

## **THE ABERDEEN INDIAN HEALTH SERVICE INFANT MORTALITY STUDY: DESIGN, METHODOLOGY, AND IMPLEMENTATION**

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*Abstract: Of all Indian Health Service areas, the Aberdeen Area has consistently had the highest infant mortality rate. Among some tribes in this area the rate has exceeded 30/1000 live birth and half the infant deaths have been attributed to Sudden Infant Death Syndrome, a rate four to five times higher than the national average. The Indian Health Service, Centers for Disease Control and Prevention, National Institute of Child Health and Human Development, and the Aberdeen Area Tribal Chairmen's Health Board collaborated to investigate these high rates with the goals of refining the ascertainment of the causes of death, improving cause-specific infant mortality rates and identifying factors contributing to the high rates. Ten of the 19 tribes or tribal communities, representing 66% of the area population, participated in a 4-year prospective case-control study of infants who died after discharge from the hospital. Infant care practices and socio-demographic, economic, medical, health care, and environmental factors were examined. The study included parental interviews, death scene investigations, autopsies, neuropathology studies, medical chart abstractions, blood cotinine assays, and a surveillance system for infant deaths. Controls were the previous and subsequent infants born on the case mother's reservation. From December 1, 1992 until November 30, 1996, 72 infant deaths were investigated. This report describes the study methods and the model employed for involving the community and multiple agencies to study the problem of infant mortality among Northern Plains Indians. Data gathered during the investigations are being analyzed and will be published at a later date.*

### Historical Account

“As I now place this meat in your mouth, we should all remember how merciful *Wakan-Tanka* is in providing for our wants. In the same manner you must provide for your children!”  
The Sacred Pipe - Black Elks’ account of the Seven Sacred Rites of the Oglala Sioux (Black Elk, 1953, 1989).

The people of the Northern Plains consider the child to be sacred and close to the Great Spirit. They charged the members of the Perinatal Infant Mortality Review (PIMR) Committee, the Infant Mortality Study Steering Committee, and the staff of the study with the job of examining why the babies in the Northern Plains were dying at excessive rates. This paper will examine the methods used to do this.

In 1988, on the advice of tribal representatives, the PIMR Committee wrote to the National Institute of Child Health and Human Development (NICHD) and the Centers for Disease Control and Prevention (CDC) regarding the high infant mortality and Sudden Infant Death Syndrome (SIDS) rates in the Aberdeen Area. This information was shared with the Aberdeen Area Tribal Chairmen’s Health Board (AATCHB). Together, the Health Board and the Aberdeen Area Indian Health Service (AAIHS) planned for a study on infant mortality among tribes in the Northern Plains. A steering committee was formed to oversee the study during its design and implementation and included members from the tribal communities, Harvard University, University of Colorado, University of South Dakota, University of North Dakota, Black Hills Laboratory, LCM Pathologists, the NICHD, CDC, and Indian Health Service (IHS). A wide range of health disciplines represented as follows: forensic pathology, pediatric pathology, neuropathology, pediatrics, nursing, family practice, obstetrics, coroners, and epidemiology.

The Aberdeen Area Indian Health Service serves 19 tribal communities with approximately 100,000 American Indian residents in North and South Dakota, Iowa, and Nebraska. From 1990 to 1992 meetings were held with tribal councils and communities to discuss the study protocol. The Principal Investigator (PI) and the staff met with each tribal council independently to discuss the protocol and solicit support for the study through resolutions of support from the tribe. Each tribe was given the complete protocol and the PI or Project Coordinator met with each council to discuss the study and answer any questions. The tribal councils were then asked for resolutions of support. During these meetings, the study design was revised to address concerns by the community. The study coordinator met with the Medicine Wheel Coalition of Medicine Men to ask their advice on the study protocol and to get their input prior to implementation of the study.

ABERDEEN IHS INFANT MORTALITY STUDY 3

Throughout this time, the Massachusetts Sudden Infant Death Syndrome Center was involved in providing support to communities experiencing infant loss. Dr. Mandell, Ms. McClain and Dr. Welty consulted with Sydney Keith, a traditional Lakota leader, to develop and print a brochure specifically for Lakota families who have lost a child to SIDS (Keith, Mandell, McClain, & Karsakov, 1992). The information brochure is unique in regard to the cultural and spiritual values of the American Indians in this area. Dr. Mandell and Ms. McClain also provided training and information seminars. The Massachusetts SIDS Center and study staff supported and participated in several healing ceremonies for the families. A grief support protocol was added to the study protocol and staff trained to provide grief counseling to the parents on the advice of the Massachusetts SIDS Center. Study staff with the assistance of the Massachusetts SIDS Center provided cultural sensitivity training for police staff, county and tribal coroners, and other health professionals. The staff supported and assisted the Healthy Start Programs in several communities in "Wiping of the Tears" ceremonies for the families for the duration of the study. Rosanne English, Director, Pennsylvania SIDS Center, provided Parent Peer Support training at the request of parents in two tribal communities.

During the study, meetings were held with elders of the tribes to address ways to reduce infant mortality on the reservations. The elders actively participated in community meetings coordinated by the study staff with the assistance of the Massachusetts SIDS Center to provide education on infant mortality and SIDS.

In 1992, the proposal for the Aberdeen Area Infant Mortality Study was fully approved by the Aberdeen Area and the National Indian Health Service institutional review boards (IRB). Ten tribal communities (nine tribes and one urban American Indian community) passed resolutions supporting participation in the study.

### Background

American Indians and Alaska Natives have historically had substantially higher infant mortality rates than Whites in the United States (Table 1). Among American Indians, the excess mortality is not due to higher death rates among neonates (infants aged 0-28 days) or infants with low-birth-weight (< 2500 g at birth) (Honigfeld & Kaplan, 1987; Kleinman, 1990; Singh & Yu, 1995).

Among infants with normal birth weights (> 2500 g at birth), however, the infant mortality rate is substantially higher among American Indians and Alaska Natives than Whites (8.4 versus 4.0 per 1,000 live births, 1996) (Indian Health Service, 1998; Pezzino & Iyasu, 1996). Furthermore, in 1985-1987, over half the infant deaths among American Indians and Alaska Natives

occurred in infants aged 28 to 365 days, the post-neonatal period, compared with about one-third of all infant deaths among other racial and ethnic groups (Table 1) (Kleinman, 1990). This was also true in 1995, when the total infant mortality rate among American Indians and Alaska Natives was 13.3/1000 live births and the post-neonatal mortality rate was 7.2/1000, compared with 6.3/1000 and 2.2/1000 for Whites respectively (MacDorman & Singh, 1998).

**Table 1**  
**Race Specific Infant Mortality Rates, 1985-1987 (per 1,000 live births)**

|               | White | Black | AI/AN |
|---------------|-------|-------|-------|
| Infant        | 8.6   | 18.2  | 13.3  |
| Neonatal      | 5.5   | 12.0  | 6.1   |
| Post-neonatal | 3.1   | 6.2   | 7.2   |

Singh, 1995

AI/AN=American Indians/Alaska Natives

Deaths from SIDS account for a large proportion of post-neonatal deaths among American Indians. NICHD defines SIDS as the sudden death of an infant less than one year of age, which remains unexplained after thorough case investigation, including a complete autopsy, examination of the death scene, and review of the clinical history (Willinger, James, & Catz, 1991). SIDS is the leading reported cause of infant mortality among American Indians and Alaska Natives, whereas for U.S. overall and for U.S. Whites, congenital anomalies are the leading cause (Indian Health Service, 1996). Death rates from congenital anomalies, short gestation, and unspecified low birth weight do not differ substantially between American Indians and White infants whereas SIDS rates among American Indians were almost three times that of Whites (Indian Health Service, 1998; MacDorman & Singh, 1998; Pezzino & Iyasu, 1996).

Among all Indian Health Service (IHS) areas, the Aberdeen Area has consistently had the highest infant mortality rate. The infant mortality rate for 1990-92 was 15.8 per 1,000 and was the highest for all IHS areas. In 1990-1992, the SIDS rate was also highest in the Aberdeen area at 4.6/1000 live births, more than four times the U.S. rate (Indian Health Service, 1996).

Historically, confirmation of the high incidence of SIDS in the Aberdeen Area has been hampered by a low autopsy rate, inadequate death scene investigations, questionable census figures, a highly migratory population, changing definitions of tribes and tribal membership, and turnover among health care providers, suggesting that the SIDS rate for the

Aberdeen Area may have been overestimated. A report in 1990 found that only about 60% of the infant deaths in this area received an autopsy (Oyen, Bulterys, Welty, & Kraus, 1990). In fact, a number of the presumed SIDS deaths reviewed by the Aberdeen Area PIMR Committee prior to the present study did not fit the classic profile of SIDS and remain unexplained.

Because these deaths did not meet the classic profile of SIDS, the initial purpose in this pilot study was to generate specific hypotheses that could then be modified and used subsequently as a model for researching infant mortality among American Indian and Alaska Native populations. As very little is known about potential reasons for the excess infant mortality in American Indian/Alaska Native populations, we decided generating hypotheses was more appropriate than testing hypotheses that have resulted from studies conducted in other populations.

#### **Study Questions and Design**

There were three main study questions:

1. What proportion of SIDS deaths reported on death certificates of study community residents meet the NICHD definition?
2. What risk factors for SIDS and for infant deaths occurring after hospital discharge can be identified by interviewing parents and reviewing medical records using a case-control methodology?
3. Are specific pathologic lesions associated with SIDS?

To help answer the study questions, existing surveillance and new research data were evaluated in addition to developing a permanent system for community-based fetio-infant death review.

#### **Study Population**

The ten American Indian tribal groups that participated in the study comprised two-thirds of the Aberdeen Area Indian Health Service population; four were in North Dakota and six in South Dakota. For each tribal group, appropriate state or tribal-enabling legislation was either in place or enacted during the study to permit investigation of infant deaths by coroners, and the relevant service unit director approved each AAIHS site. As Baines (1992) and Welty (1996) point out, tribal sovereignty needs to be respected, so we included only tribal communities that passed a resolution of support, which ensured that their sovereignty was recognized and respected. A certificate of confidentiality was obtained from the National Institute on Alcohol Abuse and Alcoholism to protect against disclosing the identities of the research participants.

## Participant Selection

### Cases

The cases for this study were all American Indian infants, who died within 365 days of birth, who had lived on or near reservations or communities participating in the study, and whose death occurred between December 1, 1992, and November 30, 1996 (Table 2). Infants were considered to be American Indian if one of the parents was an enrolled tribal member or was eligible for care at an IHS facility. Infants who died before being discharged from the hospital were excluded. However, infants who had come home from the hospital, became ill, and subsequently died in the hospital were included in the study. The cases were reported to the study staff from public health nurses, medical record department staff, emergency room staff, coroners, and members of the PIMR Committee. Some cases were identified by obituaries in Indian Country Today and local newspapers. All were extensively reviewed by the PIMR.

**Table 2**  
**Eligible Deaths in Aberdeen Area Indian Health Service Area**  
**by Year of Death**

|                             | 1992 <sup>1</sup> | 1993 | 1994 | 1995 | 1996 <sup>1</sup> | 1997 | Total |
|-----------------------------|-------------------|------|------|------|-------------------|------|-------|
| Deaths <sup>2</sup>         | 2                 | 25   | 18   | 18   | 9                 |      | 72    |
| Autopsy <sup>3</sup>        | 2                 | 19   | 13   | 14   | 8                 |      | 56    |
| Interview Case <sup>4</sup> | 2                 | 19   | 19   | 15   | 9                 | 1    | 65    |
| Control                     | 0                 | 39   | 43   | 37   | 25                |      | 144   |

<sup>1</sup> start of study December 1, 1992 and end of study November 31, 1996

<sup>2</sup>Obtained from vital statistics reports of North Dakota, South Dakota, Iowa and Nebraska

<sup>3</sup>Autopsies of the 72 deaths

<sup>4</sup>All interviews for both cases and controls including controls where the case wasn't interviewed

The decision to include an infant if born to an American Indian father was part of the protocol because most of the American Indian fathers had close ties to Indian communities. There was only one case where the father was American Indian and the mother non-Indian and in that case there were close ties to the American Indian community and even though we felt it appropriate to include that case, we were unable to locate the family.

ABERDEEN IHS INFANT MORTALITY STUDY 7

### Controls

For each eligible case, two control American Indian infants were matched by community and infant age so we could analyze all other variables including mothers' age and child's sex, as possible risk factors for infant mortality and SIDS. Control infants were identified from three sources; (a) the service unit's IHS patient registration system which included all patients receiving care at that service unit, (b) the labor and delivery log, and (c) the public health nurses' log. All three data sources were used to verify which two infants were born closest to the case infant. If the biologic mother was an enrolled member of a participating tribe but was not residing in a reservation community at the time of the case infant's birth, the next-born and previous-born American Indian infants from the service unit serving the tribe in which the mother was enrolled were selected. If any control parent was unavailable or refused to participate, the infant born immediately before or after the next-born infant was selected. When an infant twin died, we did not include the surviving twin as a control because of overmatching, instead selecting the next or previous-born infants as explained above and as Schlesselman (1982) discusses in his book on case control studies. We did, however, include a twin as a control infant when that infant was the closest infant born to a singleton case infant.

### Data collection

#### Existing Data

Both existing and new data were collected for the study. Existing data consisted of birth and death certificates, medical records (including prenatal, postpartum, and pediatric care), emergency medical services reports, autopsy reports, and police reports. Parents of case and control infants signed release forms to permit review of medical records as well as consent forms for interviews and for blood cotinine tests. Reviewing paternal medical records was initially proposed but was not done because obtaining paternal consent was often not feasible.

#### New Data

New data included the results of a death scene investigation, complete autopsies, cotinine assays, water testing, and parental interviews.

#### **Death Scene Investigation**

The death scene investigation form consisted of 233 items to be completed on all unattended deaths by coroners who had been trained in the form's use. Death scene investigation forms were completed consistently in only two tribal communities. Either the Federal Bureau of Investigation (FBI) or Tribal Police investigated all infant deaths since according to the Major Crimes Act of 1885, the FBI has to investigate any suspected crimes on reservations (Pevar, 1992), and unattended or unexpected deaths often fall into the category to be investigated. After police or FBI investigation, all of the SIDS deaths were deemed to be unexpected, not prosecutable. Records were obtained for all of the SIDS deaths from the police, emergency medical technical system, or coroner system. Randall and Randall (1999) discussed ways to address these issues.

During the time of the study, six tribes passed enabling legislation for tribal coroners. In addition, through the support of the study staff, 64 tribal members and two non-tribal individuals who work with tribes have been trained and a coroner manual developed (Randall, 1997; Randall & Randall, 1999).

#### **Autopsy**

The study autopsy protocol was more extensive than the routine forensic autopsy. The protocol involved taking microscopic sections; performing toxicology studies, a cotinine assay, and a bacterial blood culture; and measuring electrolytes, blood urea nitrogen and glucose in the vitreous humor. The autopsy and neuropathology protocols were discussed at a meeting with area spiritual leaders particularly for their cultural ramifications and were modified according to the recommendations received. Autopsies were performed primarily by two pathologists taking the lead role in following the protocol. Neuropathologic studies were carried out at Boston Children's Hospital. The protocols were revised to have all specimens destroyed, in a manner consistent with advice from spiritual leaders, within three years after completion of the study.

#### **Cotinine Assay**

Blood for the cotinine assay was collected on both cases and controls, the analysis was performed by CDC. A pilot study of available infants at a well-child clinic was utilized to test the system set up to analyze the serum cotinine. Serum cotinine data were obtained for 63 control infants but on only seven case infants. The distances required for travel of the body from the reservations to the site of the autopsy led to hemolysis of the

blood, rendering the samples unsuitable for a cotinine assay in all but the seven cases.

#### **Water Analysis**

Some of the tribes specifically requested the analysis of the drinking water in the homes of the infants who died. This request was incorporated into the study protocol and involved measuring selenium (reportedly present in abnormal quantities in some of the water in the Northern Plains), nitrates (which have caused infant deaths in these states), bacteria which are common in well water and are capable of causing fatal infection, lead (effects of various concentrations are not known), and petroleum products (which have reportedly been smelled in the local water). Well water from one home not on a system was tested and the results were negative. Homes on community water systems are tested periodically by the IHS Environmental Office and these tested negative during this time period. Each office sent a report of their tests to our office.

#### **Parental Interview**

The parental interview and consent forms had been pilot tested in four steps for ease of use and level of parental understanding prior to final approval by the National IHS IRB and the Aberdeen Area IHS IRB. In accordance with IRB guidelines on pilot testing personal interviews with no more than nine interviews at each step. Our approach was patterned after the outline by Schlesselman (1982) and Burhansstipanov (1996), and was intended to ascertain whether parts of the interview were culturally inappropriate or insensitive. After training for consistency of interviewing process, two nurse interviewers, both with four-year degrees in nursing and one of them with a Masters degree in public health, completed all the parental interviews. The nurses accompanied each other on two to three interviews every three to four months to verify that each was conducting the interview consistently and that they both executed them in the same way. After the interviews, ways were discussed to ensure consistent interview techniques.

The interviews were typically conducted within 2-4 weeks after the death, usually in the parents' home, but sometimes in another place they found acceptable as defined by Burhansstipanov (1996). Out of respect for the families' cultural practices, case parents were not interviewed in the first week after the death. If the case parents refused to be interviewed or could not be located, the medical records were reviewed for classification of death by the Aberdeen Area PIMR Committee. Control interviews were usually carried out within one to four weeks after the death of the index case. Interviews required as little as 45-minutes for foster parents for both cases and controls to as much as two to four hours for case parents and

covered socioeconomic, environmental, and demographic factors; maternal medical history; and the medical history and sleeping habits of the infant.

The interview questionnaire was highly structured; most of the questions were closed-ended but some open-ended questions were included that allowed for discussion. At the end of the interview, study participants were asked whether they felt anything could be done to improve the health of children in the area.

If either case or control infants were being cared for by foster parents when the case infant died, both the foster parents and the biologic parents were interviewed separately. Foster parents were asked the questions on infant care and socioeconomic factors and the biological mother was asked to supply prenatal information. Parents of case and control infants were paid \$10 for participation in the study but they were not told that they would be reimbursed prior to the interview and agreeing to participate. Thus payment for participation was not an incentive to participate in the study.

#### **Informed Consent and Confidentiality**

The consent forms were reviewed paragraph by paragraph with each participating parent before any questions were asked. Parents were told that neither their participation nor their responses would interfere in any way with the care they received from the Indian Health Service and that they were free to stop the interview at any time. They were given a toll-free number to call the AAIHS IRB chairman, if they had any questions regarding their participation, or if they changed their mind about inclusion in the study.

The interview nurses emphasized that the responses to all questions including those pertaining to alcohol and substance use would remain confidential. The participants were also informed that a federal certificate of confidentiality was issued to ensure that the data collected by the study would remain confidential. A copy was given to each participant. The case parents were also advised that the only exception to maintaining confidentiality would be if the interview revealed possible child abuse, in which case the appropriate authorities would be notified.

#### **Grief Counseling and Health Education**

The interviewers counseled case parents about their grief and provided information, as appropriate, on SIDS, the grief of parents, grandparents, fathers, mothers, and siblings; having more children; twin deaths; death anniversaries; and infant mortality. Parents were informed of the SIDS risk reduction messages of the "Back to Sleep" campaign and were briefly instructed on parenting skills, smoking and alcohol cessation, breastfeeding, infant and well child care, maternal care, the effects of stress, effective discipline for American Indian children, nutrition, and child abuse

ABERDEEN IHS INFANT MORTALITY STUDY 11

and prevention. We attempted to make the educational materials as culturally appropriate as possible and contacted other American Indian agencies for their educational materials on American Indian health as several authors have shown to be a necessary part of research (Burhansstipanov, 1996; Schlesselman, 1982).

**Data entry and storage**

Data were entered and stored at the study site using Epi-Info, version 5 (Dean, Dean, Burton, & Dicker, 1990) and later sent to CDC, whose staff checked for consistency and errors in data entry. Data were stored in locked cabinets and data sets were password-protected; only the data entry person and the project director knew the codes. Data was double entered for 20% of the data.

**Data analysis**

The IHS, CDC and the NICHD will jointly analyze the data with input from the Aberdeen Area Tribal Chairman's Health Board and the steering committee. Both matched and unmatched analysis, using SAS (SAS Institute, Inc., 1995), is planned. The analysis will examine factors that may increase the risk of infant mortality or SIDS. Risk factors to be analyzed, such as found by Bulterys (1990), Bulterys, Greenland, and Kraus (1990), Kraus and Bulterys (1991), Kleinman (1990), and Hoffman and Hillman (1992), include those previously described in the literature as well as other factors suggested by the study. Information on socio-demographic, economic, medical, health care, environmental, and cultural factors related to infant care practices will all be examined. As the study instruments contain a large number of variables, numerous factors will likely emerge as warranting further study.

**Quality Control**

Quality assurance for determining cause of death was consistently maintained through review of the deaths by the Aberdeen PIMR Committee and the steering committee at their biannual meetings. The PIMR Committee, which is composed of health professionals and tribal representatives from the Aberdeen Area as well as representatives from police departments, coroner departments, state health departments, universities, and hospitals; reviewed medical records, autopsy reports, death scene investigations and assigned a final diagnosis. All of the agencies involved used this forum to formulate and recommend ways to reduce infant mortality. Members of each committee signed confidentiality statements at the beginning of each mortality review session.

A fourth year medical student, a nurse practitioner, and a nurse were hired to abstract and compare the data on the records forms for consistency and conformity among all of the abstractors. This was done on the medical records abstraction, autopsy, and neuropathology forms. If discrepancies were found, they were reviewed by the co-principal investigators and corrected (Schlesselman, 1982).

### Results

The initial study results were described in a report to the tribes produced by the Centers for Disease Control and Prevention with the assistance of NICHD and IHS. Interview completion was 90% for cases and 100% for controls. The cases that were not interviewed had either left the area or were unable to be located. There were 72 infant deaths and two control interviews were completed for all cases for a total of 144 control interviews (Randall, Welty, Iyasu, & Willinger, 1998).

### Discussion

The goals of the AAIHS Infant Mortality Study (AAIMS) were to determine the cause of infant death within participating reservations of the Aberdeen Area using defined methods of case ascertainment, and to identify risk factors for sudden infant death. These goals were developed from within the community by tribal members and IHS staff through tribal meetings and the Perinatal Infant Mortality Review (PIMR) process. From study inception until its completion, the achievement of these goals involved a unique collaboration that developed between tribes, federal agencies, private organizations, state health departments, and universities. Such a collaborative effort has not often occurred in American Indian communities.

To facilitate cultural sensitivity, community involvement, and successful, sustained recruitment of participants, the various tribal councils, tribal elders, spiritual leaders, health committees, and tribal communities were involved. The tribal councils and health boards were consulted on the study design, implementation, and evaluation at regularly scheduled formal meetings. In addition tribal representatives were members of the study's Steering Committee. There were discussions of cultural issues related to the autopsy, development of appropriate consent forms and study brochures, and wording of interview questions. Specific concerns raised by tribal members such as water quality and alcohol consumption were addressed in the study.

The social success of the study, according to members of the Aberdeen Area Tribal Chairmen's Health Board, depended upon several factors (personal communication, Charles Murphy, Sept. 22, 1993). First,

we hired members from the tribal groups as staff who helped to connect the research to the community as mentioned by Burhansstipnov (1996) and Brown and Vega (1996). Second, the nurse interviewers, who are American Indian, were familiar with the culture and communities and were empathetic with the parents. These factors explain the high participation rate and the good rapport the study had with the participating tribes. As late as August 1996, additional tribes requested to become part of the study but we had to deny their request since the data collection ended November 30, 1996. Training and support services were provided to all AAIHS tribes regardless of whether they were a part of the study or not. In September 1997, a meeting was held for all tribes within the Aberdeen Area to communicate preliminary findings from the study and to obtain feedback from the tribal members on how this information should be used. A report to the tribes includes input from the meeting, a description of the study, preliminary findings, and recommendations from conference participants (Randall, Welty, Iyasu, & Willinger, 1998).

There were many challenges in accomplishing study goals in the context of serving the needs of the community. A uniform surveillance and death investigation had to be established. The surveillance system was successfully put in place with the help of the IHS Public Health Nurses, IHS Medical Records, and Northern Plains Healthy Start despite the scattered rural health facilities and large distances which are difficult to negotiate under the harsh weather conditions of the Northern Plains. The surveillance system captured all but one of the deaths in the study area within two weeks of occurrence.

The death investigation system was more difficult to establish. Annual formal training sessions were held for coroners, health professionals, and any other individuals involved in the investigation of infant death. The training addressed elements of the investigation, diagnosis, cultural sensitivity, promotion of nonjudgmental understanding of factors that contribute to infant death, improvement of local infant death reviews, improvement of referral systems for families who have experienced the loss of an infant, and the development of case management systems for those families (Randall & Randall, 1999). We attempted to obtain enabling tribal legislation for coroners on all reservations but did not succeed. At the end of the study, tribal coroners were only operating on a regular basis on three reservations. One of the tribal coroners has since been asked to serve as coroner for a neighboring tribe. State coroners, Bureau of Indian Affairs (BIA) law enforcement officials, FBI, or tribal police performed coroner functions in the other communities (Randall, 1997). Police records and emergency medical system reports were used in the cases where death scene investigation reports were not filled out completely. Through this process, a high proportion of sudden unexpected infant deaths had an autopsy and death scene investigation, which has allowed us to confirm a high rate of SIDS in this population.

In addition, a grief support system for those who suffered an infant loss needed to be established. Annual formal training was provided for health professionals in grief counseling and parent peer support groups were established on two reservations. Efforts at establishing and maintaining parent peer support groups are still underway on two reservations. There were initial concerns by some tribal chairs that the parental interviews would upset the families who lost a child. However, the combination of grief counseling, working with tribal programs to provide culturally appropriate rituals for the infant loss, and referring parents for local follow-up when indicated seemed to allay these fears. It was very stressful for the staff that interviewed the 65 parents of the infants who died, and it took an emotional toll. When similar studies are conducted, stress debriefing and/or bereavement counseling should be provided to the staff conducting interviews with next of kin.

The Aberdeen Area Infant Mortality Study is the most extensive to date to examine infant mortality among American Indians. It confirmed that among Northern Plains Indians, the incidence of SIDS is high, with about half of the infant deaths at home attributable to SIDS. With 65 case interviews, we were only three cases short of our original goal of 68. It took four years instead of the planned two because of a decline in infant mortality in the area, and the episodic nature of occurrence of SIDS cases in the region. We had 90% participation rates in the parental interviews, in spite of informing parents of the need to report suspected child abuse to appropriate authorities. The high rates likely reduced response bias (Austin, Hill, Flanders, & Greenburg, 1994; Drews, Kraus, & Greenland, 1990; Schlesselman, 1982). The small number of cases may be considered a limitation of this study. However, the Tasmanian SIDS Case-Control Study provided valuable information regarding the risks in the sleep environment, involved 62 cases, and included response rates slightly lower than our study (Ponsonby, Dwyer, Kasl, & Cochrane, 1995).

Procedures were followed to ensure the quality of the data collected. Quality assurance regarding case diagnosis was maintained through review by the PIMR and AAIMS Steering Committees of each infant death at their biannual meetings. The PIMR Committee constitutes health professionals and tribal representatives from the Aberdeen Area including representatives from the State Health Departments. The PIMR Committee reviewed medical records, autopsy reports, and DSI when available and determined the final diagnosis for every case. Through this process all of the agencies involved generated recommendations and coordinated collaboration on ways to reduce infant mortality as pointed out by Wei, Wrought, Heaton, and Kincaid (1996), see Appendix I. In addition strict quality assurance procedures existed for the abstraction of medical records.

By examining the effects and interaction of the large number of factors in this study we hope to identify associations that will lead to hypotheses regarding the risk for SIDS and overall infant mortality in this

community. The ability to test the effect and interaction of the large numbers of factors is an advantage as described by Armenian and Lillienfeld (1994) in their report on case control studies. Associations and hypotheses that emerge from this study will be examined to provide recommendations for further study and testing. The study results have been presented to tribal groups for review and approval prior to publication. The results may also enable us to develop more specific interventions for the reduction of infant mortality in the Northern Plains Indians.

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ABERDEEN IHS INFANT MORTALITY STUDY 17

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#### Authors' Notes

1. This work was done by the epidemiology Program of the Aberdeen Area (AAIHS) Indian Health Service, Rapid City, South Dakota with support

provided by the National Institutes of Child Health and Human Development (NICHD), Centers of Disease Prevention and Control (CDC), Indian Health Service (IHS), and the Tribal Chairmen's Health Board (AATCHB).

2. Dr. Krogh was killed in a plane crash in Minot, ND, on February 24, 1994 while providing services to Indian communities as the Maternal Child Health Consultant for Aberdeen Area Indian Health Service. Dr. Krogh was the Principal Investigator for this study until his early death. Through Dr. Krogh's efforts, maternal and child health, prevention of maternal substance use, infant mortality and alcohol related morbidities are still a priority in this area and we are deeply grateful for his contributions.

3. NICHD, CDC and IHS funded this study through interagency agreements. The study would not have been possible without the support provided by the Aberdeen Area Tribal Chairmen's Health Board and the ten participating tribal communities. The authors would like to thank the staff at CDC and the Office of Epidemiology, AAIHS, especially Dana Bender, RN, BSN, Nurse Interviewer, IMS; Sheila Romero, secretary, IMS; Debra Bald Eagle, secretary, IMS; Vina Conroy, secretary, IMS; and Reva Bad Wound, secretary, MCH Programs; Robert Schwartz, Data Programmer, CDC; Dave Gilbertz, Data Programmer, CDC; Holly Shulman, Ph.D., Statistician, CDC; Laurie Pope, data entry, Mary Reiner, abstractor, Karen Darling, RN, BSN, abstractor and quality assurance, Jennifer Giroux, MD, quality assurance, and members of the Steering Committee for the Infant Mortality Study (IMS), the Perinatal Infant Mortality Review (PIMR) Committee, and the Northern Plains Healthy Start for their contributions to the study.

The members of these committees are as follows: Both PIMR and IMS Committees: Christopher Krogh, M.D., M.P.H., MCH Consultant, AAIHS, Principal Investigator, Chair and Member; Lyle Best, M.D., MCH Consultant, AAIHS; Dave Brewer, Coroner for the Oglala Sioux Tribe and for Shannon County; Larry Burd, Ph.D., UND School of Medicine; Sara Dye, M.D., Chief Medical Officer, AAIHS; Solomon Iyasu, M.B.B.S., M.P.H., Medical Epidemiologist, CDC; Carolyn Lofgren, Director, Liaison Services, IHS Headquarters West; Darlene Johnson, R.N., M.S., Rosebud Hospital, served as MCH consultant for the Aberdeen Area from 1988 to 1991; Hannah Kinney, M.D., Neuropathologist, Boston Children's Hospital, Associate Professor, Harvard University; Fred Mandell, M.D., Associate Professor, Harvard University, Senior Pediatrician, Boston Children's Hospital and Director, Massachusetts SIDS Program; Mary McClain, R.N., M.S.N., Project Coordinator, Massachusetts SIDS Program; Brad Randall, M.D., forensic pathologist, Sioux Falls; Donald Habbe, M.D., forensic pathologist, Rapid City, SD; Thomas Welty, M.D., M.P.H., Medical Epidemiologist, AAIHS; Marion Willinger, Ph.D., NICHD; Harry Wilson, M.D., M.P.H., University of Texas, El Paso; Gloria Randall, P.A., Lower Brule Health Clinic; Jack Estes, Coroner, Lower Brule Tribe; Pam McCloud, R.N., Turtle Mountain Comprehensive Care Facility; Leslie Randall, R.N., M.P.H., Co-Principal

ABERDEEN IHS INFANT MORTALITY STUDY 19

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Appendix I

Reduction of Infant Mortality  
Recommendations for Parents

**BEFORE PREGNANCY:**

1. Use family planning to prevent unplanned pregnancies.
2. Stop alcohol, tobacco, and illegal drug use completely BEFORE and DURING pregnancy.
3. Take folic acid prior to pregnancy to prevent neural tube defects.
4. Take parenting classes or read books about how to be good parents.

**DURING PREGNANCY:**

5. Maintain smoke-free environments for pregnant women, infants, and children.
6. Obtain prenatal care as soon as pregnancy is a possibility and make regular prenatal visits as recommended by the prenatal care provider.
7. Eat healthy foods such as fruits, vegetables, cereals, milk products and bread.

Appendix I (Continued)

**DURING PREGNANCY (Continued):**

8. Take vitamins and iron every day as directed by your prenatal care provider.

**AFTER BABY IS BORN:**

9. Breast feed babies for 12 months if possible.
10. Take the baby to the clinic or doctor's office for regular well childcare and immunizations.
11. Buckle infants and children properly in car seats ALWAYS.
12. Place infants to sleep on their BACK.
13. Stop domestic violence, child abuse, and neglect.
14. Take infants with fever to a health care facility for evaluation and treatment.
15. Use smoke detectors in all homes.
16. Avoid overheating baby by too much clothing or too many blankets.
17. Don't take your children in vehicles where the driver has been drinking.
18. Make certain that infant caretakers do not abuse alcohol or drugs.