A Fetal Alcohol Syndrome Surveillance Pilot Project in American Indian Communities in the Northern Plains

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Synopsis

A pilot fetal alcohol syndrome (FAS) surveillance was carried out in four American Indian communities in the Northern Plains by the Aberdeen Area Indian Health Service to determine the incidence of FAS and to evaluate the feasibility of establishing continuing surveillance for FAS. Baseline data on the incidence of FAS would be used by the Indian Health Service to develop and evaluate preventive interventions, including treatment programs for pregnant women who drink alcohol.

Four of the 1,022 children included in the project were found to have FAS, a rate of 3.9 per 1,000 live births. The rate is believed to underestimate the true rate of FAS because some low birth weight children were not screened, parents or guardians were reluctant to bring children suspected of FAS for evaluation, clinicians were hesitant to diagnose possible alcohol-damaged children for fear of labeling the child, and some children with FAS died before the diagnosis of FAS could be confirmed.

If the rate of FAS is similar for the 39 percent of the infants not screened and for the 25 percent of suspected infants who were not evaluated, a rate of 8.5 cases of FAS per 1,000 live births may be postulated. The authors recommend routine screening of prenatal patients for substance abuse and establishing a tracking system for low birth weight infants suspected to have FAS or other alcohol-related developmental disorders, in an effort to establish more accurate FAS rates. Such a surveillance system would identify women at risk of having alcohol-affected infants so that appropriate treatment and counseling could be provided, possibly reducing the severity of adverse effects of alcohol on their fetuses.

AMERICAN INDIANS are a high-risk group for fetal alcohol syndrome (FAS) (*1*), although FAS is found in all racial and ethnic groups (*2, 3*). In one national study of congenital malformations among children of minority groups, the prevalence of FAS among American Indians and Alaska Natives was 30 times greater than among white children (*2*). FAS rates among American Indians and Alaska Natives have been estimated to be 1.3 to 10.3 per 1,000 live births (*4, 5*). Alcohol consumption varies among Indian tribes (*4, 6, 7*), and the incidence of FAS is likely to vary similarly (*7*).

A consensus case definition for FAS was established by the Fetal Alcohol Study Group of the Research Society on Alcoholism (*8*):

1. Prenatal and/or postnatal growth retardation (weight and/or length or height below the 10th percentile when corrected for gestational age).

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2. Central nervous system involvement (including neurological abnormality, developmental delay, behavioral dysfunction or deficit, intellectual impairment and/or structural abnormalities, such as microcephaly (head circumference below the third percentile) or brain malformations found on imaging studies or autopsy).

3. A characteristic face, currently qualitatively described as including short palpebral fissures, an elongated mid-face, a long and flattened philtrum, thin upper lip, and flattened maxilla.

However, the group discouraged the use of the term "fetal alcohol effect," believing that consensus on a definition was not possible. The group agreed that if one or two categories of the case definition were met, the term "alcohol-related birth defects" (ARBD) could be used. Concern about diagnosing children with possible alcohol damage, stemming from fears of discriminatory labeling, extends to those children not alcohol damaged, but who exhibit learning difficulties, congenital trauma or infection sequelae, malnutrition sequelae, and other nonalcohol-caused deficits.

Because of considerable variation in the susceptibility of the developing fetus to the toxic effects of alcohol, other malformations or malfunctions may be present (*2, 3, 9–13*). For example, limbs and joints may be malaligned, resulting in problems with skeletal movement. Scoliosis, clinodactyly, camptodactyly, and congenital hip dislocation are associated with maternal alcohol consumption (*13, 14*). Other characteristics seen in some FAS children are aberrant palmar creases, ear malformations, microphthalmia, hirsuitism, gross motor deficits, and general health problems, such as recurrent infections (*2, 3, 9, 10, 13, 14*). In addition to physical malformations, fetal exposure to alcohol may cause learning disabilities and behavior problems, such as hyperactivity and socially unacceptable behavior without recognition of the consequences of those actions (*12, 14, 15*).

Effects of alcohol use by the mother may be observable at birth. For example, one mother, a chronic alcoholic, while intoxicated, delivered a child with depressed fetal body movement and respiratory abnormalities, evidenced by computer monitoring during her delivery (*11*). Detectable alcohol-related disabilities may occur among 40 to 45 percent of offspring of mothers who consume alcohol during pregnancy (*5, 10*). The amount of alcohol ingested at one time, and the developmental stage of the fetus during which the alcohol was consumed, have been reported to determine the severity of the effects exhibited in the child (*5, 12–15*). Binge drinking probably causes more retardation of brain development than drinking the same amount of alcohol during a long period (*16*). Among those with FAS, brain mass is demonstrably smaller than normal, with more white matter and fewer gyri than normal (*17*).

The actual biochemical mechanisms of alcohol-induced malformation are uncertain (*18*). Ethanol is likely to be the primary teratogen, aided by the decreased alcohol dehydrogenase activity of the alcoholic woman (*19*). Further evidence is required to determine the role of paternal alcohol consumption in FAS (*20, 21*). Only maternal alcohol consumption currently is known to produce FAS in humans (*3, 10*).

Under Public Law 100–713, Amendments to the Indian Health Care Improvement Act, the Indian Health Service (IHS) is to document and achieve an FAS incidence rate of 1 per 1,000 live births or less by 1994 (*22*). Three methods to achieve the goal have been established by IHS: (*a*) to provide the needed additional care necessary for FAS victims and their families; (*b*) to promote maternal abstinence from alcohol during pregnancy; and (*c*) to encourage family planning for mothers who have previously delivered an FAS child, because the possibility of FAS among siblings increases with subsequent births (*14*). Such mothers either need to abstain from alcohol or use effective contraception while drinking to prevent the recurrence of FAS or ARBD in subsequent pregnancies (*23*). To document achievement of the objectives, FAS incidence rates need to be established.

Methods and Materials

The Aberdeen Area Indian Health Service's (AAIHS) Maternal and Child Health (MCH) Program recruited five medical students to establish and test a pilot FAS surveillance system in the Aberdeen Area in four different Indian communities during the period 1987–90. AAIHS provides

Results of FAS surveillance in four Aberdeen Area Indian Health Service units, 1987–90

Study community	Period of study	Number of births	Number of LBW infants	LBW infants tested		Suspected FAS after testing		Confirmed FAS cases	
				Number	Percent	Number	Percent	Number	Percent
Site A	10/24/87–10/23/88	435	42	33	79	7	21	2	29
Site B	10/24/88–10/23/89	166	31	24	77	11	46	2	18
Site C	01/01/88–12/31/89	182	33	12	36	4	33	0	0
Site D	08/01/88–07/31/89	239	52	27	52	2	7	0	0
Total		1,022	158	96	61	24	25	4	17

NOTE: FAS = fetal alcohol syndrome, LBW = low birth weight.

clinical and preventive services to more than 80,000 Indians in North Dakota, South Dakota, Iowa, and Nebraska. Children in those communities or reservations who were suspected by their primary care provider of having alcohol damage were referred to a geneticist or dysmorphologist for complete evaluation.

Births during a 1-year period in four AAIHS facilities of living, single-birth children who weighed less than 3,000 grams at birth, termed low birth weight (LBW) for this study, were identified by reviewing newborn delivery medical records. Morse and coworkers have reported Massachusetts Department of Public Health data on 80 children diagnosed with FAS. Of that group, only 6 had weighed more than 3,000 grams at birth, indicating that about 90 percent of children at risk for FAS may be found using that criteria (personal communication, Dr. Barbara Morse, Assistant Research Professor of Psychiatry and Program Director of the Fetal Alcohol Education Program, Boston University School of Medicine, December 8, 1988.)

Evaluation consisted of administering the Denver Developmental Screening Test (DDST) (*24–27*) to those infants at ages 5–18 months. Most DDST testing was done on home visits, with a few at the IHS hospital outpatient departments. The mothers were asked: "Did you drink during your pregnancy, and how much?," and the child's height, weight, and head circumference were measured.

Referrals to the primary care provider, usually a pediatrician, were made if the child demonstrated a 2-month or more delay in any of the four areas of the DDST, in conjunction with a history of maternal alcohol consumption during pregnancy. Referrals were made as well if the child exhibited a head circumference less than the 10th percentile on the day of the visit. If the primary care provider believed that the child possibly had FAS, the child was referred to a geneticist or dysmorphologist for confirmation of the diagnosis. Referrals were made to public health nursing or to social services, if problems were detected that required followup, such as delays in development that were not associated with a maternal drinking history.

The results of the surveillance are summarized in the table. Of the 24 suspected cases of FAS, only 4 were confirmed, a rate of 3.9 per 1,000 live births per year. Six of the suspected 24 children, a ratio of 1 to 4, have not been evaluated by a geneticist or dysmorphologist.

Discussion

Complete followup of all LBW infants was not possible. Only 61 percent were tested, and 75 percent of children suspected for FAS were seen by a dysmorphologist. If the rate of FAS is similar in children who were not screened or followed to the FAS rate for those screened and evaluated, the incidence of FAS for the entire birth cohort would be 8.5 per 1,000 live births ($0.61 \times 0.75 = 0.46$, and $3.9 \div$ by $0.46 = 8.5$).

The rate of confirmed cases of FAS in the Aberdeen Area (3.9 per 1,000), or the projected rate of 8.5 per 1,000, are likely to be low estimates because

- Children who were lost to followup or were placed in adoption or in foster care may be more likely (*14*) to have FAS or ARBD than children who were found and examined.
- Because diagnosis of FAS is difficult, clinicians are reluctant to make a definite diagnosis of ARBD for fear of labeling a child. Frequently the geneticists recommended further evaluation of developmental milestones, especially in language, in many of the suspect children, rather than making a diagnosis of FAS. Alcohol use by the mother during the pregnancy may have contributed to many of the defects that the children exhibit, even though they do not meet all of the criteria for FAS.
- Infants weighing more than 3,000 grams at birth

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were not screened, as only about 10 percent of babies with FAS have birth weights greater than 3,000 grams.

- Infants who were delivered in facilities outside the community were not included in this surveillance. Since the reservation facilities are low-risk obstetrical facilities, those mothers on the reservations who were at high risk or who had complications, indicative of low birth weights, were referred to other facilities. A greater proportion of high-risk pregnancies were likely to produce babies with FAS than low-risk pregnancies that were delivered at IHS hospitals.
- Maternal alcohol consumption may have been underreported because of the stigma that the mothers know is associated with drinking while pregnant.
- Infants with FAS may have died before FAS was diagnosed. The infant mortality rate for the Aberdeen Area was 19.8 per 1,000 live births in the period 1986–88 (*28*) and infant mortality reviews suggest that some of the babies who died had FAS or ARBD.

Thus, the true incidence rate of FAS in this population likely exceeds the calculated rate of 8.5 per 1,000 live births.

The results of this surveillance have been presented to tribal and community groups, including a 1991 meeting of the chairmen of the 19 tribal communities in the Aberdeen Area and to the first annual conference on FAS in Rapid City, SD, on December 18, 1991, as well as to professional groups locally and at two national meetings sponsored by the Centers for Disease Control and Prevention (CDC). The presentations have helped to increase community awareness of FAS and to stimulate interest in a comprehensive FAS surveillance and prevention initiative in the Aberdeen Area. CDC, IHS, the South Dakota Department of Health, and the University of South Dakota currently are implementing a statewide FAS surveillance system for both Indian and non-Indian communities.

A proposal for a FAS training program for the entire Aberdeen Area has been funded by several Federal agencies. A legislative initiative to establish a maternal treatment facility in the area is pending.

Conclusion

Counseling and treatment programs for pregnant women who drink alcohol are necessary to prevent birth defects, since maternal alcohol abuse is the most common preventable cause of birth defects. Identification of children affected by alcohol will lead to increased expenditures by local, State, and Federal agencies for remediation of diagnosed developmental deficits. Alcohol treatment and counseling during pregnancy may help avoid some of those expenditures.

The need to develop a system to institutionalize FAS surveillance is urgent (*29*). Based on our experience with the pilot FAS surveillance system, we recommend that:

1. Prenatal substance abuse in all ethnic groups be evaluated using a self-administered screening questionnaire at the first prenatal visit. The objective is to identify women who are abusing alcohol and refer them for counseling and treatment to minimize fetal alcohol exposure. Several screening questionnaires have been evaluated in the Aberdeen Area. A revised self-administered substance abuse screening questionnaire for prenatal patients is being validated.
2. Women at risk be followed by public health nurses and substance abuse counselors so that their infants can be evaluated for FAS and other ARBD-related birth defects or developmental disorders.
3. Infants weighing 3,000 grams or less at birth be evaluated for FAS and ARBD, and that a tracking system be established to follow all infants who are suspect.

Intervention will be most effective if implemented early and provided as a continuum from all aspects of society (*29*). These aspects include the school system, family planning services, prenatal clinics, church, community, and establishments where alcohol is served. Community ownership of the program is essential to the success of FAS prevention and surveillance.

FAS detection and surveillance potentially can help to (*a*) establish reasonably accurate estimates of FAS incidence, so that the impact of preventive interventions can be monitored; (*b*) identify women at risk of having children with ARBD who could be treated or provided family planning services to prevent such pregnancy outcomes in the future;

and (*c*) identify children with ARBD early so that they can be referred for appropriate treatment and evaluation of their social situation to minimize the likelihood of child abuse or neglect and to maximize their developmental potential.

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