comparison to the overall population with only 59% receiving cervical screening, 45% breast screening, and 33% colorectal screening, resulting in increased risk of late diagnosis and decreased survival rates from cancer [4].

AIs continue to be at higher risk for cancer than whites and are more likely to be diagnosed at a younger age and with more advanced disease [15]. Data released in 2014 [17] confirmed that the substantial progress in reducing cancer death rates experienced by whites over the previous two decades was not seen in AIs [18] and that cancer mortality rates remained the same or increased from previously reported data [19–23]. For example, death rates for lung, colorectal, and breast cancers showed significant declines in whites, while corresponding death rates in AIs remained unchanged or increased [17, 24–29]. For the lower 48 contiguous states, cancer incidence is consistently higher in AIs from the Northern and Southern Plains, with higher rates for breast, lung, colorectal, and cervix cancers than in non-Hispanic whites living in the same region [24]. These cancer sites have early detection/screenings available.

The 2010 Census Bureau reported that 56,010 AIs/ANs live in Colorado, of which 46,395 live in urban areas, mostly in the Denver metro and Colorado Springs areas [30]. There are more than 200 tribal nations living in the Denver metro area, and the largest tribal group is Lakota (Northern Plains), followed by Cheyenne, Kiowa (Southern Plains), and Navajo (Southwest) [31]. These data are in concordance with Denver AI data collected by Native American Cancer Research Corporation (NACR), reflecting that about 40% of AIs are from the Northern Plains and 30% are from the Southern Plains; those regions have excessive cancer incidence in comparison to other regions of the USA.

NACR was awarded a subcontract from Mayo Clinic's Spirit of EAGLES (SoE) Community Network Program to conduct a needs assessment from 2011 through 2014. This needs assessment documented that AI participants living in the Front Range of Colorado continue to experience difficulty accessing early detection screening services [32]. As such, SoE awarded a second subcontract to NACR to create a new Native Cancer 101 module focusing on cancer screening: Native Cancer 101 Module 10 "Prevention and Early Detection of Cancer (screening)." Thus, implementation of this module with follow-up phone calls assessing completion of screening comprised the pilot education intervention.

Methods

This module primarily was based on excerpts from five validated "Get on the Path to Health" curricula (breast, cervix, colon, lung, and prostate). These curricula were created during 2003 to 2005 with partial support from Mayo Clinic's Spirit of EAGLES program and validated in subsequent years. On average, 30 Get on the Path to Health workshops were conducted and evaluated each year, primarily in the Rocky Mountain, Northern Plains, Southern Plains, and Southeast regions from 2005 through 2014. Excerpts from the Get on the Path to Health curricula were selected by patient navigators and administrative team members. The original slide set numbered 200 and was considered to be too long. In collaboration with the Southeast American Indian Council, the slides were modified five times during the spring and summer of 2013 based on the feedback received from staff and participants.

Workshop Slides

Table 1 summarizes the topics of each slide. An audience response system (ARS) was used to collect demographics, pre-workshop and post-workshop knowledge, and workshop satisfaction. Interactive activities allowed the participants an opportunity to review content information. The patient navigators selected one of two participant activities to complete: Bear and Coyote or Bingo.

Participant Interactive Activities

NACR previously assessed (unpublished, 2005–2007) immediate and long-term knowledge retention by comparing a Get on the Path to Health workshop with an interactive activity to the same workshop without such an activity. In 2007, an external evaluator contacted a random sample of participants by phone 3 months following the workshop session and asked the same knowledge items assessed after workshop completion for both groups. The workshop participants who were in the group with the interactive activity had 25% higher knowledge

Table 1 Native Cancer 101, Module 10 slide topics

Title and divider slides	14
Use of ARS instructions	4
ARS demographics	5
ARS pre-workshop knowledge items	9
AI/AN all sites cancer stats	3
AI/AN breast	8
AI/AN cervix and HPV	9
AI/AN colorectal	9
AI/AN lung (and traditional tobacco use)	13
AI/AN prostate	11
Screening services	5
Post-workshop knowledge items	9
Workshop satisfaction	4
Total	103
Participant interactive activities	
Bear-Coyote/tic-tac-toe	17
26 Bingo cards	
30 Bingo knowledge questions	

retention than the comparative group. Consequently, NACR includes some type of interactive activity that allows the participant to review the content. Module 10 has two primary options for such an activity: Bear and Coyote is a true-false statement activity that also can be played as a tic-tac-toe game, and Bingo game slides reinforce screening concepts that were adapted from Great Plains Tribal Chairmen's Health Board game to be appropriate for Module 10. Bingo cards were printed and laminated to allow for repeat use.

Rationale for Patient Navigators to Conduct Community Presentations

NACR's native patient navigators are three AI women who have lived and worked within the Denver metro area for at least 20 years. They are well accepted within and trusted by the local AI community. They are trained to conduct both small group and one-on-one education sessions as well as provide patient navigation services. These services include—but are not limited to—helping with scheduling screening appointments; accompanying AIs to screening, diagnostic, and treatment appointments; and identifying and addressing barriers to cancer care throughout the cancer continuum (outreach through end of life). Based on findings from the "Native Navigators and the Cancer Continuum" [33–35] study, having patient navigators conduct community education sessions greatly increased their visibility and accessibility to AI community members. These community members were more inclined to ask the patient navigator for help with accessing screening. These supportive experiences allowed patient navigators to present and evaluate the revised Native Cancer 101 Module 10 to community groups.

In-Service and Peer Training

Patient navigators were trained on how to present and evaluate the workshop, discuss the informed consent process with workshop participants, upload workshop evaluation data onto the online evaluation program, and conduct the 3 to 6-month follow-up call assessing completion of screening. The patient navigators download the slide sets from the NACR website. Members of the administrative team conducted in-service training with the patient navigators, and they conducted peer teaching with one another. The patient navigators practiced using their ARS with the slides to increase familiarity and then role played conducting the workshop via webinars. For example, one patient navigator practiced teaching the module to another patient navigator in a role play scenario during which the second patient navigator prompted answers to frequently asked questions to enable the presenter to practice responding to questions prior to the actual implementation of the workshop.

Processes for Identifying Partners or Venues for Implementation

Patient navigators identified partners, such as Denver Indian Health and Family Resources, and potential venues, such as health fairs and PowWows, where it was feasible to include an education workshop. The partners and sponsors of venues advertised the availability of the workshop and its location and times. Interested people (i.e., convenience sample) attended the sessions. The patient navigator introduced the pilot workshop topic, collected the audience response system data, explained and discussed the slides with participants, and then facilitated either the Bear and Coyote or the Bingo screening game. Following the interactive activity, the patient navigator collected post-workshop knowledge and workshop satisfaction items. They also collected signed informed consent forms from participants willing to be contacted 3 to 6 months later by the navigator to learn about their screening status since taking part in the workshop.

Findings

The Spirit of EAGLES program reviewed the protocol for the implementation of the workshop with follow-up calls during the spring of 2014, and the Mayo IRB approval was finalized in May of 2014. The workshops were scheduled and initiated in July of 2014.

Pilot Tests

NACR native patient navigators conducted a total of nine Native Cancer 101 Module 10 workshops between July of 2014 and November of 2015 (16 months of implementation) with 150 community participants (see Table 2). Two thirds of the participants were female (*n* = 99; 66.0%), and most (*n* = 125; 83.3%) were AI. About 35% had a high school education or less, and all were adults. Workshop participants received a $10 gift card at the end of the session.

Participants Eligible for Screenings Of the 150, 6 were ineligible for screening in the following year (i.e., too young to take part in screening or had recently completed recommended screening). For the 136 who provided consents to allow the patient navigator to contact them several months following the workshop, the patient navigator asked specific questions about their age, which screening tests they had completed or have had recommended to them by a healthcare provider, and dates and locations of such screenings. Because the native patient navigators in Denver typically accompany or are present for all local AI cancer screening events, they were confident about patient self-reports. The native patient navigators also have Health Insurance Portability and Accountability Act (HIPAA) permission to review health records for about half of the participants, but because they had been present when the individuals had been screened or recommended for screening as part of their normal patient navigation roles, they did not, however, review the participants' medical records.

Table 2 Native American Cancer 101, Module 10: Demographics

	CO partner	
	No.	%
Gender		
Females	99	66.0%
Males	40	26.7%
DWTA	11	7.3%
Total	150	100.0%
Age		
18–40	41	27.3%
41–50	34	22.7%
51–60	35	23.3%
> 61	18	12.0%
DWTA	22	14.7%
Total	150	100.0%
Race/ethnicity		
AI/AN	125	83.3%
AFR-AM	1	0.7%
Asian	0	0.0%
NHW	3	2.0%
PAC IS	1	0.7%
Hispanic/Latino	0	0.0%
Other	2	1.3%
DWTA	18	12.0%
Total	150	100.0%

Increase in Knowledge

On average, 15 participants attended each workshop, but workshop numbers ranged from 3 to 20 participants overall. All participants answered between 6 and 11 identical pre-test and post-test items (an average of 8.4 items were asked as pre-workshop knowledge items, and the same items were matched for the post-workshop knowledge). The reason for fewer items included was due to the workshop running late and some of the latter topics (usually lung and/or prostate) being excluded on the post-tests; thus, non-matched items are not included in this summary. A little more than one third of the subjects (37.7%) answered the pre-workshop knowledge items correctly, and almost two thirds (63.3%) answered the post-workshop items correctly that were matched to the pre-tests. Thus, there was a 25.2% increase in knowledge from pre-test to post-test.

Workshop Satisfaction Almost all (98.1%) rated the session content as "understandable" or "very understandable" and reported that the content was useful information (see Table 3). Almost all (97.1%) said that they would recommend the workshop to others. Thus, Module 10 was very successful.

Follow-Up Calls

At the end of the workshop, patient navigators asked the participants for permission to contact them three or more months later to query whether they took part in cancer screening services for which they were eligible. Of the 144, 136 completed a consent form allowing the patient navigators to contact them and included current phone number(s) to call. The follow-up protocol was modified and specific to the participants because some reported that they would not be eligible for screening for four more months. More importantly, several workshop participants complained that they could not secure an appointment

Table 3 Workshop satisfaction (*n* = 150)

Percent	The workshop:
98.1	was "understandable" or "very understandable"
98.1	provided useful information
97.9	quality was high
97.1	would recommend to others

Table 4 Native Cancer 101, Module 10 follow-up calls and completion of screening

Total ed session participants	Signed consent forms and eligible for screening	Completed follow-up calls on screening with Nat Am Cancer 101 Module 10 participants	Number of eligible participants completed screening	Percent out of the 136 of eligible completed screening	Percent out of the 86 of eligible completed screening
144	136	86	63	46.32%	73.26%

(particularly for a colonoscopy) for 5 or 6 months. The patient navigators confirmed this complaint based on observation from their everyday patient navigation roles. Therefore, the patient navigators conducted follow-up calls between 3 and 6 months to accommodate the delay. They attempted to call up to three times to reach the participant, and the calls were conducted between 9 a.m. and 5 p.m., early evening (6–8 p.m.), and over the weekend. Those whom the patient navigators could not reach with the three calls were removed from the follow-up call list.

Of these 136 who signed consent forms and were eligible for screening, the patient navigators attempted to reach all via the three-call protocol and were successful in reaching 86 (63.2% of the 136 consented participants) (See Table 4). Each of the participants received a second $10 gift card for participating in the follow-up call. Of these 86, 63 (73.26%) completed at least one cancer screening (breast, cervix, colon, lung, prostate).

Qualitative Comments

The patient navigators took part in bi-weekly calls and webinars with the administrative team and reported on comments received following the workshop (some live and others via Facebook or e-mail). All comments were positive; a few are provided below that showcase the importance of both the patient navigation role and the intervention design:

> *I am a cancer survivor and I did not know that I needed to still be doing other screening tests. I thought the doctor would tell me that I still needed to do these.*
> *I loved playing the Bingo and it helped me remember information better.*
> *I will talk with my family tonight about what I learned today. Thank you very much.*
> *When can you do this workshop in my community?*
> *I did not know the information you presented us. NOW I know how important it is for me to take part in screenings. I am glad you are there to help me.*
> *I have tried to take part in screening but none of the programs available here allowed me to take part because I do not have any insurance. It is very frustrating.*
> *I learned today how important it is for me to take part. Please help me find services that will help me.*
> *I think survivor programs would be great … I have a special diet now and eat like my ancestors did. hahaha. it is a lot of meat with no fat, a little fruit and veggies, and hardly ever wheat and gluten…I THINK a little more education for the Indians of mixed blood is in order since almost everyone is mixed blood now. We are different and need to treat our bodies different… [ed. and need some kind of education about] what to expect after the cancer treatment would be so helpful… thanks for the gift card I am sure I will use it for gas money to go [ed. to stomp dance].*

Limitations of the Pilot Study This was a convenience sample and conducted by native patient navigators who are well known and respected in the local community. Geographic regions for which patient navigators are not well known nor non-native may have different results. In addition, due to limited funds, the implementation was 16 months allowing the pilot to be completed by the official closing date of the SoE grant. A longer interval for follow-up calls or extending the three-call protocol to six calls may have engendered enhanced results, as the patient navigators may have been able to achieve contact with more participants. The recommendations for screenings were based on US Preventive Task Force guidelines (scored A and B only) and referrals from healthcare providers. Thus, participants who wanted to be screened using colonoscopy but were younger than 50 and not “high risk” (e.g., family or personal history) were not able to qualify for colonoscopy screening.

Further, the NACR native patient navigators have HIPAA approvals from about half of the participants as part of their normal patient navigation duties and were in attendance when many of the participants completed their screening tests. Thus, self-reported screenings were validated by the patient navigators’ presence and observation at those events. For that reason, medical records were not reviewed, but this situation may differ for patient navigators working in different settings and programs. Due to budget and timing limitations, there was no control group. Implementation of this pilot test was an efficient and relatively easy way to make a difference in the community.

Conclusions

Through this pilot study, the implementation of the Module 10 workshop itself appeared to function as an intervention for the participants with 73.26% of the 86 reached by phone taking part in screenings for which they were eligible 3 to 6 months following the workshop. The environments for the workshops (e.g., Denver Indian Family Health Services, local survivorship support circles) were very supportive and played a large role in the workshops' successful execution, including obtaining consent forms and subsequent permissions for the patient navigators to implement follow-up calls to confirm completion of screenings. The sessions with community members revealed the value of education about health topics with suggested actions and need for more education on additional health topics.

As demonstrated in the "Qualitative Comments" section above, participants from the pilot tests specifically mentioned the need for more of these workshops. They did, however, request the duration to be limited to 1 h. Yet, it is worth noting that in most cases, there were so many questions and comments from the participants throughout the workshops that they usually required at least 90 min and some instances as long as 2 h.

Hyperlinks Added After the Pilot Test Was Completed

Early in 2016, hyperlinks within the slide set allowed for real-time tailoring of topics (i.e., no tailoring was allowed during the pilot test). The patient navigators used the ARS to allow the participants to prioritize the topics of most interest to them and then used the hyperlinked slides to address those topics first. If time allowed, the lower prioritized topics were addressed. For example, when working with groups of women and based on their ARS votes, the patient navigators highlighted breast, cervix, and colon slides and sequenced the slides on prostate and lung screenings to the end of the workshop. If or when the workshop was scheduled to end (i.e., 60 min), those topics were likely to not be included. The administrative team was concerned about these omissions because anecdotal data has demonstrated that women are an important catalyst for getting the males in their lives into screenings. Further, because the lung cancer screening includes information and discussion about ceremonial and medicinal uses of tobacco, the patient navigators preferred to focus on only those slides with groups most interested in lung cancer. They added the other areas (breast, cervix, colon, and prostate) as time allowed.

Overall, implementing and evaluating the Native Cancer Module 10 workshop was very feasible using the ARS for evaluation data collection. The single implementation of this workshop had a significant increase in screening behaviors among eligible participants. A large study using the workshop, combined with follow-up calls, is recommended. This module, as well as three other Native Patient Cancer 101 modules, is available as free downloads on the opening page of NACR's website (http://www.natamcancer.org).

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