ALBERTA PARTNERSHIP ON Fetal Alcohol Syndrome — Together Let's Find a Solution

Toward Optimized Practice

ALBERTA CLINICAL PRACTICE GUIDELINES

2005 Update

Administered by the Alberta Medical Association

Preface to the

PREVENTION & DIAGNOSIS OF FETAL ALCOHOL SYNDROME (FAS)

This preface was developed by a working group based on best available evidence and from a province-wide survey of physicians. It is intended to support the CPG for the Prevention of FAS and the CPG for Diagnosis of FAS. In light of the release of a national FAS guideline, this document will undergo a formal review during the 2005/2006 fiscal year.

For the purpose of this guideline, the term FAS (FAE, ARBD) is used to describe the full continuum of abnormalities attributed to prenatal exposure to alcohol

INTRODUCTION

Alcohol is a legal, socially acceptable drug the use of which is part of the daily life of many people in this country. According to one study of 6,000 pregnant women, drinking during pregnancy has increased in the past few years.[1]

In a 1998 Angus Reid survey of Canadians, 75% of women surveyed claimed to be occasional alcohol drinkers, and 25% said they drank frequently.[2] In another 1998 Angus Reid poll done for Alberta Family and Social Services, it was found that 25% of those polled felt that moderate or social drinking is acceptable during pregnancy.

FAS is the most preventable cause of birth defects.[3] Although part of the human condition for centuries, this syndrome was first documented in France in 1968,[4] and subsequently defined in 1973 in the United States.[5] Appropriate intervention can prevent FAS; however, it continues to occur in every population where alcohol is consumed.

SPECTRUM OF DISABILITY RELATED TO FAS

Many terms have been used to describe abnormalities attributed to prenatal exposure to alcohol. Fetal alcohol syndrome (FAS), alcohol related birth defect (ARBD), fetal alcohol effects (FAE), and alcohol related neurological disorders (ARND) are the most commonly used terms.

The consequences of prenatal alcohol exposure fall along a continuum, ranging from subtle neurodevelopmental and behavioral manifestations to FAS.

It is important to note that abnormalities attributed to prenatal exposure to alcohol occur along a continuum of severity, with miscarriage and stillbirth being the most severe at one end, and various birth defects not sufficient to be classed as FAS at the other end. Even among those diagnosed as FAS, the severity of motor and speech development and behavioral problems varies significantly. The less severe the physical features, the harder it is to make a diagnosis. It is, however, important to address the needs of affected individuals.

The range of disability has been described thoroughly in the literature by various researchers.[6,7] A full description can be found in a report prepared by AADAC.[8]

Results from a representative survey of Alberta physicians confirmed the need and interest in guidelines on FAS. The survey, with a response rate of 37% (348/930), found that physicians recognized the need for more specific training and information in the area of FAS prevention, diagnosis and management; and 61% noted that clinical practice guidelines would be helpful for them.

EPIDEMIOLOGY OF FAS

Alcohol Consumption Patterns

- The prevalence of alcohol consumption amongst women aged 18 to 34 years ranges from 60% to 75% with 4% considered to be alcohol abusers or alcohol dependent.[9, 10]
- An estimated 2 to 13% of young women drink heavily. However, few concerted attempts have been made to alter the drinking behavior of young women.[11]
- Lower drinking prevalence has been recorded during pregnancy: 20% less among women in general; among women who are alcohol abusers, the decrease is less than 1%.[4]
- In a national sample, 25% of women reported drinking during pregnancy.[12] No evidence indicates that the heavy drinkers are drinking any less during pregnancy.
- Recently, the Centers for Disease Control and Prevention conducted a study of the drinking patterns of pregnant women. The finding revealed that the rate of frequent drinking (defined as more than 7 drinks per week or more than 5 drinks per occasion) increased from 0.8% in 1991 to 3.5% in 1995.[13]

Incidence and Prevalence

According to various studies, the worldwide incidence of infants with FAS ranges from 10 per 1,000 births in high risk populations to 0.5 - 3 per 1,000 births in the general population.[14,15,16]

FAS is the leading cause of preventable birth defects and one of the top three leading known causes of mental disability in the western world. Although the ranking of the top three disorders varies from author to author, the literature consistently states that FAS is one of the top three known causes of mental retardation, along with Spina Bifida and Down Syndrome.[17,18,19,20]

The area of prevalence and incidence rate of FAS however, is one of controversy, and study results have noted a wide range of estimates. Some of the contributing factors include, but are not limited to, the following.

- Data has been collected in various ways - including the catchment approach, retrospective studies, and prospective studies - each with its own set of limitations. Consequently, there are difficulties in interpreting and comparing results.
- Results of some studies have been skewed by the fact that these studies have focused on communities where the target population is known to have a higher alcohol exposure profile.
- An accurate history of alcohol use in pregnancy is often difficult to obtain, so the true incidence of FAS is often underestimated.
- There are problems related to diagnosis, including inaccurate diagnosis, missed diagnosis, and lack of knowledge about FAS, leading to unrecognized cases of FAS.
- Incidence of other conditions within the spectrum of FAS, such as FAE, ARBD and ARND are more poorly defined but are suspected to be higher than that of FAS.

Given these factors, it is difficult to accurately determine incidence and prevalence rates. Although health care professionals are sensitized to look for FAS in certain populations, no woman or target population is exempt. FAS occurs in populations of every race and socioeconomic status.

Always ask all women about their use of alcohol.

High Risk Populations

In populations with a high proportion of women who drink alcohol, the incidence of FAS is higher. However, given the research available, it appears that all women need to be screened in pregnancy.

The following sample of research studies illustrates the wide variation of "high risk" groups.[21,22]

- One study notes that the risk of FAS appears to be greater in the presence of the low socioeconomic status, poverty, and lack of education that often accompany abusive drinking; women who drink and have these characteristics appear to be at higher risk of having an FAS child.

- Another recent study indicates that babies born to mothers in the following groups are at highest risk - women:
  - with a college education,
  - who are unmarried,
  - who are students,
  - who smoke,
  - in households with an annual income greater than $50,000.

- Other studies note that the incidence rate of FAS appears to be higher among certain populations. For example:
  - Studies conducted in Manitoba indicate higher prevalence rates among Aboriginal populations.[23,24]
  - Higher rates are reported among the Aboriginal population in BC.[25]
  - Other studies suggest that major factors associated with FAS are low socieconimic status, smoking, poor health, and use of other drugs.[26]

- The risk of recurrence of FAS appears to be substantially higher for families who already have children affected by FAS. In fact, the estimated risk to younger siblings with FAS is 771 per 1000 live births.[27]

What we do know for sure is that **alcohol is the common denominator in these high risk populations.** Therefore a prudent choice for women who are pregnant or are considering pregnancy is to abstain from alcohol.

MECHANISMS OF ALCOHOL TERATOGENIC EFFECTS

Alcohol is a known teratogen associated with increased pregnancy loss, malformations, growth retardation and neurological dysfunction. The precise mechanism for the teratogenic effect is a combination of toxic effects from ethanol and its metabolites, interference with cell migration, and indirect mechanisms.

The typical features of FAS result from exposure to alcohol throughout the pregnancy with alcohol-related birth defects and alcohol-related neurodevelopmental delay potentially caused by exposure during a critical interval. In addition to excessive regular intake and heavy episodic consumption of alcohol, there is also concern with consistent intake of as little as two drinks per day.[28, 29, 30]

Malformations generally result from exposure during the first trimester with anomalies commonly of the cardiovascular, skeletal, and genitourinary systems.

Alcohol related neurodevelopmental disorder can manifest as either structural changes such as microcephaly, agenesis of the corpus callosum, or cerebellar hypoplasia; or dysfunction of behavior or cognition.

Exposure to alcohol in the third trimester has a more severe effect on birth weight than exposure earlier in gestation. There appears to be a linear relationship between the amount of alcohol consumed and decrease in birth weight.[31, 32] However, there is growing evidence that reducing heavy alcohol intake, even as late as the third trimester, will result in significantly higher birth weights and significantly fewer infants with alcohol related abnormalities.

REFERRAL SOURCES

Contact your Regional Health Authority, AADAC, or the College of Physicians and Surgeons of Alberta for a list of current resources.

AREAS FOR FURTHER RESEARCH AND DEVELOPMENT

Although there has been much research regarding FAS and other disorders associated with fetal exposure to alcohol, there are a number of issues that require further study and clarification. These include the need for:

- accurate data on **incidence and prevalence rates** of FAS within Alberta;
- discussion and confirmation of appropriate **terminology** around FAS, FAE, and ARBDs;
- multidisciplinary teams with specialized training and experience in the area of FAS and diagnosis of the same;
- examination of the effect **of paternal alcohol consumption** on disorders with FAS;
- research into the **effects of the use of pharmaceuticals and other drugs and solvents**;
- **providing physicians with the necessary knowledge, skills, and tools** to properly screen women and provide accurate information about the effects of alcohol use on the development of the fetus;
- development of **specialized interventions** for women at risk of having an FAS child;
- examination of the **role and outcomes of various interventions** for FAS affected individuals; and
- development of specialized **detoxification methods for pregnant women.**

REFERENCES

1 Ebrahim S, Floyd R, Bennet E. Alcohol consumption by pregnant women in the United States during 1988-1995. Obstetrics and Gynecology, 1998; 92(2): 187-192.

2 Angus Reid Survey for the Brewers Association of Canada. April 1998.

3 Bratton R. Fetal alcohol syndrome: how you can help prevent it. Post Graduate Medical Education, Nov 1995; 98(5): 197-200.

4 Lemoine P, Harrousseau H, Borteyru JP, Menuet JC. Les enfants de parents alcooliques: anomalies observees; a propos de 127 cas. 1968. Quest Med 8: 476-482.

5 Jones K, Smith D. Recognition of the fetal alcohol syndrome in early infancy. Lancet, 1973; 2: 999-1001.

6 Sokol RJ, Clarren SK. Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring. Alcoholism: Clinical and Experimental Research, 1989; 13(4): 597-598.

7 Ottney JR. Fetal alcohol syndrome: facts and choices. A guide for the teacher. Madison, Wisconsin: University of Wisconsin, 1991.

8 Fetal alcohol syndrome and other alcohol related birth defects. AADAC, 1996.

9 Gladstone J, Nulmen I, Koren G. Reproductive risks of binge drinking during pregnancy. Reproductive Toxicology, 1996; 10:3-13.

10 Abel E, Sokol R. A revised conservative estimate of the incidence of FAS and its economic impact. Alcohol Clin Exp Res, 1991; 15(3): 514-524.

11 Kruse J. Alcohol Use During Pregnancy, AFP, April 1984; 29(4): 199-203.

12 Serdula M, Williamson D, Kendrick J, et al. Trends in alcohol consumption by pregnant women 1985-1988. JAMA, 1991; 265: 876-879.

13 Centers for Disease Control and Prevention. Alcohol consumption among pregnant and childbearing aged women - United States, 1991 and 1995. MMWR 1997; 46: 346-349.

14 Single E, MacLennan A, MacNeil P. Horizons 1994: alcohol and other drug use in Canada. Ontario: Health Canada and the Canadian Centre on Substance Abuse. 1994.

15 Abel EL. Neurotoxicology and Teratology, 1995; 17: 437-443.

16 Burgess DM, Streissguth AP. FAS and FAE: principles for educators. Phi Delta Kappa, 1992; 74(1): 24-29.

17 Warren KR, Bast RJ. Alcohol-related birth defects: an update. Public Health Rep, 1988; 103(6): 638-642.

18 Loock CA, Conry J, Bullen L (eds). Conference proceedings for FAS prevention in Canada: Train-the-Trainers Working Conference, 1994. BC FAS Resource Society.

19 Abel EL, Sokol RJ. Incidence of Fetal Alcohol Syndrome and economic impact of FAS-related anomalies. Drug and Alcohol Dependence, 1987; 19: 51-70.

20 Ottney JR. Fetal Alcohol Syndrome: facts and choices. A guide for the teacher. Madison, Wisconsin: University of Wisconsin, 1991.

21 Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-Related Neurodevelopmental Disorder. Teratology, 1997;56:317-326.

22 Ebrahim S, Floyd R, Bennet E. Alcohol consumption by pregnant women in the United States during 1988-1995. Obstetrics and Gynecology, 1998; 92(2): 187-192.

23 Square D. Fetal Alcohol Syndrome epidemic on a Manitoba Reserve, Canadian Medical Association Journal, 1997;157:59-60.

24 Chudley AE. Fetal Alcohol Syndrome - a preventable cause of birth defects and mental retardation. Manitoba Medicine, 1991; 61: 53-56.

25 Assante, KO, Robinson, GC. Pregnancy outreach program in British Columbia: The prevention of alcohol-related birth defects. Canadian Journal of Public Health, 1990; 81(1): 76-77.

26 Abel EL. Neurotoxicology and Teratology, 1995; 17: 437-443.

27 Abel EL. Fetal Alcohol Syndrome. Oradell, New Jersey: Medical Economics Books, 1990

28 Streissguth AP, Barr HM, Sampson PD. Moderate prenatal alcohol exposure: effects on child IQ and learning problems at age 7 1/2 years. Alcoholism Clinical and Experimental Research, 1990; 14(5): 662-665.

29 Wright JT, et al. Alcohol consumption, pregnancy, and low birthweight. Lancet, March 26 1983.

30 Kaminski M, et al. Moderate alcohol use and pregnancy outcome. Neurobehavioral Toxicology and Teratology, 1981; 3: 173-181.

31 Virji S. The relationship between alcohol consumption during pregnancy and infant birth weight. Acta Obstet Gynecol Scand, 1991; 70: 303-306.

32 Day N, Jasperse D, Richardson G. Prenatal exposure to alcohol: effect on infant growth and morphological characteristics. Pediatrics, 1989; 84: 536-540.

TOWARD OPTIMIZED PRACTICE PROGRAM

The successor to the Alberta Clinical Practice Guideline (CPG) program, TOP is an initiative directed jointly by the Alberta Medical Association, Alberta Health and Wellness, the College of Physicians and Surgeons, and Alberta's Health Regions. The TOP Program promotes appropriate, effective and quality medical care in Alberta by supporting the use of evidence-based medicine.

TO PROVIDE FEEDBACK

The Working Group for FAS is a multidisciplinary team composed of family physicians, obstetricians, pediatricians, geneticists, Community Medicine specialists, midwives, representatives from AADAC, Alberta Family and Social Services, Health Canada, the Alberta CPG Program, the Committee on Reproductive Care, the Nechi Institute and the public.

The Working Group encourages your feedback. If you need further information or if you have difficulty applying this guideline, please contact:

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