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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 seaboard.

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

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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 Ikayuutitig (helping each other), Ikayuutigigiitig (cooperation), Pitqiksugautaitig (honesty), Nakuqutigiitig (love), and their responsibility to their tribe. In return, the community expressed the traditional values of Irruaqsiitainriq (no mockery), Naggliktuutiqatig (compassion), Piqqakutigiitig Avatmum (gentleness), and Atlanun Kamaksritig (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 health 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.

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Building Cancer Surveillance Capacity: Wisconsin Tribal and Urban Indian Clinics

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Abstract

The cancer surveillance capacity building project was a collaborative effort of a tribal health organization, the state health department, and comprehensive cancer centers implemented in all tribal and urban program Indian clinics in Wisconsin. The project examined data available on American Indian cancer patients in clinic records, identified cancer screenings currently being conducted, and implemented a trial use of a neoplasm record form to report cases to the Wisconsin Cancer Reporting System, the state's cancer registry. At the outset, no Indian health clinics were reporting new cancer cases to the statewide cancer registry. Only 28 (50%) of the 56 American Indian cancer cases ascertained in the 2001 trial program were found in the statewide registry, and of those reported, 7 (25%) were not reported as American Indian. This suggests that underreporting of Wisconsin American Indian cancer cases may be a regular occurrence, and underscores the value of direct reporting by tribal and urban program Indian clinics to the statewide cancer registry.

Background

Research has shown that the types of cancer experienced within American Indian communities vary significantly by geographic region and tribe, limiting the ability to generalize data from one region of the country to American Indians in other regions.¹⁻⁴ Cancer mortality rates among American Indians in the U.S. appear to be the highest in the Bemidji

Area, and they appear to be increasing.^{1,3,6} Efforts to reduce this burden require sound data for program planning, implementation, evaluation, and research. However, several studies have noted significant inaccuracies in cancer surveillance information for American Indians.^{5,7,9} Cases among American Indian populations are regularly underreported due to racial misclassification and other factors.^{5,9} This project sought to improve the quality of cancer data among American Indians in Wisconsin. More accurate information on cancer incidence among American Indians in Wisconsin will enable tribes to better understand the burden of cancer in their communities and improve cancer prevention and control initiatives.

Organization

The Cancer Surveillance Capacity Building Project was conducted to assess cancer data and screening practices at Wisconsin tribal and urban program Indian clinics. It was designed to lay a foundation to implement a follow-up cancer surveillance pilot project, *Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin*, which has been funded through the Great Lakes Native American Research Centers for Health (NARCH) grant. The Capacity Building project was a collaborative effort of Spirit of EAGLES: American Indian/Alaska Native Leadership Initiative on Cancer at the University of Wisconsin (UW) Comprehensive Cancer Center and Mayo Clinic Cancer Center, the Wisconsin Tribal Health Directors Association, the Wisconsin Cancer Reporting System (the statewide cancer registry), and Great Lakes Inter-Tribal Council (GLITC).

The proposal for the Capacity Building project resulted from a discussion with the Epidemiology Center staff at the Great Lakes Inter-Tribal Council. The idea was subsequently presented to the executive committee of the Tribal Health Directors Association, the program director of the Wisconsin Cancer Reporting System, and the Principal Investigator for Spirit of EAGLES for input and endorsement. All parties enthusiastically supported the project and agreed to promote it. The proposal included a provision to distribute an equal amount of funds to each participating tribe and the one urban clinic as partial reimbursement for the professional services of clinic staff who participated in the project.

All eleven of the Wisconsin American Indian tribes, and the Gerald L. Ignace Urban Indian Clinic, chose to participate in the Capacity Building Project. A total of thirteen clinics

were contacted, including the twelve tribal clinics in the state and one urban Indian clinic. The contacted clinics included Bad River Tribal Clinic, Forest County Potawatomi (Potawatomi Health and Wellness Center), Ho-Chunk (Ho-Chunk Health Care Center and The House of Wellness – Wanaiguni Hocira), Lac Courte Oreilles Tribal Clinic, Lac du Flambeau (Peter Christensen, Sr., Health Center), Menominee Tribal Clinic, Oneida Tribal Clinic, Red Cliff Tribal Clinic, Sokaogon Chippewa Tribal Clinic, St. Croix Tribal Clinic, Stockbridge-Munsee Tribal Clinic, and the Gerald L. Ignace Indian Health Center in Milwaukee.

Objectives

The project had two primary objectives:

1. Assess and describe the information available in health clinic records for patients diagnosed with cancer; for example, what specific types of data were collected, how were the data accessed, and whether a composite report could be created.
2. Identify cancer screening and diagnostic practices currently used in each clinic.

The two secondary objectives were:

3. Use the current Neoplasm Record Form of the Wisconsin Cancer Reporting System to collect information on 10 individual cancer cases, or all cancer cases diagnosed during 2001, whichever was less, and describe the clinic staff's experience in using the form.
4. Send completed Neoplasm Record Forms to the Wisconsin Cancer Reporting System for matching with current records, and for analysis regarding patterns of care.

Methods

A graduate student in the University of Wisconsin Population Health Sciences program (KP) was hired to implement the Cancer Surveillance Capacity Building Project under the supervision of the co-principal investigator for Spirit of EAGLES (PR), and the North Central Project Coordinator for Spirit of EAGLES (RS). Project staff met on site in Lac du Flambeau, Wisconsin with representatives of the Great Lakes Inter-Tribal Council Epidemiology Center to develop an implementation process for the project. The Program Director of the Wisconsin Cancer Reporting System (LS) also participated in this meeting via conference call.

Following this meeting, the Director of the Epidemiology Center (NM-K) prepared and sent a communication to the Wisconsin Tribal and Urban Indian Health Directors that outlined the steps and timeline for the Capacity Building project. This communication included expectations and deliverables for Spirit of EAGLES, the Wisconsin Cancer Reporting System, participating tribal and urban program Indian clinics, and the Great Lakes Inter-Tribal Council. To facilitate timely project implementation,

the Great Lakes Inter-Tribal Council provided project staff (KP) with on-site workspace, including telephone and computer access.

A structured interview method was employed to obtain information on each clinic's cancer data and screening practices. Project staff (KP,RS) prepared the interview questions with input and feedback from the co-principal investigator and other project partners. A train-the-trainer model was employed to achieve the objectives regarding a trial use of the Neoplasm Record Form. Project staff (KP) was trained by Wisconsin Cancer Reporting System staff; KP, in turn, then trained tribal and urban program Indian clinic staff. Wisconsin Cancer Reporting System staff was available by telephone for consultation to both project and clinic staff.

During July and August 2002, project staff (KP) visited each clinic, conducted the structured interviews, and trained clinic staff on use and completion of the Neoplasm Record Form. Participating clinics submitted completed record forms directly to the statewide cancer registry for analysis. Reports of preliminary project findings were prepared by Spirit of EAGLES regarding cancer data and screening practices, and by the Cancer Reporting System regarding the trial use of the Neoplasm Record Form. These reports were presented to all participating clinic staff and project partners at a follow-up session held October 30, 2002 at Great Lakes Inter-Tribal Council in Lac du Flambeau. The session included time for clinic staff to share their experience with the project, and raise specific questions relative to the preliminary findings and recommendations.

Following the October 2002 meeting, the health director at each clinic was sent preliminary findings concerning available cancer data and screening practices for verification and/or correction. After the verification process was completed, a final draft report was prepared and distributed to each director for comment. The Project Director (RS) discussed the final draft with tribal and urban program Indian health directors on February 20, 2003 in Lac du Flambeau. Questions raised by the health directors were addressed through a second verification process with each clinic, and appropriate changes were made.

Results: Objective One

The first objective was to compile information about typical data collected by the clinics on cancer patients. A structured interview method was used to collect this information. Seven questions were used to obtain information regarding this objective; the specific questions appear in italics below.

Questions and Specific Findings

Note: The numbers used to present specific findings are based on twelve reporting entities, not thirteen, because one tribe sponsors two clinics. In addition, we chose to use the general term "clinics" in order to be inclusive of the Gerald L. Ignace Indian Health Center, the urban Indian clinic in Milwaukee.

- *Prior to this project, was your clinic aware of the*

Wisconsin Cancer Reporting System? If so, has your clinic ever submitted reports previously?

Six of twelve (50%) clinics were aware of the Wisconsin Cancer Report System prior to the Capacity Building project. If the clinic was aware of the system, a follow-up question asked whether the clinic had ever submitted a Neoplasm Record Form. Three of the six clinics (25% of the total) aware of the Cancer Reporting System had previously submitted a Neoplasm Report. Primary reasons that clinics had submitted reports were related to unusual cancer cases and possible cancer clustering. None of the clinics reported regular use of the Report Form to report new cancer cases.

- *What database system does your facility use to record patient information?*

Eleven of twelve clinics (92%) used the Indian Health Service database software program, Resource and Patient Management System (RPMS), to some extent. The RPMS is not available to urban program Indian Health Centers, including the Gerald L. Ignace Indian Health Center in Milwaukee. Seven of the eleven clinics (64%) using the RPMS, used it solely. Four clinics (36%) used the RPMS in conjunction with other medical software, most commonly Medical Manager. In these four clinics the RPMS was used for patient registration or as a diagnostic database.

- *Is your facility capable of identifying cancer cases? If so, what is the mechanism/procedure to identify cancer cases? Is this information readily accessible?*

All clinics were capable of identifying cancer cases. Three of twelve (25%) clinics identified cases by reviewing the actual medical records, while the remainder used the query (Q-Man) function in the RPMS. Several clinics noted that using Q-Man to identify cancer cases was cumbersome and difficult, and that they consulted the actual medical records in addition to the database query for follow-up and verification purposes.

- *Can your facility create a report or profile regarding cancer cases for your own use?*

Ten clinics (83%) indicated that it would be **possible** to create a profile of cancer cases, but it would be very difficult and time consuming using Q-Man. Several clinics indicated that it would be easier to review medical records than query Q-Man because complicated linking and merging were required to use the software program for this purpose.

- *Do your medical records contain current information on the treatment provided to cancer patients by their referring physician/facility?*

Three of twelve clinics (25%) indicated that they routinely receive information on cancer treatment provided to clinic patients by the referring physician/facility. Five clinics (42%) indicated that they received the information if the clinic requested it on an individual patient. Four clinics (33%) reported that they do not routinely have information on cancer treatment provided clinic patients and do not request it from the referring physician/facility.

- *Do you include cancer risk factors in your medical records (i.e., age, smoking, obesity, chemical dependency, environmental exposure, occupation, etc.)?*

Eight of twelve clinics (67%) included cancer risk factors in their databases; two (17%) recorded cancer risk factors in the medical records; and two clinics (17%) did not have cancer risk factor information available.

- *Do you include demographic information in your medical records (age, sex, race, education level, and income level)?*

Seven clinics (58%) maintained all demographic information on site, either in a database or in individual medical records. Four clinics (33%) had all of the demographic information except education and income level, and one clinic (8%) did not have demographic information available.

- *What degree of racial classification do your medical records contain (i.e., American Indian, tribal specific, etc.)?*

All twelve clinics identified patients as American Indian/Alaska Native in the medical records. In addition, seven clinics (58%) had tribal specific information, and one (8%) clinic had blood quantum information. All clinics require enrollment/membership information.

Follow-up Discussion with Clinic Staff

The issues that emerged through discussion with clinic staff concerned cancer case identification, referring physicians, standard protocols, and a cancer-specific database.

The RPMS was considered difficult to use for cancer case finding. For example, the RPMS query function (Q-Man) automatically includes cases where a patient has a family history of cancer, even though cancer was never diagnosed in that individual, and includes each clinic visit by this same patient. Consequently, staff noted that 'ruling out' codes was difficult when running a report, because it was necessary to look beyond the codes to see if there was an actual cancer diagnosis. Some clinic staff indicated they routinely returned to the actual medical record to confirm a diagnosis. Staff suggested that developing a template in the RPMS to help locate actual cancer cases would be more useful than to develop a new database, because of double entry demands.

Clinic staff noted that the best method of obtaining information from a referring physician was to secure a patient release of information and to request the information from the appropriate source. Some clinics have a tracking system in place with a specific staff person identified to track referrals. One clinic with a tracking system and appointed staff person reported that they have no trouble with obtaining information; they routinely call one month later if they have not received the information. Another clinic stated that they experience a problem tracking referrals and that they do not have a specific staff person assigned to follow-up on requests. This clinic calls for the follow-up reports on a case-by-case basis when requested by a clinic provider.

Results: Objective Two

The second objective examined current screening practices. The topics included cancer screenings performed by individual clinics (mammograms, pap smears, PSAs, hemocults, colonoscopies), clinic use of reminder cards, the location of tissue analyses and subsequent use of reports, and formal cancer screening protocols.

Questions and Specific Findings

- *What cancer screenings does your clinic regularly conduct? How often?*

All clinics provided mammograms, but the screening rates among clinics varied significantly (see Table 1). Two of twelve (17%) clinics had mammograms available in their facility and provided screening routinely or as providers recommended. One clinic noted that it accepted self-referrals. Three clinics referred the patient to local outside facilities. The other seven (58%) clinics offered mammograms via a mobile unit that made site visits to the clinics. The frequency of mobile unit visits varied among the seven clinics; the frequency rates were once per year, twice per year, once per month, or twice per month.

Table 1. Cancer screenings provided

Types of Cancer Screenings Provided	Clinics	Percentage
Mammogram		
- Screenings in facility	2	17%
- Patients are referred out	3	25%
- Screenings provided by mobile unit	7	58%
Pap Smear	10	83%
PSA	10	83%
Hemocult	9	75%
Colonoscopy	2	17%
Biopsies		
- Skin	10	83%
- Cervical	3	25%
Colposcopy	4	33%

Pap smears, PSAs, hemocults, and colonoscopies were provided by the clinics as routine health maintenance

based on age and gender specific guidelines, and for diagnostic purposes when recommended by a provider. Ten clinics (83%) provided pap smears, while another designated two days per year for this type of screening. Likewise, ten (83%) clinics provided PSAs, nine (75%) clinics provided hemocults, and two (17%) clinics provided colonoscopies.

- *Does the clinic send reminder cards about screenings for mammography and/or pap smears?*

Eight clinics (66%) sent reminder cards for mammography, while five clinics (42%) sent reminder cards for pap smears.

- *Does the clinic perform skin or cervical biopsies or colposcopies?*

Ten of twelve clinics (83%) were capable of doing skin biopsies, and three clinics (25%) were capable of doing a cervical biopsy. Four clinics (33%) were capable of performing colposcopies.

- *On what basis does the clinic receive tissue analysis from outside pathology laboratories? How are the reports filed?*

External pathology laboratories conducted all tissue analyses. Seven (58%) clinics automatically received the pathology report, while two (17%) received the pathology report if they requested it. Of the nine clinics that received the pathology reports, all filed them in patient medical records and one also entered them into a database specifically used for laboratory results. All clinics that performed their own biopsies automatically received the pathology report.

- *Are cancer screening practices formulated into a written protocol?*

Formulation of cancer screening practices into written protocols varied among the twelve clinics. One clinic (8%) used the American Medical Association (AMA) and American Cancer Society (ACS) recommended protocols. Two clinics (17%) had formal written protocols for mammography, and another three clinics indicated they were in the process of developing written protocols. The remaining six (50%) clinics had no formal written cancer screening protocols.

Follow-up Discussion with Clinic Staff

Clinic staff indicated that when they used the term “as suspected,” it meant both screenings included in a routine annual physical, and screenings done for diagnostic reasons at a provider’s request. Staff strongly recommended the development of written cancer screening protocols at each clinic and thought these would be very helpful in both increasing cancer awareness and education, and in standardizing practice at a particular clinic.

Results: Objectives Three and Four

Findings from the clinics' trial use of the Neoplasm Record Form will be presented in this section. The purpose of this trial use was to train tribal and urban program clinic staff in using the Neoplasm Record Form and to learn what would be found when clinic cases were matched with current Wisconsin Cancer Reporting System data. The project involved a retrospective study of cancer cases diagnosed in 2001 and found in the medical records of tribal and urban program Indian clinics in Wisconsin. For the purposes of the trial, clinics were asked to report all 2001 cancer cases in their records up to a maximum of ten cases.

Cases Reported to the Wisconsin Cancer Reporting System

There were fifty-six reported cases from the 12 clinics, with a median of four cases reported per clinic (range 1 - 10 cases per clinic). Seventeen of the reported cases were male, and thirty-nine were female.

Case Distribution by Racial Classification

Twenty-eight of the fifty-six cases reported in the study were listed in the state registry (see Table 2). Thus, one-half of the cases compiled from the clinics had never been reported to the state registry. In addition, seven (25%) of the 28 cases found in the registry were misclassified as non-Indian. Consequently, only 21 (38%) of the 56 cases reported in the pilot program were correctly reported from other sources.

Table 2. Cases found in state registry

<i>Coding</i>	Listed in State Registry	American Indian	White	Misclassified as White or Unknown	Needed Follow up with Clinic
<i>Number</i>	28	19	1	7	1

Case Distribution by Cancer Site in the Body

Generally, distribution of the 56 cases follows that of the general Wisconsin population for lung (12), breast (11), and colorectal (6) cancers. However, these figures indicate a higher distribution of leukemia/lymphoma (5) and kidney cancer (5) among Wisconsin American Indians in 2001, and a lower distribution of prostate cancer (3).

Location of Treatment

Of the fifty-six reported cases, only twelve reports included treatment information. Among those cases reporting treatment, two reported hormone therapy treatment performed at a tribal clinic. Ten reports indicated that treatment was performed by another facility. Nine of these treatments included surgery, while one was chemotherapy. Of the nine reported surgery treatments, one case each also included chemotherapy and radiation treatment.

Follow-up Session Discussion with Clinic Staff

Most clinics noted that it took about twenty minutes to

fill out the Neoplasm Record Form, commenting that it was not hard once the chart was in front of them. However, at least one clinic found that it took up to sixty minutes to complete a record form. Staff uniformly indicated that the most difficult and time-consuming task was to locate the case and go through the diagnostic codes. Staff also indicated that they expected the time needed to fill out each form would decrease once they were familiar with the format. The pathology questions in the form were often difficult to complete because this information was often absent from the chart, or in some cases, difficult to interpret. Staff also noted in cases where palliative care was the preferred treatment, there was no additional treatment information. In general, staff found that they would use the RPMS database to identify cases and then revert to patient charts to confirm diagnoses and abstract information requested by the Neoplasm Record Form.

Discussion

The Cancer Surveillance Capacity Building Project underscored the value of examining cancer patient records at tribal and urban program Indian clinics and matching them with the state cancer registry, as well as the value of engaging local clinic staff in cancer data improvement projects. The project revealed that there was similarity in the types of cancers being screened by Wisconsin tribal and urban program Indian clinics, and yet great variability in the frequency of those screenings. There was also variability in the degree of information available in clinic records on cancer patients. The interest and responsiveness of tribal and urban program clinic administrators and staff was notable and contributed significantly to the successful outcome of the project.

The design of the project included certain limitations. The structured interview process used to achieve objectives one and two relied upon the self-report of key informants who are employees of the clinics. Neoplasm Record Forms are sometimes submitted as much as twelve months following the close of the calendar year (particularly from out-of state facilities), and the analysis of this trial use of the Neoplasm Record Form was completed October 30, 2002. It should be noted that the Neoplasm Record Forms submitted by the Wisconsin tribal and urban program Indian clinics were for American Indians who received care in these clinics. This population does not necessarily represent all American Indians living in the clinic service area or in Wisconsin, nor all members of a specific tribe. One participating tribal clinic submitted the maximum number of cases requested (10) and it is not known whether the clinic had additional cancer cases diagnosed in 2001. It is also not known whether the 28 submitted records that were not previously identified in the cancer registry would have been identified through a data matching process between the Indian Health Service and the Wisconsin Cancer Reporting System.

The findings of the project have several distinct implications regarding work activities and processes that would aid

implementation of the pilot research project, *Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin*. These implications will be addressed in collaboration with the Wisconsin Tribal and Urban Health Directors Association, Great Lakes Inter-Tribal Council and the Wisconsin Cancer Reporting System. Beneficial future activities include:

1. Develop a method of regular reporting by tribal and urban program Indian clinics to the Wisconsin Cancer Reporting System.
2. Develop a database template for use in the RPMS to aid cancer case finding and reporting.
3. Phase in clinic involvement over the three years of the pilot project depending on the detail of data available on cancer patients in clinic records.
4. Provide clinics information on screening protocols for major cancers.
5. Provide training on epidemiology principles and practices for clinic staff as needed or requested.
6. Work with clinics and referring facilities to develop best practices in securing reports from referring physicians, and incorporating any risk factors and demographic information in records where they are absent.

Acknowledgements

This report presents the results of a collaborative effort to improve cancer surveillance practices among Wisconsin tribal and urban program Indian clinics. Participating partners were the Wisconsin Tribal Health Directors Association, the Great Lakes Inter-Tribal Council, the Wisconsin Cancer Reporting System, Mayo Clinic Cancer Center, University of Wisconsin Comprehensive Cancer Center, and Spirit of EAGLES: American Indian/Alaska Native Leadership Initiative on Cancer. The project was supported through a grant to Spirit of EAGLES, a National Cancer Institute-funded initiative, grant number U01 CA86098. Special thanks are due to the participating clinics for their commitment to and involvement in the project. Thanks are also due to Kathy Wiese, Assistant Director, UW Comprehensive Cancer Center, and Karen Julesberg, Project Director, North Central Cancer Information Service for their consultation on this project.

Note: the full report, *Building Cancer Surveillance Capacity: Wisconsin Tribal and Urban Indian Clinics*, is available by contacting Rick Strickland by e-mail at rick-la@uwccc.wisc.edu; telephone (608) 262-0072.

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Prestigious Scholars Program Brings Native American College Students to Washington, DC, to Experience Federal Legislative Process

How does federal health policy affect health care in Indian Country? What steps can federal policymakers take to better meet the health care needs of Native Americans and other traditionally underserved populations? How can federal health policy improve racial/ethnic minority communities' access to quality health care? Next summer, 15 minority college students and recent graduates will learn the answers to these questions and much more as Barbara Jordan Health Policy Scholars.

The Barbara Jordan Health Policy Scholars Program brings talented college students and recent graduates to Washington, DC, to intern in congressional offices and learn about health policy. The Scholars Program is open to all minority students, and Native American students are particularly encouraged to apply. The Scholars Program is now accepting applications for the session beginning in May 2004. The application deadline is January 30, 2004.

"The Barbara Jordan Health Policy Scholars Program continues the legacy of the extraordinary Congresswoman and helps to ensure that minority voices are heard when federal health policy is crafted," said Drew Altman, Kaiser Family Foundation President. "I encourage all qualified minority students to apply for this unique opportunity to experience and participate in the federal legislative process."

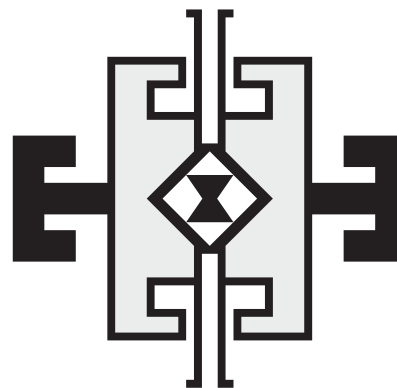
The Kaiser Family Foundation established the Scholars Program, which is based at Howard University, to honor the legacy of U.S. Congresswoman Barbara Jordan, who was a Foundation Trustee. Through the nine-week program, Scholars gain valuable knowledge about federal legislative procedure and health policy issues, while further developing their critical thinking and leadership skills. In addition to an internship in a congressional office, Scholars participate in seminars and site visits to augment their knowledge of health care issues. They also write and present a health policy research paper.

One Scholars Program alumna, Natalia Orosco, a member of the Kumeyaay Tribe who grew up on the San Pasqual Reservation, uses many of the skills she learned as a 2001 Scholar in her current position as Co-Director of San Pasqual Even Start — a family literacy program within the Reservation's Education Department. "As a native person, my father instilled in his children the importance of an education but, more importantly, using that education to benefit your people. I always knew I would return to my reservation, and the Scholars Program showed me that there are multiple levels in which you can help your community," said Orosco. "The

Program opened doors that are continuing to open, in more areas than just health policy. It is a wonderful opportunity that exposes the Scholars to health policy, employment opportunities, government issues, and unique people."

Eligible candidates for the Scholars Program must be U.S. citizens who are juniors, seniors, or recent graduates of accredited U.S. colleges or universities. Current law, medical, and graduate students are not eligible to apply to the program. Candidates are selected based on academic performance, demonstrated leadership potential, and interest in health policy. Scholars receive approximately \$5,000 in support, which includes a stipend, daily expense allowance, airfare, and lodging. While in Washington, DC, Scholars reside at Howard University. Application forms and additional information about the program are available online at www.kff.org/docs/topics/jordanscholars.html. All application materials are due by January 30, 2004.

The Henry J. Kaiser Family Foundation is an independent, national health philanthropy dedicated to providing information and analysis on health issues to policymakers, the media, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries. To set up an interview with a Barbara Jordan Health Policy Scholars Program alumna or program officer, contact Mariama Vinson or Annette Rodenas at (202) 371-1999.



Racial Misclassification for Sexually Transmitted Diseases among American Indians and Alaska Natives in Oregon State, 1995–2000

Shawn Jackson, BA, Project Specialist, the Stop Chlamydia! Project, Northwest Tribal Epidemiology Center, Northwest Portland Area Indian Health Board, Portland, Oregon; Kurt Schweigman, MPH, Registry Manager, Northwest Tribal Epidemiology Center, Northwest Portland Area Indian Health Board, at time of the study, currently affiliated with the Education and Research Towards Health Study, Black Hills Center for American Indian Health, Rapid City, South Dakota; and L. D. Robertson, MD, MPH, Director, the Northwest Tribal Epidemiology Center, at the time of the study, now a private consultant in pediatrics, epidemiology, and health research, White Salmon, Washington

Introduction

Sexually transmitted diseases (STDs) occur in epidemic proportions in the United States, and the burden of disease is disproportionately high among American Indians and Alaska Natives (AI/ANs). In the year 2000, AI/ANs had the second highest case rates of syphilis (2.6 per 100,000), chlamydia (680.2 per 100,000), and gonorrhea (114.4 per 100,000) nationally (CDC STD Surveillance Report, 2000). The incidence of STDs is increasing, the 1999 Oregon Annual STD report stated that STDs are the most frequently reported communicable diseases in Oregon (1999 Oregon Annual STD Report). To address this issue, the Department of Health and Human Services has designated STDs as one of its six special focus areas in its initiative to eliminate racial health disparities.

Several studies suggest that racial misclassification of AI/ANs is a significant problem in many areas of the United States. Racial misclassification found in cancer registries is a prime example of identifying racial misclassification of AI/ANs. Reports by Frost,^{1,2} Kwong,³ and Becker,⁴ have shown that AI/ANs are substantially undercounted in cancer registries due to misclassification. Thus, uncorrected rates for AI/ANs are often spuriously low, which underestimate the true burden of disease for AI/AN populations. There are no published reports on racial misclassification for STDs among Northwest AI/ANs. We conducted this study to ascertain more accurate estimates for the incidence of STDs among Northwest AI/ANs.

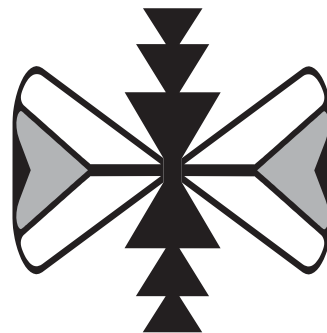
Background.

The Northwest Tribal Epidemiology Center is a tribally operated program administered by the Northwest Portland Area Indian Health Board. It was established in 1997 with the mission of providing Northwest tribes with timely, accurate,

and useful health status information. A key part of this effort is the Northwest Tribal Registry (NTR) Project that was started in January 1999. The goal of NTR Project is to improve the accuracy of health data for AI/ANs through linking the NTR with a variety of health data sets. These data sets contain health data for Northwest AI/ANs, but may not have racial identifiers or may have inaccurate racial identifiers.

The NTR is an enumeration of AI/ANs in Idaho, Oregon, and Washington. The source data for NTR came from the Portland Area Indian Health Service (IHS) Area Patient File, a compilation of patient demographic data from Indian health care facilities that use the Resource and Patient Management System (RPMS) and export patient data to the Portland Area IHS Office. RPMS includes individuals who received services from Northwest Indian health care facilities from the mid-1980s to the present. All individuals in the NTR are of proven AI/AN ancestry and have accessed health services from an IHS or tribal health care facility during this time period. The NTR was rigorously standardized, cleaned, and unduplicated for use in this linkage project.

Both the NTR and the Oregon Health Services (OHS) STD Registry underwent a stringent and extensive review process in order to gain approval to conduct this data linkage. The OHS STD Registry included data from 1995 - 2000. Prior to the linkage study, this data set was standardized for linkage variables and diagnostic information. The OHS HIV/STD/TB Program received approval to conduct the linkage from the Office of Disease Prevention and Epidemiology. We also received approval to conduct this linkage study from both the Portland Area Indian Health Service Institutional Review Board (IRB), and the IHS Headquarters-Albuquerque Area Combined IRB.



Methods

The version of the NTR we used to conduct this linkage included 146,751 AI/ANs who utilized an Indian health care facility in Idaho, Oregon or Washington between 1994 and mid-2000, and an unknown percentage of persons who were served during the years spanning the mid-1980s through 1993 (excluding those who received services only at the Seattle Indian Health Board). We obtained the OHS STD files for the years 1995 - 2000; these files contain data on all cases of syphilis, gonorrhea, and chlamydia reported to the HIV/STD/TB program during that time period (n=39,367).

The NTR-Oregon STD linkage was conducted at the Northwest Portland Area Indian Health Board using the record linkage software INTEGRITY© (Vality Technology, Inc., 2001), which employs probabilistic record linkage algorithms. This software is designed to link records in two different data files for individuals for whom data on selected characteristics (e.g., name, date of birth, social security number) are contained in both files. This software identifies not only exact - or “deterministic” - matches (i.e., records containing identical data in each field of interest compared between the two files), but also calculates the probability of a correct match in situations where there are minor differences (e.g., transposed digits in a social security number or misspellings of name or place of residence) in the selected characteristics between the two different data files for a prospective match.

The NTR and Oregon STD files were linked using the following characteristics (data elements): first and last name; year, month, and day of birth; zip code; and gender. The record linkage was conducted in a five-pass run, with each pass allowing for errors on some fields but not on others. In succeeding passes, the matching combinations were rotated so that after five rounds all possible matches were obtained using the given fields. The initial error rates for each pass were given wide margins, and then recalibrated as necessary to minimize false-positive matches. Clerical review sessions (case-by-case reviews of questionable matches) helped further clarify and separate the true matches from false matches. Upon completion of the linkage the results were extracted for data cleaning with UltraEdit3.2© and data analysis using SPSS©. All personal identifiers were permanently removed from the new files created by the linkage. However, a unique key index number was created for each linked record to allow easier repeat linkage if needed later to examine additional questions.

Definition of Terms

- **Matched AI/AN case** - a reported STD case in which the individual is identified in both the NTR and the Oregon Health Services STD Registry.
- **Race correctly classified** - a matched case for which the OHS STD Registry correctly identified the individual as AI/AN.

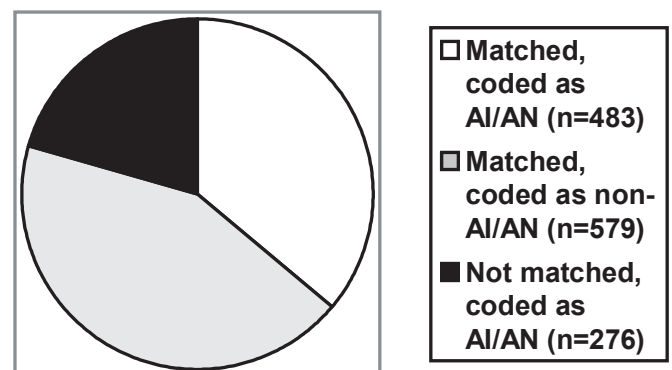
- **Race incorrectly classified** - a matched case for which the OHS STD Registry incorrectly identified the individual as non-AI/AN.
- **Unmatched AI/AN case** - a reported case in which the individual is identified as AI/AN in the OHS STD Registry, but does not match with any individual in the NTR. We included these cases in our analyses of demographic characteristics and disease-specific comparisons (see discussion below).

In calculating overall and disease-specific annual average incidence rates for the six-year period spanning 1995 - 2000, we used the US Census Bureau 1997 population projections for AI/ANs and “all races” populations as our denominators.

Results

Of the 39,367 records in the 1995 - 2000 Oregon STD files, 759 (1.9%) were originally coded as AI/AN in the STD surveillance data files. When we linked this six-year STD file with the 146,751 AI/AN records in the NTR, we identified matches for 1,062 STD cases, including 483 (45% of the 1,062 matched records) that were identified as AI/AN in both the NTR and in the STD files, and 579 (55%) that were misclassified as non-AI/AN in the STD files. In addition, there were 276 cases for which race was recorded as AI/AN in the STD files, but that did not match any record in the NTR. Thus, by virtue of the linkage with the NTR, we were able to identify a total of 1,338 cases of STDs among AI/ANs (i.e., 579 newly identified AI/AN cases, in addition to the 759 originally identified as AI/AN in the Oregon Health Services STD Registry), for an increased ascertainment of 76%. See Figure 1.

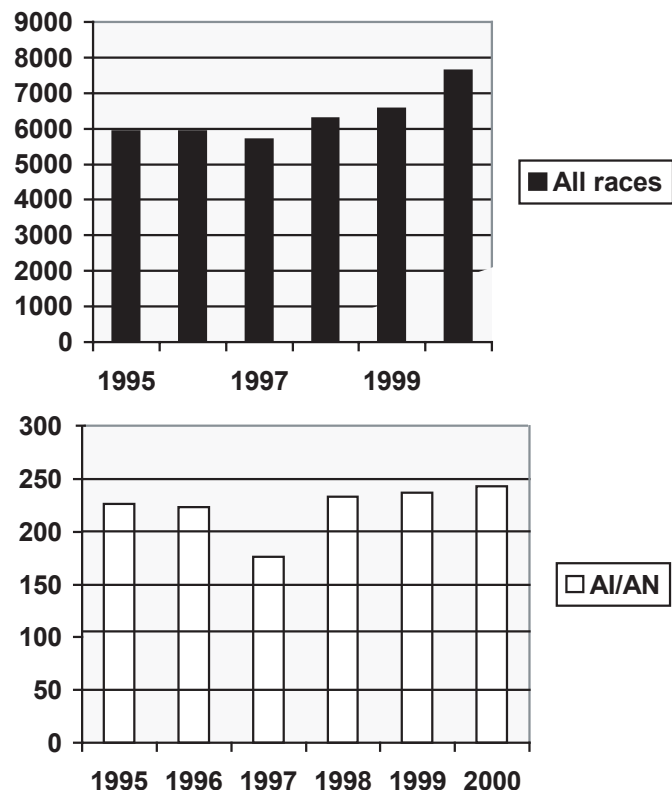
Figure 1. Oregon AI/AN STD Cases, 1995-2000 (N=1,338)



An annual average of 223 AI/AN STD cases occurred throughout the six years, but there appeared to be a slight increase in the annual number of cases throughout the time period (i.e., ranging from 176 cases in 1997 to 243 in 2000). This trend is similar to that for STD cases among all races in Oregon during the same time period (Figure 2). Of the 1,338 AI/AN cases, 1,049 (78%) were

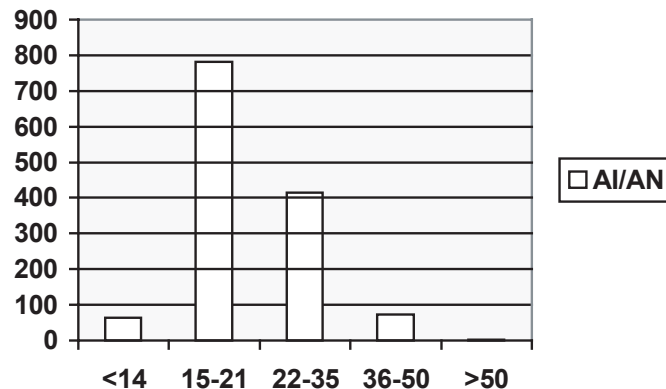
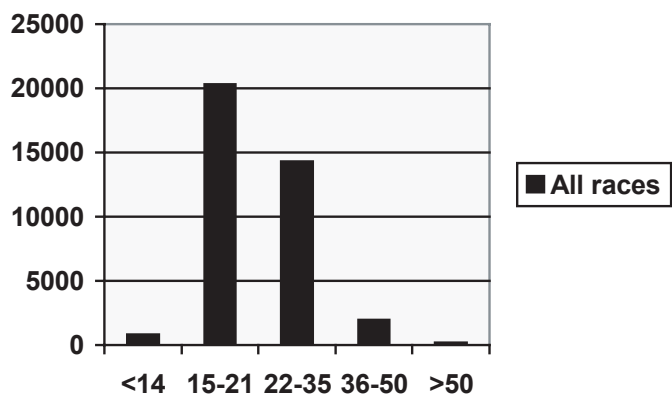
among women, compared with 26,669 of 38,016 (70%) for all races during this time period.

Figure 2. Annual Number of STD Cases in Oregon during 1995-2000, by Race



The average age at diagnosis among AI/AN cases was 21.6 years, compared to an average age of 22.5 years for STD cases among all races in Oregon during 1995 - 2000; 1,134 (85%) AI/AN cases were among adolescents and young adults (viz., 15 - 30 years of age), compared with 33,729 of 38,983 (87%) among all races. See figure 3.

Figure 3. Age-specific Number of STD Cases in Oregon, 1995-2000, by Race



Focusing on this 15-30 year old age group, we compared the average annual total and disease-specific incidence rates between AI/ANs and the total Oregon population (Table 1). For gonorrhea and chlamydia (there were no reported cases of syphilis for AI/ANs during the period) the average annual incidence rate among AI/ANs was double that for all races in Oregon (158.7 per 10,000 vs. 78.7 per 10,000 respectively). The differential was somewhat smaller among males. See Table 1 on page 171.

Discussion

This study describes racial misclassification of AI/ANs in the Oregon STD files during the years 1995-2000. After the 39,367 records in the Oregon STD files were linked with the 146,751 AI/AN records in the NTR, a total of 1,062 cases occurred in individuals listed in both databases (i.e., "matched"). Of the 1,062 cases, 579 (55%) cases were listed as non-AI/AN in the Oregon STD files; these were considered "misclassified." The remaining 483 (45%) of the matched cases were originally identified as AI/AN in both the NTR and the Oregon STD files.

In addition to the 1,062 matched cases, there were 276 STD cases that were recorded as AI/AN in the Oregon STD files, but that did not match with any individual in the NTR. Therefore, for our analyses we considered individuals listed in the Oregon STD file as AI/AN to be correctly classified. Combining the two groups we were able to identify a total of 1,338 (1062 + 276) cases of STDs among AI/ANs, (an increased ascertainment of 76%)

Based on these data, it appears that the majority of STD cases occurred among 15 - 30 year olds both for AI/AN and for all races; however, AI/ANs in this high-risk age group appeared to be affected at about twice the rate as all races in Oregon. This racial disparity was somewhat larger when comparing female AI/ANs to females of all races in Oregon. With regard to changes over the 6-year study period, rates appeared to increase slightly for both AI/ANs and all races.

This study indicated a 55% racial misclassification rate of AI/ANs in the Oregon STD files, which substantially underestimated the true burden of reportable STDs among the Oregon AI/AN population. With the addition of newly identified

Table 1. Selected 1995 - 200 Sexually Transmitted Disease (STD) cases in Oregon among 15 - 30 year olds, AI / AN and all races, by sex.

	Gonorrhea			Chlamydia			Syphilis			Total STDs		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
AI/AN Cases												
Number of cases [Note 1]	36	61	97	200	835	1037	0	0	0	236	896	1132
Average Annual Rate per 10,000 [Note 2]	9.9	17.5	13.6	55.0	238.9	145.4	0.0	0.0	0.0	64.9	256.4	158.7
All Race Cases												
Number of cases [Note 3]	1835	2032	3868	7245	21459	28712	6	2	8	9091	23495	32586
Average Annual Rate per 10,000 [Note 4]	8.7	10.0	9.3	34.4	105.6	69.4	0.0	0.0	0.0	43.2	115.6	78.7

Notes:

1. Includes cases matched in linkage between NTR and the OHD data file cases originally coded as AI/AN, and OHD
2. Denominator includes estimated number of AI/ANs in Oregon at the start of 1997, according to US Census data (obtained through the Oregon State University website).
3. Includes all cases in OHD STD Registry.
4. Denominator is the estimated number of all races in Oregon at the start of 1997, according to US Census data (obtained through the Oregon State University website).

AI/AN cases, our study shows a more complete accounting of the magnitude of disparity in the incidence of STDs for AI/ANs in comparison to that for non - AI/ANs. However, now that we have a more accurate estimate of the true magnitude and distribution of STDs among AI/ANs in Oregon, the challenge is to use these data more effectively in understanding, and ultimately eliminating, these racial misclassification disparities. Possibilities for these racial misclassification disparities include: 1) whether AI/AN communities are not fully aware of their problem with STDs (perhaps exacerbated by the historical use of state reports that apparently underestimated the disease burden); 2) a tendency among AI/ANs to be risk-takers (i.e., not protect themselves from STDs); or 3) whether prevention resources are inadequate or are not being targeted effectively.

Regardless, a long-term effect of racial misclassification may include insufficient attention to the high burden of disease from STDs among the AI/AN population. Thus, racial misclassification may lead to poor planning and ineffective implementation of programs, inadequate allocation of funds for prevention efforts among northwest AI/ANs, and lack of culturally appropriate interventions. Ultimately this may result in a further increase in the burden of disease from STDs among AI/AN communities.

Recommendations

If racial health disparities are to be addressed, accurate race - specific estimates must be available to monitor trends.

The high rates of racial misclassification found in our study will be shared with the managers of the Oregon STD program and with tribal communities in the hope that this information will stimulate discussion on how to address this misclassification problem. The results also will be shared with Northwest tribal health care programs to provide them the accurate data needed to make informed fund utilization decisions for their local communities.

Acknowledgements

The authors would like to acknowledge the assistance of Paul Stehr-Green, DrPH, MPH, in the conduct of this analysis and in the preparation of this manuscript.

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Editor's Note: The following is a digest of the monthly Obstetrics and Gynecology Chief Clinical Consultant's Newsletter (Volume 1, No. 10, November 2003) available on the Internet at <http://www.ihs.gov/MedicalPrograms/MCH/M/OBGYN01.cfm>. We wanted to make our readers aware of this resource, and encourage those who are interested to use it on a regular basis. You may also subscribe to a listserv to receive reminders about this service. If you have any questions, please contact Dr. Neil Murphy, Chief Clinical Consultant in Obstetrics and Gynecology, at nmurphy@anmc.org.

OB/GYN Chief Clinical Consultant's Corner Digest

News flash . . . Date change . . .

The Obstetric, Neonatal, and Gynecologic Care Course (the ACOG / IHS Postgraduate Course) that is usually held in September each year has been moved to June 13-17, 2004. It will still be held at the Radisson Hotel Denver SE. Sign up soon, and/or spread this news, please. See the MCH Conference web page for details.

<http://www.ihs.gov/MedicalPrograms/MCH/M/CN01.cfm#top>

Abstract of the Month

Characteristics of mothers who have children with fetal alcohol syndrome

Background: Health care providers can more effectively prevent fetal alcohol syndrome and prenatal alcohol exposure if they know more about mothers who have children with fetal alcohol syndrome (FAS) or some characteristics of FAS.

Methods: We conducted two retrospective case-control studies of Northern Plains Indian children with FAS and some characteristics of FAS diagnosed from 1981 to 1993 by using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), code 760.71. We compared mothers who had children with FAS or some characteristics of FAS with mothers who had children that did not have FAS.

Results: Compared with control mothers, 43 mothers who had children with FAS and 35 mothers who had children with some characteristics of FAS were older, had fewer prenatal visits, more pregnancies, more mental health problems, and more injuries (both total and alcohol-related). Although the prevalence of drinking was high in both case and control mothers, case mothers had more alcohol-related medical problems, drank heavily, in binges, and daily more often than control mothers.

Conclusions: Women with injuries and mental health problems should be screened for substance use. Mothers of children with FAS or of some characteristics of FAS have numerous needs that must be addressed to prevent future prenatal alcohol exposure.

Reference

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http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12949030&dopt=Abstract

From your colleagues

From Chuck North, Albuquerque, and Bob Newcombe, Alamo

Are liquid prep pap smears the standard of care now?

For this answer I abstracted some comments from Alan Waxman, Retired IHS OB/GYN CCC. Dr. Waxman is currently on the faculty of the University of New Mexico. The following is a digest of his remarks.

Thin Prep Paps are not the standard of care in women's health. Liquid preps are a commonly used Pap, however. This is largely because of good marketing. In addition, most of the literature supports that this method will pick up more dysplasia than the conventional Pap. This includes more LSIL, as well as HSIL, meaning more colposcopies for LSIL that probably won't prevent any cancers. I know of only one study, in a region of Costa Rica with a high rate of cervical cancer, where more cancers were picked up with ThinPrep. This was a largely unscreened population.

Reflex HPV is very convenient. It should not be done for LSIL, however. See the ASCCP consensus guidelines at <http://www.ihs.gov/MedicalPrograms/MCH/W/WHcancer.asp#ASCCP>

Unlike ASC-US, 84% of women with LSIL are high risk HPV positive, so HPV is useless in triaging them to colposcopy or routine follow-up. With reflex HPV, you do liquid Paps on 100% of your patients and ask for HPV only on the 5% or so with ASC-US. At least one study has shown that it is cost effective on a population basis. It is the preferred way of managing ASC-US, if you're already using ThinPrep.

There are two other factors to consider. First, cost.

How many Paps do you do? How much more will you spend for the ThinPrep? Can you afford it? If a service unit population is small, the difference in cost over conventional Paps may not matter. Second, if you have a lot of women who don't get Paps but every 4 or 5 years, a more sensitive Pap may be important.

Even without using ThinPrep, if you want to follow your ASC-US patients with HPV you can use the ThinPrep medium or you can use the Digene STM. If you're using HPV from the ThinPrep medium to triage an ASC-US on conventional Pap, then don't let them charge you for another Pap. It won't make any difference in your care.

In summary, while they are not standard of care, liquid preps have some advantages and disadvantages. While in most studies they pick up more SIL than conventional Paps, it is still far from 100% sensitive. Computer modeling has suggested that you will do more colposcopies finding LSIL, which is not premalignant, as well as finding a few more HSILs that are. Reflex HPV is very attractive for the 4-5% with ASC-US. If you can afford it, go for it. On the other hand, there are the increased costs of each pap smear, plus the extra colposcopies needed. There is no clear evidence the increased costs improve patient clinical outcomes in a screened population.

OB/GYN CCC Editorial comment:

Yes, liquid preps have some advantages and disadvantages. Another valuable benchmark, in addition to Dr. Waxman's comments, is this Level A Recommendation from the ACOG Practice Bulletin: "Evidence-based data indicate both liquid-based and conventional methods of cervical cytology are acceptable for screening." For the ACOG Summary of Recommendations, OB/GYN CCC Corner, August 2003

<http://www.ihs.gov/MedicalPrograms/MCH/M/MCHdownloads/CCCorner81703C.doc>. An abstract of the Practice Bulletin for non-ACOG Members

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12907124&dopt=Abstract

Liquid preps do present a technically more satisfying slide to look at, but that comes at a higher price tag. On balance they are an equivalent preparations in terms of clinical outcome, though. One could argue that there is a small group of patients for which a liquid prep might be most helpful. That would be the 4-5% with a true ASC-US, because they would benefit from reflex HPV testing. Unfortunately one can't tell prospectively which patients will have ASC-US.

The corollary is that you are using the more expensive preparation on the other 96% of your patients for which reflex testing offers no benefit. ACOG and ASCCP have noted that it is clinically equivalent to repeat a convention pap in 6 months for the ASC-US patient.

<http://www.ihs.gov/MedicalPrograms/MCH/W/WHcancer.asp#ASCCP>

Other factors to consider are the patient's emotional costs for the increased colposcopy referrals versus the advantages of reflex testing in ASC-US patients.

This topic will be part of the Primary Care Forum discussion on Cervical Cancer Screening, which will take place next month on the IHS Primary Care listserv. Let me know if you are interested in hearing more about the Discussion Forum
nmurphy@anmc.org

Here are some other items that we have on our MCH web site on this topic:

<http://www.ihs.gov/MedicalPrograms/MCH/M/MCHdownloads/CCCorner81703C.doc>

<http://www.ihs.gov/medicalprograms/mch/m/mchdownloads/cccorner21003.doc>

<http://www.ihs.gov/medicalprograms/mch/m/mchdownloads/cccorner21003.htm>

<http://www.ihs.gov/medicalprograms/mch/m/faqdnlds/faqthin-prepwaxman.doc>

Features: Breastfeeding

An Easy Guide to Breastfeeding for American Indian and Alaska Native Families takes the reader through the "four directions" of benefits, risks associated with not breastfeeding, "how to get started," continuation upon returning to work, and frequently asked questions.

<http://www.4woman.gov/Breastfeeding/EasyGuide.NA.pdf>

You can place larger orders for the Guide at (800) 994-9662, 9-6 Eastern Time. They have a high call volume, so you may need to keep trying. Perhaps a better approach is reach them by e-mail through their web site. Just go to the following page, fill in your info, and put your request in the Message Body section: <http://www.4woman.gov/search/contact.cfm>. If you have problems with that link, you can reach the above page through the Contact Us page under 'Contact Us electronically' at <http://www.4woman.gov/about/phoneinfo.htm>

The Contact Us link is at the bottom of their main page, <http://www.4woman.gov>.

OB/GYN CCC Editorial comment

This Guide is a unique and wonderful resource. Order some today. E-mail is the easiest way.

Other items that are available in the full text November 2003 Volume 1, No. 10 at

<http://www.ihs.gov/MedicalPrograms/MCH/M/OBGYN01.cfm> are as follows.

From your colleagues:

From Sandra Dodge: High School Students in BIA-Funded Schools, Tobacco, Alcohol, and Other Drug Use, CDC is interested in hearing from AI/AN women, HIV increasing in women, AIDS diagnoses increased 7% among women, Growing Stronger: Strength Training for Older Adults, Preventing Skin Cancer.

From Jean Howe: Have you ever heard of a low risk VBAC? Minutes from the 2003 Navajo Area Women's Health Provider Meeting.

From Rick Olson: Join your Indian Health colleagues in helping the women of Afghanistan.

From Dan Szekely: Can you use HRT in post menopausal breast cancer patients? How effective is the clinical breast exam?

Hot Topics

Obstetrics: Helping Pregnant Women Cope With Smoking Cessation.

Gynecology: Is colposcopic biopsy overused among women with a cytological diagnosis of atypical squamous cells of undetermined significance (ASCUS)?

Child Health: A Neonatal Nightmare: The Misread Label, Cardiovascular risk factors are identifiable in childhood and are predictive of adulthood, Report compares health of adolescents in the US to other countries.

Chronic Illness and Disease: New broader diagnostic criteria for pre-diabetes, National Diabetes Awareness Month - November 2003, Rheumatoid Arthritis: Clinical Evidence, Blood cultures for women with uncomplicated acute pyelonephritis: are they necessary? Treatment of Tuberculosis: Updated Recommendations.

Other: Great American Smokeout — November 20, 2003, November's National American Indian Heritage Month: Health Disparities exist.

Features

AFP: Management of Gestational Diabetes Mellitus, Antidepressants for Anxiety Disorder.

ACOG: Cervical Insufficiency.

Cochrane Library: Metformin: First choice in anovulation in PCOS, effective for metabolic syndrome.

Hormone Replacement Update: Estradiol levels should be monitored and therapy adjusted.

Information Technology: New PCC+ Prenatal Flow Sheet.

MCH Alert: School based vs Hospital based prenatal care for pregnant adolescents, Indicators related to smoking among women and girls.

Office of Women's Health, CDC: Updated Mortality Tables Available on the Healthy Women Web Site; Maternal Behaviors and Experiences Before, During, and After Pregnancy.

Patient Education: Gestational Diabetes Mellitus.

What's new on the ITU MCH web pages:

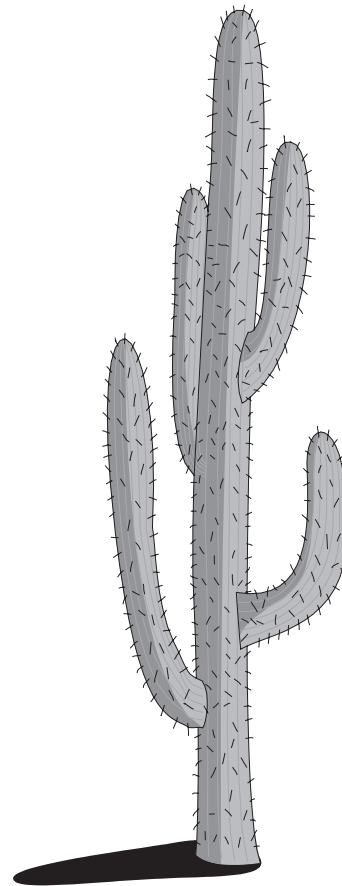
Save the Dates: Upcoming events of interest.

Did you miss something in the last OB/GYN Chief Clinical Consultant Corner?

The prior CCC Corners are archived at:

<http://www.ihs.gov/MedicalPrograms/MCH/M/OBGYN01.cfm>

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