

PREVALENCE OF FETAL ALCOHOL SYNDROME IN A REMOTE REGION OF AUSTRALIA

Rebecca Hancock, MSc Candidate, Department of Clinical Pharmacology, University of Toronto

A CRITICAL REVIEW of “Prevalence of Fetal Alcohol Syndrome in the Top End of the Northern Territory.” KR Harris and IK Bucens; *Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory. Journal of Paediatric and Child Health 2003, Vol. 39, pp. 528-533.*

Numerous previous studies in North America have found that rates of Fetal Alcohol Syndrome (FAS) are substantially higher in native populations than in the overall population.^{1,2} The prevalence of FAS has not been well studied in Australia, which has a large indigenous population experiencing similar social problems as their counterparts in North America. The objective of this study was to establish the prevalence of FAS in the Top End of the Northern Territory (NT), Australia, in both indigenous and non-indigenous populations.

The study was a retrospective chart review of medical records and outpatient letters of children seen by the Royal Darwin Hospital Paediatric staff between 1990 and 2000. Children were eligible if they lived in the Top End of the NT, which is 200,000 km.² Subjects that were identified were placed into 6 categories:

1. FAS with confirmed alcohol exposure.
2. FAS without confirmed alcohol exposure.
3. Partial FAS – alcohol exposure confirmed.
4. Alcohol-related neurodevelopmental disorder (ARND).
 - a) Microcephaly, alcohol exposure unknown.
 - b) Microcephaly, unrelated to alcohol exposure.
5. Other.

Cases were defined as having alcohol exposure, facial anomalies, growth

retardation, and CNS anomalies. Partial FAS was defined as having alcohol exposure plus two of three of the FAS characteristics. The case definitions were adapted from previous work by the American Academy of Paediatrics Committee on Substance Abuse and Children with Disabilities.^{3,4} Children categorized as “other” were the siblings of those with FAS who did not themselves qualify for diagnosis, or children with alcohol exposure and growth delays that did not fit the other categories.

The live birth rate was estimated using data from the Australian Bureau of Statistics.⁵ The minimum rates were first calculated using only cases in category 1. The overall rate from this calculation was 0.68/1000 live births. The rate in indigenous population was 1.87/1000 live births. When the rates were calculated using all cases from categories 1-4, the overall rate reached 1.7/1000 live births and the rate in the indigenous population was 4.7/1000 live births. The difference in rates between indigenous and non-indigenous populations was significant. It is important to note that there were no cases identified in the non-indigenous population in categories 1-4.

The rate calculated using only cases in category 1 is almost certainly an underestimation. The rate calculated using categories 1-4 is probably an underestimation as well, because of possible misdiagnoses and the limitations of the study design. However these findings are consistent with previous studies that have found an extremely high prevalence rate of FAS in indigenous populations, and are among the highest rates for FAS in the world.¹

The main problem with this study is that by the nature of its design (retrospective chart review) it has missed cases that did not present for medical care. Many children with FAS will not be brought to see paediatricians in the Darwin hospital for reasons related to cost and distance. Children with FAS may be brought to

see health professionals in another discipline, such as psychology or psychiatry. However, the findings are still significant as they indicate an alarming difference in FAS prevalence between indigenous and non-indigenous peoples.

The authors also found, in reviewing their medical records that the information in them was often inadequate; facial characteristics were rarely noted and birth defects were not recorded consistently. The authors found that many cases of partial FAS and ARND had been coded as "microcephaly with no cause specified." There were also 4 women who had more than one child with FAS, including one woman with 3 children with FAS. These are important observations, as they highlight the need for increased awareness of FAS among clinicians. These observations also demonstrate the need for a clinically relevant standardized test for FAS, and the authors quote the guide released by the University of Washington FAS Diagnostic and Prevention Network, which includes standardized measures for inner canthal distance, philtrum and upper lip thinness. This guide should be adapted for use in Australia to facilitate recognition of FAS among clinicians. The authors were somewhat off the mark in quoting the Seattle guide, as it is the palpebral fissure length and not the canthal distance which is the hallmark pathogenomic of FAS.

A second criticism of this study is the lack of definition of "indigenous" and "non-indigenous" status. It was not stated how patients were categorized into these groups. Perhaps a better categorization would have been residence, i.e. on or off reserves. A more detailed or clearly defined definition of race would improve the study. The authors cite a study by Abel et al (1995) that found that it is poverty not race that is the major risk factor for FAS.⁶ Future studies could determine the economic status of cases, as well as their ability to access health care. This knowledge would help to better determine which populations are at risk for FAS.

The authors also suggest that there is a possible bias in diagnosis. It is odd that there were no cases in categories 1-4 in the non-indigenous population, as data on alcohol consumption in this region shows that there is a high level of consumption among non-indigenous peoples.⁷ It is possible that clinicians are less likely to recognize excessive alcohol ingestion in non-indigenous women than in indigenous women; the clinician may also be reluctant to diagnose FAS because of its associated social stigma. Again, a standardized test to aid the diagnosis of FAS is required as this will help remove bias from diagnoses.

Despite the limitations of its design, this study is significant as it establishes the high prevalence of FAS in this area of Australia. The finding that the rates of FAS are substantially elevated in the indigenous population is in agreement with previous studies done in North America and brings further attention to this challenging issue. This study should increase awareness of FAS, and draw attention to the great need for the dissemination of available guidelines for diagnosing FAS that can be used in Australia.

REFERENCES

1. Williams RJ, Obaido FS, McGee JM. Incidence of fetal alcohol syndrome in northeastern Manitoba. *an J. Public Health* 1999; 90: 192-4.
2. Bower C, Silva D, Henderson TR *et al*. Ascertainment of birth defects: the effect on completeness of adding new source of data. *J Paediatr. Child Health* 2000; 36: 574-6.
3. Astley SJ, Clarren SK, Henderson TR *et al*. *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions. The 4-digit Diagnostic Code*, 2nd edn. University of Washington Publication Services, Washington, DC, 1999.
4. American Academy of Paediatrics. Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorders. *Pediatrics* 2000; 106: 358-61.
5. Australian Bureau of Statistics. *Population by Age and Sex, Australian States and Territories*. Catalogue no. 3201.0. ABS, Canberra, 2000.
6. Abel EL, Hannigan JH. Maternal risk factors in fetal alcohol syndrome: provocative and permissive influences. *Neurotoxicol. Teratol.* 1995; 17: 445-62.
7. Australian Institute of Health and Welfare 2002. National Drug Strategy Household

Survey: State and Territory Supplement. (Drug Statistics Series no. 100).
AIHW cat. No. PHE 37. Canberra: AIHW