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Liver Disease: A Significant Cause of Morbidity and Mortality in American Indian and Alaska Native Peoples

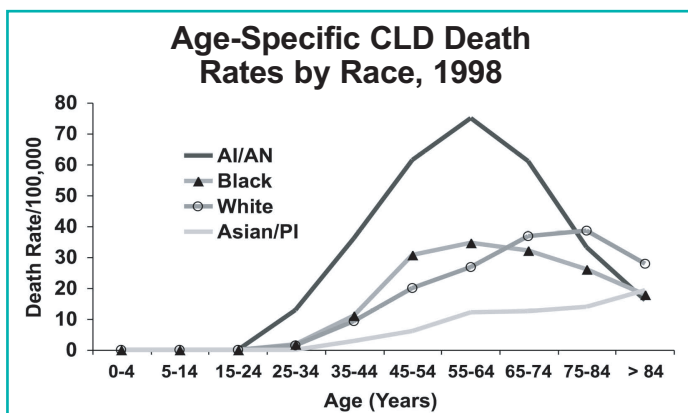
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Introduction

Although mortality due to chronic liver disease (CLD) is nearly as great as that due to diabetes mellitus among

American Indians and Alaska Native Peoples (AI/ANs), the large impact of CLD may not be fully appreciated by AI/ANs or their medical providers. A 2004 study of liver disease mortality in the United States highlighted a large disparity, reporting that liver disease was the sixth leading cause of death among AI/ANs, compared to twelfth in the overall US population. The age-specific death rate due to liver disease was over twice as high in AI/AN as in US Whites and Blacks, and over three times as high as in Asian/Pacific Islanders (Figure 1).¹

Figure 1: Age-specific CLD rates by race, 1998. Source: Vong S, Bell BP. Chronic liver disease mortality in the United States, 1990-1998. *Hepatology*; 2004;39(2):476-83.



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In the United States, hepatitis C is the most common cause of CLD, followed by alcohol-related liver disease.^{2,3} Because none of the population-based studies of CLD in the US have included large numbers of AI/AN participants, little has been known until recently about the distribution of CLD or its etiologies in AI/ANs. To help address this knowledge gap, IHS and CDC researchers recently conducted a study of CLD among American Indians at two IHS-funded medical centers in the southwestern US (“Chronic Liver Disease Among Southwestern American Indians, 2000 - 2003”). In this study, approximately 6% of adult AI/AN patients who received care at these facilities had CLD. Alcohol-related liver disease, hepatitis C, or both conditions together were the most commonly identified etiologies of CLD, accounting for slightly more than half the cases.⁴

Persons with CLD usually have no symptoms during the early stages of their disease and may not come to medical attention until abnormal liver enzymes are discovered during laboratory evaluation for other medical problems. Persons with elevated liver enzymes that persist over three to six months should be evaluated for CLD. In the Chronic Liver Disease Among Southwestern American Indians, 2000 - 2003 study, nearly a quarter of the AI/AN patients with persistently elevated liver enzymes had never received a diagnosis of CLD.⁴ It was unclear why these patients did not appear to have undergone complete evaluation for CLD. Some may have received care exclusively in urgent care settings, received part of their medical care from outside providers, or had liver enzyme elevations attributable to hepatotoxic medications or pregnancy. It is concerning, however, if medical providers failed to recognize persistently elevated liver enzymes as a marker of CLD.

Etiologies of Chronic Liver Disease

Although the prevalence of some etiologies of CLD may differ in AI/AN populations compared to the overall US population, the management of CLD is the same for AI/ANs as for other people. This article will highlight some of the most common causes of CLD among AI/ANs and discuss related diagnostic and treatment issues (Table 1). Clinicians interested in more comprehensive resources on diagnosis and management of CLD and its underlying etiologies can refer to the American Association for the Study of Liver Disease (AASLD) website (<http://www.aasld.org>) for evidence-based

Table 1. Common causes of chronic liver disease among American Indians and Alaska Native peoples

- Chronic hepatitis C
- Chronic hepatitis B
- Alcoholic liver disease
- Non-alcoholic fatty liver disease (NAFLD)
- Autoimmune liver diseases
- Autoimmune hepatitis
- Primary biliary cirrhosis

practice guidelines. The Alaska Native Tribal Health Consortium (ANTHC) Liver Disease and Hepatitis Program also has guidelines on its website (<http://www.anthc.org/cs/chs/hep>), including guidance on evaluating abnormal liver enzyme tests.

Chronic Hepatitis C. Hepatitis C virus (HCV) infection is the most common blood borne infection in the US and a leading cause of CLD.¹⁻⁵ The virus is primarily spread by parenteral exposure to the blood of an HCV-infected person, which can occur through injection drug use, receipt of a blood transfusion, or birth to an HCV-infected mother.⁶ Transmission of HCV can also occur in the health care setting and is generally associated with inadequate infection control practices, such as unsafe injection practices, contamination of multidose medication vials, or inadequate cleaning of equipment. Approximately 70 - 80% of persons who acquire HCV infection develop chronic infection, approximately 25% of whom will go on to develop cirrhosis and/or hepatocellular carcinoma (HCC) during their lifetime. Most of the 1.3% of Americans who have chronic HCV infection⁵ are asymptomatic, and many are unaware they are infected. Although the number of new HCV infections has declined since the 1980s, increased detection means that the number of patients diagnosed with chronic HCV infection is increasing. These patients are coming to medical attention, and many will need evaluation for treatment for HCV infection and care for CLD.

Hepatitis C is one of the leading causes of CLD among AI/AN patients.⁴ The IHS Divisions of Epidemiology and Disease Prevention and Program Statistics report that the number of IHS RPMS-documented visits that included a diagnosis code for hepatitis C increased from 114 in 1999 to 13,078 in 2004. The increase in IHS facility visits due to HCV infection is believed to be the result of increased screening of AI/AN patients and identification of persons with long-standing, previously undetected HCV infection, rather than an increase in newly acquired infections. In Alaska, over 1600 AI/ANs have been identified by the ANMC lab as anti-HCV positive. Of 1000 persons enrolled in an HCV follow-up study, over 700 have been found to have chronic HCV infection.⁷ Among those with chronic HCV infection, over 100 have developed cirrhosis over an 11 year follow-up period, and 20 have developed HCC. While antiviral treatment is available for anyone with chronic HCV in Alaska, few patients either qualify or want treatment.

Persons at risk for HCV infection should be tested for antibody to HCV (anti-HCV), including anyone who has ever injected illegal drugs, received a transfusion of blood products prior to 1992, or undergone long-term hemodialysis. Screening for HCV infection is also recommended for persons with persistently abnormal liver enzymes.⁶ Those found to be anti-HCV positive by enzyme immunoassay (EIA) should have this result confirmed by either radioimmunoblot assay (RIBA) or a nucleic acid test (NAT) such as HCV ribonucleic acid (RNA); EIA results with a high signal-to-cutoff ratio (generally

considered to be ≥ 3.8) are also considered a confirmed positive.⁷ Repeat testing of a negative HCV RNA test is recommended to help determine if a patient has active infection or has recovered. Between 15% to 30% of persons positive for anti-HCV will be negative for HCV RNA, indicating that they have recovered, and 70% to 85% will be HCV RNA positive and have chronic HCV infection.

Treatment for HCV infection includes pegylated interferon and ribavirin for 24 weeks for those infected with HCV genotype 2 or 3, and 48 weeks for those infected with genotype 1.⁹ There are potentially serious side effects from treatment with interferon and ribavirin, including flu-like symptoms, bone marrow suppression, and severe depression. As a result, up to one third of patients are unable to finish treatment. The probability of a sustained viral response for those who finish treatment is 40% to 50% for those infected with HCV genotype 1 and 70% to 80% for those with genotype 2 or 3. In addition, treatment is expensive. For these reasons, liver biopsy may be helpful for identifying patients who are most in need of treatment, such as those with moderate to severe fibrosis.⁹ Several new oral protease and polymerase inhibitors that target HCV are in clinical trials, and the future looks bright for better treatment regimens with a higher response rate, and hopefully shorter duration of therapy.

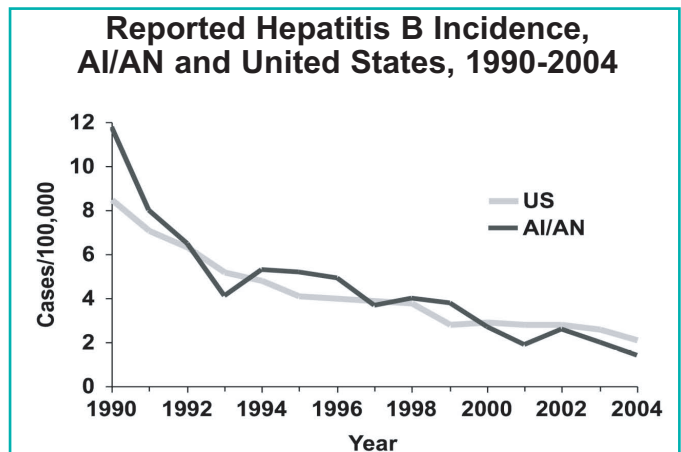
Alcohol-related liver disease. Alcohol-related liver disease (ALD) is one of the most common causes of CLD in the US. Although the prevalence of heavy alcohol consumption might be higher among AI/ANs compared to the overall US population,^{10,11} the prevalence of alcohol-related liver disease among AI/AN populations has not been well studied. In the Chronic Liver Disease Among Southwestern American Indians, 2000 - 2003, study, ALD (either alone or in combination with hepatitis C) was the cause of 48% of CLD in one site and of 26% of CLD at the other site.⁴ In persons infected with HCV, alcohol is an important co-factor in the development of cirrhosis. All patients with CLD, including those with liver disease from etiologies other than alcohol, should be counseled to minimize alcohol use or avoid it altogether.

Hepatitis B. Hepatitis B virus (HBV) infection is a blood borne infection that can be transmitted from mother to infant at birth, through sexual activity, and between persons who share drug injection equipment. HBV infection can be transmitted from contact with open cuts and scratches, most commonly seen among children in regions where HBV infection is endemic. Transmission can also occur in the health care setting and is generally associated with inadequate infection control practices, such as unsafe injection practices, contamination of multidose vials, or inadequate cleaning of equipment.¹² Chronic infection occurs in up to 90% of infants born of infected mothers, 30% of children infected before age 5 years, and 5% of those infected as adults. Approximately 15% to 25% of those who become chronically infected with HBV will die prematurely of hepatocellular carcinoma or cirrhosis.¹³ Potent antiviral medications are now available to control HBV in chronically infected persons, and can reduce the risk of

developing cirrhosis and hepatocellular carcinoma.¹⁴

Historically, the prevalence of chronic HBV infection among ANs was among the highest in the world before HBV vaccination programs were introduced into this population in the 1980s.¹⁵ As a consequence, ANs also had extremely high rates of HBV-related hepatocellular carcinoma.¹⁶ The AN population was the first in the world to receive routine hepatitis B vaccine for infants and susceptible children and adults. Routine infant and catch-up vaccination with hepatitis B vaccine led to a dramatic decline in the annual incidence of new HBV infections among ANs, and rates of new acute HBV infection are now lower in AI/ANs than those seen among the overall US population (figure 2).¹⁷ Over 1600 ANs who were chronically infected in infancy or early childhood prior to the availability of hepatitis B vaccine have been identified. Of these, 1350 are still alive, and are actively followed every 6 months with alpha-fetoprotein testing and ALT/AST to: 1) identify persons who have small HCC tumors that might undergo curable surgical resection or radiofrequency ablation; and 2) to identify persons with active liver disease who might benefit from antiviral therapy.¹⁷ These individuals remain at risk for hepatocellular carcinoma and cirrhosis.¹⁸

Figure 2. Reported Hepatitis B Incidence in AI/AN and the United States, 1990 – 2003. Source: CDC. Hepatitis Surveillance Report No. 61. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2006.



Screening for HBV infection should be considered for people in groups with high prevalence of chronic HBV infection.¹³ CDC is in the process of updating its recommendations^{12,19}; full, updated recommendations will be available at <http://www.cdc.gov/hepatitis> and <http://www.aasld.org>. Evidenced-based guidelines for treatment of HBV and screening for liver cancer^{13,14} are located on the American Association for the Study of Liver Diseases web page at <http://www.aasld.org> and on the Alaska Native Health Consortium web page at <http://www.anthc.org/chs/cs/hep>.

An effective vaccine against HBV infection was licensed

in the US in 1981. It has been recommended for persons at high risk of HBV infection since 1982, including injection drug users, persons with multiple sex partners, household contacts of persons with chronic HBV infection, patients undergoing chronic hemodialysis, and health care providers who have contact with blood and body fluids.¹² Routine immunization of infants has been recommended in the US since 1991, and catch-up vaccination of all unvaccinated children and adolescents has been recommended in the US since 1999.¹⁹

Non-alcoholic Fatty Liver Disease (NAFLD). An increasingly prevalent cause of liver disease in Americans is non-alcoholic fatty liver disease (NAFLD). In the US, the rate of overweight and obesity in both adults and children has risen dramatically over the past three decades, more than tripling over this time. Coincident with increasing rates of obesity, there have also been increases in the prevalence of diabetes and other diseases associated with the metabolic syndrome, including hyperlipidemia and hypertension. A majority of persons with the metabolic syndrome also have NAFLD. It is estimated that 30% of American adults have NAFLD and that the majority of children who are overweight also have NAFLD.²⁰ About 70% to 80% of persons with NAFLD have benign fatty liver manifested by steatosis without inflammation, a condition that rarely progresses, but 20% to 30% of persons have non-alcoholic steatohepatitis (NASH). Persons with NASH are at risk of developing cirrhosis and HCC 20 - 30 years after the development of the metabolic syndrome.

The risk factors for metabolic syndrome (and, as a consequence, NAFLD) are commonly seen in AI/AN. In the Chronic Liver Disease Among Southwestern American Indians, 2000-2003 study, approximately 13% of patients with CLD had NAFLD alone as the cause of their CLD.⁴ The Alaska Native Tribal Health Consortium (ANTHC) has begun a registry of persons with NAFLD and is conducting studies among ANs with diabetes to determine the prevalence of NAFLD in this group.

NAFLD should be suspected in anyone who has one or more risk factors for the metabolic syndrome (abdominal obesity; triglycerides ≥ 150 mg/dL, HDL cholesterol < 40 mg/dl in men and < 50 mg/dl in women; hypertension; and elevated fasting glucose).²¹ Based on Guidelines from AASLD and the American Gastrointestinal Association (AGA), persons with these findings should have liver enzymes performed.²⁰ Those with abnormal liver enzymes should have hepatic ultrasound performed to determine if there is evidence of fat in the liver. Hepatic steatosis can often be found in persons with "normal" liver enzymes who have features of the metabolic syndrome. The main reason is believed to be due to the fact that laboratories' upper limit of normal for ALT and AST are too high. Recently studies have suggested that the upper limit of normal for ALT should be 19 U/L for women and 30 U/L for men. Thus, persons with features of the metabolic syndrome

with ALT above these levels should be considered for liver ultrasound. If abnormal liver enzymes are found in persons with the metabolic syndrome, tests for other liver diseases should be undertaken, as it is not uncommon to find other liver conditions present. These include testing for HCV and HBV infections (anti-HCV and HBsAg), iron studies, and, in females, tests for autoimmune liver diseases (see below). The decision to do a liver biopsy is controversial and the benefits of a liver biopsy, namely distinguishing benign fatty liver from NASH or ruling out other liver disease, are also controversial. Providers should discuss the benefits and risk of liver biopsy with patients suspected of having NAFLD and the patient should be involved in this decision.^{20,22}

Studies have shown that losing 10 to 15 pounds (4 to 6 kg) can mobilize fat out of the liver and lower liver enzyme levels. Rapid weight loss can worsen fatty liver, so the goal should be weight loss of 10 to 15 lbs per year. In addition, exercise is beneficial for NAFLD by improving insulin resistance as well as aiding in weight loss. The recommendation is 30 to 60 minutes a day of exercise five days a week. Some studies report improvement in NASH and reduction in liver fibrosis in those who have followed these diet and exercise regimes.²²

Currently, other than diet and exercise, no evidenced-based treatment for NAFLD is available. Drugs to improve insulin resistance such as metformin and rosiglitazone may be effective in improving NASH, and large multicenter randomized controlled trials of these agents are well underway. In diabetics with NAFLD, it makes sense to attempt to include a drug that improves insulin sensitivity to their medication regime. Hyperlipidemia should be treated because, in addition to lowering cholesterol and triglycerides, these medications might benefit NAFLD. It is very important to note that drugs that improve insulin resistance or lower lipids are extremely safe and can be used in persons with elevated liver enzymes who need them. In persons with NAFLD who take these agents, there is no increased risk of severe hepatitis compared to those who do not have NAFLD, and the need for increased monitoring of liver enzymes in this situation is unclear.^{20,22} Other promising drugs include antioxidants, especially SAME (S adenylyl methionine), vitamins E and C, tissue necrosis factor or TNF inhibitors such as pentoxifylline, and lipid lowering agents, but these need to be verified in large randomized controlled trials.

Autoimmune hepatitis. Although less frequently seen, autoimmune liver diseases may be an important contributor to CLD morbidity and mortality in AI/AN. Autoimmune liver diseases are often associated with other autoimmune diseases such as rheumatoid arthritis, systemic lupus erythematosus and Sjogren's syndrome. There are three distinct autoimmune liver diseases: autoimmune hepatitis (AIH), primary biliary cirrhosis (PBC), and primary sclerosing cholangitis (PSC). AIH and PBC may occur more frequently in AI/AN than in other populations, and ANs have been found to have the highest prevalence rate of AIH in the world.²³ The prevalence

of PBC is also among the highest in the world in ANs, and PBC is the number one reason for liver transplant in First Nations persons from British Columbia, Canada. AIH and PBC are predominant in females. Any AI/AN woman with chronically elevated liver enzyme tests of unknown etiology should be evaluated for AIH and PBC. Tests for AIH include ANA, anti-smooth muscle (actin) antibody, and serum IgG. AIH, if not recognized, can be fatal within 2 - 3 years, but, if diagnosed, prolonged remission can occur in over 90% of patients with treatment with corticosteroids and azathioprine.²⁴ PBC is diagnosed by testing for anti-mitochondrial antibody (AMA). The presence of AMA is 90% sensitive and 100% specific for PBC. PBC is slowly progressive, but treatment with ursodeoxycholic acid can retard the disease progression in most persons who are diagnosed early, and may prevent the need for future liver transplantation.²⁵ PSC occurs primarily in males and is often associated with inflammatory bowel diseases such as ulcerative colitis and Crohn's disease. To diagnose PSC, an MRI cholangiogram, and, if negative, an ERCP cholangiogram, are needed.²⁶

What Can be Done to Address the Disparity in Death Due to Liver Disease in AI/AN?

CLD continues to cause significant morbidity and mortality in AI/AN patients, some of which could be prevented by prompt detection and treatment. Although alcoholic liver disease is an important cause of CLD in AI/ANs, it is far from the only cause, and the differential diagnosis of liver disease in AI/AN populations should include viral hepatitis, NAFLD, and autoimmune hepatitis. Every AI/AN with evidence of liver dysfunction should be offered a prompt, complete, and accurate workup to detect treatable causes of CLD. Currently, there are few hepatologists or infectious disease specialists within the IHS system who are available to manage patients with CLD. However, there are a number of steps that can be taken in the near future to improve care for AI/AN patients with CLD.

Primary care providers can develop expertise to diagnose and treat many patients with CLD. Providers should obtain accurate risk factor histories, particularly of intravenous drug use, and test patients for viral hepatitis as indicated. Providers should also evaluate patients with persistently abnormal liver enzyme tests (i.e., two elevations of ALT or AST at least 3 to 6 months apart) for CLD. Even patients with mildly elevated liver enzymes may have significant liver fibrosis and could benefit from treatment and counseling. Persons with cirrhosis should be screened for hepatocellular carcinoma with hepatic ultrasound and alpha-fetoprotein testing as per published guidelines, as early detection may improve survival.²⁷

Increasingly efficacious treatments for chronic hepatitis B and C are available.^{9,14} Although some treatments for chronic viral hepatitis can have serious side effects, these treatments can be effectively and safely administered by primary care providers, especially working in conjunction with pharmacists, nurses, and mental health providers, and, utilizing as consultants, physicians who are skilled in treating CLD caused

by HBV and HCV. Although many of the medications used to treat hepatitis B and C are expensive and not available on IHS formularies, pharmaceutical companies have programs to provide the medications at no cost to patients with limited financial resources.

The ANTHC in Alaska has developed a hepatology program to care for AN patients with chronic viral hepatitis and CLD. The program follows over 1350 AN with chronic HBV infection, 1,000 with chronic HCV infection and over 100 with autoimmune liver disease statewide. The ANTHC hepatology program consists of two MDs, two nurse practitioners and three nurses, along with administrative and computer support persons. Computerized registries have been developed that generate letters every six months to patients on these registries, most of whom live in isolated communities, to remind them to undergo monitoring for their specific condition. A list of patients from each community who are due for testing is sent to each hospital and rural clinic. Once a patient's blood is drawn at his/her community clinic, it is sent to a centralized laboratory at ANMC for testing. Results are automatically downloaded into the specific registry's database and reviewed weekly by a trained RN. A computer-generated letter is sent to each patient and provider informing them of the results. Abnormal results are reviewed by one of the programs MDs or nurse practitioners, and appropriate steps for further evaluation or treatment are taken. The software for this program is in Microsoft Excel, is available to other providers for AI/AN, and can be adapted to any health care program. The ANTHC hepatology program identifies patients with HBV and HCV infections who need antiviral treatment and screens for HCC to try to detect these cancers at a stage in which they can be surgically removed or ablated by radiofrequency ablation. The program provides consultation to primary care providers by conducting referral liver clinics at ANMC and all other Alaska Native tribally-owned rural clinics and hospitals throughout the state and providing statewide telephone consults. The program also conducts studies on the outcome of long-term HBV and HCV infection, autoimmune liver diseases, NAFLD, and conducts some of the longest ongoing studies of hepatitis A and B vaccine effectiveness in the world.

Several IHS clinical sites have developed innovative hepatitis C treatment programs, often in collaboration with academic institutions, to overcome barriers to treatment. At the Santa Fe Indian Hospital (Albuquerque Area), clinical providers from pharmacy, nursing, and the medical staff have been working successfully with the University of New Mexico's (UNM) Extension for Community Healthcare Outcomes (Project ECHO) to deliver comprehensive hepatitis C treatment services. The program relies upon telemedicine to deliver specialty hepatology consultation from Dr. Sanjeev Arora, a hepatologist from UNM. In Tahlequah, Oklahoma, at the W. W. Hastings Indian Hospital, a specialty clinic to treat hepatitis C has been established by the Department of Internal Medicine.

The ANTHC website (<http://www.anthc.org/chs/cs/hep>) has guidelines that primary care providers working for IHS, tribally-

owned hospitals and clinics, and other health care providers can use to help determine the diagnosis and proper treatment of AI/AN with CLD. This website has links to the website at the CDC Division of Viral Hepatitis and other websites that providers can use to learn more about how to manage patients with liver disease. In addition, the AASLD website (<http://www.aasld.org>) has evidence-based guidelines for liver diseases such as chronic hepatitis B, chronic hepatitis C, AIH, and PBC.

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Sexually Transmitted Disease Surveillance: Summary Points from the Indian Health Service STD Surveillance Report, 2004

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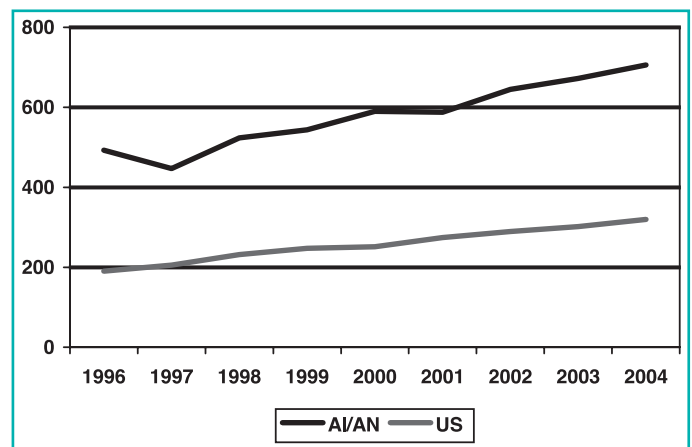
Introduction

Sexually transmitted diseases (STDs) impose a significant burden on the Indian Health Service (IHS) health care system and on American Indians and Alaska Native (AI/AN) people as a whole. AI/AN populations are one of the smallest racial groups in the US, representing between 0.9% - 1.5% of the population according to Census 2000, but are disproportionately affected by STDs. In 2004, among all races and ethnicities, AI/AN had the second highest rates of chlamydia, gonorrhea, and primary and secondary (P&S) syphilis. In 2004, reported case rates of chlamydia, gonorrhea, and primary and secondary syphilis among AI/AN were 2 to 6 times higher than comparable rates for whites. The publication of the Indian Health Surveillance Report on Sexually Transmitted Diseases (STD), 2004 represents the first report dedicated to the status of STD morbidity among AI/AN. This report summarizes key findings from the larger report that was produced as part of a collaborative effort between the Centers for Disease Control and Prevention (CDC) and IHS. Findings from this report are intended to increase awareness regarding the burden of STDs in AI/AN populations, which may lead to improvements in STD testing and clinical care, and increases in funding and research activities related to STD prevention and control in these communities.¹

Key Points and National Trends in STDs among AI/AN Chlamydia

- Chlamydia is the most common nationally notifiable disease in the US. Chlamydial infections disproportionately affect young women and are frequently asymptomatic. If untreated, chlamydial infections can result in serious complications, including pelvic inflammatory disease (PID), infertility, and ectopic pregnancy. Chlamydia can be transmitted from mother to child during delivery and can facilitate the transmission of HIV.
- In 2004, among all race/ethnicities, AI/AN had the second highest chlamydia rate (705.8 cases per 100,000 population), which was 4.9 times higher than the rate for whites (143.6 cases per 100,000 population). African-Americans had the highest chlamydia rate (1,209.4 cases per 100,000 population).
- In 2004, 16,741 of 929,462 chlamydial infections (1.8%) occurred among AI/AN. The AI/AN chlamydia rate increased by 5% during 2003 - 2004 (2003 rate: 672.2 cases per 100,000 population) (Figure 1).

Figure 1. Total Chlamydia Rates, AI/AN Non-Hispanic and US



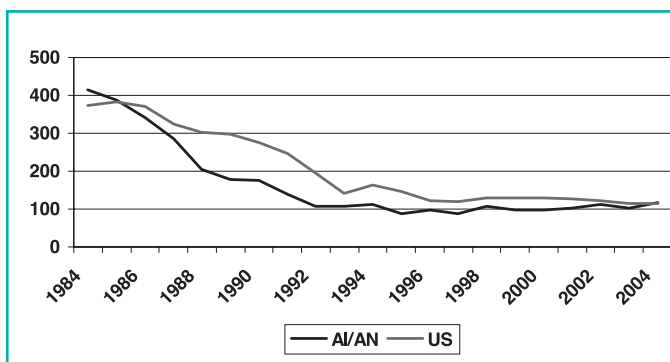
- In 2004, the chlamydia rate among AI/AN women in the US (1,127.8 cases per 100,000 females) was over 4 times higher than the rate among AI/AN men (270.9 cases per 100,000 males), likely reflecting a greater number of women screened for this infection. This rate ratio was similar to that population in the overall US.
- Among AI/AN women, the highest age-specific rates of reported chlamydia in 2004 were among 20- to 24-year olds (4,672.4 per 100,000 females) and 15- to 19-year olds (4,358.2 per 100,000 females). These two age groups also represented the highest age-specific rates among all women in the US.
- Age-specific rates among AI/AN men, while substantially lower than the rates in AI/AN women, were highest among 20- to 24-year-olds (1,144.6 cases per 100,000 males). This age group also had the highest rates among all men in the US (744.7 cases per 100,000 males)

- In 2004, the gonorrhea rate among AI/AN women in the US (155.3 cases per 100,000) females was 2.0 times higher than the rate among AI/AN men (79.0 cases per 100,000 males)
- Among AI/AN women, the highest age-specific rates of reported gonorrhea in 2004 were among 20- to 24-year olds (612.8 cases per 100,000 females) and 15- to 19-year olds (561.2 cases per 100,000 females). These two age groups also represented the highest age-specific rates among all women in the US.
- Age-specific rates among AI/AN men, while substantially lower than the rates in AI/AN women, were highest among 20- to 24-year olds (304.6 cases per 100,000 males). This age group also had the highest rates among all men in the US.

Gonorrhea

- Gonorrhea is the second most common nationally notifiable disease in the US and, like Chlamydia, is a major cause of PID, infertility, and ectopic pregnancy. Gonococcal infections may be transmitted from mother to infant during delivery and can facilitate the transmission of HIV.
- In 2004, among all race/ethnicities, AI/AN had the second highest gonorrhea rate (117.7 cases per 100,000 population), which was 3.5 times higher than the rate for whites (33.3 cases per 100,000 population). African-Americans had the highest gonorrhea rates (629.6 cases per 100,000 population)
- In 2004, 2,858 of 330,132 gonococcal infections (0.9%) reported to CDC from the 50 states and DC occurred among AI/AN. The AI/AN gonorrhea rate increased by 14.8% during 2003 - 2004 (2003 rate: 102.5 cases per 100,000 population). Comparatively, the total US gonorrhea rates decreased by 1.5% during 2004 (Figure 2).

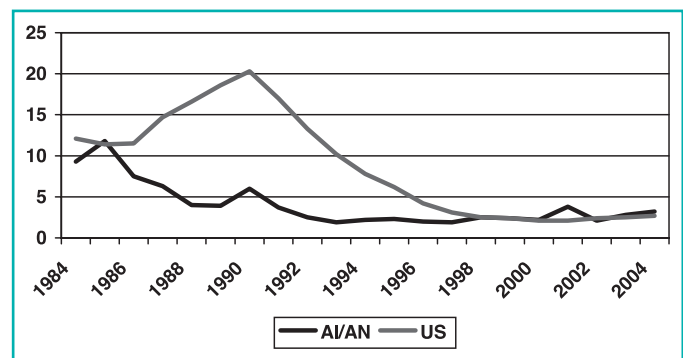
Figure 2. Total Gonorrhea Rates, AI/AN Non-Hispanic, US



Primary and Secondary Syphilis

- Syphilis, in its primary and secondary stages, is a highly infectious, but easily curable STD. If untreated, syphilis can lead to serious long-term complications including stroke, heart disease, and death. Syphilis can be transmitted from untreated mothers to their fetuses, potentially leading to stillbirths and serious congenital infection. Syphilis has been shown to facilitate the transmission of HIV two- to five-fold.
- In 2004, among all race/ethnicities, AI/AN (tied with Hispanics) had the second highest primary and secondary syphilis (P&S) rate (3.2 cases per 100,000 population), which was 2 times higher than the rate for whites (1.6 cases per 100,000 population). African-Americans had the highest P&S rate (9.0 cases per 100,000 population).
- In 2004, 77 of 7,980 P&S infections (1.0%) reported to CDC from the 50 states and DC occurred among AI/AN. The AI/AN P&S rate increased by 14.3% during 2003-2004 (2003: 2.8 per 100,000 population)

Figure 3. Total P&S Syphilis Rates, AI/AN Non-Hispanic, US



- In 2004, the male-to-female P&S rate ratio among AI/AN was 1.2, indicating a similar number of cases

being diagnosed among men and women. In contrast, for the total US the male-to-female P&S rate ratio has risen steadily since 1996, suggesting an increase in syphilis among men who have sex with men (MSM) during this time.

- In 2004, among AI/AN, age-specific P&S syphilis rates were highest among women aged 30 - 34 years (7.5 cases per 100,000 population) and among men aged 35 - 39 years (13.9 cases per 100,000 population). For the total US, the highest age-specific P&S rates were reported among women aged 20 - 24 years and among men aged 35 - 39 years.

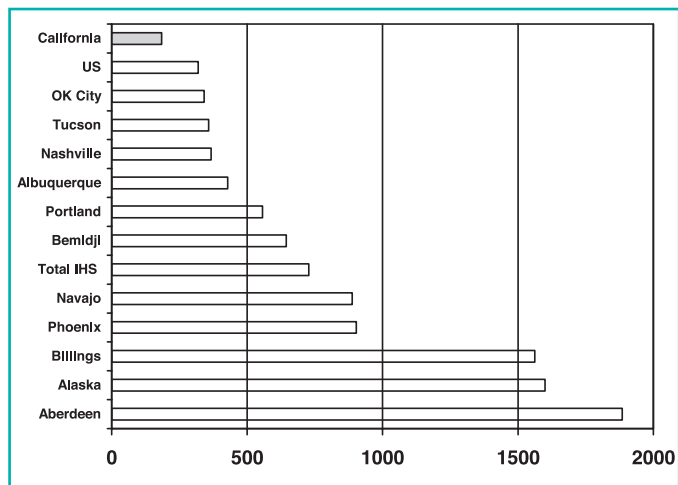
Summary of IHS Area STD Profiles

STD rates presented in the IHS STD profile section of the report include only STD cases that occurred among AI/AN residing in counties where IHS has responsibility.

Chlamydia. Among AI/AN residing in IHS service areas, the overall IHS chlamydia rate in 2004 was 727.8 cases per 100,000 population. This was 2.3 times higher than the corresponding US rate. Three IHS Areas, Aberdeen, Alaska, and Billings, had chlamydia rates 4.9 to 6 times higher than the US rate. Recent increases in reported cases and rates likely reflect the continued expansion of screening efforts and increased use of more sensitive diagnostic tests, rather than an actual increase in new infections.

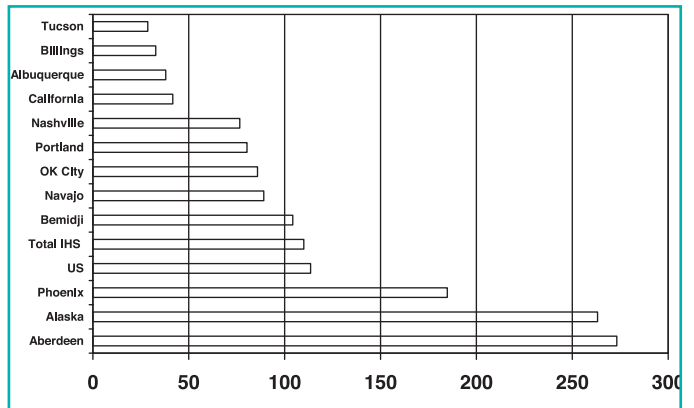
Compared to men, chlamydia rates are higher among women and reflect the fact that women are far more likely to be screened for this infection. Chlamydia rates among women are highest among those ages 15 - 24 years. In 2004, the overall IHS rate among women ages 15 - 24 was 4,363.7 cases per 100,000 population, which was 1.6 times higher than the corresponding US rate. Chlamydia rates among women 15 - 24 years ranged between 1,130.8 in the California Area to 10,599.3 cases per 100,000 population in the Aberdeen Area.

Figure 4: Chlamydia Rates by IHS Area, 2004

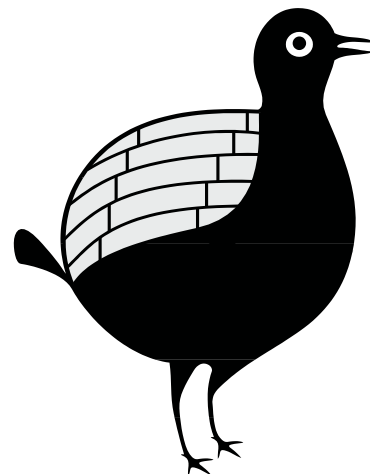


Gonorrhea. In 2004, the overall IHS and US gonorrhea rates were similar (110.0 and 113.5 cases per 100,000 population, respectively). Reported gonorrhea rates in 2004 for 3 IHS Areas, Aberdeen, Alaska, and Phoenix, were 1.6 to 2.4 times higher than the US rates. In 2004, Aberdeen had the highest gonorrhea rate (273.2 cases per 100,000 population). Four IHS Areas, Albuquerque, Billings, California, and Tucson, had gonorrhea rates < 50% of the US rate. For the overall IHS population in 2004, gonorrhea rates were higher for women (147.8 cases per 100,000 population) compared to men (72.4 cases per 100,000 population).

Figure 5. Gonorrhea Rates by IHS Area, 2004

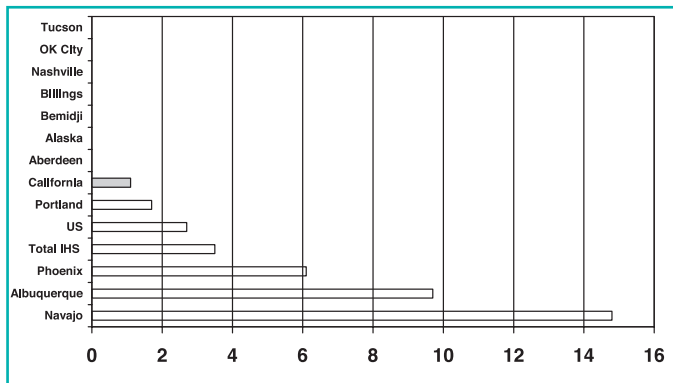


Primary and Secondary Syphilis. In 2004, 55 of 60 (92%) P&S cases diagnosed within the IHS service areas occurred in 3 IHS Areas in the southwest, Navajo, Phoenix, and Albuquerque. Seven of the IHS Areas had no P&S cases in 2004. IHS cases in the southwest have been increasing since 2001. During 2003 - 2004, among all IHS Areas, the greatest P&S rate increase occurred in the Albuquerque Area (94% increase from 5.0 to 9.7 cases per 100,000 population). The Navajo Area had the largest number of P&S cases diagnosed in 2004. For overall IHS cases in 2004, the P&S male-to-female rate ratio was 0.9, which indicates a similar number of P&S



cases occurring among AI/AN men and women. These data suggest different patterns of transmission for syphilis among AI/AN compared to the general US population, which is experiencing syphilis outbreaks among men who have sex with men (MSM) (Figure 6).

Figure 6: P&S Syphilis Rates by IHS Area, 2004



High STD Rates: Implications for AI/AN Communities

High rates of STDs in AI/AN communities are of public health concern for many reasons. These diseases mainly affect youth and are an indicator of unsafe sexual practices that can also lead to unintended pregnancy and HIV infection. Adolescents are at higher risk for STDs due to biological predisposition, participation in unprotected intercourse, engagement in multiple sexual partnerships of limited duration, and obstacles in seeking health care. High STD rates can also be indicators of limited knowledge; unclear perception of risk; and lack of, inconsistent, or incorrect use of prevention methods, such as condoms. These challenges support the need for efforts to improve awareness regarding this health disparity, to increase access to STD testing, counseling, and vaccination (e.g., Hepatitis B and HPV) and to encourage safer sex practices, including condom use, among populations at risk within AI/AN communities.

Clinical Recommendations for STD Testing and Treatment

The CDC has recently published new guidelines for STD treatment.² These guidelines include recommendations for STD testing in populations at risk as well guidance regarding prevention and control of STDs. Providers are encouraged to keep this reference readily available for use in choosing appropriate STD treatment regimens, complying with nationally recommended screening practices, and for use in counseling patients regarding safer sex behaviors. These guidelines can be viewed and downloaded from the CDC website at <http://www.cdc.gov/std/treatment/>.

The IHS STD Surveillance Report, 2004 is available electronically at <http://www.cdc.gov/std/stats-ihc-2004/IHS-STD-Report-2004.pdf>. For a hard copy of this publication or for additional information on implementing STD prevention and control activities in Indian Country, contact Scott Tulloch, Program Manager, IHS National STD Program, telephone (505) 248-4344; e-mail scott.tulloch@ihc.gov.

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Implementing the Revised IHS Strategic Plan: A Clinician's View

Chuck North, MD, MS, Acting Chief Medical Officer, Indian Health Service, Rockville, Maryland

Introduction

The Indian Health Service (IHS) has been widely recognized as a successful health care delivery system for the first 52 years of its existence. As we contemplate future years of serving American Indian and Alaska Native (AI/AN) people, I find myself reflecting about where we have come from, where we need to be headed, and what strategies can best support our increasingly diverse organization's journey into the future.

During my 30 year career I have served the IHS in the local role of a family physician, service unit director, and clinical director. I have also had the privilege of serving as Chief Clinical Consultant for Family Medicine and visiting more than 30 IHS sites. This has allowed me to meet direct patient and community needs while thinking about serving AI/AN people more globally. I now find myself acting in a full time, national leadership role, which provides the luxury of visiting and listening to IHS and tribal leaders in the entire Indian health system and from our national and global partners in public health practice.

In the past year I had the honor and privilege of serving on the Strategic Planning Workgroup that revised and updated the very first IHS Strategic Plan that was drafted in 2002. This workgroup represented one of the most diverse teams I have ever served with, bringing together expertise in clinical care, public health, epidemiology, health care administration, health care financing, community development, tribal sovereignty, education, environmental health, engineering, planning, and facilities construction. But despite the diversity of this team and the inevitable struggles involved in reconciling differing opinions and strategies for realizing the IHS mission, a significantly new and different plan emerged, with a high level of concordance within the workgroup, such that it was on target to take the IHS to a new level. I didn't realize at the time how useful this process and product would be in my role as an advocate for national excellence system wide.

I believe our revised plan represents far more than a bureaucratic exercise to update the original. It reflects the lessons learned in implementing the initial plan, as well as the emerging realities of today's social and political environment. The revised plan was completed in less than a year by busy professionals with full time jobs. None of us doing the writing were freed up in any significant way from normal work

responsibilities. We did it with only an initial two-day face-to-face meeting, followed by monthly conference calls and the electronic sharing of draft sections. Because I somewhat naively volunteered to serve as lead in writing one of the four sections (Strategic Goal 2: Provide Accessible, Quality Health Care) and assisted with another (Introduction) it became my weekend hobby. It also allowed me to clarify the values of our organization and reflect on what activities have truly added efficiency to our system of care. Looking at the new Plan, I believe it was worth the effort, because what we developed can provide everyone in the Indian health system, whether federal IHS, tribal, or urban, a working agenda to continue progress in accomplishing our mission.

Thus I would like to encourage readers of *The Provider* to secure a copy of this document and read it in its entirety. Beautiful, hard copy booklets are widely available, and the whole report is on the IHS website. You may even find yourself in one of the many photos of our employees and communities. Area Offices and local units may want to use parts of the plan to develop a more focused, local strategic plan and for accreditation and improvement purposes. Let us take a glimpse of this plan's critical elements. I would like to briefly provide an outline and some personal comments that may be relevant to *Provider* readers.

Strategic Outlook and Planning Challenges

The revised IHS Strategic Plan for 2006 - 2011 began with a systematic assessment of the health care environment in which the IHS now functions and revealed a sobering reality reflected in the four critical planning challenges that underpin the development of this plan. They are:

1. Health care costs and the gap between disparities in health status and funding for AI/ANs will be difficult to address with historical approaches and anticipated appropriations.
2. The Indian health system must be able to assure an adequate workforce.
3. The Indian health system must expand and enhance its performance-based culture.
4. The development and implementation of innovative models of health care delivery must be expanded.

There is an alignment of national goals to decrease health disparities and local clinician goals to close the gap we see daily in health status and resources for medical care in our local

hospitals and clinics. I feel strongly that we can improve our effectiveness, efficiency, and quality of care by facing these challenges and redesigning our care system to meet them. We may need to work harder to meet some of them, but they all require thinking smarter and incorporating innovations into our system.

The plan addresses three broad strategic goals that begin with an “outcome vision” of how long term success would look and objectives for what elements are essential for realizing the outcome vision. Each of these objectives is supported by brief discussions of the purpose and desired outcome of the objective, followed by the strategies for accomplishing them. With this structure in mind, I would like to highlight each of the three strategic goals, which are summarized very well in the introduction to the plan.

Strategic Goal 1. Build and Sustain Healthy Communities

Outcome Vision: By 2011, AI/AN communities will experience improved health status and well-being through adopting healthy lifestyles as a result of:

1. a functional, community-based public health infrastructure to monitor and address public health issues such as injury prevention, suicide surveillance, environmental surveillance, or other local priorities
2. a sustained and active wellness program; and
3. an organized emergency preparedness management program, with improved access to community and behavioral health information, to make informed decisions by all the stakeholders.

Objective 1.1: Mobilize and involve AI/AN communities to promote wellness and healing.

Objective 1.2: Develop public health infrastructure with tribes to sustain and support AI/AN communities.

Objective 1.3: Assist tribes and AI/AN communities in identifying and resolving community problems by improving access to information.

Objective 1.4: Strengthen emergency management in AI/AN communities.

This strategic goal recognizes the critical importance of using improved public health support to empower communities by embracing wellness and healing more proactively. We simply must reduce the burden of preventable diseases and conditions that are causing suffering, dysfunction, and pain. By participating in community-based programs, clinicians can extend their influence outside of the medical visit and reach a larger audience. In this spirit, the strategic plan embraces the concept of community-oriented primary care as an essential part of improving community health through empowerment. This model is based on a proactive, collaborative approach between the local health care system and the community that includes four critical processes:

1. Defining and characterizing the community

2. Identifying community health problems
3. Developing emphasis areas by planning/modifying the health program
4. Monitoring the effectiveness of the program modifications

Accomplishing these clearly places heavy demand for converting community-specific health data into understandable health information and allowing the community the opportunity to wrestle with these challenges. To do this requires the local data, knowledge, educational skills, and patience. It also requires the community trusting you for health information and inviting you to participate in raising the health status of the public.

You can probably all name several examples of clinician involvement in community efforts to immunize children and adults, especially as new vaccines are introduced and before flu season. Through the efforts of multidisciplinary teams of health professionals, we have raised breast feeding levels, decreased smoking rates, increased screening for breast and cervical cancer, and educated the public about diabetes.

Through our ongoing efforts to increase automobile safety and prepare for pandemic influenza, clinicians can partner with environmental health professionals. This partnership can be very helpful when new diseases emerge in our communities, such as the Hantavirus Pulmonary Syndrome. The cooperation exhibited during the emergence of this virulent new infection was a textbook case of community-oriented primary care serving as an effective tool to prevent disease.

Strategic Goal 2. Provide Accessible, Quality Health Care

Outcome Vision: By 2011, the IHS service population will have experienced improved quality, acceptability, and access to health care through continuous consumer feedback and participation in health care planning and improved efficiency in service delivery and maximizing of alternative resources:

1. in facilities with sufficient physical capacity
2. staffed with an adequate supply of adequately trained and culturally competent providers to address the needs of the AI/AN people
3. improved clinical measures from quality clinical data obtained from the Electronic Health Record and other improved information systems
4. all resulting in reduced health disparities for American Indians and Alaska Natives.

Objective 2.1: Provide accurate and timely clinical data on the health of American Indians and Alaska Natives.

Objective 2.2: Support the delivery of quality health care by maximizing alternative resources.

Objective 2.3: Expand and maintain an adequate workforce.

Objective 2.4: Provide comprehensive and effective primary health care services.

Objective 2.5: Improve the safety and quality of health care.

Objective 2.6: Provide quality health information for decision making to patients, providers, and communities through improved information systems.

The overarching theme in this section can be summarized by saying that we need to become an organization that values the culture of quality in all that we do so that we can reduce the indefensible health disparities that are the norm in our communities. Our health care delivery at the most basic level needs to be designed so that patients, families, and communities have ready access to the highest quality, culturally competent professionals. Many of our clinics and hospitals would benefit from formal redesign efforts to meet these goals.

The plan promotes the integration of behavior health services into primary care clinics to rapidly address issues of substance abuse, mental health problems, social problems, and adverse childhood experiences. We advocate the use of linked and searchable electronic health records, use of the chronic care model, group visits, and innovative ways of communicating with patients such as web-based teaching and electronic mail.

We recognize the need to support and develop health care professionals by expanding relationships with colleges and universities that will train our workforce in the future. We support mentoring programs for junior staff and development of executive health care leaders through formal career development programs. We are working on national guidelines for financial support of continuing health professional education necessary for licensure and continued cultural competences.

As the baby boomer generation continues to age and retire, there will be a gap in the professional workforce that makes it increasingly important to recruit replacement professionals and to retain our junior workforce.

Strategic Goal 3. Foster Collaboration and Innovation across the Indian Health Network

Outcome Vision: By 2011, the Indian health network will have emerged as a well coordinated and increasingly synergistic coalition that is significantly contributing to the realization of the IHS Mission and Goal through:

1. the coordinated sharing of information, pooling of resources, and development of new organizational structures
2. the development, evaluation, and diffusion of effective health care innovations
3. successful Indian health advocacy, culminating with the reauthorization and funding of the Indian Health Care Improvement Act.

Objective 3.1: Expand coalitions and partnerships to build a dynamic Indian health network.

Objective 3.2: Develop new structures within the Indian health network to increase collaboration and innovation to improve and advocate for the health care of the AI/AN population.

This strategic goal acknowledges that it is critical that we develop new technologies, alternative resources, and a network that helps provide them and share them if we are to continue improving the health status of AI/AN people. It is about expanding coalitions and partnerships that support the Indian health system, nurturing and supporting innovations, and having the communication network in place to share best practices across the system.

The future of Indian health will come from innovations being used today and partnerships with external organizations that breathe new life into our system. We have robust relationships with other federal agencies that provide us funding for technology development, research, and direct patient care. In many cases tribes and AI/AN corporations have had more flexibility to innovate and leverage resources. The federal side of our system may be able to benefit from these models, which will improve the system for the future.

I urge you to read this short chapter and dream about future collaborations and innovations that you would like to see at your work unit. Your dreams may become the reality that improves access to care and the effectiveness of our interventions, and elevates the health status of your community to new heights.

Conclusions

An organization that fails to implement a strategy for improvement will be mediocre in the future. An organization that utilizes all of its resources to support innovation and collaboration, and celebrates its success has a very bright future. We have an organization with a very clear mission and a very well defined process to carry out that mission. We are recognized nationally and internationally as a rare example of an integrated health care system that joins provision of direct medical care and public health with a maximum amount of community involvement. I am as excited about the values we profess and the system we operate as I was 33 years ago when I had my first IHS experience. We have many challenges to meet in the future, from aging facilities to a rising tide of chronic disease. We will meet these challenges more completely and successfully if we take the time to read and study the Strategic Plan 2006 - 2011 and make it a reality.

Eight Years of Infant Mortality Reviews in the Aberdeen Area of the Indian Health Service

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Abstract

Objective. To present outcomes from eight years of reviews of consecutive infant deaths in the Aberdeen Area of the Indian Health Service (AAIHS) from 1998 to 2005 and to identify risk factor for infant mortality.

Methods. The Aberdeen Area Perinatal Infant Mortality Review Committee (PIMR) has completed the standardized review of 233 infant deaths in the AAIHS from 1998 to 2005. Summary data for the cohort were examined and then compared by mortality category and three age-at-death groups.

Results. Sudden infant death syndrome accounted for 28% of all infant deaths in the AAIHS. Prematurity was the second most prevalent cause-specific mortality category, accounting for 24% of all infant deaths. Regarding the mothers of infants included in the infant mortality reviews described in this paper, 38% had experienced a previous infant death. A late start of prenatal care and decreased number of visits was evident in many of the deaths. No significant daily or seasonal pattern was found to the deaths.

Conclusions. The PIMR has a need for an expanded data set including data on substance use, mental health needs, and systematic reviews of all fetal deaths after 20 weeks of gestation. Without knowing more about the mothers and their behaviors during pregnancy and post partum, the number of deaths cannot be reduced, or interventions developed.

Background

Infant mortality rates (IMR) are increased in Native Americans compared to the US All Races rates.¹ The Aberdeen Area adjusted IMR of 12.5 is increased by 74% compared to the US All Races rate and increased by 40% compared to the All IHS rate.² Rates of IMR also vary widely by age of infant death.^{3,4} Deaths before the 28th day of life (neonatal mortality) are often related to factors occurring during pregnancy, labor, and delivery. In the AAIHS from 1996 to 1998, the neonatal mortality rate was 5.6, higher than the US All Races rate of 4.8 and the All IHS rate of 4.4.² A second widely used category of

IMR is the post-neonatal mortality rate (deaths from the 28th day of life to one year of age). In the AAIHS the post neonatal mortality rate was 6.9, an increase of 176 % compared to the US All Races rate, and an increase of 57% compared to the All IHS rate.² Many of the increased rates of post-neonatal mortality are due to increased rates of sudden infant death syndrome (SIDS).⁵ The SIDS rate in the AAIHS is 27.6 per 1,000 live births, a rate increased by 158% compared to the US All Races rate, and by 52% when compared to the All IHS SIDS rate.²

In a previous publication we have discussed the development of the AAIHS PIMR as a response to a decade of increased rates of infant mortality in the AAIHS.⁵ In this paper we expand our discussion of the results of PIMR reviews for 233 consecutive infant deaths in the AAIHS.

Methods

The detailed methodology of the identification of Indian infant deaths leading to PIMR review and the incremental strategy of collection of state death certificates and the local service unit review process have been described previously.⁵ Briefly, the goal is to review every infant death in the AAIHS utilizing a systematic review process as a strategy to increase the standardization of the process and the resulting data. Race is determined by birth certificate data or if one or both of the parents are enrolled members of a tribal nation. The AAIHS includes four states (North Dakota, South Dakota, Nebraska, and Iowa) and nineteen tribal nations. A notification of each Indian infant death is first sent to the local IHS service unit for a local review. This is an important step in completing the medical records and for obtaining local input that can be very helpful in understanding the complex psychosocial issues that may be related to the infant death. The results are then forwarded to the PIMR for review. If the birth or death certificates or autopsy report have not been attached to the file, they are added whenever they become available.

In this paper, we present the results of PIMR reviews of 233 consecutive infant deaths from 1998 to 2005. Eligibility included infants born to at least one Indian parent in a live birth with a weight over 500 grams. The deaths reported in EagleStaff et al. are also included in this cohort.⁵ For convenience and to facilitate analysis, the deaths were grouped into three categories of approximately equal size: 1) Prematurity, 2) SIDS, and 3) Other. The Other category is a combination group of deaths from causes other than SIDS or

prematurity (e.g., congenital anomalies, homicide, or infection). None of the individual mortality categories in the Other mortality category were large enough to be used as a unique comparison group individually. We examined the summary data for the total group and then compared the mortality groups and the three age-at-death groups. We used Chi-Square and one-way analyses of variance in the analysis. This project was approved by the University of North Dakota Institutional Review Board.

Results

Table 1 presents summary data of study variables for the 233 infant deaths. Mortality recurrence was common. We found that over one-third of the infants (38%) had a previous sibling death. Nearly two-thirds (62%) of the deaths were males (ratio 1.7 to 1), with a nearly equal distribution of excess

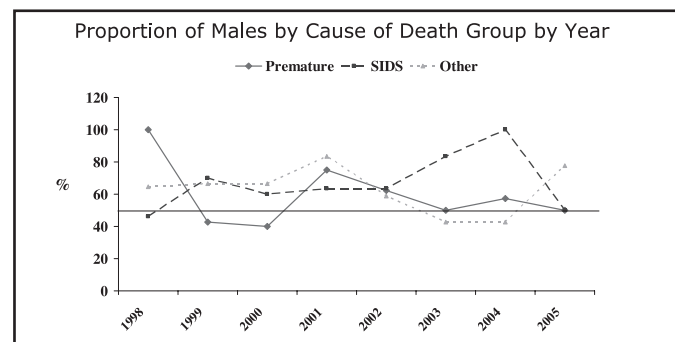
Table 1. Demographic data for 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service

	n	(%)	n	Mean	S.D.
Year					
1998	39	(16.74)			
1999	26	(11.16)			
2000	29	(12.45)			
2001	33	(14.16)			
2002	36	(15.45)			
2003	30	(12.88)			
2004	23	(9.87)			
2005	17	(7.30)			
Gender					
Female	87	(37.66)			
Male	144	(62.34)			
Birth weight			217	2,264.00	1,295.00
Gestation			218	33.07	6.80
Trimester Prenatal Care Began					
First	146	(66.97)			
Second	52	(23.85)			
Third	20	(9.17)			
Number of Prenatal Visits			218	6.47	
4.56					
Mothers Age			226	24.34	5.48
Parity			224	2.08	2.11
Previous Deaths					
None	139	(62.33)			
One	54	(24.22)			
Two	20	(8.97)			
Three	8	(3.59)			
Four	2	(0.90)			
Age at Death in Days					
1 to 21	88	(47.31)	186	64.55	83.79
22 to 90	43	(23.12)			
91 to 365	55	(29.57)			

Cause of Death		
Premature	57	(24.46)
SIDS	65	(27.90)
Other	111	(47.64)
Day of Death		
Sunday	34	(17.62)
Monday	24	(12.24)
Tuesday	39	(20.21)
Wednesday	19	(9.84)
Thursday	26	(13.47)
Friday	20	(10.36)
Saturday	31	(16.06)
Month of Death		
January	18	(9.33)
February	15	(7.27)
March	15	(7.77)
April	15	(7.77)
May	10	(5.18)
June	10	(5.15)
July	19	(9.84)
August	19	(9.84)
September	17	(8.81)
October	19	(9.84)
November	11	(5.70)
December	25	(12.95)
Birth Certificate	193	(82.83)
Death Certificate	210	(90.13)
Local IMR Done	150	(64.38)
Area IMR Done	194	(83.26)
Autopsy	70	(30.04)
Death Scene Invest	27	(11.59)
Recommendations	221	(94.85)

male deaths across the three cause of death categories (Figure 1). The mean birth weight was 2,264 grams, and the mean gestation period was 33 weeks. Sixty-seven percent of the mothers began prenatal care in the first trimester and the mean

Figure 1. Proportion of male deaths (62%) (n= 144) by year and cause of death category for 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service for the years 1996 to 2005. For two deaths gender was not available



number of prenatal visits was 6.5. At death the mean age of the infant was 65 days and the mean maternal age was 24 years. In this sample 41% of the deaths occurred within the first three weeks of life.

Birth certificates were located for 83% of the infants and death certificates were obtained for 90% of the infants. Local death reviews were completed for 64%, autopsies for 30%, and death scene investigations were completed for 12% of the cases. The PIMR attributed 24% of the deaths to prematurity and 28% to SIDS. Wednesday and Friday were the days of the week with the lowest prevalence of deaths (10% each), while Tuesdays had the highest prevalence at 20% (Table 1). We did not find a season effect. The months with the lowest proportion of deaths were June (5.1%), May (5.2%) and November (5.7%). The months with the highest proportion of deaths were December (12.9%), August, July, and October (each 9.8%). We examined the data for effects from day of the week, proportion of deaths on weekends, month of the year, or season of death by age at death. We did not find evidence of any significant effects for these time periods. This was a concern due to the extremely rural area of the AAIHS. We were also concerned about access to care on weekends or holidays.

With the PIMR meeting annually and the possibility of 18 - 24 months passing before both a birth and death certificate can be received for each infant, obtaining comparably full data sets in years 2004 and 2005 was difficult.

Group Comparisons by Cause of Death

When comparisons were made by mortality category, infants who died from prematurity had significantly ($p < 0.001$): lower birth weights (674 grams), shorter gestation (23.8 weeks), and younger age at death (5.9 days) than the SIDS or other mortality categories (Table 2). In figure 2 we present the

Figure 2. Rates of low birth weight (< 2500 grams) by cause of death category in 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service for the years 1996 to 2005 (Chi-Square = 91.80, $p < .001$)

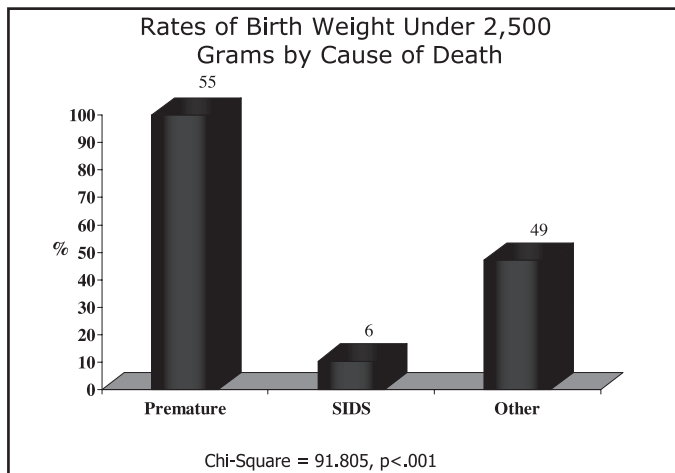


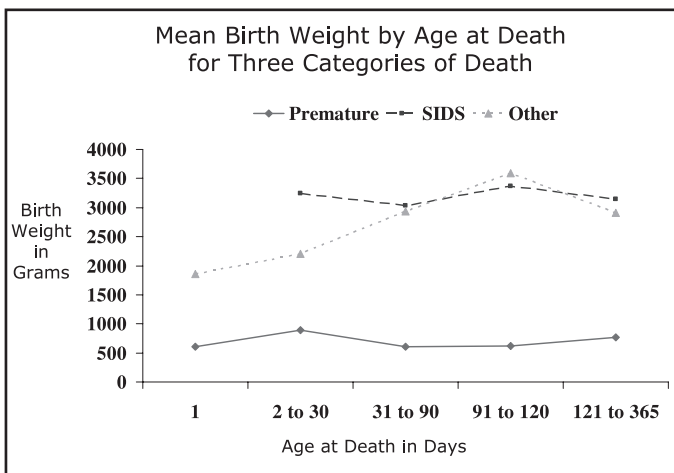
Table 2. Descriptive data for deaths after a live birth comparing cause of death

	n	Mean	StD	Min	Max	p
Birth Weight						
Premature + &	55	674.36	368.23	113	1,950	<.001
SIDS * &	58	3,190.55	651.57	1,021	4,309	
Other * +	104	2,588.35	1,126.97	369	4,928	
Gestation						
Premature + &	54	23.78	3.12	17	34	<.001
SIDS * &	60	37.97	2.23	27	42	
Other * +	104	35.07	5.12	21	42	
Number of Prenatal Visits						
Premature + &	56	3.54	2.52	0	10	<.001
SIDS *	60	8.03	4.76	0	20	
Other *	102	7.16	4.61	0	20	
Mother's Age						
Premature	57	24.23	5.06	17	36	.344
SIDS	61	23.56	5.71	15	43	
Other	108	24.83	5.55	14	39	
Previous Births						
Premature	57	2.16	2.08	0	9	.775
SIDS	59	2.20	2.38	0	12	
Other	108	1.98	1.98	0	11	
Age at Death						
Premature + &	46	5.91	17.63	1	117	<.001
SIDS *	49	93.90	69.77	13	348	
Other *	91	78.40	96.23	1	338	

* different from prematurity
+ different from SIDS
& different from other

number of infants with low birth weight (< 2,500 grams) for each of the three mortality categories. In figure 3 the trend lines mean birth weights over the eight year period are

Figure 3. Birth weight (grams) by the three causes of death categories for 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service for the years 1996 to 2005



presented by cause of death category. The mothers of infants dying from prematurity had significantly fewer (3.5) prenatal visits ($p < 0.001$) (Figure 4). The mothers of infants who died of SIDS were more likely to begin prenatal care after the first trimester ($p < 0.001$) (Figure 5) and were less likely to have had a previous death of a live birth (Figure 6). Autopsies were more likely to be completed in the SIDS (68%) versus Prematurity group (7%) or the mortality category of Other (30%) ($p < 0.001$). Death scene investigations were much more common in the SIDS group (52%) than in either the Prematurity (0%) or Other (9%) category ($p < 0.001$). The proportion of deaths attributed to SIDS appears to have declined since 2002 (Figure 7).

Figure 4. Number of prenatal visits by cause of death category for 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service from 1996 to 2005. Mean number of visits was 6.5 (sd 4.6 visits)

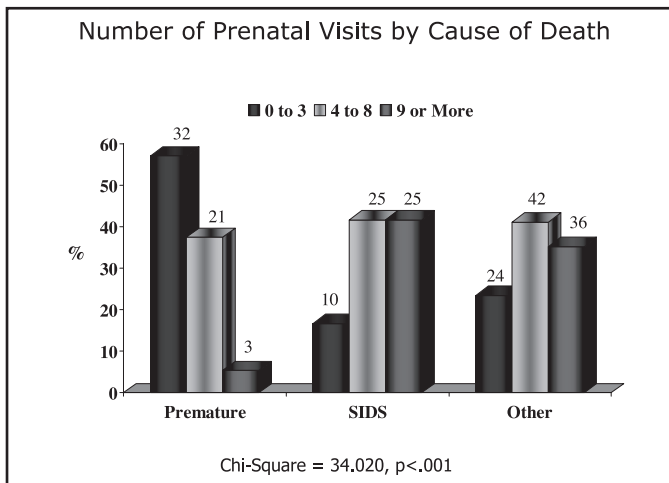
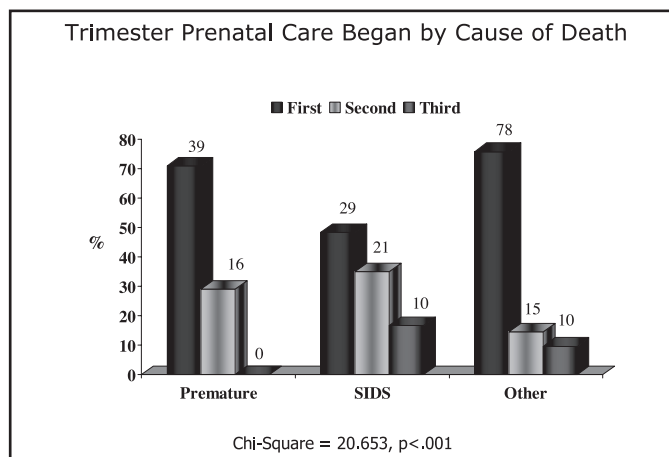


Figure 5. Trimester prenatal care was begun for 233 Indian infant deaths in the Aberdeen Area of the Indian Health Service from 1996 to 2005. Care started in first trimester for 66.9% of mothers, second trimester 23.8% of mothers, and third trimester for 9% of mothers



Group Comparisons by Age-At-Death

In table 3 we present comparisons of the means and ranges for the study variables by age-at-death category for the deaths. For infants dying in the first 21 days of life, birth weights of 1,336 grams were significantly lower and gestation significantly shorter by 28.2 weeks ($p < .001$). The mothers of these infants also had significantly fewer (5.3) prenatal visits ($p < 0.001$). We then examined the study variables for the three age-at-death categories. Only two variables were significant in this analysis. We found that autopsies ($p < 0.001$) and death scene investigations ($P < .001$) were more likely to be completed for older infants.

Discussion

In this paper we present data on eight consecutive years of infant death reviews from the AAIHS. In the AAIHS, infant

Figure 6. Prevalence of previous infant or child deaths born to mothers of the current infant death by cause of death category for 233 consecutive Indian infant deaths in the Aberdeen Area of the Indian Health Service for the years 1996 to 2005 (Chi-Square = 8.62, $p = .071$)

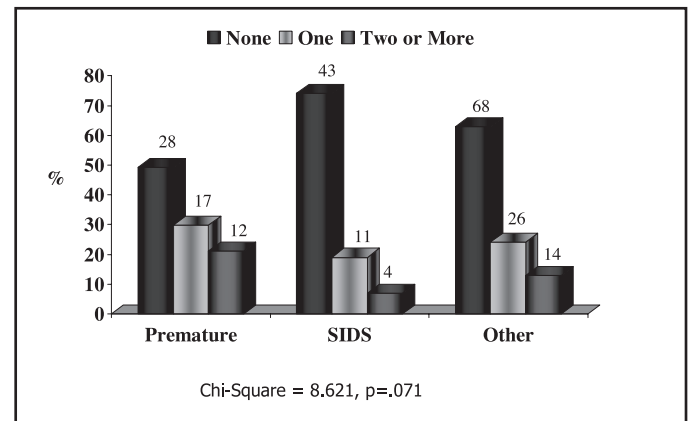
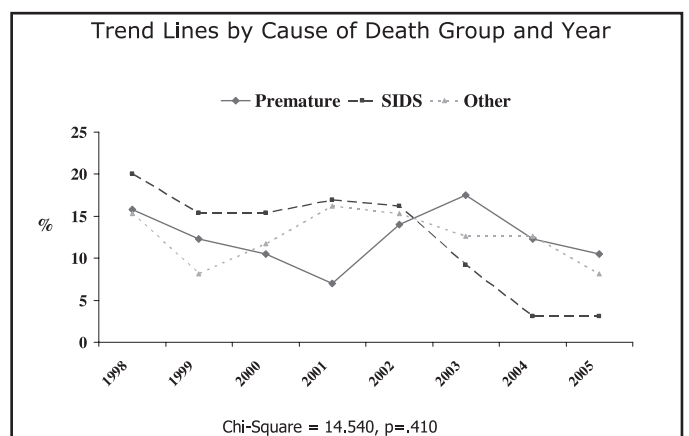


Figure 7. Trend lines for cause of death by year for 233 Indian Infant deaths for the years 1996 to 2005 in the Aberdeen Area of the Indian Health Service (Chi-Square = 14.50, $p = .410$)





mortality is a recurrent event with, 38% of the mothers having had a previous infant or child death before the death of this current infant. Thus, mortality prevention should begin with a careful investigation of the mother's previous history. The data from this study (young maternal age, late start of prenatal care, low number of prenatal visits) indicate that resource allocation for additional surveillance and enhanced prenatal care should be discussed with these women multiple times, including inter-pregnancy intervals. Given the increased mortality rates, service units and the AAIHS would benefit from specialized training on identification and management of mortality risk indicators. Service units and specialty care referral centers should be involved in this training. Development of local and AAIHS teams to increase the number of prenatal visits, rate of home visiting, and assessment of barriers to access to care would be important topics for this training. Increased surveillance of smoking, alcohol and other substance abuse, domestic violence, and social support are additional specific goals that could be monitored. Individualized prenatal plans to manage these problems should be charted. This may include case conferences with home visiting programs (Healthy Start, public health nursing). In a previous study of the same population, home visiting by a nurse was associated with reduced risk for death from SIDS.⁶ Regular case reviews of high risk pregnancies may be an intervention worthy of further discussion.

Nationally, the leading cause of death in Indian infants is congenital anomalies, followed by SIDS and prematurity. In

this sample, SIDS was the leading cause of death followed by prematurity.⁷⁻⁹

Since much of the AAIHS is remote and access to care due to clinic schedules may result in an access problem, we examined day of death as a potential measure of this concern. We did not find a trend for increased mortality by day of the week or month that was statistically significant. This is a reassuring finding.

Prematurity is a major problem in the AAIHS where 25% of the infant deaths resulted from prematurity. Improved strategies for risk factor surveillance may be beneficial and this would almost certainly require development of strategies to include non-IHS providers, since many women obtain prenatal care at non-IHS sites or present for delivery at these sites. This issue is further compounded by the very rural nature of the IHS sites and the non-IHS providers. Development of cooperative training efforts with the four state health departments, medical and nursing colleges and state medical and nursing associations may be a useful consideration. This training should also emphasize inclusion of midwives, physician assistants and nurse practitioners.

Substance abuse services, mental health services and smoking reduction programs urgently need improvement. This is a current priority in the AAIHS and should be continued. The lack of systematic data on substance use and mental health in the charts for many of these deaths is a barrier to improved understanding of the role of these important risk factors that have been identified in previous studies as potential causal factors.⁶ Current data collection systems do not adequately examine dose of smoking or alcohol, and this limits the value of these data. Improved methods developed in this area are available and should be considered for inclusion in routine prenatal assessment in the AAIHS.¹⁰ This may allow earlier identification of alcohol use as a problem requiring intensive or inpatient treatment. Currently, additional resources in this area are limited, and additional referrals may result in the need for increased treatment capacity.

Limitations

The data presented here have been difficult to obtain. The birth and death certificates must be obtained from four different states, each with unique issues about data sharing. The local reviews involve multiple IHS facilities and 19 tribal nations. The autopsies are completed in more than eight locations. We are unable to estimate how our classification of deaths by the PIMR may influence these findings. The effect of the classification of death by the PIMR would likely be most important for SIDS, since this is the mortality category with the most problematic criteria to apply in the context of an infant death. The data presented here should be useful in the development of specific priorities for reductions in infant mortality in the AAIHS. However, the data from the PIMR does have several limitations which require discussion. Firstly, data on SIDS is strongly influenced by the rigid criteria for

classification, and it is likely that these estimates represent only a proportion of actual deaths from SIDS in the AAIHS. Application of the current criteria for SIDS in this setting is problematic, e.g., the prevalence of previous deaths in the AAIHS is very high, and excluding SIDS as a diagnosis based on this history may serve to underestimate the number of actual SIDS cases. The number of death scene investigations is also very low, and an ongoing effort to improve this has occurred and needs to be continued. The identification of these issues and developing a systematic plan to address them has been successful in the past for the PIMR. In the early years of the PIMR the lack of completed autopsies was a major barrier for the PIMR. After identification of this problem the PIMR made completion of autopsies for unexpected deaths a priority, and the number of autopsies rose rapidly. While an occasional case of expected death does not have an autopsy, this is now a rather uncommon problem. A current issue now is the lack of death scene investigation, and this is one of the issues that could be addressed in the future by the PIMR.

Outcomes from the PIMR

The PIMR made recommendations for changes in care for 97% of the deaths, which fell into three broad categories. The first were routine recommendations for grief counseling for parents, families, and daycare providers where a death occurred. The second was a recommendation for enhanced and early prenatal care, especially for women who had an infant death from prematurity or a previous death. The third was a recommendation for genetic consultation after the birth of a



child with congenital malformations.

One of the goals of the PIMR was to improve the database available to examine risk and causal factors for SIDS and to examine the process of classification of infant deaths, especially for SIDS. In this task the AAIHS PIMR has made important improvements as demonstrated in this article. The AAIHS has made improvements in the numbers of deaths investigated, the number of infants with autopsies, and the number of death scene investigations. This effort has been gradual, in part due to the geography of the AAIHS, where infant deaths may occur 100 miles from a health care facility with expertise in infant mortality or pediatric services. The majority of the 19 tribal nations in the AAIHS are in rural or frontier settings. The autopsies are often completed 200 or 300 miles from the site of the death. Severe winter weather is a very important factor for at least five months of the year in the AAIHS.

The PIMR has several unique strengths that have evolved over the years. These include contact with the law enforcement agencies listed above, the involvement of local IHS service units, and ongoing contact with the multiple tribal nations and regional referral centers where some deaths occur. The 19 individual tribal nations represent different cultures with widely differing belief systems about infant deaths. The committee works diligently to respect these beliefs. The PIMR also works to connect parents, child care personnel, and others, with grief support services. This has been one of the important accomplishments of the PIMR and the cooperating agencies.

Increased attention to population studies examining specific child care practices may also be useful in the identification of variables for risk reduction models.¹¹⁻¹³ Several strategies for improved risk factor education have been examined in the AAIHS, and the programmatic value of these efforts should be considered as a potential strategy for mortality risk reduction.

As this paper and the previous publication from the AAIHS PIMR have demonstrated, the data from this process improve as the number of cases reviewed increases. Case control studies using linked existing data sets may also be a useful and inexpensive next step to improve the identification of risk factors and the magnitude of risk from these factors.

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The authors acknowledge and appreciate the work and assistance of the many members of the Aberdeen Area Perinatal and Infant Mortality Review Committee, whose efforts over many years have made this work possible. They also acknowledge the support of the AAIHS, and the state and local agencies who have collaborated with the PIMR over the many years of work on this problem. They appreciate the participation and support of the National Institute of Child Health and Development and the Centers for Disease Control and Prevention.

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Open Door Forums: A National Discussion Platform to Foster Integration Efforts of the Director's Health Initiatives

On October 25, 2006, the first Open Door Forum took place, and Dr. Grim was an active participant as he emphasized the importance and potential to make a substantial difference in health care by increasing the integration of chronic care, health promotion/disease prevention and behavioral health efforts. These quarterly Open Door Forums provide opportunities for direct communication on topics of critical importance for all Indian health system staff. The Open Door Forum workgroup uses the forum calls to share the latest information about the Director's Initiatives, to describe information about the excellent integration work being done in all of the IHS Areas, and to answer questions from the participants.

Following Dr. Grim's opening comments, the three leads from the chronic care, health promotion/disease prevention and behavioral health initiatives provided summaries of integration activities to date. At the end of the three presentations by Dr. Ty Reidhead, Alberta Becenti, and Gary Quinn, questions from the participants were fielded by program staff, HQ staff, and service providers from the field. If you missed this kickoff event, you can view the transcript at the Director's Three Health Initiatives website which can be found at www.ihs.gov/NonMedicalPrograms/DirInitiatives/index.cfm.

The second Open Door Forum was held on January 25, 2007, and three IHS Areas, Albuquerque, Nashville, and Tucson co-hosted this forum. This was the first time callers heard integration activities directly from the IHS Areas. As he did on the first Open Door Forum, Dr. Grim summarized the current activities at the national level.

The first presenter was Dr. Rashad Massoud from the Institute for Healthcare Improvement (IHI), and he described the strategic partnership between IHI and the Indian Health Service (IHS). This partnership is focusing on the chronic care initiative, but with strong linkages to both the behavioral health and health promotion/disease prevention initiatives. Dr. Massoud added that this collaboration is focused intensively to develop better models of care and improving care for chronic conditions, as well as getting highly leveraged adoption of the changes. IHI is working with the IHS on prototyping what great care for patients with chronic conditions can be, and then spreading it throughout the Indian health system and, at a later stage, reaching thousands of AI/AN people.

The other main direction for this partnership is an emphasis on improving care for patients with chronic conditions through a care design component that focuses on

designing care, not for individual conditions, but looking at changes that cut across multiple conditions. The result will be a very highly leveraged way of addressing chronic conditions; changes that can affect one condition are likely to affect others. The IHS and IHI, by addressing chronic care in this way, will create an opportunity to get better results for the population as a whole rather than addressing them condition by condition. Dr. Massoud commented that this work is starting this year with 14 pilot sites that have been selected in a specific way such that they represent different types of care delivery, and include primary care delivery, as well as hospital care. These pilot sites will include federal as well as tribal and urban programs in a variety of geographic distributions. The purpose of this strategy is to develop the prototype in such a way that it is very robust, and when we go to spreading it, we are almost ready for changes that would be applicable across many or most sites in the Indian health system.

From the Albuquerque Area, Tony Danielson, the Director of Behavioral Health and Tribal Support, stated, "Probably the most important thing, at least for Behavioral Health that resulted from the state reorganization, was the development of what's called a local collaborative." This collaborative occurred when the state of New Mexico reallocated their behavioral health dollars and put all the money into one pot. Then they contracted with one group to coordinate, manage, and decide how all of the state funds would be spent for behavioral health. However; in developing this new system of care, the state now had a process to receive input from patients or consumers in the communities. Our local collaborative serves as the voice of the tribes for the purpose of identifying their needs for behavioral health services and passing that on to the state."

Dr. Chuck North reported, "The Albuquerque Service Unit went through a delivery system redesign a few years ago, which was partially funded by a HRSA Healthy Communities Access Program (HCAP) grant, and we found that integrating pharmacy, behavioral health workers, and point-of-care testing into our primary care clinic has greatly assisted us in the ability to manage patients with chronic disease and comorbid conditions, especially mental health and substance abuse conditions. The chronic care model studies show that delivery system redesign, self-management support, decision support for primary care providers, and clinical information systems are crucial. The Indian Health Service has many of these features already, and our job I think is going to be to integrate them further."

Theresa Clay, the Health Promotion/Disease Prevention specialist for the Albuquerque Area, described her work with the Community Wellness Champion Forum. Ms. Clay mentioned how these forums were conducted last year in partnership with the Navajo Area. She stated, “The forums focused on promising practices that were working in our Native communities and the sharing of projects and efforts with others in recognizing our local change agents who we called champions in the communities. We offered workshops such as marketing efforts and grant writing. The stories or programs shared at the forum are gathered and documented in a storybook to capture all of the innovative programs that are working in communities to share with others. A link to the two storybooks is provided on the Director’s three initiatives website. We encouraged assessment of community resources in order to develop community-based wellness plans.”

From the Nashville Area, Mary Wachacha shared, “At our forums this past year, we encouraged assessment of community resources to develop community based wellness plans in order to conduct assessments and surveys and to use that information to develop and implement community wellness and action plans. In HP/DP, chronic care, and behavioral health, we encouraged self-management and supported the patient’s need to make personal decisions. And again, we try to change the system to support the patient, rather than requiring the patient to fit the system. Lastly, is documentation, documentation and documentation!”

Phyllis Spears, the Health Promotion/Disease Prevention Coordinator for the Tucson Area reported, “I think a shining example of the integration of the three initiatives of chronic care, behavioral health and health promotion/disease prevention are the Indian Health Service school health programs on the reservation. This adolescent and child clinic meets the patient on their own terms and in their own environment. It’s administered by nurse practitioners in the schools who are immersed in the community and develop an awareness of the social, cultural, and medical issues and needs in the community. In the summer of 2006, they did 200 sports physicals. Behavioral health services are provided now in the schools through a partnership between the Indian Health Service and the tribal behavioral health programs. Counseling is now available full time, five days a week in the school. A school-wide immunization program keeps students up-to-date, not only with routine immunizations, but also flu vaccinations. An eye screening and eyeglass program is coordinated with the IHS optometry staff coming into the schools. A walking program at Santa Rosa Indian Health Center was developed by the IHS Diabetes Prevention Program and includes not only fitness activities and nutritional counseling, but evaluation through BMI measurements and calculations. The program partners with staff from the Healthy O’Odhams Prevention Program (HOPP) and the STEPS project, a state school project partnering with schools both on and off the reservation.”

Here are two examples of the interaction between callers and the hosting Area presenters: (The complete transcript is available at the Director’s Initiatives website)

- “Hi. My name is Taryn Kaye and I’m the Wellness Director for the Tucson Indian Center and I believe this question would be for Alberta Becenti. We were getting prepared to submit our continuation application for our health promotion grant. Are there any specific directives for each Area HP/DP coordinator to collaborate with the tribes and urban programs?”

“We encourage our Area HP/DP coordinators to work with the tribes and the urban programs. We provided four regional grant writing trainings and strongly encouraged the tribal and urban participants to collaborate with their Area coordinators as well. We encouraged the recipients to collaborate with other organizations and other programs as well.”

- “My name is Mark Veazie with the Native American Cardiology Program. I want to thank the sites for an excellent presentation. I wanted to ask a question of Mary Wachacha. I was interested in some specific examples of that linkage to the families of those patients for detecting and managing risk factors and presumably some of the highest risk people, which would be the family members of patients with chronic care needs and extending the chronic care model out to that point and that would, of course, include involvement of HP/DP staff in the care of chronic care patients.”

Mary Wachacha replied, “I think that we probably have a whole list of initiatives from our tribes where they have integrated their community resources into the hospital and vice versa.

The third Open Door Forum took place April 25 and highlighted the Director’s three health initiatives on chronic care, behavioral health, and health promotion/disease prevention from the Alaska and Billings Areas. Following the Open Door Forums, a transcript of the teleconference will be available at the Directors’ Initiatives website for those who miss this event. The transcripts of the previous two Open Door Forums are available under “What’s New” of the Director’s Initiatives website.

After the April 25, 2007 call, feedback will be solicited from the Open Door Forum participants by using a Survey Monkey. After the call, callers will receive information about the survey through an e-mail message. The survey will be designed to elicit caller’s comments on this session and suggestions for future sessions. We really want to make these sessions something that is valuable to you and will help you to learn more about the initiatives and what other sites are doing.

If you have questions, please contact one of the Director’s Three Initiatives leads: Health Promotion/Disease Prevention: Alberta Becenti at Alberta.Becenti@ihs.gov; Chronic Disease: Dr. Ty Reidhead at Charles.Reidhead@ihs.gov; or Behavioral Health: Bryan Wooden at Bryan.Wooden@ihs.gov.

Heads Up! Tools for Physicians for Diagnosing and Managing Concussion

An estimated 75 - 90% of the 1.4 million traumatic brain injury (TBI)-related deaths, hospitalizations, and emergency department visits that occur each year are concussions or mild traumatic brain injury (MTBI). Concussions or MTBIs are caused by a blow or jolt to the head that disrupts the way the brain normally works. Symptoms of MTBI or concussion may appear mild, but can result in a number of problems: persistent headache, pain, fatigue, vision or hearing problems, memory problems, confusion, sleep disturbances, or mood changes. Physicians can play a key role in helping to prevent MTBI and in appropriately identifying, diagnosing, and managing it when it does occur.

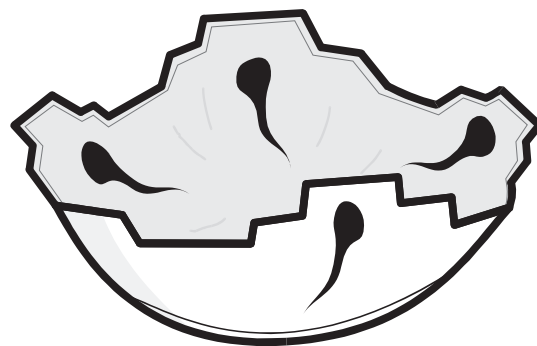
In an effort to address this important public health problem, the Centers for Disease Control and Prevention (CDC), in collaboration with the Indian Health Service, as well as other federal, professional medical, sports, and voluntary organizations, has recently updated and revised the “Heads Up: Brain Injury in Your Practice” tool kit for physicians. This tool kit was developed to provide physicians with a more individualized assessment of MTBI and to help guide the management, recovery, and referral of patients with MTBI. One of the key components of the tool kit is the Acute Concussion Evaluation (ACE) assessment tool, which can help physicians with their initial evaluation and diagnosis of patients of all ages with a known or suspected MTBI or concussion.

In addition to the ACE, the revised tool kit contains practical, easy-to-use clinical information and tools, such as:

- The “Facts for Physicians” booklet with information on diagnosis and management of MTBI
- The ACE Care Plan, an information sheet to help guide a patient’s recovery
- Fact sheets in English and Spanish on preventing concussion
- A palm card for the on-field management of sports-related concussion
- A CD-ROM with downloadable kit materials and additional MTBI resources

The “Heads Up: Brain Injury in Your Practice” tool kit can be ordered or downloaded free of charge at www.cdc.gov/ncipc/tbi/Physicians_Tool_Kit.

To learn more about concussion or MTBI and/or for more information on CDC’s TBI-related educational materials, research, and programs, please visit CDC’s Injury Center on the Web at www.cdc.gov/injury. For questions, please contact CDC toll-free at 1-800-CDC-INFO (1-800-232-4636).





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PRESORTED STANDARD
POSTAGE AND FEES PAID
U.S. DEPT. OF HEALTH & HUMAN
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PHOENIX, AZ
PERMIT NO. 5691

CHANGE SERVICE REQUESTED

OFFICIAL BUSINESS
PENALTY FOR PRIVATE USE \$300