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Development of a Culturally Appropriate Smokeless Tobacco Cessation Program for American Indians

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Abstract

This study describes a multiphasic approach to the development of a smokeless tobacco cessation program targeted for American Indians (AI) of different tribal nations. The authors gathered formative data from a series of focus groups and interviews to investigate the knowledge, attitudes, and beliefs of AI and smokeless tobacco (SLT) use. Predominant themes emerged from four major topic areas (SLT use, initiation and barriers, policy, and program development) across both studies. This study further assessed educational materials developed for the cessation program for scientific accuracy, readability, and cultural appropriateness. Program materials were scientifically

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accurate and culturally appropriate. The average corrected reading grade level was 6.3 using the Fry formula and 7.1 using the SMOG formula. Based on this research, a detailed approach to formative research can be used in combination with input from community members to develop health interventions that address health disparities for a specific population.

Keywords

formative evaluation; American Indian; tobacco cessation

INTRODUCTION

American Indians (AI) have an especially high risk of tobacco-related diseases and deaths due to their high prevalence of tobacco use compared to any other racial/ethnic subgroup in the United States. The rate of smokeless tobacco (SLT) use among AI is higher than Whites (5.3% vs. 4.3%, respectively) and more than double that of other racial/ethnic minority groups (1.3% for Hispanics, 1.8% for African Americans, 3.1% for person reporting two or more races) (Substance Abuse and Mental Health Services Administration (SAMHSA), 2014). This is likely an underestimate due to the wide variation in SLT use by region and tribe.

Over the last 30 years, rates of SLT use have been rising in some tribal communities with historically low rates (Mendlein et al., 1997; Redwood et al., 2010). Our own research has shown rates of SLT use as high as 10% among adults in our region and 19% among college students (Choi, Nazir, et al., 2016). AI smokers also have more difficulty trying to quit smoking compared to other racial/ethnic groups (USDHHS, 1998), evidenced by their significantly lower quit ratios (41% of AI whoever smoked have successfully quit versus 51% of Whites) and low rates of longterm cessation success (5% of AI smokers who have made quit attempts have succeeded for 3 months or more) (Centers for Disease & Prevention, 2004). The same is thought to be true of SLT users, but there is no evidence in the literature. Based on our previous research in smoking cessation (Choi, Beebe, et al., 2016; Choi et al., 2006; Christine M Daley et al., 2011; C. M. Daley, Greiner, et al., 2010; Christine Makosky Daley et al., 2006), we are of the opinion that low quit rates may be partially due to a lack of culturally appropriate SLT cessation programs that include educational materials specifically tailored to an AI audience. Our own All Nations Breath of Life smoking cessation program was a culturally tailored program that produced significantly better quit rates than either a non-tailored control (Choi, Beebe, et al., 2016) or compared to similar studies for AI in the literature (Christine Makosky Daley et al., 2017). It is our hope that the same will be true for our culturally tailored smokeless tobacco cessation program.

The Center for American Indian Community Health at the University of Kansas Medical Center and the Center for American Indian Studies at Johnson County Community College partnered with the local American Indian community to begin developing a culturally tailored smokeless tobacco cessation program, named *All Nations Snuff Out Smokeless (ANSOS)*. The primary goal of ANSOS is to discourage the recreational use of commercial

SLT among AIs, while allowing those who use tobacco traditionally for religious and spiritual purposes to continue to use it for prayer, ceremony, and other traditional ways. The program was developed with an understanding of the diversity of AI cultures and tribal nations and is designed to be used in any multi-tribal population and modified for use with a specific tribe. The creation of ANSOS involved AI from reservations, rural communities, and urban areas to ensure it meets the needs of multiple types of Native communities. The first phase of the research plan was specifically designed to gather formative data and guide the research team through program development. Here, the process and resulting program are described.

METHODS

This formative research used a combination of qualitative and quantitative methods to guide the research team through a three phase research plan to develop an SLT cessation program. Data collection proceeded in two initial phases, beginning with a series of focus groups and interviews, followed by a rigorous three-part assessment to determine the scientific accuracy, readability, and cultural appropriateness of accompanying educational materials. A third phase, the goal of this formative research, is to determine the generalizability and acceptability of the ANSOS program through a series of pilot tests. Our approach described here supported the partnership established between the local AI community and our research organization. Community members contributed to our formative research through study recruitment, conducting focus groups and interviews, data analysis and interpretation, drafting of this and other manuscripts, and community dissemination of preliminary results.

Focus Groups and Interviews

AI community members residing in Kansas were recruited using posters, flyers, and through word-of-mouth at Native-specific events (i.e. powwows). Eligible participants were screened in person and provided written informed consent. Six focus groups with a total of 27 participants were conducted over a seven month period. Each focus group was moderated by an AI research team member, who self-identified as AI. The focus group moderator was assisted by an additional research team member who in some cases was AI and in some cases was not. A moderator's guide, co-written by members of the research team and the lead investigator and consisting of open-ended questions based on our previous experience and research, directed each session. Topics included traditional and recreational SLT use and knowledge and attitudes of SLT and its use, as well as opinions on program development.

In addition to the focus groups, two in-depth interviews were conducted during this study with individuals who could not make it to the focus groups. Interviews with these individuals were conducted because participant offered useful insight to our study, therefore it was important to ensure their opinions were heard.

A related study carried out by our research team used focus groups (10 focus groups, n=54 participants) and individual interviews (2 interviews, n=2 participants) as part of a large longitudinal study that sought to examine the knowledge, attitudes, and beliefs about all types of tobacco use. Eligible participants were screened in person at a tribal college in Montana, and provided with written informed consent. Data collection followed a similar

format and moderator's guide. The information gathered from this study directly related to the formative research being carried out for the ANSOS program. Study outcomes from both the Kansas and Montana groups were analyzed together.

Data analysis occurred through a combination of methods including: constant comparative method data analysis (Kolb, 2012) and a CBPR protocol previously developed by the research team (C. M. Daley, James, et al., 2010). Initially, coding was used to systematically organize and review each transcript. Three independent researchers, blinded to each other, coded the data. Each coder was a member of the research team, either an AI community researcher or a non-AI academic researcher. Coders grouped data into the major content areas and inductively coded for themes. Both an etic and emic reviews were then performed on the coded transcripts. The emic reviewer, offering an insider's perspective, specifically assessed the themes for cultural appropriateness, determining if statements accurately and respectfully described things from the perspective of someone within the culture. The etic reviewer focused more on wording of the themes and if they accurately represented the original raw data. By keeping the etic or outsiders perspective, the project gained insights that a community member might have missed because he or she was too intimately involved with the data. There were no significant differences found among strata or location; therefore, themes across the groups were analyzed together. Theme consensus and how to interpret them was determined by the entire research team.

Scientific Review—All materials were reviewed for scientific accuracy by a panel of four experts in tobacco control and AI research, representing different fields of expertise. For any brochure to be labeled suitable for our program, all experts had to find no scientific inaccuracies of any kind or any outof-date information. If any inaccuracies were found, we corrected them prior to using our educational materials in the pilot study.

Readability Assessment—Two readability formulas, the Fry and SMOG (Simplified Measure of Gobbledygook), were used to evaluate program materials. Educational materials were scored by two independent scorers, both trained to use each method and both having no part in the development of the materials for the ANSOS program. The Fry was developed to ensure materials have a level of readability that is understandable by a large portion of the population and has been validated for assessing patient education materials (USDHHS, 2009). Like the Fry formula, the SMOG formula has been proven as an accurate and simple tool and is widely used in the patient education literature (Bernard, 1995; Mc Laughlin, 1969; Meade & Smith, 1991).

We used two formulas to verify that the reading grade levels we found were accurate. The primary scorer assessed the readability of each of the nine curriculum sections individually, and a secondary scorer assessed three of the sections individually, to establish investigator reliability. Modifications were made to materials found to be grade 8 or above; materials were then reassessed to ensure all of them were at an appropriate readability level prior to program implementation.

Cultural Review—We conducted individual interviews (n=22) to determine what community members would like to see in the educational materials for ANSOS, including

cultural appropriateness, topics, graphics, layout and design. Participants were given information about the study and provided written and verbal informed consent.

Interviews were conducted by two trained AI members of the research team. The moderators guiding the interviews were trained by the PI to establish consistency. All participants were asked the same questions within a flexible framework. Participants were asked questions from the same loose set, with no defined ordering of the questions. Participants were encouraged to talk about their opinions and views through open-ended questions. All interviews were audiotaped using digital audio recorders to keep participants adequately deidentified and the recording were transcribed verbatim by a professional transcription service, excluding any identifying information. Participants' opinions of the program curriculum were the primary source of data. Once an initial review of materials was completed by the local AI community, our research team, including program facilitators all of AI descent, carefully went through all materials to ensure that nothing was included that could potentially be considered culturally insensitive or inappropriate. Demographic results for the focus groups, interviews, and cultural reviews are in Table 1.

RESULTS

Focus Groups and Interviews

Four predominant topic areas emerged from the data and include: (1) knowledge, attitudes, and beliefs about SLT and SLT users; (2) beliefs about initiation of use and barriers to quitting; (3) attitudes regarding the relationship between policy and tobacco use, and (4) suggestions for the creation of a culturally tailored SLT cessation program.

Participants had definable knowledge, attitudes, and beliefs about SLT and SLT use. They discussed in detail their initial experiences with SLT use and identified potential influences to start using SLT, as well as barriers to quitting. A reoccurring theme between smoking, tobacco-free policies, and the use of SLT was apparent as participants saw a complex relationship between smoke-free policies and the poly use of tobacco products. Furthermore, participants were able to address what they wanted in a cessation program from a first-hand perspective and discussed a variety of recommendations for the ANSOS program. A detailed description of the themes, in addition to participant statements are located in the Table 2.

Scientific Review

At the completion of our scientific review, only minor modifications were made to ensure full and up-to-date information from our participants.

Readability Assessment

The initial Fry scores for the individual sections ranged from a reading grade level of 3 to a reading grade level of 11. The mean SMOG score for all materials was slightly higher, ranging from 6 to 9. Four of the nine sections required modifications to lower the reading grade to the desired level (at or below grade 8): Chew & Native people, Stress reduction, Traditional tobacco, and Weight management. After modifications were made, reassessment

of the program material resulted in an overall reading grade level lower than the initial assessment. Readability assessment pre and post test results are depicted in Table 3.

Cultural Review

No materials were found to be culturally insensitive or inappropriate to the AI community by the interview participants, research team, or program facilitators. However, interview participants had several suggestions to make the materials more targeted to the population and improve the overall appearance. Suggestions for improvement included the addition of images, colors, and content to appeal to a Native audience.

Suggestions most targeted to this population involved the inclusion of images of Native individuals to relate to program participants. One participant recommended "use images with the culture that Native people can relate to," while another suggested "use pictures of what it can do, as well as testimonies of people who quit because of what chewing has done to them." In general, they wanted program materials to be more visually appealing to the audience. Participants suggested printing the materials in bright colors (e.g. red, yellow, and orange) to grab the attention of program participants. They also thought that program curriculum should include facts, statistics, and explanations of traditional use specific to the AI community. According to one participant, "the program should talk about the ceremonial use of tobacco and the non-traditional use of tobacco, because there is a difference." Another participant stated, "I would like to see more statistics about how many Natives actually died from chew each year."

Program Components

The findings of this study provided valuable feedback that was used to develop ANSOS program components. ANSOS addresses SLT cessation through four basic components: group support sessions, individual telephone counseling, a culturally-tailored curriculum, and culturally-tailored incentives. As shown in Table 4, the developed program follows an intense timeline for 12 weeks, with follow-up to 6 months. Participants have the option to participate in a one-time education option if they cannot participate in the full 12-week session.

The primary component is a series of weekly group-based support sessions, led by an AI facilitator. Prior to group sessions there is one in-person individual meeting with the facilitator for program explanation, consent process, and baseline measures. All group sessions begin with team building and discussion among members about things they are experiencing in their lives, both those related to use of tobacco and other things that may help or hinder quit attempts. The first group session is the quit date for all participants to ensure they go through the process together. Between groups, facilitators contact participants for individual telephone counseling sessions to see how they are doing, discuss personal issues related to quitting, answer any questions that the participants might have, and to remind them of the next group.

Educational materials have been designed to be used in any multi-tribal population and modified for use with a specific tribe. The curriculum consists of a series of education booklets given at the start of the program. Participants will receive incentives at various

program points. During each group support session, participant receive a weekly "quit kit" (i.e. hard candy, gum, stress ball, etc.) to help avoid chewing. Additionally, participants receive culturally-appropriate items after meeting weekly milestones, and significant information about the diversity of traditional tobacco use.

DISCUSSION

AI communities face an ongoing challenge of effectively addressing tobacco related health disparities. Effective approaches to the prevention of tobacco related disease in this community requires a specific and tailored cessation program. It is critical to identify and describe the influence of cultural perspectives within the community. Cultural knowledge and beliefs have a direct influence on the ways communities choose to access health education and treatment services.

The primary purpose of this investigation was to gather formative data needed to develop a culturally tailored SLT cessation program for AI. The ANSOS program was developed with the understanding that AI are a heterogeneous population, with diverse cultures and tribes. An intervention that may be effective for one racial/ethnic group may not be effective for another group, making the development process unique in itself.

This study contained two primary limitations. First, the number of participants was small in comparison to the number of AI living in the United States. Second, this study was conducted in a limited geographic region, which included areas of Kansas and Montana. Therefore, the generalizability of study results may be limited across contexts and populations. However, multitribal representation within our study population derives from different parts of the country. Our research team identified behaviors upon which we can intervene to encourage education and screening throughout AI communities.

An extensive formative process was followed to evaluate our own development process and outcomes to ensure suitability for our program population. We believe the process by which this assessment was conducted may be a useful tool for anyone wishing to develop targeted educational materials for other communities or topic areas. This process shows that the development of culturally appropriate educational materials for any program is lengthy and time consuming. Despite time constraints, to determine the effectiveness of any targeted educational materials, potential confounds must be removed. Both scientific inaccuracies and high reading grade levels can easily lead to problems making content difficult to understand. Additionally, culturally insulting images or words can make a program irrelevant or offensive, and clearly must be removed. Furthermore, developing the framework of any program requires thoughtful attention to the specific needs and wants of community members. The significance of using a CBPR approach to ensure any program meets the needs of community members cannot be overemphasized in developing meaningful partnerships in AI communities that address current health disparities that are important to the health of tribal members.

CONCLUSION

Addressing potential problems allows for the cultural targeting of a program to be tested more effectively, making the time it takes to complete a multi-step assessment worthwhile. The process of broadening and refining a culturally tailored intervention is crucial for successful program development and dissemination. If successful, our conceptualization of intervention research using a multifaceted approach may be repeated to address additional health disparities due to SLT use in AI communities.

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Table 1.

Comparative Demographics across Studies (N = 107)

Demographic Variable	n	%
Gender		
Male	68	63.5
Female	39	36.4
Age		
18–29	58	54.2
30+	48	44.9
No Answer	1	0.9
SLT Use Status		
Never	49	45.8
Current/Former	58	54.2
Data Collection		
Kansas Focus Group		
Male	25	23.4
Female	2	1.8
Kansas Interview		
Male	1	0.9
Female	1	0.9
Montana Focus Group		
Male	30	28.0
Female	23	21.5
No answer	1	0.9
Montana Interview		
Male	0	0
Female	2	1.8
Cultural Interview		
Male	11	10.3
Female	11	10.3

Table 2:

Theme Development

Торіс	Theme	Participant Statements
SLT Use	1. Participants described a user of SLT to be someone who purchases and uses it on an occasional or regular basis, in no particular quantity.	 "Someone who chews tobacco on a consistent regular basis". "It's in their mouth all the time or an empty bottle with them" "Anyone who buys and uses it".
Initiation and Barriers	2. Participants believe individuals start using SLT primarily due to the influence of people around them and continue to chew due to addiction, habit, or social influence; despite known health effects.	 "Peer pressure and curiosity". "It just becomes habit, especially if you've done it most of your life". "The addiction, your body needs that nicotine kick". "If I stop I'll lose all my friends". "You can lose your teeth or it could give you mouth cancer" & "Lip, mouth, gum cancer".
Policy	3. Participants saw a complex relationship among smoking, smoke-free policies, and the use of SLT.	 "If they're around people who don't have cigarettes, they'll go to the next best thing which is chew". "On basketball trips the coach would get mad if he smelled cigarettes smoke, so I would just chew". "If you ever ran into a chewer, you wouldn't really see it". "There are tobacco free zones, but I sat there and chewed, no one ever said anything to me, you weren't allowed to have it, but you can be discreet about it".
Program Development	4. Participants had numerous suggestions for creating a culturally tailored program to quit using SLT.	 "I've tried a six week program and I didn't feel it was long enough", while another stated, "once a week would be all that I could handle". "You've got people to support you and to help you and keep you accountable" (referencing group-based programs). "Being a past user is more important than race" (on group leader). "Topics showing facts. Pictures of cancer or sports figures with no jaw", while others agreed that scare tactics are important because "they are reality". Referring to potential incentives: "things to settle cravings", "gift cards to get groceries, just simple stuff you earned", and "something to do with execise".

Table 3.

Readability Assessment Pre-Post Results

Curriculum Section	Fry	Fry Corrected	SMOG	SMOG Corrected
Chew & Native people	11 th grade	8 th grade	9th grade	9 th grade
Congratulation you have quit	4 th grade	4th grade	8th grade	8 th grade
Coping with withdrawal	7 th grade	7 th grade	7 th grade	7 th grade
Friends/family & quitting	6 th grade	6 th grade	8th grade	8 th grade
Preparing to quit	3rd grade	3rd grade	6 th grade	6 th grade
Stress reduction	7 th grade	6 th grade	9th grade	7 th grade
Traditional tobacco	8 th grade	8th grade	9th grade	9 th grade
Weight management	7 th grade	7 th grade	9th grade	7 th grade
Why do people chew	8 th grade	8 th grade	8th grade	8 th grade
Average Reading Grade Level	6.8	6.3	8.1	7.7

Table 4.

ANSOS Timeline

Session	Type of Session	Topics Covered
Screening	In-person or via Telephone	Eligibility criteria
Intake	Individual In-person	Program information and start date, quit date information, questions about the program, personal use history, pharmacotherapy
Week 1 -or- One-Time Educational Session	Group In-Person and Telephone	Facts about chewing tobacco, share personal stories with group, more questions about the program
Week 2	Group In-Person and Telephone	Team Building, Coping with Withdrawal
Week 3	Group In-Person and Telephone	Stress Management I
Week 4	Group In-Person and Telephone	Social Support I
Week 5	Telephone	Personal Issues
Week 6	Group In-Person and Telephone	Weight Management, Healthy Eating and Exercise
Week 7	Telephone	Personal Issues
Week 8	Group In-Person and Telephone	Stress Management II
Week 9	Telephone	Personal Issues
Week 10	Group In-Person and Telephone	Traditional Tobacco
Week 11	Telephone	Personal Issues
Week 12	Group In-Person and Telephone	Social Support II; Staying Quit, Program Feedback
Month 6	Group In-Person	Evaluation of program