

Characteristics of Grandmothers who have Grandchildren with Fetal Alcohol Syndrome or Incomplete Fetal Alcohol Syndrome

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Abstract *Introduction* Characteristics of Northern Plains American Indian maternal grandmothers who had grandchildren with fetal alcohol syndrome (FAS) or incomplete FAS are described to more effectively prevent fetal FAS and alcohol use during pregnancy. *Methods* Study 1 had 27 maternal grandmothers who had grandchildren with FAS and Study 2 had 18 grandmothers with grandchildren who had incomplete FAS (cases) which were compared with 119 maternal grandmothers who had grandchildren without FAS (controls). The grandchildren were born between 1981 and 1993 on the Northern Plains. Medical records were manually reviewed for each case and control grandmother. Data were analyzed using Mantel–Haenszel chi square. *Results* Study 1 case grandmothers were more likely to experience medical problems (70.4%) including trauma (48.1%) and injuries (51.9%) than the controls.

Most of the Study 1 and 2 case grandmothers (92.6% and 77.8%, respectively) had alcohol use documented in their medical records compared to less than half of the control grandmothers. Seven (15.6%) of the case grandmothers had more than one grandchild in either Study 1 or Study 2. *Conclusion* Maternal grandmothers who had grandchildren with FAS had significantly higher rates of alcohol use and alcohol-related medical problems than control grandmothers. Antenatal care providers should screen pregnant women for alcohol use at their first visit. The provider needs to ask the women who are using alcohol about their mothers' use of alcohol to provide appropriate care and counseling for the women and prevent FAS.

Keywords Fetal alcohol syndrome · Characteristics maternal grandmother · American Indian · Alcohol

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Introduction

Fetal alcohol syndrome (FAS) is the most common cause of preventable mental retardation in the United States [1–3]. The incidence of FAS in the Northern Plains American Indians in 1993 was estimated at 8.5 children per 1,000 live births [4]. The incidence of FAS in the United States in 1990 was 2.2 cases per 1,000 live births [2]. Fifty-six percent of Northern Plains American Indian women reported alcohol use during pregnancy [5].

The consequences of alcohol use during pregnancy were less well known at the time that the grandmothers of children with FAS delivered their own children. In the late 19th century, physicians prescribed alcohol for pregnant women to reduce morning sickness and decrease the difficulties of childbirth [6]. In the 1940s, physicians thought

that alcohol use during pregnancy would not cause harm to the fetus [7]. Physicians have used alcohol to delay the onset of labor [8, 9]. In the second half of the 20th century, some women had been prosecuted for “drug-related behavior during pregnancy” [6]. Health care providers who determine alcohol use among prenatal patients and their patients’ mothers could identify additional risk factors for FAS. The purpose of this study was to determine alcohol use and medical problems related to alcohol, including trauma and injuries among the maternal grandmothers of the Northern Plains American Indian women who have grandchildren with FAS or incomplete FAS.

Methods

At four Northern Plains Indian Health Service hospitals or clinics, children with FAS or some characteristics of FAS (referred to as incomplete FAS hereafter) were identified by using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), code 760.71 [10] from 1981 to 1993. The ICD-9-CM code 760.71 includes alcohol and other noxious influences that affect the fetus through the placenta or the newborn through breast milk, and includes FAS.

In this study, FAS cases were defined as children who met all five of the following criteria based on documentation in their medical records: (1) alcohol exposure during the before sibling, index child, or after sibling pregnancies or maternal history of any alcohol consumption, (2) FAS diagnosed or noted as a suspected diagnosis by a physician, (3) one or more facial features characteristic of FAS, (4) growth deficiency (height or weight ≤ 10 th percentile for age), and (5) central nervous system (CNS) impairment [11]. If children met only 1–4 of these criteria, they were defined as cases having incomplete FAS [12]. The term incomplete FAS has been used to describe these children in Study 2 since the children did not meet the diagnostic criteria for Partial FAS. The Institute of Medicine definition of Partial FAS requires the children to have facial features and either growth retardation or central nervous system neurodevelopmental abnormalities [3, 13]. Facial features were not always documented in the children’s medical records, therefore Partial FAS could not be used to describe the children with some characteristics of FAS. Partial FAS is one diagnosis of the fetal alcohol spectrum disorders (FASD). Fetal alcohol spectrum disorders describe a spectrum of structural anomalies and behavioral and neurocognitive disabilities caused by prenatal alcohol exposure [13].

Of 142 medical records in the four communities that had an ICD-9 code of 760.71, 43 (30%) met five FAS case criteria. Of the remaining 99 medical records, 35 with 1–4

FAS case criteria were randomly selected. Thus, this report contains two separate analyses of data abstracted from medical records of the maternal grandmothers who were identified and whose medical records were available: one based on 27 case grandmothers whose grandchildren had FAS compared to 65 control grandmothers (Study 1), and the second based on 18 case grandmothers whose grandchildren had one to four characteristics of FAS compared to 54 different control grandmothers (Study 2). In addition, the grandmothers who had grandchildren with FAS were compared to the grandmothers who had grandchildren with incomplete FAS. The methods used for both studies were identical. For each case child, two control children were selected from the same community of residence: one who was the child born immediately before the birth of the child with FAS or the child with incomplete FAS and one who was the child born immediately after the case child. If the control child had FAS, the next nearest child born by date was selected. The characteristics of the mothers and children with FAS have been described in separate studies [12, 14].

When the maternal grandmother could be identified and her medical record was available for review, the medical records were manually abstracted by trained study personnel. The entire medical record was reviewed to identify the maternal grandmothers’ reported use of alcohol, and alcohol-related medical problems, trauma, and injuries. The Indian Health Service (IHS) has a unified medical record that included inpatient, outpatient and emergency room records, and provided extensive information on most cases and controls. Two maternal grandmothers had both case and control grandchildren and excluding them from the analyses did not change the results, thus these two grandmothers were included in the analysis.

The Mantel–Haenszel chi square test was used to determine statistical significance of differences in categorical variables [15, 16]. Odds ratios (OR) and 95 percent confidence limits (CL) were used to assess the strength and statistical significance of the associations.

The Aberdeen Area IHS and the national IHS Institutional Review Boards and four Northern Plains Tribes reviewed and approved the study protocol.

Results

Study 1 and Study 2 medical records of (27 and 18, respectively) case grandmothers and (65 and 54, respectively) control grandmothers were reviewed. Study 1 and Study 2 case grandmothers were more likely to have used alcohol (92.6% and 77.8%, respectively) compared to the control grandmothers (43.1% and 38.9%, respectively). Study 1 case grandmothers were more likely to have

experienced medical problems including trauma and injuries than the control grandmothers. Study 1 and Study 2 case grandmothers were more likely to have alcohol-related injuries and trauma than the control grandmothers (Table 1). Seven case grandmothers had more than one case grandchild in Study 1 or Study 2. Two case grandmothers had case and control grandchildren (Table 2). Significantly more Study 1 case grandmothers (8/27–29.6%) than their controls (7/65–10.7%) were deceased at the time of the medical record review ($P = 0.03$). Study 2 had similar findings (4/18–22.2% of the case grandmothers were deceased versus 6/54–11.1% of their controls), but the differences were not significant ($P = 0.26$).

Discussion

Most of the Study 1 and 2 case grandmothers (92.6% and 77.8%, respectively) had alcohol use documented in their medical records compared to less than half of the control grandmothers. Some birth mothers who have children with FAS have reported their own mothers' use of alcohol [5, 17]. One study found 45.5% of the women who drank during pregnancy also had parents who drank [5]. Maternal grandmother alcohol use may have contributed to alcohol-related neurodevelopmental disabilities for mothers who have children with FAS [3, 14, 18]. In a separate study, 30.2% of the daughters born to the case grandmothers had problems possibly related to their mothers' prenatal alcohol use and were 24.5 times more likely to have had a mother who also used alcohol than control daughters. These case daughters had children with FAS [14]. An animal study found female rat pups born to females with prenatal alcohol exposure had smaller weight gain in the first week of life and had a deficiency in neuromotor development when compared to the sucrose-treated and control rat pups [19].

In this study, seven (15.6%) of the case grandmothers had more than one grandchild in either Study 1 or 2. Perhaps the effects of prenatal alcohol exposure are magnified to FAS in the second generation of heavy maternal alcohol use. The health care providers may have missed some

diagnoses of FASD for the daughters of these grandmothers. Table 2 shows the intergenerational effect of FAS or incomplete FAS in the second generation of maternal alcohol use in this study.

The case grandmothers experienced more trauma and injuries than the control grandmothers. Women who abuse alcohol are more likely to experience sexual and physical abuse [20–22]. Drinking alcohol may be one means of coping with the violence [20]. In a separate study, the daughters of the case grandmothers also experienced more trauma and injuries compared to daughters of control grandmothers [14].

In addition to the trauma and injuries, the Study 1 case grandmothers were more likely to have medical problems related to alcohol than their controls. Alcohol affects every organ in the body [23] and women are less likely than men to recover from the biological damage caused by alcohol [24]. In a separate study, the daughters of the case grandmothers also experienced more medical problems related to alcohol compared to daughters of control grandmothers [14].

Significantly more Study 1 case grandmothers than their controls were deceased at the time of the study. Mothers who have children with FAS have a higher death rate than mothers who have children without FAS [25–27]. This study suggests that grandmothers who have grandchildren with FAS also have a higher mortality rate than grandmothers who have grandchildren without FAS.

This study raises the following questions: What effect does prenatal alcohol exposure have on each successive generation? Are women who have prenatal alcohol exposure more likely to drink alcohol? Is prenatal alcohol exposure a risk factor for drinking alcohol at an earlier age? Does prenatal alcohol exposure contribute to an abusive pattern of alcohol use? Do daughters with prenatal alcohol exposure drink more alcohol than their mothers? Is the risk of FAS greater with the second generation of maternal alcohol use? Is FAS linked to a genetic factor in some families? When a child is diagnosed with FAS, should the mother also be evaluated for FASD? How many daughters of these grandmothers had an FASD but were not

Table 1 Percent of maternal grandmothers with alcohol use, medical problems, trauma and injuries

	Study 1 FAS*			Study 2 Incomplete FAS*		
	Cases $n = 27$	Controls $n = 65$	Odds Ratio**	Cases $n = 18$	Controls $n = 54$	Odds Ratio**
Alcohol use	92.6	43.1	16.07 (3.52–151.36)	77.8	38.9	5.50 (1.40–23.41)
Alcohol-related medical problems	70.4	24.6	7.09 (2.42–22.68)	55.6	33.3	2.50 (0.74–8.64)
Alcohol-related injuries	48.1	13.8	5.64 (1.82–18.46)	33.3	9.3	4.76 (1.02–23.53)
Alcohol-related trauma	51.9	13.8	6.53 (2.12–21.42)	44.4	16.7	4.00 (1.26–15.45)

* None of the differences between Study 1 and Study 2 cases are statistically significant.

** Ninety-five percent confidence limit in parentheses

Table 2 Intergenerational effects of FAS and incomplete FAS. Grandmothers who have more than one grandchild with FAS or incomplete FAS

Grandmothers	Daughters	Grandchildren
A Case grandmother used alcohol	A1 Daughter used alcohol during pregnancy A2 Daughter used alcohol during pregnancy	A1.1 Case grandson with FAS A2.1 Case grandson with FAS
B Case grandmother used alcohol	B1 Daughter used alcohol during both pregnancies	B1.1 Case grandson with FAS B1.2 Case grandson with FAS
C Case grandmother used alcohol	C1 Daughter used alcohol during both pregnancies	C1.1 Case grandson with FAS C1.2 Case granddaughter with FAS
D Case grandmother medical record was not available for review	D1 Daughter used alcohol during pregnancy D2 Daughter used alcohol during pregnancy D3 Daughter used alcohol during pregnancy	D1.1 Case grandson with FAS D2.1 Case granddaughter with FAS D3.1 Case granddaughter with incomplete FAS
E Case grandmother used alcohol	E1 Daughter used alcohol during both pregnancies	E1.1 Case granddaughter with FAS E1.2 Case grandson with incomplete FAS
F Case grandmother used alcohol	F1 Daughter used alcohol during both pregnancies	F1.1 Case grandson with incomplete FAS F1.2 Case grandson with FAS
G Case grandmother medical record was not available for review	G1 Daughter used alcohol during pregnancy G2 Daughter used alcohol during pregnancy	G1.1 Case granddaughter with incomplete FAS G2.1 Case granddaughter with FAS
H Case grandmother used alcohol*	H1 Daughter used alcohol during pregnancy H2 Daughter did not have alcohol use recorded in medical record	H1.1 Case grandson with incomplete FAS H2.1 Control grandson—Study 2
I Case grandmother used alcohol*	I1 Daughter used alcohol during pregnancy I2 Daughter did not have alcohol use recorded in medical record	I1.1 Case grandson with incomplete FAS I2.1 Control granddaughter—Study 1

* Since excluding the two grandmothers who had both case and control grandchildren did not change the interpretation of the results, they were included in the analysis

Letter (i.e., A) = grandmother

Letter and number (i.e., A1) = one daughter in study, A2 = second daughter in study

Letter and number.number (i.e., A1.1) = one child born to daughter A1, A1.2 = another child born to daughter A1, A2.1 = one child born to daughter A2

diagnosed? What social impact does a grandmother who uses alcohol have on the grandchildren? What interventions can most effectively interrupt the repetitive cycle of maternal alcohol use documented in this study?

Based on this study, alcohol use by maternal grandmothers seems to be a risk factor for FAS. Screening women for substance use during pregnancy is essential to intervene with women who are drinking during pregnancy [28]. In the screening process, the health care providers need to ask prenatal patients about their mother's alcohol use. Screening for alcohol use should occur when women seek medical care for trauma or injuries whether or not she is pregnant [5, 14, 28]. These events provide opportunities to offer counseling and treatment to women who are using alcohol. In-patient treatment and protective custody in women's shelters may be necessary to help women who need more assistance to abstain from alcohol use during pregnancy [6].

The limitations of the study include the inability to interview the grandmothers and mothers or examine the children. Also, the abstractors were not blinded to the case/control status of the grandmothers. Since excluding the two maternal grandmothers who had both case and control grandchildren did not change the interpretation of the results, they were included in the analysis.

In conclusion, physicians need to screen women for substance use during pregnancy to identify additional risk factors of FAS. Health care providers should ask prenatal patients who are using alcohol to describe the alcohol use patterns of their mothers. Women using alcohol should have a chemical dependence assessment completed to determine the extent of their alcohol use. The chemical dependence assessment becomes even more important for women who have mothers who also used alcohol. Based on this assessment, appropriate treatment should be provided

to the women including interventions to decrease alcohol use during pregnancy. Determining successive generations of maternal alcohol use could be helpful in identifying risk factors for FAS. Health care providers need to ask prenatal patients using alcohol to describe the alcohol use patterns of their mothers. Numerous interventions for women who use alcohol during pregnancy are needed to reduce the risk of FAS in future generations.

More research is needed to understand the generational effects of alcohol use among women and their children. Community-based interventions to assist families who have chronic problems with alcohol use need to be implemented and evaluated. More effort is needed to diagnose mothers with FASD when health care providers learn their mother's also used alcohol. Since FASD are life-long disabilities, more research is needed to identify interventions that work effectively for women who have FASD.

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