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Editor's Note: In commemoration of World AIDS Day (December 1) and consistent with the Department of Health and Human Services plan to designate the December issue of The Provider *as the annual issue devoted to AIDS, we present the following article.*

Breaking the Silence

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Background

Alaska is known as the "last frontier" for good reason. Alaska Native communities representing 229 Federally recognized tribes are spread over a massive geographic area (586,412 square miles) encompassing the arctic coast of the Iñupiaq peoples, the broad river deltas of the Yupik and Cup'ik, a vast interior region of the Athabascan tribes, numerous islands including the Aleutian chain of the Aleut and Alutiiq, and the southeast coastal rainforest which are the homelands of the Eyak, Tlingit, Haida and Tsimshian tribes. Alaska is the largest State in the U.S., larger than the entire southeastern U.S. from the Atlantic coast to the Texas border, from the Gulf of Mexico to the Ohio River. Amid two oceans and three major seas, Alaska has as many miles of seacoast as the combined Atlantic and Pacific seaboards.

Alaska averages 1.08 persons per square mile, in comparison to a population density of 74.31 persons per square mile for the entire United States. Two-thirds of the state population live in three urban areas and the rest reside in scattered, remote hub towns and small villages across the state. Enormous distances, vast mountain ranges, stretches of tundra, glaciers, impassable river systems, and open waters separate communities within the state. The distance from many communities to the nearest medical facility is equivalent to the distance from New York to Chicago. A highway and rail system connects the three urban centers, leaving the rest of the vast land area accessible only by airplane and boat.

Alaska Native people have many strengths, rich cultures, and histories of survival in harsh conditions. Despite these assets, Alaska Native people are faced with many social, medical, and economic problems. HIV/AIDS is slowly rising in importance among these problems since it has disproportionately affected Alaska Native people.[1] While Alaska Natives comprise only 16% of Alaska's total population, they account for 21% of HIV infections, with Native women being the

In this Issue...

fastest growing group of new infections. Of all reported cases of HIV/AIDS over the age of 15 in the state, Alaska Native females account for 40% of HIV/AIDS cases, and yet represent only 16% of the population. Alaska Native males represent 19% of HIV/AIDS cases and make up only 14% of the population. These numbers are rising as more Alaska Natives are becoming infected with HIV and progressing to AIDS.

Alaska Natives are also disproportionately affected by sexually transmitted diseases (STDs).[2] STDs are closely linked to HIV infection because both can be transmitted during unprotected sexual activity. In 2001, Alaska Native males and females of all ages represented 45% of reported chlamydia infections and 52% of gonorrhea infections, while making up only 17% of Alaska's total population. Chlamydia and gonorrhea infection rates continue to rise, with no end in sight. In fact, the State of Alaska currently has the highest rate of chlamydia infection in the country. These statistics are even more alarming when one considers that an STD infection makes a person three to five times more likely to be infected with HIV when exposed through sexual contact, and renders the victim more infectious to others.

Alaska Natives fall below the state average for many social and economic indicators that contribute to their risk for infection. These include the proportion who have graduated high school (31%, vs. 88% for the state); teen pregnancies (54% vs. 26%); per capita income ($12,759 vs. $22,660); persons living below the federal poverty level (20% vs. 9%); percent unemployed (20% vs. 7%); substance abuse (9% vs. 7%); and cirrhosis deaths (18% vs. 10%). This confluence of circumstances and vulnerabilities creates an efficient system for the spread of disease. All that's needed is the introduction of more HIV into the population and one can imagine the makings of an epidemic.

Barriers to HIV Prevention

There are many barriers to HIV prevention in rural Alaska. Lack of access to HIV counseling and testing services for Alaska Natives is a recognized and significant challenge. Travel to regional hubs and the urban center of Anchorage in order to receive health care is extremely expensive, yet necessary for people from remote villages. Basic medical services are provided by trained and competent health aides in village clinics. However, they are only involved in drawing blood for testing; results must be given to the client at a regional hub or by an itinerant provider.

Even when HIV testing is offered, there is a perceived lack of confidentiality. This is partly because of the size of the villages, a close-knit extended family structure, and wariness toward medical systems. Confidentiality is often seen as the biggest barrier to HIV testing. Another barrier related to the perceived lack of confidentiality is that HIV exposure/risk behavior may be underdisclosed to providers (e.g., individuals may not disclose MSM (male to male) sexual behavior, or drug use).[3] It is also culturally inappropriate to openly discuss sexual matters, especially between genders.

Other barriers to HIV prevention are the overwhelming stresses that other issues such as suicide, substance abuse, and unintended injuries rates place on an already burdened medical system. When HIV education is introduced in some areas, it seems to be the least of the communities' worries. Native communities have had a difficult time relating to HIV as a disease because it has been thought of as a gay white male disease for so many years. This has led to a widespread stigmatization of HIV/AIDS and those individuals who are infected.

Case Example

The Northwest Arctic Borough covers approximately 36,138 square miles in Northwest Alaska on the Chukchi Sea. The Borough is roughly the size of Indiana, with an approximate population of 7,400, of which 82.5 percent are Iñupiat Eskimo, making it the largest concentration of Iñupiat people in the world. Average temperatures range from the 40s to 60s in the summer to 15 to 20 degrees below zero during the winter months. There are eleven villages and the hub town of Kotzebue in the borough. However, there are no roads connecting any of the villages or Kotzebue with the rest of Alaska. Kotzebue is situated 26 miles above the Arctic Circle on the northwestern shore of the Baldwin Peninsula and is the commercial center of the borough, serving as both a shipping hub for Northwest Alaska and a transfer point between Anchorage and the villages. Kotzebue's airport supports daily jet service to Anchorage and Nome, as well as smaller propeller-driven aircraft to the villages. Subsistence activities remain an integral part of village life.

The case study begins in late June 2002 when the Alaska Native Health Board (ANHB) received a call from a health educator in Kotzebue requesting support for an HIV related situation in her region. She said that an Iñupiaq man from a small village (pop. < 500) was recently diagnosed with late stage AIDS and transported to the Alaska Native Medical Center in Anchorage for treatment. He did not know he had HIV and was concerned that he may have transmitted the virus to other people from his area.

After much discussion and soul searching, he and his family decided that they must tell the residents of their village about this; anything less would leave "blood on their hands." As an Iñupiat Eskimo family, they believed that every Iñupiaq is responsible to all other Iñupiat for survival; this traditional value guided their decision. In accordance with another traditional value, Ilagiik (family relations/roles), one of the man's sisters, Selina Moose, was chosen to fly back to the village from Anchorage and arrange a community meeting to tell them about her brother's disease. The family also decided to work with the Maniilaq Association (a regional nonprofit health organization) so that staff members could accompany her to give health education information and do HIV testing after the meeting. In effect, the family was going to give up the security of confidentiality for their values and their people.

As the time of the meeting approached, all involved held

their breath and waited in anticipation for the villagers' reactions. Many were reminded of horror stories that other villages faced when this kind of disclosure was made public. In fact, in one village where such a disclosure was made public, the residents were quickly shunned, no planes would land at the village to bring supplies or people in or out, no mail was delivered, and residents who were rumored to have lived there were ostracized. The village had to eventually change its name, and to this day, there are erroneous rumors about a village in Alaska where everyone has HIV. All involved knew what was at stake.

To the relief of many, the community embraced and supported the family. Of course, there was a brief time of fear and anger. Some residents were fearful that they might have contracted the disease through casual contact, and some wanted to place blame. The Maniilaq Association staff helped by providing health education services for the community and by offering HIV testing. Several villagers were tested for HIV that day and many more were reassured that they were not at risk.

As fear and anger began to fade, the villagers accepted the news. When the man returned home from Anchorage, his friends and neighbors visited him and brought him the traditional Native foods he loved and the friendship he needed. It was clear that the community respected that the family based their decision to talk about HIV/AIDS on traditional Iñupiat values such as Avatmun Ikayuutitiq (helping each other), Ikayuutigiigiitiq (cooperation), Pitqiksugautaitiq (honesty), Nakuaqutigiitiq (love), and their responsibility to their tribe. In return, the community expressed the traditional values of Irruaqsiitainriq (no mockery), Naggliktuutiqatiq (compassion), Piqpakkutigiitiq Avatmum (gentleness), and Atlanun Kamaksritiq (respect for others).[4] This reaction may seem incredible to people outside the culture, but not to the Iñupiat, because this is the way it has been for thousands of years.

As is common in rural and remote communities, the news spread quickly throughout the region. The village heath aides, public health nurses and staff at Maniilaq Association were inundated with calls from concerned residents who were fearful about a perceived "AIDS epidemic" in the region. It was at this point that staff in Anchorage from the Alaskan AIDS Assistance Association, Alaska Native Tribal Health Consortium, and Alaska Native Health Board met to coordinate case management, treatment, and education services for people in the region.

It was ANHB's role to work with the Maniilaq Association to provide community education for the region. ANHB quickly planned trips by charter plane to all eleven villages in the region and to the Red Dog zinc mine to hold town hall meetings. ANHB and Maniilaq Association staff began to assemble a team for the meetings, and after many discussions and consultations with community members in the region, it was clear that local people should lead the team. Ross Schaeffer, Sr., Northwest Arctic Borough Mayor and a traditional hunter, became involved as a political and cultural Native leader; Ella Jones, Wellness Counselor for Maniilaq Association, became involved as a Native elder and spiritual leader; and Barbara Cole, Health Education Manager of Maniilaq Association joined ANHB staff as a health educator. Other professionals joined this team, lending their expertise and perspective to the presentations.

When we were all assembled, we discussed how the town hall meetings were to be structured. We came up with the following outline. Ella Jones provided a welcome, both in Iñupiaq and English; discussed the purpose of trip; reminded people of Eskimo prophecy of coming illnesses; acknowledged the courage of the HIV positive man and his sister; and spoke of their family's selfless action in telling people of his disease in hopes of preventing an epidemic. She then did an opening prayer.

Ross Schaeffer, Sr., spoke next with greetings and acknowledgment of HIV/AIDS as a serious concern within the region, the state, and the world. He reminded people that we must work together and help one another through these difficult times. Mr. Schaeffer then introduced Tiny Devlin from ANHB, who discussed the cultural issues associated with HIV, such as the lack of sex education in the days of missions and boarding schools, and related that someone with HIV needs the same kind of love and support that is given to someone with cancer.

Michael Covone from ANHB and Barbara Cole from Maniilaq Association would then give HIV/AIDS educational facts and information, and dispel myths in a conversational and non-technical manner. Other team members then discussed how alcohol, substance abuse, domestic violence, sexual abuse, and other issues are connected to HIV/AIDS. Toward the end of the meetings, Barbara Aragon, an American Indian story teller and researcher, would share a traditional story from her area about cooperation and the need to help each other in difficult times.

The town hall meetings were well received in all of the villages. They seemed to resonate with the communities and helped to reduce the fear and misconceptions that abounded. In total, we reached approximately five hundred and ten people in the region. This is an unprecedented accomplishment for rural Alaska. Never before has culturally appropriate HIV/AIDS education reached so many in such a meaningful way.

Replicability

The model is well suited for populations whose residents are dispersed over a large geographic area, have intact traditional cultural systems, and where health care and social services are provided from a central location. The model is community initiated and supported. It requires in-depth collaboration and power sharing with a broad base of decision makers and community leaders to achieve a clear, consistent, culturally appropriate message. This model represents another approach for HIV/AIDS education in rural areas, as it is fundamentally different from typical public health approaches that often focus on the dissemination of information, rather than the needs of the communities. It helps to engage people on an emotional level

that is compatible with their values and culture, which in turn allows them to deal with difficult issues more easily. Once people are engaged on an emotional level and feel supported, they begin to ask questions about the disease and about transmission. This is much more effective than giving unsolicited information, which people often do not use.

Lessons Learned

We have more work to do in order to fully understand and implement this model in other communities in Alaska. In our experience so far, we have learned some lessons and offer them as guidelines for other programs.

- Recognize that communities often have answers to their own problems. Change the paradigm from providers as experts to providers as supporters of community-driven change. It is our job to highlight and enhance the efforts of community heroes.
- Learn the community and/or tribal protocols and follow them. There are formal and informal power systems in each community; showing respect for these systems builds trust and credibility. Learning about community and/or tribal protocols may take time and effort, but is a necessary step in reaching Native communities.
- In collaboration with community leaders, utilize community/cultural values as the basis of prevention messages. This supports and bolsters the communities' strengths and respects the unique ways of thinking that communities develop.

> "For thousands of years, our people have utilized their values to survive. We had to work together, we had to share, we had to make a commitment to our tribe and take responsibility to lead our tribe in order for us to survive. To survive the future we have to continue to utilize these values."

- Community members or people who are acknowledged as credible community leaders should deliver prevention messages.

> "It takes courage and, you know, a strong person to do something like this.... It's really appreciated, and that's what is needed for this to continue on. For people to remember, that, you know, it's a disease that can kill people."[5]

- Talk with the entire community rather than just the school, clinic staff, or village council. Many Native communities and cultures value collective decision-making and believe it is everyone's responsibility to hear and talk about the health and well being of the people. Targeting intervention to subpopulations often does not work in Native communities because of this value.

> "It [the community presentation] was good because you guys came out and were real strong. And just told everyone what was going on. And so everybody knew and they were aware. I think it made a big impact. It's probably going to make a lot of change for other places too."[5]

- Focus on a strengths perspective rather than a deficit perspective. Helping communities to remember times they successfully dealt with difficult issues can help motivate them to deal with other issues. Help community members to feel collectively and individually empowered to make a difference.

> "Everybody can make a difference. Just one person can make a difference. If you are that one person, it's awesome when you get the feeling inside that you know you have done something to help others."[5]

Next Steps

ANHB created a documentary about this experience called "Breaking the Silence, Strengthening the Spirit" in collaboration with regional leadership and with funding from the National Native American AIDS Prevention Center. The video effectively tells the story of the Iñupiat family and shares some of the cultural strengths and values that are the underpinnings of the model. This video has received national attention since its debut. In fact, when Secretary of Health and Human Services, Dr. Tommy G. Thompson, and the Assistant Surgeon General/Indian Health Service Interim Director, Dr. Charles W. Grim, visited Alaska this fall, they both honored Selina Moose for her courage, and the Alaska Native Health Board for its program. They recognized the model as one of great importance.

With such support, we have more work to do. We plan to further develop the model and produce it for dissemination to other communities, further distribute the documentary, and, most importantly, we plan to continue the trusting relationships we have developed with the communities and people of rural Alaska.

References

1. "HIV Infection in Alaska Through 2000," Prepared by the Division of Public Health, Dept. of Health and Social Services, State of Alaska.
2. Gonorrhea in Alaska 2001 & Chlamydia in Alaska 2001, Prepared by the Division of Public Health, Dept. of Health and Social Services, State of Alaska.
3. "AIDS and HIV Infection in Alaska" Recommendations and Reports, Volume No. 2 Number 2, October 1, 1998 *State of Alaska Epidemiology*. 29 July 2003. *http://www.akepi.org/bulletins/docs/rr1998_2.htm.*
4. "Iñupiat Ilitquasiat" Alaska Native Values for the Curriculum. University of Alaska Fairbanks, Alaska Native Knowledge Network. 29 July 2003 *http://www.ankn.uaf.edu/Values/inupiaq.html.*
5. Personal communication Zazell Staheli July 2002