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Fetal Alcohol Spectrum Disorders

A Native American Journey to Prevention

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Fetal alcohol spectrum disorders, the most common preventable cause for mental retardation, is the result of prenatal alcohol exposure. There is no safe amount of alcohol during pregnancy. Native Americans have a higher risk of alcohol abuse than the general US population. The fetal alcohol spectrum disorders prevalence rates for Native Americans range from 1.0 to 8.97 per 1000 births. Nurses and health care providers working in collaboration with tribal fetal alcohol spectrum disorders prevention specialists can greatly, and positively, impact the physical and mental health and well-being of children in Native American communities. **Key words:** *alcohol, fetal alcohol spectrum disorders, FASD, Native American, prevention*

LABOR AND DELIVERY NURSES working in the southwestern United States experience frustration when women in labor arrive to the unit for delivery smelling of alcohol or high from drugs they had used to numb their labor. Many of the women were from Native American tribes and reported having other children affected by alcohol exposure.

A journey of enlightenment and compassion emerged out of the frustration of caring for women who abused alcohol and other drugs during pregnancy. The author had the opportunity to get to know many of the Native American women who abused alcohol during pregnancy, and hearing their stories was a privilege. The women were from varied ethnic and socioeconomic backgrounds and all wanted to have healthy babies; however, many lacked knowledge about the risks or needed support and counseling to treat their addictions or dependencies. The journey to prevention is critical to improving the health of future children in our communities.

BACKGROUND AND SIGNIFICANCE

Explorers and settlers introduced the Native Americans to alcohol.[1] Multiple generations of Native American women experienced the influences and effects of alcohol. Women want to have healthy babies. Creating culturally sensitive prevention programs can support women, children, and families living with the influences of alcohol. These programs integrate traditional and Western strategies to prevent fetal alcohol spectrum disorders (FASDs), but also support the children and families living with the long-term effects of an FASD.[2]

Fetal alcohol spectrum disorder is the most common preventable cause for mental retardation. The spectrum describes the structural anomalies and behavioral and neurocognitive disabilities that result from the effects of alcohol consumption during pregnancy.[3-5] Fetal alcohol spectrum disorder is an overarching term for a continuum of disorders

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including fetal alcohol effects, fetal alcohol syndrome (FAS), alcohol-related birth disorders, and alcohol-related neurodevelopmental disorders.[3,6]

A direct correlation exists between the amount of alcohol consumed, the trimester of use, and the degree of alcohol effect on a child.[3] Children with an FASD possess varying degrees of behavioral problems including hyperactivity and attention deficits. Children with an FASD may suffer from heart defects, sight and hearing problems, and joint anomalies.[7] Increased risks of oral clefts have also been associated with FASD and binge drinking in early pregnancy.[8]

CONTRIBUTING FACTORS

May et al[3] explored the relationship of alcohol consumption and other risk factors that result in an FASD. Fetal alcohol spectrum disorders affect all ethnic and socioeconomic groups' worldwide. According to reports in the literature, Native Americans have higher rates of alcoholism with higher rates of FASD. Although there is an increased prevalence in the general population in the United States, Native American rates of FASD range from 1.0 to 8.97 per 1000 births.[1,3]

Native American tribes across the United States have participated in prevention initiatives supported by the Substance Abuse and Mental Health Services Administration and National Organization on Fetal Alcohol Syndrome. The only tribal program that continues to be sustainable is the Navajo Nation Fetal Alcohol Spectrum Disorders Prevention Program.

NAVAJO NATION FETAL ALCOHOL SPECTRUM DISORDERS PREVENTION PROGRAM

Many Navajo families live with the problems associated with an FASD. Even though the Navajo rate of FASD is below the average of other Native American tribes, there have been increased numbers of children exhibiting characteristics of alcohol-related birth defects. The Navajo Nation Health Review Board has recognized a need to research more accurately the current prevalence of FASD for the Navajo Nation.

Navajo families have a long history of managing problems associated with an FASD. In the late 1970s, FAS programs started in Tuba City, Arizona, on the Navajo Nation to establish networks of support for women, children, and families dealing with alcohol use and its effects on the pregnant woman, child, and family.[9]

The Navajo Nation is the only Native American tribe to have a designated FASD prevention program. The Department of Behavior Health, Division of Health for the Navajo Nation oversees the Navajo Nation Fetal Alcohol Spectrum Disorders Prevention Program.

In 1973, the first diagnosis of FAS was a Native American child from the Apache tribe. The diagnosis led to a research focus on Native American risks and prevalence for Fetal Alcohol Syndrome (now FASD). Kathy Masis, MD, and Philip May, PhD, in the 1980s and early 1990s, did extensive research through the Indian Health Service at Tuba City Indian Medical Center. In addition, they provided education and support to health care providers, counselors, and educators. Ann Streissguth, from the University of Washington provided training for Native Americans and the Indian Health Service about Fetal Alcohol Spectrum/Fetal Alcohol Effects.

In 1990, the Navajo Nation took over the prevention efforts from the Indian Health Service and created a pilot prevention model. The FASD prevalence rates for the Navajo Nation remain at 2.5 per 1000 births as compared with the national prevalence rates of 1.5 per 1000 births. The numbers only measure children diagnosed with specific physical characteristics. There is no accurate estimate of the numbers of children affected by alcohol exposure without the physical findings (L. Akshie, oral communication, August 1, 2008).

Trained by Drs Masis and Streissguth, Louise Shabi-Ashkie has been with the Navajo Nation FASD Prevention Program since its inception,

has met each family who had a child suspected of having FAS, and is responsible for all program activities as well as for creating the entire prevention program (L. Akshie, personal communication, August 1, 2008). Veronica Garnenez joined the Navajo Nation FASD Prevention Program in May 2005.

The FASD prevention program has integrated training content from the Substance Abuse and Mental Health Services Administration FASD 101 and materials from the National Organization on Fetal Alcohol Syndrome to develop creative, culturally sensitive, and developmentally appropriate educational programs given to more than 45 000 individuals. The prevention activities for the Navajo Nation FASD Prevention Program include participation in health and communities fairs, Navajo Nation Fun Runs, veteran's events, Navajo puberty ceremonies, school education programs, and media relations. The Peer Educator Program, funded by National Organization on Fetal Alcohol Syndrome, provides education to students (aged 11 to 18 years) across the Navajo Nation. The prevention program partners with Children with Disabilities and the National Charity Organization out of Phoenix, Arizona, to provide resources for children and their families. The prevention program provides technical support and education to teachers, health care providers, parents of special-needs families, foster parents, grandparents, and community members. In addition, the prevention program advocated for a billboard with the message "Have a healthy baby. Drinking Alcohol will cause an FASD" and the contact phone number to the Navajo Nation FASD Prevention Program (L. Akshie, personal communication, August 1, 2008).

Beckett[2] researched "Navajo children and families living with fetal alcohol syndrome (FAS)/fetal alcohol effects (FAE)." The grounded theory research study explored "What are the social and cultural factors and processes that Navajo families use to manage care for a child with FAS/FAE?" Integration of the study results into the Navajo Nation FASD Prevention Program facilitated improved prevention strategies, education, and outcomes for the Navajo population.

Attributed to the success of the Navajo Nation FASD prevention program is the passion and dedication of the staff; strong community connections; integration of community attitudes, values, and beliefs into prevention strategies and education; and ongoing community strategies for prevention. The successful program goals included providing prevention education and information about birth defects from alcohol exposure (FASD) to populations at large; high risk groups (teens and pregnant women); and Department of Behavioral Health Service's staff, clients, and their families. In addition, another successful program goal offered a comprehensive Peer Education Program to educate children (aged 11-18 years) about the risks of alcohol consumption and pregnancy (L. Akshie, personal communication, August 1, 2008). The Navajo Nation Department of Behavioral Health FASD provided training to staff and educational activities for women, men, youth, and families.

Ongoing community strategies for prevention include providing education to community members, health care providers, teachers, and counselors; forming partnerships with schools, local clinics, hospitals, and regional medical centers; and developing collaborative prevention programs for perinatal substance abuse with drug/alcohol treatment and counseling for woman and families. Partners in the plan include the Navajo Division of Behavioral Health community agencies and counselors for alcohol treatment and prevention services, the Medicine Man Association, and collaboration with Northern Arizona Healthcare-Flagstaff Medical Center for program development in the areas of prevention and interventions for women, children, and families (L. Akshie, personal communication, August 1, 2008).

The large geographical region of the Navajo Nation challenges the success of the Navajo Nation FASD prevention program because of limited transportation to services for prevention and intervention. Absent are treatment

programs, parenting classes, and support groups specific for childbearing or pregnant women for perinatal alcohol and drug abuse or dependency. The Navajo Nation needs community-based educational programs for prevention and intervention activities (built on existing programs within Navajo Behavioral Health).

INTERVENTIONS MAKING A DIFFERENCE

Nursing and health care professionals working in collaboration with tribal behavioral health and substance abuse prevention experts can make a difference in the prevention of FASD.[2,10] Prevention toolkits developed specifically for Native American communities are now available through the SAMHSA.gov online resource.[11] Substance Abuse and Mental Health Services Administration FASD Center for Excellence, in collaboration with the National Institute of Alcohol Abuse and Alcoholism and the National Institutes of Health, Office of Research on Minority Health developed a "Brief Intervention" program to provide women at risk a one-on-one intervention at key times during the pregnancy and during the postpartum period. Evidence supports the Brief Interventions' positive outcomes, versatility, and cost-effectiveness.[6,12]

CONCLUSIONS

Fetal Alcohol Spectrum Disorders are 100% preventable. Native American women are at an increased risk to deliver a child with an FASD because of multigenerational alcohol abuse. The Navajo Nation FASD Prevention Program is making a difference and increasing awareness for women, children, and families. Healthy, alcohol-free pregnancies are the goal to produce healthy babies. The Navajo Nation FASD Prevention Program demonstrated the effectiveness of collaboration between Native American health care providers, counselors, teachers, tribal leaders, and community health nurses to positively impact the outcomes for women and children through the creation and support of FASD prevention programs.

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