CREATING A CULTURALLY APPROPRIATE WEB-BASED BEHAVIORAL INTERVENTION FOR AMERICAN INDIAN/ ALASKA NATIVE WOMEN IN SOUTHERN CALIFORNIA: THE HEALTHY WOMEN HEALTHY NATIVE NATION STUDY

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Abstract: Health disparities in fetal alcohol spectrum disorders (FASD) are of high importance to American Indian/Alaska Native (AI/AN) communities. We conducted focus groups and interviews with 21 AI/AN women and key informants in Southern California to modify a brief, Web-based program for screening and prevention of prenatal alcohol use. This process resulted in several important program modifications and was essential for fostering partnerships between researchers and the community, engaging community members in research, and identifying community priorities.

INTRODUCTION

Fetal alcohol syndrome (FAS) is a pattern of congenital malformations that includes pre- and postnatal growth deficiency, microcephaly, characteristic craniofacial anomalies, and mental deficiency (Jones, 2005). FAS is recognized as the leading known, completely preventable cause of birth defects. Estimates of the birth prevalence of FAS vary according to the population studied and the method of ascertainment (Abel, 1995). However, FAS represents only the most severe end of the spectrum of effects seen in some children of women who drink during pregnancy. Increased rates of growth deficiency and neurobehavioral deficits have been noted in the offspring of women who drink moderate or even lesser amounts of alcohol (O'Connor, Brill, & Sigman, 1986; Streissguth, Barr, & Sampson, 1990). The broad spectrum of alcohol effects, now encompassed by the umbrella term fetal alcohol spectrum disorders (FASD), might be six times more prevalent than the full-blown syndrome (Sampson et al., 1997).

American Indian/Alaska Native (AI/AN) women in the U.S. have poorer health across several outcomes, as compared to the general population. The infant mortality rate among Native women within the 35-state Indian Health Service area is 28% higher than the overall rate (8.8 vs. 6.9 per 1000 live births, respectively; Indian Health Service, 2008). Some of the highest rates of FAS in the U.S. have also been reported among AI/AN populations (Abel, 1995; May & Gossage, 2001). While prevalence estimates vary widely, data suggest that at least some AI/AIN groups are at high risk (May & Gossage, 2001; May et al., 2009). As such, FASD is of considerable public health interest, and represents a health disparity that is of high importance to AI/AN communities.

There are more than 550 federally recognized tribes in the United States, each with a unique history, geography, and culture. It is not surprising, then, that the patterns of alcohol use are also heterogeneous across AI/AN groups and differ from those found in general U.S. population surveys. Beals and colleagues compared quantity and frequency of reported alcohol use in the general U.S. population to that of Southwest and Northern Plains tribes (Beals et al., 2003). Results suggest that alcohol use patterns vary by region and that AIs from both regions are more likely to be lifetime abstainers of alcohol than the U.S. population overall. Others have identified a high rate of alcohol consumption among Northern Plains AI women attending a prenatal clinic, where 74.% consumed alcohol prior to pregnancy and 16.2% consumed any alcohol while pregnant (May et al., 2004). The proportion of Southern California AI/AN women of childbearing age who consume alcohol in quantities and patterns that would be of concern for the development of the embryo in the early weeks of pregnancy is unknown.

Half of pregnancies in the U.S. are not recognized until the fifth or sixth week of gestation, by which time a significant proportion of embryonic development has already been completed (Jacobson, Jacobson, & Sokol, 1996). Therefore, non-pregnant women of childbearing age represent an important audience for interventions aiming to reduce alcohol-exposed pregnancies. The Screening, Brief Intervention, and Referral for Treatment (SBIRT) approach has been shown to be effective in reducing drinking among women of childbearing age (Floyd et al., 2007; Manwell, Fleming, Mundt, Stauffacher, & Barry, 2000). SBIRT is based on Motivational Interviewing, a directive approach to enhance intrinsic motivation for behavior change (Miller, 2002). A Web-based SBIRT intervention was recently developed for use among non-pregnant women of childbearing age who receive Women, Infants, and Children (WIC) services in Southern California. In a small randomized controlled trial, 150 women were randomly assigned to receive either this Web-based intervention followed by personalized feedback, or general information about FASD and the risks of alcohol use during pregnancy. The intervention was unique in that it was designed to modify drinking behaviors that might not be "risky" for non-pregnant women, but could be risky if a woman became pregnant and continued them. The motivation to change was linked directly to the

health of a future baby. In this study, both conditions (the general information and the Web-based intervention, with or without personalized feedback) resulted in reduced risky drinking occasions for women (Delrahim-Howlett et al., 2011). Study participants rated this brief Web-based intervention as both feasible and acceptable.

Culturally appropriate and individually tailored health promotion efforts are sometimes more effective than generalized approaches (Kreuter, Oswald, Bull, & Clark, 2000; Skinner, Campbell, Rimer, Curry, & Prochaska, 1999). However, it is unclear whether this is the case for programs aimed at preventing or treating substance abuse among AI/AN women. A limited number of studies, generally focused on FASD prevention, have evaluated the effectiveness of alcohol treatment and prevention approaches for AI/AN women (Masis & May, 1991; Montag, Clapp, Calac, Gorman, & Chambers, in press; Peterson, Berkowitz, Cart, & Brindis, 2002). Many interventions are not rigorously evaluated and their program results are often not published in peer-refereed journals, so it is difficult to ascertain whether culturally appropriate substance use prevention programs are more effective in changing behavior than are standard approaches (Hawkins, Cummins, & Marlatt, 2004; Hodge, Jackson, & Vaughn, 2010; Montag et al., in press). Despite a lack of clear evidence, researchers working with AI/AN populations have emphasized the importance of both community involvement and cultural relevance in interventions, and have demonstrated the positive impact of culturally appropriate approaches to substance use prevention programs (Baydala et al., 2009; Hawkins et al., 2004; Jiwa, Kelly, & Pierre-Hansen, 2008; May & Moran, 1995; Montag et al., in press; Noe, Fleming, & Manson, 2003).

We describe the planning and development phase of a Web-based SBIRT intervention to reduce alcohol-exposed pregnancies among AI/AN women representing nine tribes in Southern California. The purpose was to engage Native women, community leaders, and Indian Health clinic staff members in the process of adapting an existing theory-based intervention, which has proven effective in other populations, for use in one AI/AN community by making it culturally appropriate and including relevant individualized feedback messages. Given the heterogeneity in alcohol use among Native women (Collins & McNair, 2002), we aimed to develop a site-specific program for this region. We summarize the process of recruiting participants; obtaining and incorporating feedback; and modifying the intervention design and content to make it culturally appropriate, understandable, accessible, and relevant to AI/AN women of childbearing age. Our methods and experiences could be useful as a guide to other researchers and practitioners involved in modifying existing programs for cultural appropriateness, particularly with AI/AN populations.

METHODS

The planning and development phase, conducted over the first year of the project, included preliminary qualitative research and community outreach to adapt the intervention culturally. The original project aims proposed 4-6 focus groups with AI/AN women of childbearing age (18-45 years old) and Native and non-Native key informants (clinic staff who had familiarity and experience with the topic and population). Focus groups were conducted between April and October 2010. The primary aims were to evaluate an existing Web-based SBIRT program designed to prevent risky alcohol use among women of childbearing age (Delrahim-Howlett et al., 2011); and modify elements of this program for AI/AN women in this Southern California community, including cultural appropriateness, comprehension, accessibility, and relevance.

The planning and development phase also included discussions with and feedback from tribal board members, the Medical Director of the local Indian Health clinic, medical and behavioral health clinic staff, and outside consultants with experience in alcohol use prevention research among AI/AN populations. The purpose was to ask these individuals to assist in the development of a culturally appropriate program, gain support from clinic staff and the tribal community, encourage community engagement, and integrate with existing research projects in the community and with ongoing clinic activities. Feedback was obtained through presentations to tribal board members and clinic staff, and informal discussions with clinic staff and consultants.

Methods of focus group recruitment included flyers posted throughout the clinic, flyers given directly to patients by health care providers, verbal and written information provided by research assistants in the clinic waiting rooms, and informal word of mouth. Women interested in participating were asked to contact a study research assistant based at the clinic who provided more information and enrolled participants. We conducted groups with both key informants and Native women of childbearing age. We aimed to notify as many Native women, ages 18-45 years, as possible about the opportunity to participate in one of the focus groups. We sought to include women from different age groups, and both mothers and women who had not had children. Five women of childbearing age who consented to participate did not attend a focus group. Three women of childbearing age and one key informant completed an individual interview rather than a focus group because of low attendance and scheduling challenges.

This study was approved by the Institutional Review Boards of the local Indian Health clinic, University of California San Diego, and San Diego State University. Each participant completed oral and written informed consent procedures prior to the focus group or interview. With participant consent, each focus group session/interview was audio-recorded using a tabletop digital recorder. Focus groups/interviews were facilitated by the study coordinator and Native research assistants trained in qualitative interviewing. We used a semi-structured interview guide with open-ended

questions; focus groups/interviews were 1-2 hours in length. Participants received a $20 gift card. During the focus groups/interviews, participants were asked to review each section of the Web-based program and comment on the following: overall program design; program name; colors, images, and graphics; ease of use; perceived community receptivity; comprehension of specific wording; comfort in completing the program; relevance of personalized feedback messages; relevance for community; general suggestions for improvement; and ways to increase cultural appropriateness of the program. These core items were included in all groups, but the interview guide was also flexible to encourage conversation and allow for new topics of interest to arise. Due to its length, the full guide is not included here; examples of interview questions included: What do you think about the way these images/words look? What do you think your friends and relatives would think about this program? What do you think about the information in this section? Can you think of anything that would make this program more meaningful and capture women's attention?

We transcribed all focus groups/interviews and used cross-case, inductive analysis to identify themes, sub-themes, and patterns in the data (Patton, 1990). The analysis of focus group data—including reading text, coding data and developing themes, reducing data to essential points, and identifying key modifications— was an iterative process and continued though the data collection process. Two researchers independently reviewed the data and began developing codes, themes, and sub-themes. The final themes required consensus between the two coders and were finalized after rechecking the original transcripts to ensure that the meaning and intent of the participant comments were accurately captured. After completing analyses and incorporating key modifications, we tested the revised Web-based program during three individual interviews where participants were asked to evaluate and provide detailed comments on the revised program. Because of serious confidentiality concerns within the community, we elected not to provide any identifying details of participants in our results.

RESULTS

Recruitment and Participation

A total of 21 participants—15 AI/AN women of childbearing age and 6 key informants—attended focus groups or were interviewed individually, and two Native women of childbearing age returned to test the revised Web-based program. Focus groups and interviews consisted of 1 to 6 participants each.

Focus group results

Generally, participants had a positive response to the program and liked the Web-based format. One participant reported, "I think it's good [that it's Web-based] because some people would maybe be embarrassed to enter some information to a stranger, and about their family history, some people get weirded out." Several participants also reported that the program might help raise awareness about alcohol use during pregnancy. One young woman said:

> It's good! It kind of scares you straight for a little bit. You don't normally see this, you just think, Oh a couple of drinks, but you know, really, health-wise it's a lot of calories. It hurts your health and your baby, it's sad. But our generation or people that live around here, and who probably didn't know they were pregnant, are out drinking.

Participants identified five key areas to address to facilitate making the intervention culturally appropriate, understandable, accessible, and relevant to AI/AN women of childbearing age in this community.

1. **Make the program more personal and relatable to women by including pictures and a personal story about having a child affected by alcohol use during pregnancy**

Following the advice of the Native women participants, we changed the graphics and colors throughout the program, incorporating earth-tone colors and modifying graphics to make the content more understandable. We also added a logo designed by Native staff and volunteers that was intended to appeal to a broad range of women in the community. The logo featured a medicine wheel with four silhouettes of women across different life stages (adolescence, pregnancy, motherhood, and older adult). Because participants also felt it would make the program more personal and relatable, we included pictures of Native women, babies, and children. Another important change was the addition of a short audio clip from a Photovoice exhibit entitled "Picture This" (Healthy Generations Family Support Program, 2008). This project involved giving cameras to women from Sioux Lookout and asking them to use the pictures they took, along with their words, to express their points of view and experiences as parents of children with FASD. With this video clip, we were able to address a specific shortcoming identified by focus group participants by incorporating the oral tradition that is important in many Native cultures.

2. **Emphasize confidentiality**

Because participants identified confidentiality as a critical concern, we included a written confidentiality statement on the home page emphasizing that all answers would be kept confidential and would not affect medical care received now or in the future. We also created a brief video

introduction to further emphasize confidentiality. The video was about 1 minute in length and introduced the purpose of the program, emphasizing that answers to questions and personalized feedback were confidential, were for personal use alone, and would not be seen by others, including health care providers. Focus group participants identified a trusted health care provider who has served the community for over 35 years to be featured in the video. In planning for the intervention, we also developed strategies to ensure availability of a private office space where participants would be able to complete the intervention within the clinic, where it would implemented during the study.

3. Incorporate family and community orientation

Women discussed both family and community culture as important influences on alcohol use behavior in this community. One Native woman described the role of family this way:

> Well I think the family plays a huge role. I would say probably a greater role in an individual's life out here than it does in the general population, just because we are so intertwined and so it really depends on the family members on what decisions the family is going to make. Like if she has family members who are active in their alcoholism, she's going to be influenced and really it's because the messages that she's hearing from them could be so different than what she might be hearing from people who are choosing not to drink.

While this program is not designed to modify behavior at the family or community level, we were able to honor these values by emphasizing during the video introduction described in Theme 2 that the information provided in the intervention was for the benefit of the individual, family, and community. For example, the introduction stated that the program was designed for "you and other women in our community" and discussed importance of healthy lifestyle choices for all women who are pregnant or may become pregnant. We also included important tailored feedback messages about the influence of family alcohol use on future risk of alcohol dependence, as well as recommendations about the importance of spending time with family and friends who do not drink.

When participants were asked what women in the community would think of this program, feedback was mixed. One woman reported a positive outlook, saying:

> I liked the family risk part, mine was really high, which I assumed it would be, but it was an interesting part of the feedback section. A lot of people don't realize that if your family has drinking problems, you are more predisposed to having a higher drinking risk as well.

However, another had a more pessimistic perspective, reporting that her friends and relatives "would probably laugh at it. They are all alcoholics."

4. Tailor content to our community

We modified the wording used in the program, including feedback messages, to improve relevance and understanding. For example, participants advised us that women in the community would prefer if we described the bloodstream using the words "blood system." In the series of questions evaluating alcohol use, we included examples of common drink types such as alcoholic energy drinks. We also added information to address perceived norms about widespread alcohol use among young women in the community. As one woman reported, "[The feedback section] said that 50% of women don't drink at all, which I thought was interesting, because I honestly don't know anyone else besides myself that doesn't drink!" To adjust perceived norms about drinking, the Screening, Brief Intervention, and Referral for Treatment approach includes feedback to compare an individual's drinking with the norm of someone in a relevant, similar population. Overall, focus group participants reported a dislike for having their own drinking behavior compared with that of the general U.S. population, and felt it irrelevant. We hoped to obtain reference data that included AI/AN women of childbearing age with the same or similar tribal affiliation, but these data are unavailable. As an alternative, we added the following true/false question to adjust norms: "Most women aged 18-44 who are members of Southwest tribes currently drink alcohol." When a user answers the question, the feedback explains the results of a recent study reporting that most women of childbearing age who are members of Southwest tribes are not current drinkers (Beals et al., 2003)

5. Include more information about how women's alcohol use can negatively impact children's health.

Focus group conversations identified some common myths about alcohol use during pregnancy in this community. One participant said:

> Yeah I remember the misinformation. I remember friends telling me like it's okay to drink as long as you only drink... Old wives tales mix with misinformation and you get things like "It's okay to drink as long as you only drink in the morning so your body metabolizes it". Or "It's okay to drink wine". Like I said, with my first pregnancy, I heard it was okay if you did everything. Like drugs in moderation, or drinking as long as you followed the rules. I heard you could smoke cigarettes like a chimney as long as you smoked lights.

We added a series of true/false questions to help dispel some of these myths, including the perceived safety of drinking wine during pregnancy, drinking in the morning, and drinking beer to help with nausea. In addition, we developed 16 individually tailored, computer-generated feedback messages to encourage changes in alcohol use, or continued healthy practices, based on current contraception use, pregnancy status, and reported alcohol use over the past 2 weeks. Finally, we added significant content on the importance of avoiding alcohol use during pregnancy, even before pregnancy is recognized, as well as information about FASD, emphasizing that alcohol use during pregnancy has a lifelong impact on children, but this impact is completely preventable if alcohol is avoided during pregnancy.

DISCUSSION

The main goal for the planning and development phase of the study was to modify an existing Web-based SBIRT intervention to create a culturally appropriate intervention for prevention of alcohol-exposed pregnancies among AI/AN women in Southern California. While other FASD prevention programs have been developed and demonstrate the importance of incorporating the local culture, circumstances, and norms of AI/AN communities (May, 1995; May & Moran, 1995), we are aware of no other Web-based programs. This planning and development phase was critically important and resulted in significant changes to the content and design of the Web-based SBIRT. Importantly, it also provided the opportunity for community involvement and for researchers to begin building trust with women in this community.

Participatory research methods are increasingly recognized as central to successful community-research partnerships, particularly for addressing health disparities (Macaulay et al., 1999; Wallerstein & Duran, 2006; Williams et al., 2010). While it is unclear whether a culturally appropriate program will be more effective in changing women's drinking behavior during pregnancy (Hawkins et al., 2004; Hodge et al., 2010), the process of engaging the community and gaining feedback on community priorities in the early phases of research was essential. Focus group participants also emphasized the value of cultural appropriateness, saying that interventions, including the language within them, must be understandable to the average community member and delivered only after consulting with tribal members. Consistent with other research (Williams et al., 2010), women in this community perceived a lack of benefit from research studies and general skepticism of research. One Native woman said:

> Indian Health needs to do a study and have the results out in that community all the time, not on a Web site, not in a library…Everybody does health surveys. Smoking,

> drinking, you know it. Hey, this is my life, all I've ever heard about is studies, I've never seen the results in my community. I've never had anyone come to me and be like, I need to tell you this. Ever!

Another added "Every anthropologist, every historian has come and taken from us and done nothing but take and they never give back." This distrust of research is not surprising given historical research abuses, including coerced sterilization of women and controversial genetic research involving the Havasupai people (Mello & Wolf, 2010; Torpy, 2000). Although participants were not asked specifically about their feelings toward research studies, they mentioned these examples as a reason why some in the community might be hesitant to participate in a study. These comments reinforce the need for continued involvement of community members in research.

Throughout the planning and development phase, early discussions with tribal leaders, the Medical Director of the clinic, clinic staff, and consultants were also essential. The Medical Director played a significant role with intersecting obligations as a clinician, tribal member, Co-Principal Investigator on this study, and Co-Leader of the Native American Research Centers for Health which has a mission to decrease health disparities between AI/AN populations and other groups in California. His leadership allowed us to successfully engage tribal board and community members, educate and involve clinic staff, identify key informants for focus groups, plan for possible barriers, and develop solutions to support the acceptance and success of the study within the clinic and community.

We also experienced some unique challenges to conducting this study within the structure of an Indian Health clinic. Time for IRB approval was significantly longer than expected. This delay was due in part to the involvement of three collaborating institutions. Our experience indicates a need to plan for 12 months of development time to accommodate review and re-review of protocol and promotional materials, including iterative amendments by three IRB committees. Another significant challenge was lower-than-expected participation by Native women. Even after extensive clinic-based recruitment efforts by clinicians and research staff, only about 30 women expressed interest in participating in a focus group and even fewer attended. The best participation rates came by reaching out through informal networks, such as word of mouth, and by holding focus groups/interviews during midday lunch breaks so that clinic staff could participate. Finally, we identified a concern among community members that research activities would not be distinct from clinical medical care. This concern may, in part, explain why recruitment efforts in the clinic were less effective than community-based informal recruitment. While the clinic offers an ideal location for recruitment, it appears important to increase awareness that research is being conducted for the benefit of the community as a whole and is separate from services provided by the clinic.

The qualitative component of the study has both strengths and limitations. Important strengths include the fact that focus groups/interviews represented both a diverse group of AI/AN women from several Southern California tribes and key informants, such as clinic staff, who have extensive experience working with Native women in this region. However, study participation rates were lower than expected and some focus groups contained only one or two women. While this individual-level feedback was valuable, it lacked the synergistic discussion that occurs in focus group settings. As with all qualitative research, results are not representative of all AI/AN women of childbearing age. It is likely that additional modifications would be needed for use in other tribes and regions. Such changes could include modifications to the text to increase comprehension, modifications to the design to appeal to the unique culture and aesthetic of the community, and content changes to address community-specific needs for knowledge and understanding about the risks of alcohol use during pregnancy. Although we did not find that tribal concepts regarding prevention of alcohol use during pregnancy were significantly different enough to warrant more sweeping changes to the intervention, this may not be the case in other regions.

The planning and development phase of this study provided an opportunity to involve community members, tribal leaders, and clinic staff in the research process as well as to modify an existing Web-based SBIRT intervention to be culturally appropriate and relevant to Native women in this region. While it is unclear whether this effort will result in a more effective behavioral intervention, this process allowed us to develop important relationships and trust within the community, without which we could not move forward. In particular, women in this community have emphasized the importance of cultural appropriateness and inclusion of tribal members in all phases of research. Both AI/AN women in this community and clinic staff have demonstrated an interest in prevention of FASD and provided positive feedback on the use of a Web-based SBIRT program to prevent alcohol-exposed pregnancies. This program has the potential to provide a culturally appropriate, cost-effective approach to assess and prevent prenatal alcohol use.

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