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## The Northwest Tribal Diabetes Surveillance Project

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#### **Abstract**

Background: For Calendar Year 1996 the reported prevalence of type 2 diabetes mellitus among American Indians and Alaska Natives in the Indian Health Service Portland Area (Washington, Oregon, and Idaho) was 4.2%. However, both the quantity and quality of the data upon which this published Indian Health Service (IHS) rate is based are known to be limited. As part of the effort to improve the data, the Northwest Tribal Diabetes Surveillance Project was established to assist tribal diabetes programs with building sustainable infrastructure for diabetes data collection, case management, and surveillance. The Project includes three primary steps: 1) assessing program capacity for diagnosing and monitoring diabetes; 2) providing training and assistance; and 3) analyzing the incidence and prevalence data to determine more accurate rates.

*Methods:* Visits were made to all 44 Indian health care programs in the Portland Area. Diabetes grants were reviewed to identify needs and establish a work plan. Training was provided on the Resource and Patient Management System (RPMS) computerized health information system. A diabetes register, screening policy, and tracking system were developed.

Results: In the first ten months, the number of tribes using the RPMS diabetes register increased by 29%, the number of programs using a case management system for diabetic patients increased by 37%, and the number of programs documenting diabetes patient education in medical charts increased by 44%. For the 1999 IHS Diabetes Audit, 32 (74%) of the programs plan to participate, compared to 1998 when only 12 programs (26%) participated.

Conclusions: Through on-site evaluations and technical assistance, Portland Area tribes are making substantial progress

in developing infrastructure for diabetes management and surveillance. This will enable Northwest tribes to be able to report reliable diabetes data for their respective communities in 1999. The methods developed can be utilized by others in Indian Country to improve their capacity for surveillance of diabetes and other diseases.

#### **Background**

According to the American Diabetes Association (ADA), one in five American Indians and Alaska Natives (AI/AN) has diabetes. Of those people who have diabetes, one third do not know they have it. For Northwest tribes, the all ages prevalence rate of diabetes has been reported to be 4.2% - about twice the national all races rate (IHS, 1996) an increase over the published rate of ten years ago. This high prevalence of diabetes creates a tremendous health burden for Northwest AI/AN people and Indian health care programs. Even so, the true extent of the diabetes disease burden is not known. There are numerous limitations to the data on diabetes and its associated complications. Without accurate data, Indian health care programs are

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navigating in the fog without instruments, for there is no way of knowing whether the burden of disease from diabetes is increasing, staying the same, or decreasing.

In 1997 Congress allocated an additional appropriation to the Indian Health Service to help Indian health care programs cope with the accelerating epidemic of diabetes in Indian country. The allocation of this funding was based on the reported prevalence rates of diabetes in each IHS Service Area. This much needed allocation made the limitations in the diabetes data for Northwest AI/AN even more apparent in the following ways:

- 1) There was no central location for data on diabetes among Northwest AI/AN.
- The majority of the primary care data on diabetes were scattered among the individual tribes' Indian health care programs.
- The availability and accuracy of data from most Northwest tribal health care programs had not been evaluated.
- 4) The published prevalence rates were based on samples which might not be representative. For example, in the Portland Area, the prevalence rate was based on less than 25% of the AI/AN population.
- 5) These racial identifiers were missing or inaccurate in external data sets containing information about the complications of diabetes.

Because of concern about data limitations, the IHS earmarked a portion of the new diabetes funds toward data improvement. In consultation with the tribes, each IHS Service Area developed an allocation methodology for distribution of these funds to determine more accurately the prevalence of diabetes.

In the Portland Area (Idaho, Oregon and Washington), 44 tribal diabetes grants were funded in 1998 from the special diabetes appropriation. Thirty-eight of the grants went directly to tribal health programs and five were awarded to IHS diabetes programs. At the recommendation of the Portland Area Fund Distribution Workgroup, the funds for data improvement were awarded to the Northwest Tribal Epidemiology Center (The EpiCenter) located at the Northwest Portland Area Indian Health Board (NPAIHB). With these funds the Northwest Tribal Diabetes Surveillance Project was established. This project is working collaboratively with the Northwest Tribal Registry Project, which utilizes a database of Northwest AI/AN to perform record linkage studies with other health datasets to determine the true prevalence of AI/AN in these datasets. From these results, more accurate measures of disease burden will be obtained for diabetes and other diseases.

The goal of the Northwest Tribal Diabetes Surveillance Project is to assist the Northwest tribes in building sustainable infrastructure for diabetes data collection and case management systems, in order to establish accurate Area-wide prevalence rates. The benefit of establishing sustainable infrastructure is that the tribes will be able to maintain their systems after the grant funds are exhausted. The data collection system incorporates all departments in the health care program and systematizes the process to ensure reliability. The case management system assists in improving care by providing a means for tracking patients and their care. The methods created and used are also applicable to other health care programs and to other diseases. Project objectives include:

- Obtaining more complete and accurate prevalence rates of diabetes and its associated complications in Portland Area AI/AN communities.
- Ascertaining and standardizing methods of diagnosis and reporting of diabetes in Northwest Indian health care programs.
- Training and providing technical assistance in establishing diabetes data collection and case management systems.

#### Methods

The project objectives are being accomplished through three primary steps:

- 1) On-site baseline assessments of each program.
- 2) Individual assistance for site-specific questions.
- Training on using RPMS for diabetes management and surveillance, the IHS Diabetes Audit, and "Epidemiology 101."

This initial assessment is completed jointly by the Diabetes Surveillance Project Director and the local program diabetes coordinator or team. The initial assessment provides baseline information for measuring changes over time in the respective Northwest Indian diabetes programs, and gathers information on:

- · Case ascertainment criteria
- Documentation and uses of data
- Standards of care by providers
- · Quality assurance methods
- Type of patient education
- · Case management systems and forms
- Presence or absence of a diabetes register, diabetes team, and an active diabetes screening policy

The program assessment compares current practices to established standards of diabetes care and education. For example, studies have shown the use of a diabetes team for clinical care and for planning has improved clinic-wide consistency of care. Similarly, a diabetes register has been shown to provide accurate counts of those at risk, and when combined with case management, allows for tracking of individual patients. An active screening policy identifies asymptomatic persons at risk for diabetes, and recommends regular screening to detect changes in glucose tolerance before symptoms develop.

The information gathered in the initial assessment guides the second step, training. The expressed needs of the local programs determine the number and type of training activities offered by NPAIHB and the IHS Portland Area Diabetes Program, which include the Resource and Patient Management System (RPMS), the IHS Diabetes Audit, Epi-Info statistical software, and an introduction to epidemiology basics. In addition, the Project Director has provided individualized onsite assistance for all of these and for the IHS standards of care for type 2 diabetes, grant writing, development of a customized case management system, and an active diabetes screening policy. The types of services provided are determined by the diabetes program coordinator or team. Working as a team to assess the program, review grant objectives, and design short-term and long-term work plans ensures ownership by the tribal program, standardization of data collection protocols, and accountability for completion.

It is paramount to have the program staff's involvement in, understanding of, ownership of, and commitment to the development of these systems. It is important in the process of developing a sustainable infrastructure that the work plan is customized for the program's and tribe's particular needs. This is especially important because each diabetes program offers different services and has very different grant objectives. The Project Director reports on each visit with an outline of the work plan established and calls to follow up on progress made towards achieving the whole plan objectives.

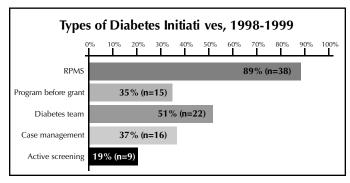
Networking has been an integral part of the program development process. A list of all the diabetes coordinators has been distributed to the coordinators in order to allow programs to share information. Regional meetings have also been set up to enable the coordinators to share program trials and tribulations. The meetings have served as a learning opportunity, a networking session, and as a support group. Through the Northwest Tribal Diabetes Surveillance Project, tribes have been connected to other tribal programs, resources, and networking circles that had not existed before. The program coordinators have been encouraged to participate in county, state, and national level diabetes groups.

#### **Results**

All 43 Northwest Indian health care programs with an IHS diabetes grant have been visited and assessed (see Figure 1) during the first year. An additional diabetes program operated by the IHS Urban Clinic at the Western Oregon Service Unit was also visited and assessed. The Western Oregon Service Unit did not receive an IHS special diabetes grant but did agree to work with the Diabetes Project in order to make the data collected on the Portland Area complete. The following results thus include the 43 diabetes programs with IHS special diabetes grants and Western Oregon Service Unit, making the total of programs visited and assessed 44.

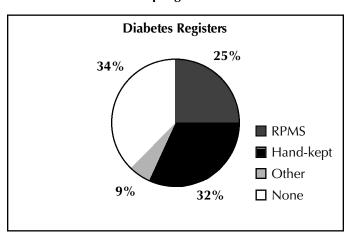
In the first year, three group training activities on the RPMS Diabetes Management System and two on the IHS Diabetes Audit and Epi-Info software were conducted (RPMS is the computerized health information system used by almost all Indian health care programs). Attending these activities were 41 tribal health staff members for the RPMS Diabetes System and 12 for the Diabetes Audit.

Figure 1. The number of Northwest tribal diabetes pr ograms with each of these features



The initial assessment showed that 39 (88.6%) of the 44 Northwest tribal diabetes programs use RPMS. Sixteen Indian health care programs already had established diabetes programs before the 1997 IHS diabetes grants; now there are a total of 44 diabetes programs in the Portland Area (an increase of 65%). At the time of the first-year program assessments (between July 1998 and April 1999), 23 (52.3%) programs were using a Diabetes Team to provide patient care and planning; 17 (38.6%) had an established case management system for patients with diabetes; and 9 (20.5%) had an active diabetes screening policy (see Figure 1). There were 29 (65.9%) programs that had a diabetes register and who could therefore provide a baseline diabetes prevalence rate. Out of the programs with a diabetes register, 14 had a hand-kept register, 11 had an RPMS register, and 4 used some other type of register (see Figure 2). In addition to tracking those persons with diabetes in a register, 13 (44.8%) programs tracked the number of complications associated with diabetes, and 8 (27.6%) tracked first-degree relatives of the person with diabetes for screening purposes.

Figure 2. The different kinds of diabetes registers within the Northwest tribal diabetes pr ograms



All sites followed either the IHS or ADA Standards of Care; however, only 20 (45.5%) programs were conducting quality assurance evaluations for the care provided. It is essential for the health care programs providing direct care to measure the quality

of the care provided. The IHS Diabetes Audit provides an easy method for assessing the care provided and allows for easy data comparison between programs. Historically, the only programs that have participated in the IHS Diabetes Audit have been the service units. In 1998, there were twelve programs that participated in the Audit. Seven other sites participated in other types of care audits: four used site-developed audits and three used audits provided by their state diabetes control programs. For the 1999 IHS Diabetes Audit, 32 programs have indicated they plan to participate, and ten have already participated in training on the Audit and Epi-Info, the accompanying software.

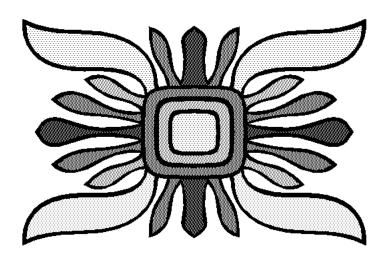
Improvements are being documented in the Northwest tribal diabetes programs. Preliminary numbers show the number of tribes using the RPMS Case Management System for the IHS Diabetes Register has increased by 29%. The number with a case management system for patient care has increased by 37%. In the data collection area, 44% programs have begun to document patient education in medical charts. Four clinics have invested in major data chart abstraction projects in order to improve the quality of data in their RPMS system and to establish baseline information for their diabetes projects. These projects have benefited the programs by providing accurate information for the health summaries, RPMS diabetes audits, and Q-man searches.

#### Conclusion

In the first year, the Northwest Tribal Diabetes Surveillance Project has been able to establish diabetes surveillance capacity among Northwest Indian health care programs. The individual programs have developed sustainable infrastructure for diabetes data collection and case management systems. Through group training and individual assistance, the tribes will now be able to report reliable diabetes prevalence and incidence rates for their respective communities and tribes. The Northwest tribes will also have the capacity to maintain these systems on their own to improve patient care. The surveillance infrastructure and the methods used to develop the systems can be used in other areas of health care as well as for other diseases. Other tribes and clinics can adapt these same surveillance development methods in order to improve their data collection and case management systems.  $\square$ 

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## Fatal Injuries Among American Indian and Alaska Native Infants, 1992-1994

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#### **Abstract**

Injuries are the leading cause of death among American Indians and Alaska Natives (AI/AN) between the ages of 1 and 44. AI/AN suffer from injury mortality rates over three times greater than the majority population. Although injuries are a leading cause of death and disability among the AI/AN population, few studies have investigated the role of injuries among AI/AN infants. The objectives of this study, therefore, are to describe the recent trends in infant mortality among AI/AN and to explore the role of injury as a cause of infant death in this group. To meet these objectives, this study analyzes vital event data according to the infant's age in months and the reported cause of death.

During 1992-1994 there were 872 infant deaths among AI/AN, 64 of which are attributed to injury. Homicide, the leading cause of fatal injury among AI/AN infants, accounted for 43 percent of all infant deaths, and occurred at a rate more than twice that experienced by the U.S. All Races population. Injuries become the second leading cause of death by the fifth month of life, and the leading cause of death by the tenth month of life. Further, by the fifth month of life the composition of injuries diversifies, as falls, fire/burns, and drowning become leading causes of injury mortality. The data demonstrate that this method of analyzing infant death is a worthwhile endeavor and should be considered in future investigations of infant mortality.

#### Introduction

Injuries are the leading cause of death among American Indians and Alaska Natives (AI/AN) between the ages of 1 and 44.<sup>1,2</sup> During the 1992-1994 triennium, the age adjusted injury mortality rate among AI/AN was 94.5 deaths per 100,000, compared to 30.3 for the entire United States.<sup>2</sup> The AI/AN injury mortality rate is, therefore, more than three times greater than that experienced by the total population residing in the United States. According to the Indian Health Service (IHS), each year more than 1,300 AI/AN people die from trauma as a direct result of injuries. Although injury morality rates have declined by 70 percent since 1972, injuries remain one of the most significant public health concerns in Indian communities.

The economic cost of injuries is extraordinarily high among AI/AN. An estimated 10,000 hospitalizations and as many as 50,000 patient days are spent in IHS and contract care facilities each year due to injury trauma. <sup>3</sup> More than 300,000 outpatient

visits to IHS and tribal treatment facilities are also attributed to the treatment of injuries. Overall, more than \$150 million is spent on the treatment of AI/AN injury victims each year.

Despite the documented high incidence of morbidity and mortality due to injuries among the AI/AN population, an exhaustive literature search produced just one study that has specifically addressed the role of injuries as a cause of infant death. The review of the literature demonstrates that those deaths associated with sudden infant death syndrome (SIDS) and congenital anomalies often overshadow the role of injuries as a cause of infant mortality. However, as the third leading cause of death among AI/AN infants overall, and a leading cause of death during the postneonatal period (see Table 1), the epidemiology of injuries among infants must be more clearly understood.

#### Objectives of the Study

The purpose of this study, therefore, is to utilize a refined method of analyzing infant deaths among AI/AN in order to achieve the following objectives:

- To describe the recent trends in infant mortality among AI/AN during the period 1992 through 1994 by analyzing the leading causes of infant death according to the infant's age in months; and
- 2. To provide a descriptive account of the role of injuries as a cause of infant death among the AI/AN population during the same period.

#### Methodology

The IHS Demographic Statistics Team generated the AI/AN vital event statistics utilized in this study. The Demographic Statistics Team derives AI/AN vital event statistics from data furnished annually to the IHS by the National Center for Health Statistics (NCHS). The NCHS obtains birth and death records for all U.S. residents from the State Departments of Health, based on information reported on official state birth and death certificates. The standard cause-of-death groupings used by the NCHS, derived from the International Classification of Diseases, 9th Revision (ICD-9), were used in this research. Due to the nature of this reporting system, the data are subject to the degree of accuracy of the reporting by the states to the NCHS.

To compensate for the small number of AI/AN in many Indian communities, the IHS averages vital event statistics over three year periods, centered on the year being studied. The 1992-1994 triennium represents the most current set of complete data available for analysis.

To meet the objectives stated above, this study has utilized the vital statistics data available to the IHS to describe the recent trends in infant mortality among AI/AN during 1992 and 1994. These trends in infant mortality are described by ranking the ten leading causes of death according to the age of the infant. The infant's age is analyzed month-by-month. Rather than condensing the postneonatal period into one category, the present study has subdivided the 11 months of this period into eleven different categories and ranked the leading causes of death for each. For example the ten leading causes of death among AI/AN infants during the sixth month of life are described by reading column six of Table 1.

A second set of data was generated in the same manner, however these data focus specifically on the leading causes of death by injury type. Injuries are defined by a classification system that describes external causes of injury, or E-codes. The E-codes utilized in this study are those that describe fatal injuries and are included in the range E800 through E949.

To establish the denominator, the number of live births, the IHS aggregates death counts reported in state vital records. From these data, the IHS projects the number of AI/AN who reside in counties "on or near" federal Indian reservations in the 35 "reservation states" in which the IHS has health care responsibilities. These 35 reservation states are aggregated into geographic units referred to as the IHS Service Areas. The residents of these Areas are termed the IHS Service Population. The number of live births

that occurred among this population during 1992 and 1994 was used as the denominator in this study.

In order to make comparisons between the AI/AN population described above and the national infant population, additional data from the Centers for Disease Control and Prevention (CDC) were obtained. This comparison population, termed the U.S. All Races infants, includes all infants (including the IHS Service Population infants) who died in the United States during 1992 and 1994.

The U.S. All Races data were also derived from the NCHS and generated in the same manner, as were the data for the IHS Service Area. The ten leading causes of infant death were ranked by the infant's month of age and by leading cause. The same methods were also used to formulate the leading causes of fatal injury data for the U.S. All Races infant population. Due to the larger size of this infant population, however, the National All Races data were able to present the ten leading causes of injury death by month of age, compared to the IHS Service Area data that were limited to the five leading causes of injury death. The same E-codes used to produce the AI/AN infant mortality data were also used to generate the U.S. All Races infant mortality data. The number of live births for the U.S. All Races population was derived in the same manner as were the IHS Service Area data, from annual birth counts reported in state vital records. The

Table 1. Leading causes of death, by month of age, American Indian and Alaska Native Infants, 1992-1994

#### Age by Month Rank 2 4 5 6 8 10 11 12 Total SIDS 505 5405 505 Congesida intenti Jaintention: Arromalies bijanie: Injurius Injuries 43 210 Contenit ongenita contenits Consenita 2 Anomalies Cestation . natios Injurier ma faos knj unios ln juri . madies America likes ps. indikano za Anomalie Anomalies 14 193 Congenital Congenita Congenital Homicide Homicide Homicide Comp. of Placenta Congenital Unintentional h-lomicide Conponital Linintentiona 3 Injuries Injuries Respiratory 4 Injuries & Influenza & Inflorenza & fortherers & Influenza & Influenza Injuries a influenza à influenza Maternal Respiratory Intrasterina Howicide Homicide Unintentional **Bospinatory** Hossicida Short 5 Distress Gestati Comp. Нурокія & hillwoods terrauterine Maternal Respirators 6 Gestation Нурожів Coesa. 7 Placenta 26 8 Comp. & Influenza Unintentional 9 Hossicide Intraster ine 10 15

Data Source: Demographic Statistics Team, IHS. NCHS Mortality Tapes, 1992-1994. Includes all American Indian and Alaska Natives in the IHS Service Areas.

month-by-month analysis of infant mortality among the U.S. All Races population is described in Table 2.

In a review of the published literature, only one study was found that specifically addressed the role of injuries as a cause of death among AI/AN infants.<sup>4</sup> This study was published in the IHS journal, *The IHS Primary Care Provider*. The literature review failed to reveal any published studies that have attempted to analyze infant mortality by month of age during the first year of life. Only one author has attempted to analyze infant mortality by month of age, and this was done in a cursory manner, secondary to other analyses.<sup>5</sup> It is clear that an analysis of infant mortality by month of age and by leading cause is an original and worthwhile endeavor.

#### Limitations

The nature and scope of this study suggest certain inherent limitations. The study's greatest limitation is its focus on a small population, over a short period of time. There were just 872 infant deaths and 100,199 live births during the 1992-1994 triennium. In order to achieve a more statistically sound analysis, additional years would need to be included in this study.

The study's focus on a small population over a short period of time limits this analysis in another way. Regional differences in infant mortality for AI/AN could not be considered because the events were too infrequent for the time period included. As a

result, this study was forced to maintain a national focus. Therefore, data at the state or local level could not be collected and meaningfully interpreted.

Additionally, both racial misclassification and the decision of the NCHS to not link birth and death certificates for the three-year period of this study likely resulted in an underestimation of the actual number of AI/AN deaths occurring during these years. Although the IHS has attempted to make adjustments to correct for racial misclassification on birth and death certificates, it is expected that some AI/AN infant deaths will continue to be underreported in these records. The problem is exacerbated, as linked data were not available during 1992 and 1994.

#### **Outcomes**

The infant mortality rate among American Indians and Alaska Natives continued its slowly declining trend during the 1992-1994 triennium. The infant mortality rate during 1992-1994 was 8.7 deaths per 1,000 live births before adjusting for the misclassification of Indian race on death certificates. While this infant mortality rate represents only a small decrease from the 1991-1993 triennium (8.8 deaths per 1,000 live births), it does denote a 255 percent drop in the infant mortality rate compared to the period 1972-1974, when it was 22.2. The infant mortality rate, after adjusting for miscoding of Indian race, is 10.9. This adjusted rate is 30 percent greater than the

Table 2. Leading causes of death, by month of age, US All Races infants, 1992-1994

#### Month of Age

Rank	1	2	3	4	5	6	7	8	9	10	13	12	Total
канк			_	-		_	-	-	_				
1	Congenital	5105	SD6	SDS	5105	SIDS	SIDS	Congenital	Congenital	Congoritat	Unistentional Injuries	Deineantional Injuries	Congenital
'	Anomañes	3,073	3,657	2,656	1,514	771	452	Arromaties	Anomalies	Anomaites	169	198	Anomalies
	15,471		41	#		F	# In I	323	263	187			21,432
2	Short Contation	Congenital	Congesital Anomalies	Congunital	Congenital	Congonital	Congenical	5835 282	5IDS 176	Lesimentiosal Injuries	Congenital Anomalies	Congunital	5ID5 13.633
-	12.384				Anomalies	Asomaties	Anomales 377	282	176	166		Anomolies	13,633
		1,720 Unintentional	959 Pneumonia	744 Lisinsontional	S84 Unintentional	473 Unintentional	577 Unintentional	Linintestional	Unintentional	SIOS	161 SIDS	170 Homicide	Short
3	Buspinatory Distress	Injuries	& influenza	hr jurios	Injuries	bjaries	Injuries	Injurios.	Injuries	99	63	S8	Gestation
	5,102	300	295	257	215	219	281	166	162	30	6.5	50	12,384
	Masenai	Prieustonia	Unintention	Pseumonia	Procumonia	Preumonia	Posuseosia	Homicide	Homicide	Hossicide	Homicide	905	Respiratory
4	Comp.	& Influenza	all trajunion	& Influenza	& Influenza	a influenza	& luftuenza	70	54	51	18	47	Distress
	4.077	281	292	243	165	94	86						5,370
	Comp. of	Intestinal	Remainder	Remainder	Homicide	Remainder	Homicide	Peeumonia	Priesestossia	Рвизтопіа	Ринциковіа	Pseumonia	Maternal
5	Placienta.	infections	Respiratory	Respiratory	ВУ	Bespiratory	68	& Inflancza	& influenza	& influenza	& Influenza	& Influenza	Comp.
	2,898	269	141	137		75		49	4.5	36	36	35	4,077
,	Porimatali	Septiceroia	Homicide	Hossicida	Stomainder	Homicide	Remainder	Remainder	HIV	Remainder	Mallignann	Malignant	Comp. of
6	infections	267	129	99	Respiratory	68	Respiratory	Respiratory	30	the spiratory	Neoplasms	Neoplases	Placenta
	2,317				76		45	42		25	25	27	2,896
7	letrasterine	Stemainder	Septicomia	Septicemia	Septicomia	Septicemia	Resp. Distr.	Septicemia	Stomainder	Malignass.	HIV	Remainder	Carintentional
'	Hypoxia	Respiratory:	113	82	56	45	Syndrame	27	Respiratory	Neoplases	24	Respiratory	Injuries
	1,534	188					32		26	17		21	2,606
8	Neonatal Hemoer,	Resp. Distr.	Bronchitis	Hosochitis	Bronchisis	HW	HIV	HW	Viral Disease	HEV	Remainder	Septicemia	Perinatal Infections
	908	Syndrome	73	70	46	42	31	24	20	14	Respiratory	18	2.44B
		123	Brown Peters	exect orbit	1104	W	Book and the Control	hd-En con		Marin and the Control of the Control	17	1.00	-,
9	SE0S 843	Homicide 119	Resp. Distr.	Moningitis 33	HIV	Bronchitis	Bronchitis 28	Malignant Neoplassa	Septiconsia 19	Brosefuitis	Sopticemia 19	HW 17	Proumonia
-	843	119	Synctrome 59	33	40	.33	18.	20	19	12	19	17	& leftues2a 1,689
	Birth Trauma	Perinasal	1 Marting	Viral	Resp. Distr.	Resp. Distr.	Septicemia	Meningitis	Malignari	Meningkis	Maningitis	Gastritis	In trauterine
10	635	Infections	Infections	Diseases	Syndrome	Syndrome	24	16	Neoplasms	12	11	10	Hypoxia
	4.7.3	111	55	3.3	29	25	2.4	1.0	16	1.2	''	10	1,534

Data Source: National Center for Injury Prevention and Control, CDC. NCHS Mortality Tapes, 1992-1994. Includes all races in the United States.

#### U.S. All Races rate of 8.4.

There were a total of 872 reported infant deaths among AI/AN during the 1992-1994 triennium. Slightly less than one half of the infant deaths among AI/AN occurred during the neonatal period (47 percent), versus 64 percent among the U.S. All Races population. The leading cause of death among AI/AN infants during the neonatal period was congenital anomalies, which accounted for one-half of the deaths during this period. Congenital anomalies were also the leading cause of death for the U.S. All Races infants during the neonatal period, but accounted for just one-third of the deaths during the first 28 days of life.

Other important causes of infant deaths during the neonatal period, for both populations, are those conditions that relate to certain inherent congenital conditions or circumstances of birth, such as disorders relating to short gestation, respiratory distress syndrome, maternal complications, and complications of the placenta. These conditions are the five leading causes of infant death for both the AI/AN and U.S. All Races infant populations (see Tables 1 and 2).

Although congenital anomalies continue to threaten the lives of infants throughout the first year of life, infant mortality during the postneonatal period is largely a result of environmental causes. For example, the leading cause of death among AI/AN during this 11-month period is SIDS, a group of conditions whose etiology remains relatively unclear, but may be associated with environmental circumstances. Congenital anomalies and injuries are the second and third leading cause of death during this period, respectively.

The three leading causes of infant mortality among AI/AN during the postneonatal period, SIDS, congenital anomalies and injuries, account for 85 percent of all deaths during this period. These three causes are also the three leading causes of death among the U.S. All Races infants during the postneonatal period. Nationally, these causes of infant death accounted for 82 percent of the deaths during the same period.

Injuries, both intentional and unintentional, provide a clear example of the value of analyzing infant deaths by month of life. When compared to other conditions occurring during the first month of life, injuries are (relatively) less of a threat to an infant's well being. However, by the second month of life, unintentional injuries and intentional injuries increase to the fourth and seventh leading causes of death, respectively.

Contrary to the findings for both SIDS and congenital anomalies, injuries steadily increase as a cause of infant mortality. For example, among AI/AN infants, unintentional injuries increase from the fourth leading cause of death during the second month of life to the leading cause of infant mortality by the tenth through the twelfth months of life. Similar trends are found among the U.S. All Races population where unintentional injuries are the third leading cause of death during the second month of life, but increase to the second and finally leading cause of infant death the tenth and twelfth months, respectively.

Table 3. Leading causes of infant death among Al/AN, 1992-1994

Cause	N
SIDS	210
Congenital Anomalies	193
Injuries	64
Pneumonia & Influenza	37
Short Gestation & Low Birthweight	31
Respiratory Distress Syndrome	27
Complications of the Placenta	26
Maternal Complications of Pregnancy	3.7
Intrauterine Hypoxia and Birth Asphyxiation	15
Ali	620

For both infant populations, intentional injuries occur less frequently than unintentional injury, but follow the same pattern of increase as age increases. Among the AI/AN population, homicide occurs at the rate of 15 deaths per 100,000 live births. This form of intentional injury is the tenth leading cause of death during the first month of life, but increases to the third leading cause of death by the sixth month. Overall, 15 deaths among AI/AN infants were recorded as a result of homicide during this three-year period. The numbers may seem small, but when calculated as rates, are nearly twice those of the rest of the country (see Table 2).

#### Discussion

While a descriptive account of infant deaths during the neonatal and postneonatal periods can be informative, an analysis of the leading causes of infant death by month provides a more detailed description of the leading causes of infant mortality. By analyzing infant deaths by month of age, subtle trends in infant mortality are revealed. Specifically, the application of this refined analysis defines the increasingly important role of injuries during the first year of life. Recognizing these subtle trends in infant mortality is one way to provide researchers with valuable information regarding the epidemiology of fatal injuries among infants. This information, when properly applied, can lead to more effective injury prevention strategies. The two preceding tables provide a visual presentation of the value of analyzing infant mortality by month of life (see Tables 1 and 2).

A number of interesting injury-related discoveries have been made through the application of this refined infant mortality analysis. One of these findings is that AI/AN infants experience higher rates of fatal injuries because injuries become a leading cause of death earlier in life than among the U.S. All Races population. For example, unintentional injuries increase from the ninth cause of death during the first month of life to the second leading cause of death by the fifth month of life (see Table 1).

Table 4. Comparison of infant mortality rates\* by injur y cause, Al/AN vs. U.S. All Races, 1992-1994

Al/AN vs. U.S. All Races, 1992-1994						
	Number of Deaths (AI/AN)	Al/AN Rate (1992-1994)	U.S. All Races Rates* (1992-1994)	Ratio of AI/AN to U.S. All Races		
Unintentional	49	48.90	21.68	2.26		
Homicide	15	14.97	8.17	1.83		
Motor-Vehicle	10	9.98	4.33	2.30		
Drowning	5	4.99	1.97	2.53		
Fire / Burn	4	3.99	2.70	1.48		
Falls	1	1.00	0.43	2.32		
All Injuries	64	63.87	29.85	2.14		

- \* Rates are calculated per 100,000 live births.
- Source of U.S. All Races live birth data: Ken Keppel, Division of Reproductive Statistics, NCHS (personal correspondence 09/01/98).

This trend translates into infant mortality rates among AI/AN that far exceed those of the U.S. All Races infant population when injury causes are compared. Although the number of fatal injuries among AI/AN are small, when converted into a rate, AI/AN die from injuries at rates surpassing the rest of the country for every injury cause (see Table 4). In fact, overall, AI/AN infants are more than two times as likely to suffer a fatal injury than their U.S. All Races counterparts.

Among the U.S. All Races infant population, unintentional injuries are not one of the ten leading causes of death until the second month of life (see Table 2). Unintentional injuries are the third leading cause of death among U.S. All Races infants between the third and ninth months of age; comparatively, unintentional injuries are the second leading cause of death among AI/AN by the fifth month of life. Therefore, although both populations experience steady increases in the rank of fatal injuries as age increases, injuries become a leading cause of death among AI/AN infants at an earlier age. The result of this trend is extraordinarily high rates of injury death among AI/AN infants.

Another interesting finding is the lack of variation in the number of injury deaths during the first year of life. Recognizing that the number of AI/AN infant deaths during the three-year interval of this study is small, injury deaths nevertheless vary little by month of age (see Table 1). Unintentional injuries range between three and six deaths per month, with just two exceptions (the sixth and ninth months). Similarly, intentional injuries fluctuate between one and five deaths. It is likely that even less variation would exist if the number of years included in the study were increased.

While the number of injury deaths varies very little from one month to the next, the composition of these injuries does change as age increases. During the first four months of life AI/AN infant injury mortality is attributed entirely to homicide and motor

vehicle-related deaths. By the fifth month, however, the composition of injuries begins to change. In addition to homicide and motor vehicle-related deaths, drowning, falls, and fire/burns begin to account for a portion of infant injury death. These three additional mechanisms of injury accounted for five, four, and one death during the 1992-1994 triennium, respectively. One explanation for the changing composition of fatal infant injury is the increased exposure to environmental hazards that is synonymous with the enhanced mobility of an infant that is learning to crawl.

The third, and possibly most surprising finding associated with this research, is the significant role of intentional injuries (in this case homicide) as a cause of death among AI/AN infants. As Table 4 indicates, infant mortality due to homicide resulted in 15 deaths per 100,000 live births during the period 1992 through 1994. The AI/AN homicide death rate is therefore nearly twice that of the U.S. All Races rate of 8.2 deaths per 100,000 live births. Additionally, homicide deaths among AI/AN account for 43 percent of all infant injury deaths during the 1992-1994 triennium.

Lastly, although other types of fatal injuries begin to increase during the fifth month of life, homicide and motor vehicle-related deaths are the only two causes of injury death among AI/AN infants that remain a significant cause of death throughout the entire first year of life. These two causes account for nearly 40 percent of all injury-related infant deaths. These are important trends to recognize, particularly when considering the development and implementation of interventions designed to prevent infant deaths. Interventions that are effective in reducing these two leading causes of infant mortality could lead to a substantial reduction in the infant mortality rate among AI/AN.

#### Conclusions

Despite the wealth of knowledge describing the epidemiology of injuries among AI/AN, few studies have addressed the role of fatal injuries among AI/AN infants. Studies that have attempted to characterize injuries as a cause of death among AI/AN infants have not analyzed mortality by the infant's age in months. Therefore, these trends have been, to some degree, distorted to this point.

To address these shortcomings, this study analyzed infant mortality through the application of a more refined approach. In doing so, the role of injuries as a cause of infant death was more clearly defined. This analysis has demonstrated that injuries are a significant cause of infant death among AI/AN, and has described subtle trends in injury mortality by the infant's age in months. Homicide and motor vehicle-related deaths are common injuries throughout the first year of life, while other injury types fail to emerge as causes of infant mortality until the fifth month of life. Thereafter, the composition of fatal injuries diversifies, causing injuries to become the leading cause of infant mortality by the tenth month of life.

The efforts to characterize the role of fatal injuries among AI/AN made in this study will be of little consequence if they are not evaluated and adopted by other researchers in the medical

community. A collective effort must be made to incorporate techniques such as those utilized here when the mortality experience of infant populations is being described. Opportunity for the application of these methods abound in the United States as infant mortality has been identified by both the Department of Health and Human Services<sup>6</sup> and the Indian Health Service<sup>7</sup> as an area of high priority. Presented with the tools to more accurately describe and analyze deaths among infants, the challenge that remains is developing and implementing sound strategies to reduce these preventable deaths.

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#### POSITION VACANCIES

Editor's note: As a service to our readers, The IHS Provider will now publish, on a space available basis, notices of clinical positions available. Indian health program employers should send brief announcements on an organizational letterhead to: Editor, The IHS Provider, The IHS Clinical Support Center, 1616 East Indian School Road, Suite 375, Phoenix, Arizona 85016. Submissions will be run for two months, but may be renewed as many times as necessary. Tribal organizations that have taken their tribal "shares" of the CSC budget will need to reimburse CSC for the expense of this service. At this time we do not plan to run ads for "positions wanted." The Indian Health Service assumes no responsibility for the accuracy of the information in such announcements.

### Certified Registered Nurse Anesthetist Claremore, Oklahoma

The Claremore PHS Indian Hospital is seeking a certified registered nurse anesthetist. This is a full time position in a three member department covering two operating rooms. Night call is taken from your home and does not involve trauma or a labor epidural service. Anesthetics are provided for a wide range of both inpatient and outpatient services including general surgery, obstetrics and gynecology, dentistry, and podiatry.

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Send CV to Paul Mobley, DO, Clinical Director, Claremore PHS Indian Hospital, 101 South Moore, Claremore, Oklahoma

74017-5091; phone (918) 342-6433; or fax (918) 342-6517.

#### Family Physician Sisseton, South Dakota

The Sisseton Indian Health Service Hospital has immediate openings for two family practice physicians to practice the full scope of family medicine, to include obstetrics. Competitive salary and career benefits as a federal employee are offered. To discuss this opportunity, please contact Audrey German at (800) 553-2145; e-mail agerman@tnics.com; or mail your CV to the Sisseton IHS, P.O. Box 189, Sisseton, SD 57262.

#### RN Float Positions Whiteriver, Arizona

The Whiteriver Service Unit is a 45-bed hospital nestled in the tall, cool pines of the White Mountains of Arizona, serving the White Mountain Apache Tribe and surrounding areas. Because the area abounds in beauty and nature, with more than 40 lakes and 600 miles of rivers, there is virtually every outdoors activity available. The Whiteriver Service Unit has three openings for RN GS-10 float positions. The incumbent will float between the Outpatient, Ambulatory Surgery, and Emergency Departments, and the Obstetrics, Pediatrics, and Adult Care Units. Knowledge in the above mentioned areas is required. Certification is required in two of the following areas: ACLS, PALS, TNCC, NRP, and ALSO. Come and join one of the stellar service units in the Indian Health Service and enjoy year round mild weather and rewarding work in a beautiful setting. For further information, please contact Donna Huber, RN, Nurse Executive, at (520) 338-4911.

Editor's note: This is the third in a series of articles by Dr. Kitzes on the subject of pain and palliation (see also the October 1998 and February 1999 issues of The Provider. Readers who would like to know more about this subject are encouraged to examine two additional resources.

The Model Guidelines for the Use of Controlled Substances for the Treatment of Pain is a policy document of the Federation of State Medical Boards of the United States, Inc. published in May 1998. These guidelines focus on "encouraging the medical community to adopt consistent standards, promoting the public health by facilitating the provision of adequate and effective pain control and educating the medical community on treating chronic pain within the bounds of professional practice." Their address is 400 Fuller Wiser Road, Suite 300, Euless, Texas 76039-3855. Their phone number is (817) 868-4000. Go to their website at http://www.fsmb.org/ and look under "policy documents" to see these guidelines.

The second resource is the consensus statement of the American Academy of Pain Medicine and the American Pain Society entitled The Use of Opioids for the Treatment of Chronic Pain. The purpose of the joint statement is to "help foster a practice environment in which opioids may be used appropriately to reduce needless suffering from pain." The address of both organizations is 4700 West Lake Avenue, Glenview, Illinois 60025-1485. The AAPM may be reached by phone at (847) 375-4731; their website is http://www.apainmed.org/. The APS may be reached by phone at (847) 375-4715; their website is http://www.apainsoc.org/. The statement may be obtained at either organization's website.

## Chronic/Intractable Pain Management: Opioid Therapy

Judith A. Kitzes, MD, MPH, Chief Medical Officer, Albuquerque Area Indian Health Service, Albuquerque, New Mexico

#### Introduction

Pain is part of the human experience, and is a frequent and compelling reason for seeking health care services. While pain perception is clearly influenced by personal and cultural factors, some aspects of the pain experience appear to be universal. Pain greatly affects a person's well being, intruding into everyday activities, causing worry and emotional distress, and disrupting social performance. Little has been published about pain and pain management in American Indians and Alaska Natives. An Internet search for medical articles relating to pain and, specifically, Native Americans returned only two titles.<sup>1,2</sup>

American Indians and Alaska Natives, and more commonly the elderly, experience the painful manifestations of diabetes mellitus, arthritis, heart disease, cancer, traumatic injury, and other chronic conditions. In addition, these same elders probably experience unrelieved, severe, end-of-life pain similar to that documented in the largest study to date investigating end-of-life care in the United States (SUPPORT), where 40% of persons dying experienced severe pain most of the time.<sup>3</sup>

#### **Definition**

Pain is a complex phenomenon, a mix of unpleasant sensory

and emotional experiences. Unfortunately no standardized biological markers exist and the most accurate evidence of pain and its intensity is based on the patient's self report. Therefore, a concise definition of chronic/intractable pain remains elusive. The following are several definitions:<sup>4-6</sup>

- Pain present most of the time for a period of six months or more during the prior year.
- Persistent or episodic pain of a duration or intensity that adversely affects the function or well being of the patient, attributable to any nonmalignant etiology.
- Pain resulting from a chronic condition or terminal process.
- Pain from an acute injury that lasts longer than expected.
- · Pain for which there is no discernible cause.
- Pain in which the cause cannot be removed or otherwise treated and no relief or cure has been found after reasonable efforts.

#### **Pain Management Principles**

The following are important principles to follow in the management of patients who are experiencing pain:

- 1. Assess for pain.
- 2. Try to establish the cause of the pain.
- 3. Use interdisciplinary team management.
- 4. Accept the subjective nature of pain.
- 5. Establish a therapeutic alliance with the patient (and family).
- 6. Don't delay in treatment of pain.

7. Use standardized pain management guidelines.

Let's look at each of these in detail.

#### Routine Assessment of Pain as the Fifth Vital Sign

Clinicians appreciate the potential clinical harm a person can experience from undetected fever, tachycardia, hypertension, or tachypnea. Unassessed, and therefore untreated pain may cause increased pulse, blood pressure, and respiration; fatigue; sleep disturbance; anxiety; anger; depression; and decreased activity and mobility, all risk factors for declining health status in the elderly. Routine pain assessment as a fifth vital sign can be as simple as using one of the established verbal or visual pain intensity charts and documenting the patient's self report. Characterization of the nature of the pain includes its location, quality (dull, sharp, tingling, shooting, stabbing, electrical), temporal profile (onset, duration, pattern), severity, and exacerbating or relieving factors.

#### Attempt to Establish the Cause of P ain

Understanding the cause of pain can often point to specific palliative treatment. Pain should not be accepted as "inevitable." Evaluate the pain for its relationship to the underlying disease, to current or prior treatment, to known complications of the disease, or to some unrelated pathology.

### Use of Other Members of an Inter disciplinary Team for Assessment and Management

The expertise of nurses, social workers, pharmacists, spiritual counselors, physiotherapists, behavioral health specialists, and complementary therapy specialists is key to adequate pain management. Therapy may include pharmacologic and non-pharmacologic interventions, education of the family and caregivers, and ongoing review and updating of the plan.

### Accept the Patient's Self Report of Pain and Establish a Therapeutic Alliance

Only by accepting the patient's self report and examining one's concerns about the potential use of high doses of medication can the provider and patient enter into a therapeutic alliance based upon mutual consent, respect, and interdependence. Often, in our settings, the family needs to be a part of this alliance. Only if palliative goals are arrived at together can successful outcomes be achieved.

#### Do Not Delay Treatment of Pain

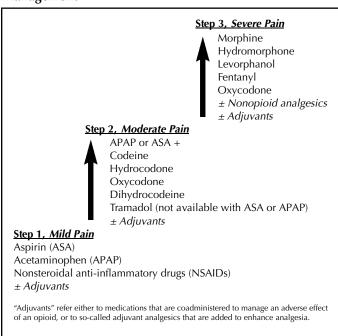
It is not appropriate to withhold treatment for pain while awaiting investigations of the underlying etiology. Unmanaged pain may lead to changes in the nervous system that could reduce its responsiveness to future treatment.

#### **Use Standardized Pain Management Guidelines**

Analgesic drugs are the mainstays of managing pain, with the choice of drug mandated by the severity of the pain. Medications should be administered in standard doses at regular intervals in a stepwise fashion. Patients should not have to earn their medication by experiencing breakthrough pain. If a nonopioid or a weak opioid is not sufficient, a strong opioid should be used. Adjuvant analgesic drugs such as corticosteroids, nonsteroidal antiinflammatory drugs, tricyclic antidepressants, anticonvulsants and some antiarrhythmics may be added at any time.

Morphine is the most commonly used strong opioid analgesic. Once dose titration is achieved, maintenance can be accomplished through sustained release morphine preparations. Rectal and subcutaneous morphine preparations are also available. Intravenous administration is rarely required. Adequate pain management must include close attention to the constipating side effects of opioids.<sup>7</sup>

Figure 1. The WHO Three Step Ladder for Pain Management 8



#### **Additional Advice**

All pain management guidelines take into account the difference between opioid "physical dependence" and "addiction." Physical dependence is the physical adaptation to the presence of an opioid and is characterized by signs of withdrawal. Addiction is a sociologic term that refers to compulsive drug use, severe psychological dependence and continuing use despite harm. Persons with chronic pain and terminal illness on continuous opioid therapy may become physically dependent, but only one percent have the potential for addiction. Tolerance to opioids is not common. Increasing doses of morphine are usually explained by disease progression, not pharmacologic tolerance.

Many physicians have an exaggerated view of the risk of respiratory depression when using opioids to relieve pain. Pain is a potent stimulus to breathe, and pharmacological tolerance to respiratory depression develops quickly. Opioid effects are quite different from those experienced by a patient who is not in pain who receives similar doses. As doses increase, respiratory

depression does not occur suddenly in the absence of overdose. Adequate ongoing assessment and appropriate titration of opioids will prevent severe respiratory depression. In the practice of palliative medicine, opioids are used as a therapeutic intervention for dyspnea.<sup>9</sup> In terms of organ toxicity, opioids, unlike aspirin, acetaminophen, NSAIDS, or other alternative analgesics, are known to be relatively safe and nontoxic, even for long term treatment.<sup>10</sup>

#### **Summary**

The Mayday Scholars Survey, Barriers to Effective Pain Management, 1999, states, "The practice of pain management suffers because clinicians, patients, insurers, and policymakers fail to understand the effects of pain and effective treatments."

There are many obstacles to compassionate pain management in our society. However, as clinicians, we can continue to educate ourselves to the "effects of pain and effective treatments" and become healers, not barriers.

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#### **Resources for Guidelines**

American Geriatrics Society: The Management of Chronic Pain in Older Persons Guidelines. 770 Lexington Avenue, Suite 3000, NY, NY 10021

Agency for Health Care Policy and Research (AHCPR): Clinical Practice Guidelines for Cancer Pain and Acute Pain. www.ahcpr.gov

American Academy of Hospice and Palliative Medicine: Primer of Palliative Care, www.aahpm.org

American Medical Association: Education for Physicians on End-of-life Care. www.ama-assn.org

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