

ALASKA NATIVE AND RURAL YOUTH VIEWS OF SEXUAL HEALTH: A FOCUS GROUP PROJECT ON SEXUALLY TRANSMITTED DISEASES, HIV/AIDS, AND UNPLANNED PREGNANCY

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Abstract: Background: *The disparity in rates of sexually transmitted diseases (STDs), HIV/AIDS, and unplanned pregnancy between Alaska Native (AN) and non-AN populations, particularly among young adults and females, is significant and concerning. Focus groups were conducted to better understand the knowledge, attitudes, and beliefs of rural Alaska youth (both AN and non-AN) and communities regarding STDs, HIV/AIDS, and unplanned pregnancy and to determine the best methods to educate and facilitate behavior change in AN youth regarding these issues.* Methods: *A convenience sample of AN and rural youth (n = 105) from 5 communities in Alaska, ages 15-24 years, participated in 21 focus groups. Focus group participants were divided by sex and age. We assessed themes related to knowledge, attitudes, and beliefs about STDs, HIV/AIDS, and unplanned pregnancy, as well as perceptions of how youth prefer to learn about sexual health issues.* Results: *The major themes identified were: (1) sexual health is not viewed only in relation to a physical act; (2) there is a basic understanding of sexual health, but youth have a lot of unanswered questions pertaining to STDs and HIV/AIDS; (3) sexual health messages should be delivered via the Internet and school; (4) youth want to hear messages promoting STD/HIV testing and condom use; (5) easier access to condoms is needed; (6) alcohol and drug use affect sexual behavior and risk taking; and (7) issues of confidentiality and embarrassment affect health care-seeking behaviors for sexual health issues.* Conclusions: *One of the fundamental principles of public health practice is community participation, which asserts that success in achieving change is enhanced by the active participation of the intended audience in defining their own high-priority solutions. Our findings—driven by youth themselves—are critical in designing and implementing future sexual health interventions and promoting greater community involvement and acceptance.*

INTRODUCTION

Young adults, regardless of race, are at a significantly greater risk for sexually transmitted diseases (STDs) compared to the general population due to high incidence of unprotected sex, biological vulnerability to infection, frequent partner changes, and difficulty accessing health care (Centers for Disease Control and Prevention, 2002). Alaska has had the highest or second highest rate of chlamydia in the U.S. since 2000 (Cecere, Senft, & Jones, 2011a) and, in 2010, Alaska had the third highest rate of gonorrhea in the nation (Cecere, Senft, & Jones, 2011b). There are discernible disparities in the rates of STDs between the Alaska Native (AN) population and non-AN populations (Gesink Law, Rink, Mulvad, & Koch, 2008; Kaufman, Shelby, et al, 2007; Wong, Swint, Paisano, & Cheek, 2006). Of the total chlamydia and gonorrhea cases in Alaska in 2010, 47% and 74% were in the AN population, respectively; 68% and 58% were under the age of 25, respectively (among the total AN and non-AN population; Cecere, Senft, & Jones, 2011a, b). In Alaska, the AN teen birth rate (age 15-19) was 82.7 per 1,000 in 2008, compared to a rate of 30 per 1,000 in the non-AN population (Sophie Wenzel, personal communication, May 16, 2011). AN people also are overrepresented in statewide HIV infection incidence (Boyette & Jones, 2011).

The disparity in STD and teenage pregnancy rates, and the continuing risk of HIV infection in the AN population, particularly among young adults, are significant and concerning. However, there are limited published data on the contribution of these factors to sexual health and STD transmission in the AN population. This article reports results from a qualitative research project involving AN and rural youth concerning STDs, HIV/AIDS, and unplanned pregnancy.

A fundamental principle of successful public health practice is community participation, which asserts that success in achieving change is enhanced by the active participation of the intended audience in defining its own high-priority solutions. The objective of this study was to discover what AN and rural youth knew about STDs, HIV/AIDS, and unplanned pregnancy and to determine the best methods to educate and facilitate behavior change in AN and rural youth regarding these issues. The results of this study were critical in the development of appropriate sexual health promotion methods for rural Alaska youth.

METHODS

A convenience sample of AN and rural participants was recruited from 5 rural communities in three distinct geographic areas of Alaska, each served by a regional tribal health organization. The study protocol was approved by the Alaska Area Institutional Review Board, the Alaska Native Tribal Health Consortium Health Research Review Committee, and respective regional tribal

ethics committees. All but one of the communities involved in the study were located off the road system and were accessible only by small aircraft, with seasonal access by snowmobile or boat. Communities ranged in populations from 400 to 8,800.

The research questions were: (1) What do AN and rural youth, community leaders, health care workers, and elders know, believe, and think about STDs, HIV/AIDS, and unplanned pregnancy? (2) Which types of public health programs are most attractive to AN and rural youth, community leaders, health care workers, and elders? (3) Which types of public health programs would encourage participation from AN and rural youth? (4) What key public health program strategies would initiate awareness in AN and rural youth and encourage “readiness” to learn more about STDs, HIV/AIDS, and unplanned pregnancy? (Of note, this paper only reflects the findings from focus groups with youth. Results from in-depth interviews with community stakeholders will be presented elsewhere at a later date.)

Focus group and in-depth interview participants were recruited by flyers posted in schools, clinics, groceries, and laundromats, and by public announcements on shortwave radio. In each community, attempts were made to include focus group participants who met the following criteria: American Indian/AN or otherwise eligible for care at the local tribal health clinic (in many areas non-ANs are eligible for services at tribal clinics because the clinics are the only health care facilities available); between the ages of 15 and 24 years; able to give informed consent; and, if under the age of 18, having a valid consent form signed by a parent/guardian. Community leaders, church leaders, health care workers, teachers and school employees, and elders were recruited to participate in in-depth interviews. Consent was obtained from all participants, and parental/guardian consent was obtained for minors (those under the age of 18). Each participant was reimbursed for their time and/or any travel expenses with a \$25 pre-paid credit card.

The research team conducted 21 focus groups in five rural communities. Focus groups took place in schools and senior centers and lasted 75-90 minutes. Moderators facilitated discussion using a guide that was tested prior to use in the study (Appendix A). The guide was tested in pre-study focus groups to ensure ease of use, comfort level, and validity of questions with AN youth. Focus groups were digitally audio-recorded and professionally transcribed. Resulting transcripts were analyzed for themes and content using the qualitative computer software Atlas Ti (www.atlasti.com). Focus groups were conducted separately for males and females and stratified into old (19-24 years) and young cohorts (15-18 years).

Overall, 105 AN and non-AN rural youth ranging in age from 15-24 years participated. Participating youth self-selected and thus might not be representative of all youth in the community. No general differences were found between the older and younger cohorts, except that most participants in the older cohort already had children.

RESULTS

MAJOR THEMES

Overall perception of sexual health: Sexual health does not only relate to the physical

Focus group participants relayed a comprehensive understanding of the term sexual health. Some of the themes surrounding sexual health related to physical sexuality (being sexually active, how sexually active one is), communication with partners, and the feeling of “scary” (because of sex being a taboo subject, something that is not talked about and that can lead to negative consequences). Concepts related to sexual health included being educated, knowing the effects of alcohol/drugs, understanding the possibility of pregnancy, and having an awareness of specific STDs (from crabs, to warts, to gonorrhea, to HIV), as well as being healthy. Questions about sexual health triggered responses regarding relationships, condoms, STD testing, drinking, teenage pregnancy, and STDs in general. Although focus group participants were not specifically asked to define sexual health, they were asked what thoughts or feelings the topic of sexual health brought up.

I think sexual health is just being educated about basically what can happen when you are sexually active, and how to prevent things and just how to be careful.

Embarrassment: Issues of confidentiality and privacy affect health care-seeking behaviors for sexual health issues and condom-seeking behavior

Embarrassment was brought up often as a theme. Being embarrassed was related to clinic visits for STD/HIV checkups and testing, or for obtaining condoms. The reason appears to be concern about confidentiality and privacy when seeking help or care for sexual health issues. Both confidentiality and privacy were related to the fear of people finding out about clinic visits for sexual health care and the belief that people “don’t talk about it (sex).”

Confidentiality and Privacy

And another thing is our clinic is so small that you can hear all the conversations and people knowing what you’re going there for. It kind of makes you feel like you have to be more quiet.

I don’t think anyone would go to the health aides and ask them because they’re maybe scared to come forward and try to ask about that stuff.

Condoms

I've had a friend who asked me to get them (condoms) from the clinic because she's too embarrassed to go.

I don't know very many teens that want to walk into the store, grab a pack of condoms. You know, go down to the store, grab some condoms, go up to the front desk and go to the check stand...

Preferred methods of receiving information: Sexual health messages should be delivered via the Internet and schools

Overwhelmingly, the Internet, school, and television were cited as the main platforms youth wanted to go to in order to receive information about sexual health. Other potential sources mentioned by focus group participants were experts from outside their community and parents. Village clinics were also mentioned as potential places to go to get sexual health information.

Well, a lot of people are like they don't want to go and ask somebody. They get embarrassed or something. So I think the Internet's a good way because not everyone's knowing what you're doing. So you could look it up. You could learn this stuff and no one has to know you're doing this and you don't get embarrassed. It makes it a lot easier for people who have questions but are too embarrassed to ask people these questions.

To get the awareness out I think they should do a lot more in the schools because teenagers spend most of their time in school...

Preferred intervention messages: Youth want to hear messages promoting STD/HIV testing and condom use

Focus group participants mentioned that STD/HIV testing, condom use, waiting to have sex, abstinence, and having fewer sexual partners are all messages that should be conveyed to youth. They did not want to just hear one message; rather, they wanted a multitude of messages reflecting the various options available that will help them remain healthy.

Tell them to use a condom at all times, tell them to get tested and make sure it (chlamydia) doesn't stay in our community. Don't need that stuff around here.

If you tell kids not to do anything, you know they're going to do it. So just tell them to be safe and promote condom using, and other things to prevent pregnancies or diseases.

Just be safe man: Use a condom every time.

Top thing is use a condom. That's like the biggest thing, the most important thing.

Knowledge about sexual health: There is a basic understanding of sexual health, but youth have a lot of unanswered questions pertaining to STDs and HIV/AIDS

Focus group participants had many questions and exhibited a desire for increased knowledge, especially about STDs, HIV/AIDS, symptoms, and available treatments. There was a general sense of “Nobody is talking to us.”

Is there a shot or medicine that you can get for you not to get it (chlamydia)?

Can you cure chlamydia with antibiotics?

What does it do to you and like all the symptoms (chlamydia)?

Who brought it to this place? Or who brought it to Alaska (chlamydia)?

I think that especially teenagers should get so much more information than they are getting now about the outcomes of some of the things, like pregnancies and then the long-term diseases like STDs and stuff. I think that it'll probably change how people think about having unprotected sex. And it might make the girls—if the guy doesn't—if he wants to have sex, and he doesn't have a condom, to make the girl stand up and say “no” because she knows that she could be infected or get pregnant.

Alcohol and drugs

Focus group participants also recognized the impact of alcohol and drug use on sexual behavior and risk taking.

Because of drugs, like when you are drinking and stuff, you don't know what you are doing.

Kids get wasted and then don't think about a condom, and they wake up the next day, and they're like, "Oh, she's pregnant. That sucks. My life's ruined."

I think that the most concern is people drinking alcohol and getting too drunk, and don't even remember that they messed around or something. And it's just that people should just be careful and try not to drink that much.

Sexual health priorities

Male and female participants' themes were largely similar throughout the focus groups. Both genders saw the Internet and school as good places for getting sexual health information, recognized the importance of getting tested, understood the direct effects of drinking on sexual behaviors and choices, were concerned about the effect of STDs on the health of unborn children (i.e., about giving a disease to a fetus, general health of mother and baby), and wanted to know about the symptoms of and treatments for STDs. However, female participants were more concerned about teenage pregnancy than their male counterparts. Table 1 breaks down the top themes in focus groups for females and males.

Table 1
Top Themes of Participant Responses

Females	Males
Sexual health information should be delivered via the Internet	Sexual health information should be delivered via the Internet
Sexual health information should be delivered in the schools	Sexual health information should be delivered in the schools
We need to hear more messages about getting tested	We need to hear more messages about getting tested
Drinking and drugs affect sexual risk taking	Drinking and drugs affect sexual risk taking
Unease of getting sexual health information and health care at the local clinic	Unease of getting sexual health information and health care at the local clinic
What are the symptoms/treatments for STDs	What are the symptoms for STDs; how do you know you have an STD
How do STDs affect your unborn children	What is the treatment for STDs
There is overall acknowledgement of teenage pregnancy and the potential impact	How do STDs affect your unborn children

DISCUSSION

The social context of sexual health care in Alaska is impacted in every way by Alaska's size and the distribution of its people across the state. More than 200 of Alaska's 336 communities are accessible only by airplane or boat, community health aides and midwives are the primary health care providers, health care provider turnover is high, and limited resources and competing health care priorities often render health care provision and education challenging (Tulloch, de Ravello, & Taylor, 2006). Most Alaska communities are not only remote but very small—fewer than 500 people. In these small communities, the primary health care provider is often a relative or lifelong acquaintance. Such close relationships can make seeking health care for sexual health not only difficult, but sometimes seemingly impossible. The tremendous need for sexual health care is complicated by reduced access and limited resources, especially for treatment of illnesses that may be stigmatizing or embarrassing.

The findings of this focus group project provided an initial understanding of the impact of living in a small rural community on sexual health care and how that worldview can affect knowledge, attitudes, and beliefs about STDs, HIV/AIDS, and unplanned pregnancy. Moreover, focus groups indicated that AN and rural youth might have unique knowledge, attitudes, and beliefs concerning these subjects. Themes regarding privacy, ease of access to sexual health information, and availability of condoms emerged as concerns of AN youth regarding sexual health. Youth also voiced preferences for how and from whom they would like to receive sexual health information. Social and behavioral issues of alcohol and drug use and discomfort surrounding the subject of sexual health within the community were noted to be contributors to unsafe sexual behaviors.

These data provided a background and foundation for action to reduce the burden of STDs among AN and rural youth. The information gathered in the focus groups was used to build a culturally appropriate and community-driven intervention. Based on the focus group results, a sexual health intervention emerged with a Web site for AN and rural youth at its core that offers education and health promotion as well as STD/HIV screening and treatment. *I Know Mine* (www.iknowmine.org) is the major outcome of this focus group project and is intended to give youth the tools necessary to make healthy decisions when it comes to sexual health. Through *I Know Mine*, youth can:

- Order condoms (based on focus group desire to have easier access to condoms);
- Order chlamydia and gonorrhea home testing kits via the Johns Hopkins University *I Want the Kit* program (Gaydos et al., 2006a;b; 2009; based on limited access to health care in small villages, and confidentiality and privacy concerns, focus group participants in one area were asked about the acceptability of home testing kits and were overwhelmingly supportive);

- Ask sexual health questions of Anchorage-based providers and find sexual health information (based on embarrassment about asking sexual health questions) and information on the importance of knowing your STD/HIV status, including testing locations (based on desire to know more about testing); and
- Watch videos and read stories about STDs, HIV/AIDS, and unplanned pregnancy, so that youth know that no question is stupid and no story is unique.

I Know Mine is managed and maintained by the HIV/STD Program Services at the Alaska Native Tribal Health Consortium. The Web site was developed by a local marketing company in Anchorage, Alaska using market research to focus on the target audience. Materials uploaded to the Web site are reviewed by a team of doctors, nurses, and public health professionals to ensure accuracy and are reviewed by AN youth to ensure the value of the content. Questions posed and condom orders placed via the Web site receive a response in no more than 2 business days—usually within 24 hours. Many of the stories and videos uploaded to the Web site are created or reviewed by local youth to ensure accuracy and connection to the target population.

Placing sexual health interventions within a cultural context and structuring them within a conceptual framework can give communities a voice and a chance to determine their own health (Gesink Law et al., 2008; Holkup, Tripp-Reimer, Salois, & Weinert, 2004; Kaufman, Desserich, et al., 2007). The findings discussed in this article—driven by the youth themselves—have been critical in designing and implementing future sexual health interventions and will, we hope, promote greater community involvement and acceptance.

A strong sense of autonomy and self-determination is an important aspect and enduring vision of AN communities. The vision for the focus group project was to create an initiative maintained and endorsed by local communities by learning as much as we could from the communities and working in partnership with them, and by linking ideas from the focus groups directly to subsequent intervention objectives. Every community has its own set of interests, values, and viewpoints. By utilizing a community-based and educational approach to focus on STDs, HIV/AIDS, and unplanned pregnancy as population health problems in local AN communities, each community's unique abilities to help build successful initiatives were realized.

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ACKNOWLEDGEMENTS

This work was undertaken by the Alaska Native Tribal Health Consortium Department of Community Health Services and tribal health partners throughout the state of Alaska, with funding from the Indian Health Service National STD Program.

We would like to thank Scott Tulloch, Lori de Ravello, and Melanie Taylor for their guidance in the project, James Williams for his tireless efforts to see this project into fruition, and all focus group participants for sharing their stories.

Appendix A
Focus Group Questions

1. What are your top three health concerns?
2. What comes to mind when I say "sexual health"?
3. What about sexual health are you most concerned with?
 - What makes you pick that?
 - What have you heard about that?
 - What are ways to avoid that?
 - What thoughts, concerns, feelings come to mind regarding that?
 - Where do you usually get information regarding that?
4. I noticed that you didn't say (pregnancy, gonorrhea, Chlamydia, HIV/AIDS); can you tell me why these issues are not concerns for you? (IF NECESSARY)
5. What comes to your mind when I say "sexually transmitted disease" or "sexually transmitted infection," also known as STDs or STIs?
 - Why did you say that?
 - What thoughts, concerns, feelings come to mind regarding that?
 - Where do you usually get information on that?
6. What are some reasons why you would seek out more information on sexual health or STIs?
7. Chlamydia is the most commonly reported sexually transmitted infection in the United States. Every year, it is estimated that 2.8 million Chlamydia infections occur. Alaska has the second highest rate of Chlamydia infections in the U.S. and Alaska Natives suffer from this infection at 4 times the rate of non-Native persons.^{1,2}
 - What questions does this raise for you?
 - What would you want to know about this?
 - What information would you want?
 - How would you like to receive this information?
8. Gonorrhea is caused by a bacterium that grows very well in the reproductive tract in women and urethra in men and women. This bacterium can also grow in the mouth, throat, eyes, and anus.³ It is estimated that in the United States, 700,000 new cases of gonorrhea occur each year.⁴ Like Chlamydia infections, gonorrhea infections also have a disproportionate burden in the Alaska Native population.⁵
 - What questions does this raise for you?
 - What would you want to know about this?
 - What information would you want?
 - How would you like to receive this information?

¹ Centers for Disease Control and Prevention. (2005). Reporting of Chlamydial Infection—Massachusetts, January-June 2003. *Morbidity and Mortality Weekly Report*, 54(22), 558-560.

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³ Centers for Disease Control and Prevention. *Sexually Transmitted Diseases*. Atlanta, GA: Author. Retrieved from www.cdc.gov/std/Gonorrhea/STDFact-gonorrhea

⁴ Centers for Disease Control and Prevention. *Sexually Transmitted Diseases Treatment Guidelines 2002*. Atlanta, GA: Author. Retrieved from www.cdc.gov/std/treatment/default

⁵ Cecere, D. (2007, May 16). Gonorrhea—Alaska, 2006. *State of Alaska Epidemiology Bulletin*, 19, 1. Retrieved from www.epi.hss.state.ak.us/bulletins/docs/b2007_20.pdf

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Appendix A, Continued
Focus Group Questions

9. (For female groups) There is a new way to test for STIs that is used in other areas of the United States. It involves you, and not a doctor, health aide, or nurse, inserting a swab 1 inch into the vagina. This test can detect Chlamydia, gonorrhea, and another infection called trichamonoiasis. Would you feel comfortable doing a test like this?⁶
- Why/Why not?
10. HIV is passed from one person to another when infected blood, semen, or vaginal secretions come into contact with broken skin or the mucous membranes of an uninfected person. Pregnant women can also pass HIV to their baby during pregnancy or delivery, or through breast-feeding.⁷ At the end of 2003, it was estimated that there were over one million persons in the U.S. with HIV/AIDS.³ In Alaska, as of 2005, there were 1,048 HIV/AIDS cases reported.⁸ Add data on cases among Alaska Natives - ?
- What questions does this raise for you?
 - What would you want to know about this?
 - What information would you want?
 - How would you like to receive this information?
11. Pregnancy is considered to be unplanned when the woman did not want to be pregnant (unwanted) or desired a later pregnancy (mistimed). Women with unplanned pregnancies are more likely to find out that they are pregnant later than women with intentional pregnancies—making intendedness a factor in the newborn's birth outcome. Teenagers are the highest at-risk group for unplanned pregnancy. In Alaska 45.3% of pregnancies are unplanned.⁹
- What questions does this raise for you?
 - What would you want to know about this?
 - What information would you want?
 - How would you like to receive this information?
12. One of the end goals of this project is to develop a program and education materials for Alaska Native youth to prevent STI in your community. If you were to develop a program and materials for girls and guys your age in ____, what messages about STI, HIV/AIDS, and unplanned pregnancy would you try to convey?
- Would you....
- Talk about preventing STIs and pregnancy through abstinence? (why and why not)
 - Talk about preventing STIs and pregnancy by promoting condom use? (why and why not)
 - Talk about preventing STIs and pregnancy by decreasing sexual partners or waiting to have sex? (why and why not)
 - Are there any other ideas of how to prevent STIs in your community
13. If we were to develop a program, based on these messages to reach guys and girls your age to get them interested and wanting to learn more about methods of reducing STI, HIV/AIDS, and unplanned pregnancy, how would we go about doing this?
- There are certain programs that have had success in other areas in the past. I am going to tell you a little bit about a couple different programs and I want you to tell me what you think of them
14. Remembering everything that we have talked about today, what are the most important things you would include in a program or education campaign for ____?
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Appendix A, Continued
Focus Group Questions

- ⁶ Wiesenfeld, H.C., Lowry, D.L., Heine, R., Phillips, R., Krohn, M.A., Bittner, H....Sweet, R.L. (2001). Self collection of vaginal swabs for the detection of Chlamydia, gonorrhea, and trichomoniasis. *Sexually Transmitted Diseases*, 28(6), 321-325.
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