



THE IHS PRIMARY CARE PROVIDER



A journal for health professionals working with American Indians and Alaska Natives

March 2003

Volume 28, Number 3

Successful Strategies for Increasing Breast and Cervical Cancer Screening: Lessons Learned from Tribal Programs

Carlyn E. Orians, MA, Senior Research Scientist, Battelle Centers for Public Health Research and Evaluation, Seattle, Washington; Julie Erb, MPH, Director, Cherokee Nation Cancer Programs, Tahlequah, Oklahoma; Paula M. Lantz, PhD, Associate Professor, School of Public Health, University of Michigan, Ann Arbor, Michigan; Jennie R. Joe, PhD, MPH, Professor, Department of Family and Community Medicine, and Director, Native American Research and Training Center, University of Arizona, Tucson, Arizona; Linda Burhansstipanov, DrPH, MSPH, CHES, Director, Native American Cancer Initiatives, Inc., Pine, Colorado; and Edward B. Liebow, PhD, Director, Environmental Health and Social Policy Center, Seattle, Washington

Introduction

Late diagnosis of and early mortality due to breast and cervical cancers are serious challenges for health care providers and tribal leaders serving American Indian and Alaska Native women. The Indian Health Service (IHS) estimates that the 1996-98 age-adjusted, miscoding-adjusted mortality rate for cervical cancer was 68 percent higher (4.2 versus 2.5 per 100,000 female population) for American Indians and Alaska Natives than for all races combined (1997), with especially high rates found in the Bemidji (7.3) and Oklahoma (6.3) IHS Areas.¹ Aggregate breast cancer mortality rates during this same period were lower among American Indians than for all races combined (15.6 versus 19.4), but higher than average rates have been documented in some IHS Areas, including Portland (24.7) and Billings (22.3).¹ Although the relative rate of breast cancer may be lower in some Native American populations than among the general population, the absolute number of women affected by this disease make it – along with cervical cancer – a serious women's health issue in American Indian and Alaska Native populations.^{2,3}

To address this health concern, the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354) was amended in 1993 to permit direct funding of tribes,

tribal organizations, and urban health centers serving American Indians and Alaska Natives to provide cancer early detection services to eligible women.^{4,6} The national program's goal is to reduce mortality from breast and cervical cancer among underserved women, including older women, women with low incomes, uninsured and underinsured women, and women in racial and ethnic minority groups.⁶

The American Indian/Alaska Native Initiative of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is administered by the Centers for Disease Control and Prevention (CDC). The Initiative currently provides funding to 13 tribal programs. This article highlights the findings from a recent study, conducted in collaboration with the funded tribal programs at the request of CDC, to examine how the comprehensive early detection model has been adapted to meet the needs of Native American communities.⁷ At the

In this Issue...

- 53 Successful Strategies for Increasing Breast and Cervical Cancer Screening: Lessons Learned from Tribal Programs
- 58 Nonalcoholic Fatty Liver Disease and Nonalcoholic Steatohepatitis
- 60 Perspective: Should Indian Health Care be an Entitlement?
- 65 PDA and HIPAA Compliance
- 67 Nutrition and Chronic Kidney Disease
- 68 Opioid Dose Escalation in the Treatment of End-of-Life Pain
- 69 Brochure: Colorectal Cancer Screening Initiative
- 71 Executive Leadership Development Program Receives Special Recognition
- 72 The Native Investigator Development Program
- 72 Position Vacancies
- 73 Meetings of Interest

time the study was conducted in 2000, 15 tribal programs received funding from CDC (see Figure 1). The comprehensive model includes several program components: public education and outreach; screening and diagnostic services; tracking and follow-up; professional education; and partnerships, coalitions, and advisory boards. Participating health agencies are also required to identify and secure resources for cancer treatment services for women in need, regardless of their ability to pay.

This article provides selected findings from an in-depth case study of five tribal programs. The five case study sites were chosen because of their interest in participating, their success in moving beyond the start-up phase (all were funded during the first year of the Initiative in 1994), and the variety of geographic and cultural settings in which they operate. The five programs are the Arctic Slope Native Association (Barrow, Alaska); the Cherokee Nation (Tahlequah, Oklahoma); the Cheyenne River Sioux Tribe (Eagle Butte, South Dakota); the Southcentral Foundation (Anchorage, Alaska); and the South Puget Intertribal Planning Agency (Shelton, Washington).

Case study data were collected through semi-structured interviews with program staff and community leaders (n=141), 16 focus groups with eligible women (n=132), and a review of program documents. The study was implemented using a participatory research model that involved tribal program staff as equal partners in defining and carrying out the study, including planning the week-long site visits, reviewing the coding scheme for the interview data, and interpreting findings. The findings presented here provide insights for other tribal communities interested in increasing breast and cervical cancer screening or other preventive and early detection services. Detailed information is provided on the Cherokee Nation early detection program to illustrate one program's experience with program implementation.

Program Implementation

Prior to implementing this comprehensive screening program, the cancer screening services available to women in these tribal communities were very limited, and screening mammography was especially rare. Furthermore, as is still common today throughout Indian country, the under-funded health care system in most of these communities was oriented to acute care services, not preventive care; people went to the doctor or nurse only when they were sick, not when they were feeling well. The tribes that applied for funding were motivated by a desire to increase access to services, educate the community on the value of preventive and early detection services, use limited health care resources in a more cost-effective manner, and improve the quality of local data.

Illustrative statements by respondents in the tribes include:

- *I think "... the tribes ... made the right decision that health care is kind of a community capacity building activity and to be effective you have got to have it on the reservation. You gotta have it accessible."* (SPIPA).

- *"Prior to this program I know that specifically for breast cancer screening, it was not available and when it was available, it was rarely available. Very difficult to get there. So, the women just were not being screened."* (Cherokee)
- *"There was no real concerted effort to go out and get people, especially the women over 40." "The whole process of deciding to go for the grant was based on the fact that IHS did not do screenings. So we were going to do it through the tribe."* (Cheyenne)
- *"The mammography van . . . was not available."* (Cherokee)
- *"The grant was a way "to get consistent providers at the clinics."* (SPIPA)
- *"There were a lot of things attached to this grant that I saw as great benefits. One being an opportunity to attempt to get true American Indian data . . . collected by the tribes, for the tribes, to be utilized by the tribes."* (SPIPA)
- *"Tracking and follow up was a big piece that was missing."* (Cherokee)

The challenges encountered in implementing this screening program were many and varied, as were the strategies tribal organizations used to address them. Notable among these strategies are the following:

- *Demonstrate the benefits of screening to women in the community and to clinic staff.* Demand for the new or expanded early detection services has been created through extensive one-on-one outreach and targeted media campaigns. Outreach and education efforts consistently feature culturally appropriate gift exchanges and Native iconography. Cancer survivors increasingly play a role in promoting the program. Demand has also been enhanced through "in-reach" to clinic staff and administrators to educate them about the program and the value of adding these preventive services to the existing mix of services. Program champions within the clinic setting have proven invaluable.
- *Develop a system that can deliver services to women under challenging conditions.* Most programs serve rural or remote populations, often in harsh climates, with limited transportation options. Programs typically have used one of two strategies to improve access to services, or a combination of the two: 1) travel women to services, or 2) take the services to the communities. Mobile mammography plays an important role in most communities in bringing services to local clinics. Providing transportation to women has also been very important in some remote settings such as the Alaska bush.
- *Develop the data management infrastructure to support the program.* Data management capabilities are frequently underdeveloped in Native American health care

settings. Thus, a major implementation challenge was to build the capacity to meet the CDC's reporting requirements and to utilize data effectively within the program to support intensive follow-up and case management services, reminder systems, and other surveillance activities. Several software programs are readily available. Programs have benefited from training opportunities in data management provided by CDC.

- *Recruit and retain competent providers.* Other implementation challenges include identifying and retaining qualified clinical staff. Solutions have included flexible staffing arrangements (e.g., job sharing, itinerant nurses) and offering professional training to nurse practitioners to provide high quality screening services. Respondents reported that American Indian and Alaska Native women strongly favor female providers. The most effective providers were described as having a holistic approach to health, interpersonal skills to make women feel respected and cared for, and a team spirit that makes them willing participants in all aspects of the comprehensive program, including education and outreach.
- *Establish an effective working relationship within the tribe and with IHS.* To integrate a screening program with existing services, tribal programs have found that it is critically important to present the new program as one that provides supplemental services, thereby enhancing existing services rather than competing with them. Tribal programs have found that obtaining the support of key stakeholders at the outset enhances success.

Cherokee Nation: A Case Example

To give a flavor for how one program has adapted the comprehensive program model to its distinctive setting, Cherokee Nation's experience is described. The Cherokee Nation has jurisdiction over a large land area covering all or a part of 14 counties in northeastern Oklahoma. Within this area, the Cherokee Nation operates eight outpatient health clinics that provide ambulatory health care to members of the tribe and other eligible patients. The Cherokee Nation was one of the first tribes to enter into a compact with the Federal government for health care delivery. Under the terms of the compact, the tribe provides primary health care directly to tribal members rather than using the IHS system to meet their needs, although the Cherokee Nation continues to use IHS hospitals for some services. The Cherokee Nation Health Service employs over 600 people and provides services to more than 100,000 patients a year. Numerous health promotion and disease prevention programs are offered at the clinics, including the breast and cervical cancer early detection program. The Cherokee Nation program was among the first tribal programs that CDC funded (1994) under the American Indian/Alaska Native Initiative.

Before the program started, the Cherokee Nation was able to provide its members with some breast and cervical cancer

screening, but screening did not receive high priority among health services, and long travel times and long wait times were a major deterrent. Tribal staff saw the CDC initiative as an opportunity to improve the delivery of important preventive services and to show that cancer, when detected early, can be survived.

Program start-up. A significant amount of capacity building was needed before screening could begin. This included building grants management capability, hiring program staff, securing equipment and space, implementing a tracking and reporting system, securing a mobile mammography provider, developing an outreach and education component, and securing treatment resources. A great deal of energy was also expended to solicit and maintain the support of the tribal government. The program was into its second year before screening began.

Program model. Initially, the program adopted a decentralized model in which each clinic was given responsibility for patient education and recruitment, screening, and reporting. This placed too heavy a burden on individual clinics. A more centralized system quickly evolved in which program staff operating from a central office took over most of the responsibility for these activities. In this model, which was in place when the study was conducted in 2000, screening occurred in each clinic on specialized "CDC screening days." On these days, program staff from the central office traveled to the specific sites to be on hand to provide support to the screening clinic, including education and reporting. Providers from the clinic performed the screening tests.

With the addition of more case management staff, the program model has continued to evolve. The program currently offers "CDC screening days" at some of the clinics, but women are continuously enrolled at seven of the screening sites. By placing case managers at these sites to work with clinic staff, the program could decentralize this aspect of the program, ensuring that every eligible woman who walks in the clinic door to receive screening is enrolled in the program.

Strategies for ensuring women get treatment. The Cherokee Nation has been very innovative in securing funding for women in need of cancer treatment. Program staff requested that a portion of the tribal fuel taxes collected be set aside to fund treatment for CDC program clients. The resulting appropriation by the Cherokee Nation Tribal Council enabled the tribe to establish ongoing funding (administered by the contract health office) for treatment for patients with nonmetastatic disease. Subsequently, the Tribal Council voted to increase the appropriation to the Cherokee Nation treatment fund and to extend the benefits to all members of the tribe needing non-palliative treatment for any type of cancer. Thus, this program strategy has become a major initiative within the tribe for meeting the cancer treatment needs of all members of the Cherokee Nation.

Strategies for sustained service delivery. The success of

the Cherokee Nation's program over the past eight years is in part due to the following:

- Having champions or strong supporters of the program in each clinic;
- Retaining key staff (low rates of staff and screening provider turnover);
- Focusing on communication channels;
- Securing and maintaining support from tribal leadership; and
- Having strength in all program components.

Program Impact

Does the comprehensive program model work in American Indian/Alaska Native communities? The answer is a resounding YES! The tribal programs value the services they are able to provide through this program. Through FY 2000, the tribal programs provided one or more mammograms to 16,859 Native American women and one or more Pap tests to 25,333 Native American women. In total, 148 cases of breast cancer (47 in situ and 101 invasive), 168 cases of cervical intraepithelial neoplasia III or in situ cervical cancer, and five cases of invasive cervical cancer were detected. Women who have been diagnosed with cancer have received treatment, and communities are beginning to see that cancer can be survived.

The tribal programs value the chance this program affords to shift attention within their communities from acute care to preventive health services. The comprehensive screening programs have increased the level of awareness concerning breast and cervical cancer and have brought greater attention to the value of preventive and early detection health services. The programs have also elevated the importance of women's health care, and by so doing, they have helped acknowledge the importance of older women in the fabric of society, women who so often think of looking after themselves only when the needs of everyone else in the family have been met.

Last, but not least, the tribal programs value the opportunity the program provides to further their goals of self-determination. Historically, Native American women have looked to federal agencies rather than to state or county agencies for health care provision, primarily to services provided through the IHS. Over the past decade, many tribes have increased their roles in managing these services. This program provides another vehicle for increasing local control. It allows the tribal programs to shape the services to meet their own needs and, very importantly, to offer services that are managed by people who women trust and in clinics where they are comfortable going for care. □

Further Information

To find out more about the American Indian/Alaska Native Initiative of the National Breast and Cervical Cancer Early Detection Program, contact:

Julie A. Erb, MPH
Co-Chair, Tribal Region, NBCCEDP
Director, Cancer Programs
Cherokee Nation Health Services
P.O. Box 948
Tahlequah, Oklahoma 74465
918-458-4491 phone
918-458-6267 fax
julie.erb@mail.ihs.gov

For more information about the recently completed study "Strategies for Breast and Cervical Cancer Screening Among American Indian and Alaska Native Women," upon which this article is based, please contact:

Carlyn E. Orians, MA
Senior Research Scientist
Battelle Centers for Public Health Research and Evaluation
4500 Sand Point Way NE, Suite 100
Seattle, Washington 98105-3949
206-528-3320 phone
206-528-3550 fax
orians@battelle.org

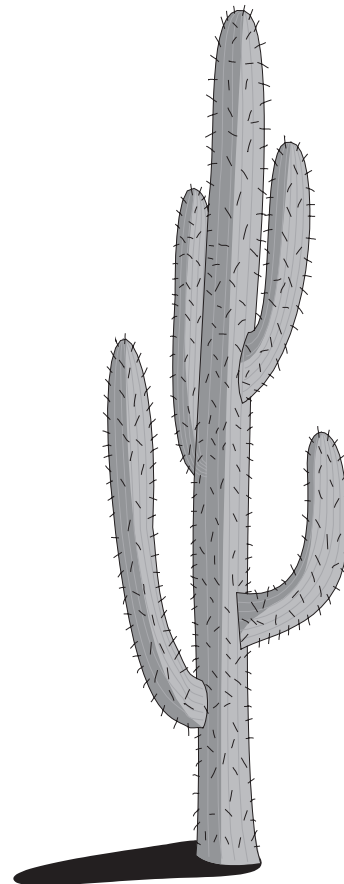


Figure 1. Tribal programs participating in the American Indian/Alaska Native Initiative, 2000



References

1. Indian Health Service. *Regional Differences in Indian Health 2000 2001*. Rockville, Maryland: Indian Health Service, July 2002.
2. Partin MR, Korn JE, Slater JS. Questionable data and pre-conceptions: Reconsidering the value of mammography for American Indian women. *American Journal of Public Health*. 1997;87:1100-1102.
3. Mahoney MC, Michalek AM. The health status of American Indians and Alaska Natives: Lessons for cancer educators. *Journal of Cancer Education*. 1999;14:23-7.
4. U.S. Congress. Public Law 101-354: The Breast and Cervical Cancer Mortality Prevention Act of 1990. *Congressional Record* 136, 1990.
5. U.S. Congress. Public Law 103-183: The Preventive Health Acts of 1993. *Congressional Record*, 1993.
6. Henson RM, Wyatt SW, Lee NC. The National Breast and Cervical Cancer Early Detection Program: A comprehensive public health response to two major health issues for women. *J Public Health Manage Pract*. 2(2):36-47: 1996.
7. Orians CE, Lantz PM, Liebow EB, et al. *Strategies for Breast and Cervical Cancer Screening Among American Indian and Alaska Native Women*. Final report prepared for CDC, Division of Cancer Prevention and Control. Battelle Report #100/02/001, April 2002.



Nonalcoholic Fatty Liver Disease and Nonalcoholic Steatohepatitis

Steve Livingston, MD, Alaska Native Medical Center, Viral Hepatitis Program, Anchorage, Alaska

Nonalcoholic fatty liver disease (NAFLD) was once considered a benign condition. In 1980, however, Ludwig¹ at the Mayo Clinic reported 20 patients who had evidence of alcoholic hepatitis on liver biopsy, although none had a history of alcohol abuse. Furthermore, three of these patients developed cirrhosis when followed over a period of ten years. He coined the term nonalcoholic steatohepatitis (NASH) to describe these findings.

The histologic hallmark of NAFLD is hepatic fat, or steatosis, predominantly macrovesicular, representing excess accumulation of triglyceride-filled vacuoles within hepatocyte cytoplasm. An estimated 10-25% of patients with NAFLD have histologic changes of NASH, which may include steatosis with inflammation, fibrosis, and even cirrhosis. Patients with NAFLD but not NASH (i.e., steatosis with no inflammation on liver biopsy) are thought to have an excellent long-term prognosis, with little chance of progressing to severe liver disease.^{2,3}

NAFLD appears to be a frequent condition in the United States. In the National Health and Nutrition Examination Survey III, liver enzyme abnormalities due to fatty liver were estimated to be present in 24% of the population.⁴ In addition, NASH has been given as the histologic diagnosis in 7-11% of liver biopsies in the U.S. and Canada. In one study of patients with NASH, 21% had fibrosis on initial biopsy and 43% demonstrated progression of fibrosis over four years.⁵ An estimated 8-20% of patients with NASH develop cirrhosis.

Obesity and diabetes mellitus type 2, which are both common in American Indians and Alaska Natives, have been shown to be risk factors for NAFLD and NASH, as have hypertriglyceridemia and advancing age. Steatohepatitis also can occur secondary to alcohol abuse; acquired metabolic conditions such as rapid weight loss, acute starvation, and total parental nutrition; surgical procedures, such as jejunioileal bypass for morbid obesity and extensive small bowel resection; certain inborn errors of metabolism; and various drugs and toxins.

Most patients with NAFLD are asymptomatic, although right upper quadrant pain, fatigue, and hepatomegaly have been reported. Mild to moderate elevations of serum transaminases occur in at least 70% of patients, with alanine aminotransferase (ALT) generally higher than the aspartate aminotransferase (AST), unless cirrhosis is present. There may be a mild elevation in alkaline phosphatase in up to one-third of patients, and gamma-glutamyl transpeptidase (GGT) frequently is elevated. Ultrasonography often shows a diffusely

echogenic liver consistent with fatty infiltration. On computed tomography (CT) scan, areas with fatty change show abnormally decreased attenuation, while on T1-weighted magnetic resonance imaging (MRI) imaging, fat has high signal intensity.

While NAFLD can be suspected on clinical grounds such as elevated liver transaminases, compatible ultrasound, and presence of risk factors, the presence or extent of transaminase elevation has not been shown to correlate with the diagnosis of NASH. Furthermore, imaging techniques document fat but not inflammation. The definitive diagnosis of NASH is made only by liver biopsy. Biopsy findings can be graded based on extent of steatosis and inflammation, and staged for fibrosis.⁶

Research to determine the pathophysiologic mechanism of NASH indicates that almost everyone with this condition has insulin resistance.^{7,8} This leads to increased uptake of fatty acids in hepatocytes, causing steatosis. Steatohepatitis is promoted by the induction of cytochrome P450 2E1 and others, leading to oxidative stress and further induction of various cytokines, which cause influx of inflammatory cells and promote fibrosis. Prominent among these is tumor necrosis factor alpha (TNF- α), which also is increased in alcoholic hepatitis. In addition to oxidative stress, glutathione, a powerful antioxidant in hepatocytes, is decreased in patients with NASH.

Many patients with NASH meet the criteria for the Metabolic Syndrome, also called Syndrome X, which includes patients with obesity, insulin resistance, hypertension, and hypertriglyceridemia. Some researchers feel that NASH may be the hepatic manifestation of this syndrome.

Evaluation of patients with suspected NAFLD should include liver function tests, fasting glucose, lipid profile, complete blood count, and liver ultrasound. Laboratory signs of decreased liver synthetic function, indicating advanced fibrosis or cirrhosis, can include hypoalbuminemia, elevated prothrombin time, elevated total bilirubin, and thrombocytopenia. Tests for other causes of liver disease should include hepatitis C antibody; hepatitis B surface antigen; iron and iron binding capacity for hemochromatosis; antinuclear antibody, smooth muscle antibody, and serum IgG for autoimmune hepatitis; mitochondrial antibody for primary biliary cirrhosis; and ceruloplasmin in patients younger than 45 years, for Wilson's disease.

A liver biopsy should be considered in patients with NAFLD since it is the only way to make a definitive diagnosis of NASH. This is important for natural history and prognosis as well as treatment. Whether a biopsy should be deferred in patients with NAFLD and an attempt made to normalize liver transaminases first with treatment is unknown. Likewise, it is not known if patients with normal liver transaminases and

abnormal ultrasound consistent with NAFLD should have liver biopsies.

Evidence-based guidelines for treatment of NASH are not available. A logical first approach could include a weight reduction program, exercise, and antioxidants. Several studies have shown improvement in histologic changes of NASH with weight reduction. The weight loss should be gradual, as rapid loss can lead to increased fibrosis. Exercise decreases insulin resistance. Vitamin E is an antioxidant that suppresses TNF- α , and has been shown to decrease transaminase levels in NASH. Improved histologic findings in NASH patients were noted when vitamin E was combined with vitamin C in one double blind, placebo controlled trial.⁹ These vitamins are inexpensive and relatively safe medications to consider in NASH patients.

A number of small studies have been reported using other medications, and larger trials are underway. Some of the drugs that have been shown to improve liver transaminase levels or histology in NASH include metformin, the thiazolidinediones (rosiglitazone and pioglitazone), ursodeoxycholic acid, gemfibrozil, atorvastatin, and N-acetylcysteine.

Use of metformin and the thiazolidinediones in patients without diabetes for the treatment of NASH should be reserved for clinical trials at the present time. Metformin improves insulin resistance and inhibits TNF- α . The thiazolidinediones enhance insulin action, but their long-term effects on the liver are unknown, and the prototype for this drug class, troglitazone, was taken off the market due to severe hepatocellular damage resulting in a number of deaths. Ursodeoxycholic acid is a membrane stabilizer with cell protective effects; it is well tolerated but may be cost prohibitive.

Gemfibrozil, which is used for hypertriglyceridemia, may inhibit fatty acid mobilization from adipose tissue. N-acetylcysteine, commonly used to treat acetaminophen toxicity, is a glutathione precursor and strong antioxidant. Both drugs have been shown to improve aminotransferase levels in patients with NASH.

Future directions in evaluation and treatment of patients with NASH include the NASH Clinical Research Network, instituted in June 2002, under the auspices of the National Institute of Diabetes and Digestive and Kidney Diseases. Eight regional research centers were designated and a national NASH registry was established. Preliminary plans call for multi-center clinical trials to assess the efficacy of a number of medications, including metformin and rosiglitazone.

In conclusion, NAFLD is a common condition whose occurrence parallels the increase in obesity in North Americans, including American Indians and Alaska Natives. Since Native Americans have a higher rate of death due to liver disease than non-Natives (the fifth leading cause of death in AI/AN, versus the tenth leading cause in the general population), NAFLD could play a significant role either as a cofactor or alone as a cause of serious liver disease. NASH may be the primary cause of cryptogenic cirrhosis, which represents up to 20% of cirrho-

sis in the U.S. In the next few years more information likely will become available on the natural history and potential intervention strategies to prevent progression of this disease. □

References

1. Ludwig J, et al. Nonalcoholic steatohepatitis. Mayo Clinic experiences with a hitherto unnamed disease. *Mayo Clinic Proc.* 1980;55:434-438.
2. Matteoni CA, et al. Nonalcoholic fatty liver disease: a spectrum of clinical and pathological severity. *Gastroenterology.* 1999;116:1413-1419.
3. Teli MR, et al. The natural history of nonalcoholic fatty liver; a follow up study. *Hepatology.* 1995;22:1714-1719.
4. Clark JM, et al. Nonalcoholic fatty liver disease: The most common cause of abnormal liver enzymes in the U.S. population. *Digestive Disease Week.* 2001, Abstract 344.
5. Bacon B, et al. Nonalcoholic steatohepatitis: an expanded clinical entity. *Gastroenterology.* 1994;107:1103-1109.
6. Brunt E, et al. Nonalcoholic steatohepatitis. A proposal for grading and staging the histological lesions. *Amer J Gastroenterology.* 1999;94(9):2467-2474.
7. Pagano G, et al. Nonalcoholic steatohepatitis, insulin resistance, and metabolic syndrome: further evidence for an etiologic association. *Hepatology.* 2002;35(2):367-372.
8. Chitturi S, et al. NASH and insulin resistance: insulin hypersecretion and specific association with the insulin resistance syndrome. *Hepatology.* 2002;35(2):373-379.
9. Harrison S, et al. Vitamin E and vitamin C in the treatment of nonalcoholic steatohepatitis. A prospective, randomized, placebo-controlled clinical trial. A preliminary report. *Digestive Disease Week.* May 2002, Abstract M1332.



Should Indian Health Care be an Entitlement?

The following is the first of three papers that were written during each authors' participation in the Kaiser Family Foundation's Native American Health Policy Fellowship last year.

Herminia Frias, Henry J. Kaiser Native American Health Policy Fellow 2002; currently, Acting Network Services Manager, Pascua Yaqui Tribe Behavioral Health Program, Tucson, Arizona

Introduction

The purpose of this paper is to discuss the proposed legislation to make funding for health care for American Indians and Alaska Natives (AI/AN) an entitlement. Despite the federal trust responsibility and federal laws that authorize the United States to provide health care to AI/AN, Indian health care has historically been underfunded. The Indian Health Service (IHS) budget is appropriated annually. Some have proposed that Congress make Indian health care an entitlement similar to Medicare or Medicaid in order to remove Indian health care from the vagaries of the annual appropriations process. This paper is an analysis of the concept of entitlement for Indian health care. It proposes two options for entitlement programs, discusses the pros and cons of each option, and examines their potential impact on the IHS. It concludes that the greatest benefit of changing to an entitlement program is the removal from the appropriations process. However, there are concerns about tribal sovereignty, eligibility, and the changing role of the IHS.

Background

Indian Health Legislation. Over the last century, the federal trust responsibility to provide health care for AI/AN has developed and been defined by the United States Constitution, treaties, statutes, federal agency rules and practices, executive orders, and numerous court rulings. The Snyder Act of 1921 (25 U.S.C) was the first legislative authority for Congress to appropriate funds specifically for Indian health care.

Approximately 1.5 million AI/AN receive health care through the IHS, an agency under the Department of Health and Human Services. AI/AN enrolled in federally recognized tribes access IHS care through a system of hospitals, health centers, school health centers, health stations, and satellite clinics located on or near Indian reservations.

In 1976, the Indian Health Care Improvement Act (IHCIA) was enacted based on the finding that the health status of AI/AN ranked far below that of the general population. The Act stated the following: "The Congress hereby declares that it is the policy of this Nation, in fulfillment of its special

responsibilities and legal obligations to the American Indian people to assure the highest possible health status for Indians and urban Indians and to provide all the resources necessary to affect that policy" (DHHS, 2002a). Through this Act the federal government was able to implement policies and health programs directed towards elevating the health status of the AI/AN population to a level at parity with the general U.S. population. Despite this national policy, significant health disparities still exist, and AI/AN have a shorter life span and higher rate of infant mortality, among other indicators. For example, AI/AN death rates are higher for many diseases like alcoholism (670%), tuberculosis (650%) and diabetes (318%).¹

The Indian Self-Determination and Education Assistance Act of 1975 (Public Law 93-638) reinforced the concept of tribal sovereignty. PL 93-638 as amended builds upon IHS policy by giving tribes the option of staffing and managing IHS programs in their communities and provides for funding for improvement of tribal capability to contract under the Act.

During the 107th Congress, Representative George Miller introduced the Indian Health Care Improvement Act Amendments of 2001. This legislation would serve to reauthorize the Indian Health Care Improvement Act and would provide additional clarifications and provisions for Indian health. Section 815 of this bill established a National Bipartisan Health Care Entitlement Commission to review and analyze the recommendations on the concept of entitlement. A study committee would make recommendations to Congress about health services for AI/AN as an entitlement, including possible effects on existing health care delivery systems and the sovereign status of Indian tribes.

The Indian Health Service Budget. Each year the president prepares and submits a budget to Congress for review and action. Annual appropriations bills are subjected to the authorization-appropriations process, a laborious endeavor of establishing need and requesting adequate funding. The IHS is a discretionary program that receives its funding through this annual appropriation process. Although the IHS is an agency under the DHHS, it, and virtually every other AI/AN program, receives its funding from the Interior appropriations bill, one of the 13 general appropriations bills. This is because from 1924 until 1955, Indian health care was the responsibility of the Bureau of Indian Affairs until it was transferred to the

Department of Health, Education, and Welfare, subsequently renamed the DHHS, and the IHS was established as a separate entity to provide these services. Therefore, not only must IHS compete with other AI/AN programs, but it also has to compete with other non-AI/AN programs and non-health related programs within the Interior's jurisdiction.

In fiscal year 2003, the Bush Administration proposed approximately \$23.6 billion for the Department of Interior Appropriations with \$2.5 billion specifically slated for the IHS (an increase of \$67 million or 2%). Between 1993 and 1998, IHS appropriations increased only 8% while the medical inflation rate rose 20.6%. Therefore, when both the rate of medical inflation and service population are factored in, actually there was a decrease of 18% in the per capita appropriation for Indian healthcare.² For fiscal years 1999 through 2002, appropriations increased at a faster rate, with a total increase of \$548.5 million.

Underfunding of Indian Health Programs. The type of health care received varies from tribe to tribe depending on their economic status, population, and location. For example, some tribes can afford to supplement IHS funds and provide additional services such as adult dental care, mental health, and transportation. Tribes close to urban settings may also have more access to specialty care and public transportation. However, for poor, isolated, and economically depressed tribes, it can be difficult for them to obtain even basic health care services. All tribes are subject to the limitations of a finite amount of money; once these funds are depleted, tribes are forced to look to alternative funding sources or go without.

In 1998, Congress asked the IHS to develop a health status and resource deficiency report for each Indian tribe and service unit. A Level of Need Funded Workgroup (LNF) was established to determine an acceptable methodology for funding federal Indian health programs and to determine what it would take to provide an equitable level of health care services to all eligible AI/AN. The LNF Workgroup compared IHS personal health benefits with the Federal Employee Health Benefit Plan (FEHB). The LNF actuarial methodology determined that \$2,980 per person of Indian health funding would be needed to assure benefits equivalent to those in a mainstream health plan, and it also demonstrated a remarkable 46% disparity in Indian health care funding. This study revealed that a health care benefit package similar to the FEHB plan for the potential service population of 2.4 million AI/AN would cost \$7.4 billion. The initial benchmark figure of \$2,980 represented a defined benefit package for personal medical services such as visits to doctors, dentists, and nurse practitioners; hospital care; and other health services provided to the individual. This did not include the public health or "wraparound" services that IHS provides as part of the benefit packages. These services include sanitation facilities construction, community health representatives, public health nursing, public health education, and environmental monitoring and remediation. The LNF process was helpful in revealing and quantify-

ing the significant and disparate underfunding of Indian health programs when compared to a defined federal health benefits package.

Additionally, the cost for contracting PL 93-638 tribes has increased significantly between 1989 and 1998, from \$125 million to \$375 million. In 1998, Congress appropriated almost \$280 million towards the \$375 million in tribes' allowable contract support cost, resulting in a shortfall of about \$95 million.³ These significant shortfalls in funding have made it increasingly difficult for the IHS to keep up with the rising cost of health care and the increased health care demands of AI/AN.

Proposal for Making Indian Health an Entitlement

Leaders in Indian health care have discussed the chronic underfunding in the Indian health care system and the persistent health disparities of this population. They have considered whether making Indian health care an entitlement program would help improve the health status and health care services for AI/AN.

Federal Health Entitlement Programs. Although many have referred to Indian health care as an entitlement, it is not. Entitlement programs have eligibility criteria and defined benefits set by law. The Federal government is required to provide benefits to any person, business, or unit of government that seeks such benefits and that meets the criteria. Congress has control over the spending levels for these programs indirectly by defining eligibility and setting the benefit or payment rules. Once the criteria are established, the government is legally required to make the payments to eligible recipients.⁴ The major types of federal health care entitlement programs are Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP).

Medicare provides a defined set of health care benefits to individuals over the age of 65 and the disabled. Under Medicare Part A, a patient has access to inpatient hospital care, skilled nursing facility care, home health care, and hospice care. Under Medicare Part B a beneficiary pays a monthly premium for doctor services, other medical and health services, specified preventative health services, and home health services.

Medicaid and SCHIP are federal-state entitlement programs. The Federal government gives states money each year to insure indigent people and children who meet eligibility criteria determined by the state. Medicaid is a means-tested individual entitlement with a federally defined minimum benefit package. States have the option of covering additional services and receiving federal matching funds for the cost of those services. SCHIP is a federal block grant to states that does not entitle individuals to a federally defined benefit package. Under Medicaid and SCHIP, beneficiaries seek medical services through state approved Managed Care Organizations (MCO) or from fee-for-service providers.

Unlike discretionary programs, entitlement programs do not compete against other programs in the annual appropria-

tions process. Instead they are automatically funded and increased yearly with respect to service population and inflation. Entitlement programs are funded through mandatory or direct spending. These expenditures can constitute more than half of the federal budget. For example, in fiscal year 2003, the proposed federal budget for the Department of Health and Human Services was \$471 billion. Entitlement programs like Medicare, Medicaid, and SCHIP constituted 89% of the budget. The remaining 11% was left to fund, among other things, discretionary health programs (not necessarily limited to those in the Department of Health and Human Services) such as the Center for Disease Control and Prevention, the National Institutes of Health, the Substance Abuse Mental Health Service Administration, and the IHS.

A change from a discretionary program to a mandatory (entitlement) program requires an Act of Congress and can be facilitated by amending existing authorizing legislation such as the Snyder Act or the IHCA to define Indian health care as an entitlement. Alternately, a new piece of authorizing legislation can be introduced that defines AI/AN health care as an entitlement. Such action could eliminate the chronic underfunding and discretionary status of the IHS budget; therefore a thorough analysis of the concept of entitlement for Indian health is needed.

Analysis of Indian Health as an Entitlement

An entitlement program will remove IHS from the competitive appropriations process, potentially improving access to care and reducing health disparities. As an entitlement, tribes can choose to structure their programs based upon other federal entitlements; they may structure their programs similar to Medicare and Medicaid, with a federally defined minimum benefits package, or they can administer a program similar to the SCHIP, as a tribal-federal block grant. This section will discuss the pros and cons of these options and their potential impact on the IHS.

Medicare/Medicaid Model. Under the Medicare/Medicaid model, individual tribal members would be eligible for a federally defined minimum set of services based on federally defined eligibility. In this model the Center for Medicare and Medicaid Services (CMS) can contract with fiscal intermediaries like Blue Cross and Blue Shield (BC/BS) to process claims. IHS on the other hand, can process claims itself or contract with fiscal intermediaries like BC/BS.

Pros of Medicare/Medicaid Model. The Medicare/Medicaid model has the advantage of helping individual AI/AN whether they reside on or off the reservation (urban Indians). By providing eligible members with a defined benefit package through a provider card similar to Medicare they could potentially increase their provider pools, improving access to health care. In case of an emergency, AI/AN would be at liberty to seek care at more hospitals or facilities without having to worry about out-of-pocket fees. This model can reduce the amount of dollars lost by hospitals or other healthcare providers for non-pay-

ment because they are not IHS providers.

Cons of a Medicare/Medicaid Model. Entitlement programs require a defined benefit package. However, the benefits package established by the LNF Workgroup did not include the comprehensive public health program services, a critical component of Indian health care. Although there are crude estimates of the cost of providing primary care services to AI/AN, the cost of the wraparound services has not been determined.

Currently, IHS, tribal, and urban program providers determine eligibility criteria and services provided. A federal means-tested eligibility could weaken tribal sovereignty by reducing the tribe's power to determine who receives health care services. The eligibility might be based on tribal membership, or even a minimum documented blood quantum.

SCHIP Model. Tribes may decide to adopt a system similar to states' SCHIP, allowing tribes the freedom to define eligibility criteria and a benefit package based on individual tribal needs through a federal-tribal block grant system. Tribes could choose to develop an MCO, or contract with another MCO or the IHS.

Pros of SCHIP Model. Using the SCHIP model, tribes can continue to enforce their tribal sovereignty by establishing eligibility criteria and a benefit package based on individual tribal needs. This system is similar to the current PL 93-638, where tribes contract their health care dollars from IHS to administer their own health programs. In this model, all 561 tribes could provide a minimum health benefits package and possibly additional wraparound services to meet their unique health care needs and regional differences. For example, the villages of Alaska may decide to allocate specific funding for transportation while the tribes in the southwest may focus more money on diabetes prevention services.

Cons of SCHIP Model. Not all tribes have the capacity to administer their own health care system, and for smaller tribes it may not be cost-effective for them to do so. Tribal health administrators would need to be business savvy in order to implement a cost-effective health care system. Every tribal health administrator and government will need technical experts and staff to implement and sustain a health care system as comprehensive as the current IHS system. The IHS has had to struggle to recruit and retain just those experts needed for the number of tribes who currently administer their own health care under PL-93-638 contracts.

This type of block grant entitlement does not necessarily ensure annual budget increases. In fact, SCHIP funding decreased from \$4.275 billion for FY 2001 to \$3.15 billion for FY2002.⁵ Since tribes would receive a block grant, if the money runs out, many beneficiaries would be put on a waiting list, hindering access to care. In emergent situations, tribes or tribal members would be responsible for reimbursements to hospitals or other health care providers.

As with the Medicare/Medicaid model, AI/AN may be left out because they are not enrolled members of tribes or are members of non-federally recognized tribes, or they do not meet the

minimum blood quantum established by their tribe.

Entitlement programs are not immune from government controls. For example, the Kaiser Family Foundation found that many states are facing a significant rise in Medicaid cost and, therefore, budgeting shortfalls. To deal with these increases, many states are implementing cost containment strategies. Some states have implemented policies that control the cost and use of prescription drugs, limit payments to providers, eliminate some benefits, or restrict eligibility.⁶

Tribal health administrators may be faced with similar budget shortfalls. If the cost of providing health care for AI/AN becomes too expensive, tribal governments may be put in a difficult situation of reducing costs through methods similar to states. Even worse, the Federal government may implement their own cost containment methods on tribes through continued budgetary increases but reduced services.

Impact on the Indian Health Service. An entitlement program structured after either of the model programs may have a significant impact on the different roles of the IHS. Medicare, Medicaid, and SCHIP are insurance programs and purchasers of managed care. The IHS, however, is a provider, purchaser, and Federal advocate. As a provider, it provides health care services and is reimbursed on the basis of services it bills. As a purchaser, IHS pays for other health services that they do not provide. Finally as an advocate, the IHS is responsible for ensuring comprehensive health care services for all AI/AN.

Under the Medicare/Medicaid model, the IHS can continue its provider role for AI/AN who decide to continue to receive health care through the IHS. In fact, it is possible to improve current services by increasing the financial resources, allowing providers more program flexibility. Providers have become dependent on reimbursements to sustain their health care systems. In fiscal year 1997, IHS and tribally operated facilities were projected to receive \$184 million in Medicaid reimbursements, or about 10% of the amount appropriated from Congress.⁷ The IHS may also continue to purchase health care services from specialists, and the IHS can continue its role as an advocate for ensuring comprehensive health care services for its beneficiaries.

Under the SCHIP model, the IHS could continue to provide services on a fee-for-service basis for the tribes who decide to continue to receive health care from them. However, the IHS role as purchaser for contract health services would be eliminated because tribes would be responsible for the purchasing additional health care services. Tribes would also be responsible for health advocacy.

Under both models, the IHS would still be responsible for providing or purchasing the essential public health services, since they are not amenable to inclusion in the defined benefit package. Since it would be difficult to determine the cost of providing these public health services, the IHS might opt to keep them as a discretionary program.

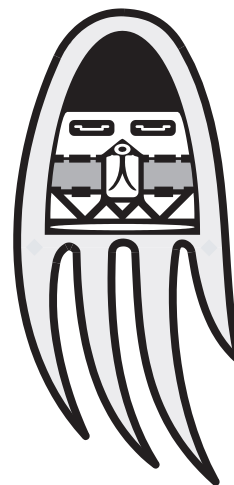
Conclusion and Recommendations

As the cost of health care continues to skyrocket, and as the

IHS continues to struggle to meet these demands with limited dollars, it is important that the entitlement concept be studied soon. National health care expenditures are expected to grow faster than the gross domestic product for the rest of the decade, rising from 13.2 percent in 2000 to a projected 17.0 percent in 2011.⁸ Entitlement programs like Medicare, Medicaid, and SCHIP will increase automatically to account for projected inflation and enrollment increases. Furthermore, the number of tribes that enter into PL-638 contracts may also continue to increase, exacerbating the problem of inadequate appropriations from Congress. It will be extremely difficult for the IHS to keep up with these projected cost increases without a significant increase in its budget.

In conclusion, the greatest benefit of changing Indian health care to an entitlement is its removal from the competitive appropriations process. If an entitlement program is not enacted, the IHS will continue to be subjected to the uncertainties of this appropriations process, making it difficult to reduce health disparities with the current system of rationed health care. However, there is concern over an entitlement program's potential effects on tribal sovereignty, eligibility, and the changing role of the IHS.

An entitlement does not make Indian health care synonymous to welfare; instead it reinforces the Federal government's trust responsibility to AI/AN and strengthens the federal policy to provide all the resources necessary to improve the health status of AI/AN. However, regardless of how it is accomplished, a fundamental change in federal financing is needed to ensure dependable, stable, and sustained health care for AI/AN.



This paper supports the development of an Entitlement Commission similar or identical to that proposed by Representative Miller. Based on preliminary observations, such a commission should begin with a comprehensive analysis of entitlement programs and their potential impact on the current health care delivery system, tribal sovereignty, and the three-function role of the IHS (provider, purchaser, advocate). Once a program design is established, a study to determine entitlement program administration should be completed. Other key issues beyond the scope of this paper that should be investigated further are the inter-tribal controversy regarding entitlements and the political barriers to entitlement legislation. During the 106th and 107th Congresses, the Indian Health Care Improvement Act was introduced but not passed. Therefore, instead of depending on Congress to pass a bill that includes an entitlement study, it may be useful to seek a private health policy foundation to fund a commission to examine the concept of entitlement.

An Indian health entitlement program is a complex issue about which there is very limited information available. It will be a laborious task for a commission to study this issue, but the results of this study could impact Federal policy and change the current method of Indian health care financing. The IHS is a unique system of care that has the potential to provide the highest quality standard of care for AI/AN if the primary barrier is eliminated: inadequate funding. □

References

1. Shalala, Donna E., Trujillo, Michael H., Hartz, Gary, P.E., D'Angelo, Anthony J. *IHS. Regional Differences in Indian Health 1998-1999*. Indian Health Service, 2002.
2. Dixon, Mim. Mather, David T, Shelton, Brett L. Roubideaux, Yvette. *Organizational and Economic Changes in Indian Health Care Systems*. p.105. In: Dixon M, et al. *Promises to Keep: Public Health Policy for American Indians and Alaska Natives in the 21st Century*. American Public Health Association, 2001a.
3. Wells, Jim. *Indian Self-Determination Contracting. Shortfall in Contract Support Costs and Alternatives for Funding Them*. Testimony Before the Committee on Indian Affairs, U.S. Senate. Statement of Jim Wells, Director, Energy, Resources, and Sciences Issues Resources, Community and Economic Development Division. United States General Accounting Office. 1999
4. Committee on the Budget Majority Caucus. *Basics of the Budget Process, A Briefing Paper*. U.S. House of Representatives 107th Congress, 2002.
5. Kaiser Commission on Medicaid and the Uninsured (KCMU). *Trends in CHIP Expenditures: State-by-State Data*. The Henry J. Kaiser Foundation. October 2001.
6. Ellis, Eileen, Gifford, Kathy, Hamish, Rekah, Wachino, Victoria, Smith, Vernon. *Kaiser Commission on Medicaid and the Uninsured, Medicaid Spending Growth: Results from a 2002 Survey*. The Henry J. Kaiser Family Foundation, September 2002.
7. Schneider, Andy, Martinez, Jo Anne. *The Center on Budget and Policy Priorities for the Kaiser Commission on the Future of Medicaid. Native Americans and Medicaid: Coverage and Financing Issues*. Kaiser Family Foundation, 1997.
8. Alliance for Health Reform. *Health Care Cost & Health Coverage*. August 2002.

Additional References

1. Henry J. Kaiser Family Foundation. *The President's Fiscal Year 2003 Budget: An Overview of Health Programs*. Henry J. Kaiser Family Foundation, 2002.
2. Indian Health Service. *Comprehensive Health Care Program for American Indians and Alaska Natives*. Indian Health Service, 2002.
3. LNF Work Group Report. *Level of Need Funded: A study to measure the costs of a mainstream package of health services for Indian people*. p2. Indian Health Service. 1999.



PDA and HIPAA Compliance

Scott Hamstra, MD, Whiteriver, Arizona; Chris Lamer, PharmD, CDE, Cherokee, North Carolina; and Carol Miller, BSN, MBA, McLean, Virginia; all with the Information Technology Support Center, Tucson, Arizona

The Health Insurance Portability and Accountability Act (HIPAA), passed by Congress in 1996, is a comprehensive law that addresses a number of health care issues, including privacy standards, security standards, and reasonable safeguards for providers who store and/or transmit patient related clinical information. *Privacy* standards address confidentiality policies and procedures governing the use and disclosure of protected health information (PHI). Privacy regulations were approved in April 2001 with an implementation of these standards effective April 14, 2003. *Security* standards address the physical and technical safeguards for storage and transmission of protected health information. The implementation data for the new HIPAA Security regulations is scheduled for April 21, 2005. HIPAA regulations do not specifically address the Personal Digital Assistant (PDA), but the regulations do address protecting patient information and transmitting these data, and this, in turn, ultimately affects the PDA.

So, if I own a PDA, do I have to abide by the HIPAA regulations?

Well, the answer is yes and no. There are over 500 health-care-specific applications for Personal Digital Assistants. The majority of these applications are either reference databases (such as personal address books and telephone numbers, or to-do lists) or medical calculators. If these were the only types of applications used, the HIPAA regulations would not apply. Because of the links to reference and clinical resources, PDAs tend to increase the provider's efficiency as well as improve the quality of patient care. Therefore, more and more providers are adding other programs that enable them to view and interact with patient data, such as lab or x-ray results, clinical patient notes, or charge capture, on their PDAs. Both the storage and accessibility of patient data *and* the *electronic* transmission of these patient data are where the HIPAA requirements will apply.

So again, what are the issues that I have to be concerned with regarding PDAs and HIPAA?

There are several issues that a provider must address, especially when the PDA contains patient-related clinical information.

Issue 1: Lost, Stolen, or Misplaced PDA. Because of their

size and portability, and sometimes due to just plain forgetfulness, a PDA may turn up missing. Recent studies suggest a loss rate of at least 30%. Because of this, patient data may be accessible by unauthorized individuals. There are several questions that the provider needs to address.

First, did the user have in place reasonable safeguards, such as a password or other means, to protect the patient data? Password protection, built in to Palm OS, Windows based, or other comparable PDAs, is the first line of defense. As an example, with Palm you can enter a password that unlocks and shows hidden records; then with another password you can lock the PDA. Only by reentering the authorized password will the PDA unlock. However, please note that without any protection (password or encryption), the general and patient-related information can be accessed by anyone.

Second, does anyone else have access to your PDA data? Once a provider places patient data on his or her PDA, he/she also needs to take steps to limit access to that PDA.

Issue 2: Synchronization, Beaming, and Wireless Transactions. These means of receiving or transmitting patient data create another protection issue. To review the various methods of transmission, *synchronization*, via a cradle, transfers information from a central database to the PDA (e.g., lab or x-ray results, patient information, consultative notes, and so on). Clinics that authorize the provider to use these methods should develop prior agreements with the provider and a process to authenticate the provider's identity before data are transmitted. In addition, for the protection of all parties, it is recommended that an audit trail of those who synchronized and what data were transmitted be maintained by the service unit.

Wireless providers have immediate, real time capability to receive and send patient-related data. This process of transmission is more vulnerable than synchronization. Wireless solutions can utilize a public or private network. HIPAA requires encryption for the transmission of data over public networks, whereas encryption is optional for others. Sharing data from a wireless over the Internet represents potential security issues; however, more and more health care facilities are using a wireless virtual personal network (VPN) that allows PDA users to connect securely from remote locations just as laptop users do today.

Beaming is the ability to transmit or "beam" information from one PDA to another via an infrared information stream. When beaming in the presence of other PDAs, it is possible for another device to inadvertently pick up the transmission. It is recommended that beaming take place in the presence of only two PDAs for the duration of the transmission. Low end wire-

less PDAs require a direct infrared line of sight, usually at a distance of between six inches and three feet, so data transmission is less vulnerable. However, high end PDAs and the newer technologies such as Blue Tooth, allow broader transmission ranges; therefore potentially creating greater access by unknown parties.

Issue 3: Ownership of the PDA and HIPAA Compliance.

One would naturally assume if the provider owns his or her PDA, he or she should be responsible for security and maintenance of the confidentiality of patient data. However, if the clinic or facility owns the PDA, who is responsible for protecting the PHI, the clinic or the provider? The best answer is both. As a protective measure, if the provider has access to clinical information, the clinic should have the provider sign an employee confidentiality agreement in which he or she agrees to safeguard patient information and take responsibility for its protection. Also, another point to establish is whether the service unit officially supports the use of PDAs and/or the integration of patient data therein.

Issue 4: PDA Repairs. Another issue affecting the vulnerability of the PDA is repairs. Like many small electrical devices, PDAs have the capacity to malfunction and require repairs. Before sending the PDA for repair, make sure that any PHI has been erased from storage and rendered completely inaccessible to the service technicians.

So what do other providers do?

Most providers using PDAs for patient data utilize a user ID or password level of security. Most of the PDAs sold today are already equipped with a password protection utility requiring the user to enter a password before accessing any of its data or functions. This simple safeguard will ensure that patient information is protected in the event that the PDA is lost, stolen, or accessible by someone other than the provider. To maintain security, the provider should be required to reenter their user ID or password every time they enter the application. Likewise, each PDA should have a “time out” feature, requiring a provider to reenter his ID or password again when the unit is left on and inactive for a predetermined period of time. This feature *will not* prevent individuals with technical skills from accessing this information. Encryption will protect any health care information that travels over an open network (e.g., the Internet, wireless application data transfers, etc.).

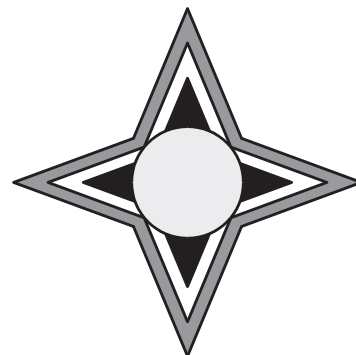
So given all this information, what should I do?

- Providers need to be aware of the HIPAA requirements regarding security of patient data that are collected, stored, or transmitted.
- If you are using your PDA only as a resource for general clinical information, you need not worry about HIPAA.
- If you have patient-related data on your PDA, reasonable safeguards need to be put in place to protect these data.

- Each provider needs to know what data are on the PDA and remove data that are no longer needed or relevant.
- Likewise, the clinic should also be aware of what types of patient-specific clinical information there is to be found on the provider’s PDA, so that the clinic is aware of what information there is that might potentially be compromised.
- Periodically, system passwords need changed.
- Providers need to know who will be notified if the PDA is lost.
- If patient-specific data are *stored* on the device, the data should be encrypted and access should be password protected.
- If patient identifiable data are *transmitted during synchronization*, provider authentication should be required before transmission, and an audit trail should be maintained.
- If patient identifiable data are *transmitted wirelessly*, provider authentication should be required before transmission, data should be encrypted during the transmission, and an audit trail should be maintained.
- To protect data if the PDA is lost or stolen, utilize as the first defense a user ID and password.

Conclusion

PDA usage is continuing to grow because they provide portability, easy storage, and access to information. HIPAA regulations regarding privacy, security, and transmission of patient-related clinical data will effect how providers use PDAs, today and more so in the future. The challenges of compliance must be met. Future risks such as virus infections are on the horizon. Because infrared transmission has so little security and is very vulnerable, “beaming” places additional demands for privacy and security. Even though there are no failproof methods of securing data on a PDA, there are many protection and encryption processes available to the provider for securing the data on the PDA. The next article will list and describe the various password protection and encryption applications available, as well as their website references. □



Nutrition and Chronic Kidney Disease

Andrew S. Narva, MD; and Theresa A. Kuracina, MS, RD, CDE, both from the Indian Health Service Kidney Disease Program. Albuquerque, New Mexico

This article is the seventh of a series about chronic kidney disease and its management based on the new National Kidney Foundation guidelines. If you missed previous articles in this series, please log onto the IHS website. Archived issues are found at the Clinical Support Center's web page.

Why worry about nutrition in chronic kidney disease?

Malnutrition increases morbidity and mortality for patients starting dialysis. Inadequate protein and calories result in the malnutrition seen in chronic kidney disease (CKD). Anorexia due to uremia, altered taste sensation, catabolism, metabolic acidosis, and decreased functional status are but a few of the factors relating to this malnutrition.

Who should be assessed for malnutrition?

Patients at Stage 3 and higher (glomerular filtration rate \leq 60 mL/min/1.73 m²) should be referred for nutritional assessment by a registered dietitian (RD). The RD can assess current intake, make recommendations, and monitor for changes in nutritional status.

For those with glomerular filtration rates $<$ 20 mL/min/1.73 m², the evaluation should include at least *one value from each* of the following clusters:

1. Serum albumin
2. Edema-free actual body weight, percent standard (NHANES II) body weight, or subjective global assessment ((SGA); and
3. Normalized protein nitrogen appearance (nPNA) or dietary interviews and diaries

Protein recommendations (KDOQI)

Protein restriction should be considered for patients with GFR $<$ 25 mL/min/1.73m² (Stage 4). Patients should consume no more than 0.6 grams of protein/kilogram/day. If the patient cannot or will not tolerate this level, use 0.75 g protein/kg/d. At least 50% of the protein should be obtained from high quality protein sources.

Controversy exists regarding dietary protein and its effect on Stages 1 - 3 (GFR 30 and above). Lower protein consumption was not found to delay the progression of CKD in the Modification of Diet in Renal Disease study. However, subsequent meta-analyses indicate that protein restriction may slow progression. KDOQI guidelines state "there is insufficient evidence to recommend for or against routine prescription of dietary protein restriction for the purpose of slowing the progression of chronic kidney disease; individual decision-making is recommended, after discussion of risks and benefits."

Although the advisability of restricting protein to $<$ 0.6 g is uncertain, even achievement of 0.6 - 0.8 g/kg intake in fact reflects a decrease in protein intake for most Americans.

Calorie recommendations (KDOQI)

Adequate calories are needed to maintain nutritional status. Recommended caloric intake for patients with GFR $<$ 25 mL/min/1.73 m² (Stage 4) is based on age, as follows:

- Under age 60, use 35 kilocalories/kilogram/day (kcal/kg/d)
- Over age 60, use 30 - 35 kcal/kg/d.

Sodium recommendations (American Dietetic Association)

Sodium is involved in fluid balance. Patients who are indiscreet with sodium intake may have edema and elevated blood pressure. KDOQI does not address sodium restriction. The American Dietetic Association's National Renal Diet recommends 1000 - 3000 mg of sodium per day for patients with CKD. Patients should be counseled to avoid table salt in cooking and at the table. Processed foods including canned soups, canned vegetables, and canned meats are high in sodium and should be limited.

Phosphorus and Calcium Recommendations (KDOQI)

Phosphorus and calcium are involved in the metabolic bone disease seen in CKD. Their imbalance places the patient at increased risk for calcification of soft tissues and appears to be involved in increased rates of cardiovascular mortality. Phosphorus binding medications are routinely prescribed to help control phosphorus. These minerals become an issue early in the progression of CKD, at Stage 2 (GFR about 60 - 80 mL/min/1.73m²). Serum levels of phosphorus and calcium appear "normal." However, parathyroid hormone levels increase and Vitamin D levels most likely decrease. It is their imbalance that sets the stage for bone disease.

A future article will specifically address bone disease and its treatment. □

Opioid Dose Escalation in the Treatment of End-of-Life Pain

The following article is the sixth in an ongoing series in support of the development of a unified approach to palliative care services for American Indians and Alaska Natives. Each presents brief, concise facts and information for providers of palliative care.

Judith A. Kitzes, MD, MPH, Soros Foundation, Project on Death In America Faculty Scholar, University of New Mexico Health Science Center, School of Medicine, Albuquerque, New Mexico

- Escalate opioid dosage based on patient's self-assessment of pain level.
- Patients in general do not notice a change in analgesia when dose increases are less than 25% above baseline.
- If using opioid plus non-opioid fixed combination, do not exceed daily ceiling for non-opioid (e.g., oxycodone plus acetaminophen).
- Try to use single opioid agents (e.g., oral/parental morphine).

As a terminal disease progresses, opioid escalation may be necessary to control the pain. The following guidelines apply to patients with normal renal and hepatic function.

Percentage increase from baseline

Mild-moderate pain: 25-50% above baseline, irrespective of starting dose

Moderate to severe pain: increase 50-100% baseline

Frequency of dose escalation depends on half life of the drug

Short-acting, single agent oral opioids (morphine, oxycodone, hydromorphone), not combination products: escalate every two hours

Sustained release oral opioids: every 24 hours

Fentanyl transdermal or methadone: no less than 72 hours

For elderly patients, or those with renal/liver disease, dose escalation percentages and frequency need to be reduced by 50%.

During the stage of imminent death, when fluid intake and urine output decrease, do not immediately discontinue opioid treatment, due to the potential for precipitating a withdrawal

syndrome. Instead, switch from routine dosing, to an "as needed basis," adjusting for expressions of continued pain.

References:

1. Handbook of Cancer Pain Management. Wisconsin Cancer Pain Initiative, 5th Edition, 1996.
2. Physicians Desk reference, 2002.
3. Weissman, D. Fast Fact and Concepts #20: Opioid Dose Escalation, September 2000. www.eperc.mcw.edu.
4. American Medical Association, EPEC: Education for Physicians on End-of-life Care, Module 12. www.epec.net.

Health care providers should exercise their own independent clinical judgement. Accordingly, official prescribing information should be consulted before any product is used.



Support for this Initiative

The Indian Health Service provides pre-formatted patient information that can be distributed to patients. In addition, standard patient instructions for FOBT are also available for distribution at your facility.

Monitoring of Colorectal Cancer Screening Rates

The GPRA+ Clinical Indicator Reporting System Software is designed to help you monitor your screening rates. This software enables you to generate patient lists of who has and has not been screened.

In addition, your facility will be able to monitor their rates of colorectal cancer screening.

Please refer to *How to Document Colorectal Cancer Screening* for further information about appropriate RPMIS documentation.

For further information, please contact

Theresa Cullen, MD, MS at (520) 670-4803;
theresa.cullen@mail.ih.s.gov

Bruce Finke, MD at (505) 782-7357; *bfinke@abq.ih.s.gov*

Charlton Wilson, MD at (602) 263-1537; *charlton.wilson@pinc.ih.s.gov*



Colorectal Cancer Screening Initiative Clinical Reference Guide

Colorectal cancer is a common, lethal, and *preventable* disease. 90% of cases occur after age 50.

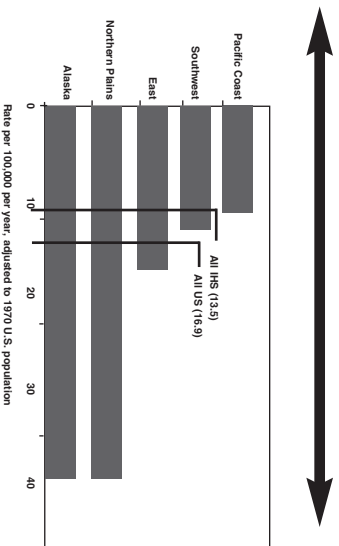
**Indian Health Service
February 2003**

Incidence of Colorectal Cancer in American Indian and Alaska Native Communities

The Indian Health Service (IHS) is committed to improving the quality of clinical care for American Indians and Alaska Natives. Colorectal cancer in American Indian and Alaska Native people has an age adjusted mortality rate of 13.5 per 100,000, compared to US All Races rate of 16.9. However, there are Areas within the Indian Health Service that exhibit much higher rates than US All Races.

The following graph illustrates recent rates of colorectal mortality in different American Indian/Alaska Native populations.

All/AN Mortality Rate, Colorectal Cancer, By Region, Both Sexes, 1994-1998



Current Rates of Screening within the Indian Health Service

RPMS data reveal low rates of colorectal cancer screening. Even if one annual rectal exam is considered an adequate screen for colorectal cancer, screening rates are consistently less than 10% for most Areas of the Indian Health Service. Screening methods that rely on sigmoidoscopy and/or colonoscopy are consistently less than 5%.

What to do?

The Indian Health Service colorectal cancer screening initiative is designed to make it easier for you to incorporate screening into your clinical practice. As you know, many options exist for screening methods. Recently, the United States Preventive Services Task Force (USPTF) has recommended that:

Clinicians screen men and women 50 years of age or older for colorectal cancer.

The USPTF found fair to good evidence that several screening methods are effective in reducing mortality from colorectal cancer. The USPTF concluded that the benefits from screening substantially outweigh potential harms, but the quality of evidence, magnitude of benefit and potential harms vary with each method.

The USPTF found good evidence that periodic fecal occult blood testing (FOBT) reduces mortality from colorectal cancer and fair evidence that sigmoidoscopy alone or in combination with FOBT reduces mortality. Further information is available at www.ahrq.gov/clinic/uspstf/uspstfcol.htm.

Recommendations

Potential screening options are numerous. However, within the Indian Health Service setting, access to care and cost constraints may limit local provider options.

As a result, the Indian Health Service is recommending the following:

1. Renewed emphasis on colorectal cancer screening
2. Improved patient education about colorectal cancer screening
3. Fecal occult blood testing every year if possible; every 2 years at a minimum
4. Appropriate follow-up for positive FOBT results
5. Additional screening options if available
 - a. Flexible sigmoidoscopy within the last 5 years
 - b. Annual FOBT plus flexible sigmoidoscopy every 5 years
 - c. Double contrast enema every 5 years
 - d. Colonoscopy within the last 10 years

Executive Leadership Development Program Receives Special Recognition

On December 16, 2002 the IHS Executive Leadership Development Program (ELDP) received special recognition from Syracuse University's Partnership for Public Service as one of twelve outstanding federal leadership development programs.

ELDP collaborates with federal, tribal, and urban Indian health care systems to develop and increase leadership and management skills. In addition, participants develop new relationships and networks with other executives within the Indian health care systems. Several of the participants have received promotions and increased responsibilities since completing ELDP.

SESSION DATES:

Session One – Omaha, Nebraska

March 10 - 14, 2003

June 23 - 27, 2003

Session Two – Aurora, Colorado

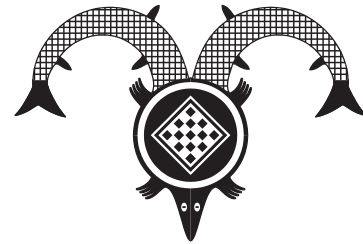
July 28 - August 1, 2003

Session Three – Aurora, Colorado

August 18 - 22, 2003

The IHS Clinical Support Center is the accredited sponsor.

For more information, contact Elaine Alexander, BSN, Executive Leadership Development Coordinator, Indian Health Service Clinical Support Center, Two Renaissance Square, Suite 780, 40 North Central Avenue, Phoenix, Arizona 85004-4424; telephone (602) 364-7777; fax (602) 364-7788; e-mail ELDP@mail.ihs.gov; website www.ihs.gov.



The 7th Annual Elders Issue

The May 2003 issue of THE IHS PROVIDER, to be published on the occasion of National Older Americans Month, will be the seventh annual issue dedicated to our elders. Indian Health Service, tribal, and Urban Program professionals are encouraged to submit articles for this issue on elders and their health and health care. We are also interested in articles written by Indian elders themselves giving their perspective on health and health care issues. Inquiries or submissions can be addressed to the attention of the editor at the address on the back page of this issue.

The Native Investigator Development Program

The Division of American Indian and Alaska Native Programs within the Department of Psychiatry at the University of Colorado Health Sciences Center has recently been awarded a five year Resource Center for Minority Aging Research (RCMAR) which focuses on Native Elder health. Since American Indian/Alaska Native (AI/AN) researchers have conducted few studies of the health of Native American elders in the US, a primary objective of the RCMAR is the training of Native American investigators. Thus, the purpose of the RCMAR's Native Investigator Development Core is to improve the research capabilities and skills of AI/ANs from the social, behavioral, and health sciences, thereby increasing the number of such individuals who are able to design, secure external support for, and conduct research in areas of Native American aging.

Candidates from fields such as medicine, nursing, anthropology, psychology, public health, sociology, and other social and behavioral sciences are encouraged to apply but must meet the following requirements: have Native American status, with documentation as needed and/or appropriate of tribal affiliation; be the recipient of an advanced degree such as an MD, PhD, DSW, EdD, or the equivalent, in one of the social, behavioral, or health sciences; and demonstrate the relevance of and need for training of this nature with regard to future plans and career development.

Inquiries are encouraged and may be directed to Dedra Buchwald, MD, Associate Director, NERC/RCMAR, UCHSC: MailStop F800, P. O. Box 6508, Aurora, Colorado 80045-0508. Instructions for applying to the program may be obtained online at <http://www.uchsc.edu/ai/nerc>.

POSITION VACANCIES □

Editor's note: As a service to our readers, THE IHS PROVIDER will publish notices of clinical positions available. Indian health program employers should send brief announcements on an organizational letterhead to: Editor, THE IHS PROVIDER, The IHS Clinical Support Center, Two Renaissance Square, Suite 780, 40 North Central Avenue, Phoenix, Arizona 85004. Submissions will be run for two months, but may be renewed as many times as necessary. Tribal organizations that have taken their tribal "shares" of the CSC budget will need to reimburse CSC for the expense of this service. The Indian Health Service assumes no responsibility for the accuracy of the information in such announcements.

Executive Director

Santa Ynez Tribal Health Clinic; Santa Ynez, California

The Santa Ynez Tribal Health Clinic is seeking an Executive Director. The Executive Director is responsible for the administration and management of the clinic, comprised of Medical, Dental, and Social Services Departments. He or she

will coordinate resources and supervise programs, including grant procurement, budgets, revenues, facilities, personnel, program oversight, Accreditation Association for Ambulatory Health Care (AAAHHC) accreditation, contract requirements and regulations, HIPAA compliance, and applicable county, state, and Federal laws.

Requirements include not less than three years' experience working in public health or a health service agency with progressive responsibility, and a Masters Degree (MBA, MHA, or MPA). Administration of American Indian programs is desirable. Candidate must have administrative experience, leadership ability, good character, and knowledge of the local Indian community. Native American preference applies. EOE.

The clinic is located 30 minutes north of Santa Barbara in the beautiful Santa Ynez valley. Please send resumes to Barbara Muller by fax to (805) 686-2060; by mail to P. O. Box 539, Santa Ynez, California; or by e-mail to barbara@sythc.com.



Change of Address or Request for New Subscription Form

Name _____ Job Title _____

Address _____

City/State/Zip _____

Worksite: IHS Tribal Urban Indian Other

Service Unit (if applicable) _____ Social Security Number _____

Check one: New Subscription Change of address

If change of address, please include old address, below, or attach address label.

Old Address _____



THE IHS PRIMARY CARE PROVIDER

A journal for health professionals working with American Indians and Alaska Natives



THE IHS PROVIDER is published monthly by the Indian Health Service Clinical Support Center (CSC). Telephone: (602) 364-7777; fax: (602) 364-7788; e-mail: the.provider@phx.ihs.gov. Previous issues of THE PROVIDER (beginning with the December 1994 issue) can be found on the CSC Internet home page (www.csc.ihs.gov).

Wesley J. Picciotti, MPA*Director, CSC*
John F. Saari, MD*Editor*
E.Y. Hooper, MD, MPH*Contributing Editor*
Cheryl Begay*Production Assistant*
Elaine Alexander, RN*Exec. Leadership Dev. Prog. Coordinator*
Theodora R. Bradley, RN, MPH*Nursing Consultant*
Erma J. Casuse, CDA*Dental Assisting Training Coordinator*
Mary Beth Kinney, MPH, EdD*Dental Education Specialist*
Edward J. Stein, PharmD*Pharmacy Consultant*

Opinions expressed in articles are those of the authors and do not necessarily reflect those of the Indian Health Service or the Editors.

Circulation: The PROVIDER (ISSN 1063-4398) is distributed to more than 6,000 health care providers working for the IHS and tribal health programs, to medical schools throughout the country, and to health professionals working with or interested in American Indian and Alaska Native health care. If you would like to receive a copy, send your name, address, professional title, and place of employment to the address listed below.

Publication of articles: Manuscripts, comments, and letters to the editor are welcome. Items submitted for publication should be no longer than 3000 words in length, typed, double-spaced, and conform to manuscript standards. PC-compatible word processor files are preferred. Manuscripts may be received via e-mail.

Authors should submit at least one hard copy with each electronic copy. References should be included. All manuscripts are subject to editorial and peer review. Responsibility for obtaining permission from appropriate tribal authorities and Area Publications Committees to publish manuscripts rests with the author. For those who would like more information, a packet entitled "Information for Authors" is available by contacting the CSC at the address below or on our website at www.csc.ihs.gov.

Dept. of Health and Human Services
Indian Health Service
Clinical Support Center
Two Renaissance Square, Suite 780
40 North Central Avenue
Phoenix, Arizona 85004

PRESORTED STANDARD
POSTAGE AND FEES PAID
U.S. DEPT. OF HEALTH & HUMAN
SERVICE
PERMIT NO. G-5691

CHANGE SERVICE REQUESTED

OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE \$300