

Statement of the Public Affairs Committee of the Teratology Society on the Fetal Alcohol Syndrome

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Since the initial observations over 25 years ago that alcohol (ethanol) is a human teratogen (Jones and Smith, '73; Jones et al., '73), concerns regarding the prenatal effects of alcohol as a significant public health problem have been raised throughout the world. Much effort has gone into the delineation of a physical and neurobehavioral phenotype, numerous studies have focused on the birth prevalence of those phenotypes in various populations, and countless experiments have documented the prenatal effects of alcohol in a variety of animal species. Investigations into the risks of drinking small and moderate amounts of alcohol during pregnancy have been undertaken, education and prevention campaigns have been implemented, and programs to benefit affected children have been established.

Although there are numerous gaps in knowledge when considering the full spectrum of effects of prenatal exposure to alcohol, several unresolved problems relating to the diagnosis and prevention of the most severe end of the spectrum, fetal alcohol syndrome (FAS), are of particular importance. The following five points describe these issues and the Public Affairs Committee's recommendations in response to each.

IMPROVED RECOGNITION OF FETAL ALCOHOL SYNDROME

With the exception of only the most severe cases, recognition that a child has been affected by prenatal exposure to alcohol is extremely difficult in the newborn period and may remain so up to 4 years of age. Short palpebral fissures and a smooth philtrum, two of the characteristic features of FAS, are difficult to appreciate in a crying, uncooperative newborn infant. Furthermore, FAS features such as short nose and low nasal bridge involve subjective judgements, and an additional feature, epicanthal folds, is normal in some ethnic groups. The result is that FAS goes unrecognized in the newborn period and beyond in an alarming number of cases (Stoler and Holmes, '99) and consequently children who could benefit from services may not be appropriately referred. In addition, physicians

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are frequently loath to initiate discussions of alcohol use during pregnancy with their patients, and pregnant women and new mothers are often unwilling to volunteer information that could suggest high-risk alcohol use. Furthermore, inability to validate maternal reports of exposure, along with variability in research protocols on the way exposure information is collected, recorded, and analyzed, makes it difficult to define high-risk patterns of alcohol use. Currently available biomarkers of alcohol exposure are not yet adequate to screen pregnant women for alcohol use or abuse (Stoler et al., '98; Bearer, '01).

Recommendations

We recommend that information regarding prenatal alcohol exposure be incorporated into the standard newborn evaluation form. This would remind pediatricians to check the prenatal records and spend time with the mother inquiring about any exposure to alcohol, especially when infants are born small for gestational age. In those cases in which a positive history is elicited, a physical examination focused on screening for FAS should be performed.

We recommend that research be encouraged to develop more successful methods of eliciting disclosure of alcohol consumption information. We also recommend that researchers develop agreed-on standards for measuring, reporting, and analyzing alcohol consumption patterns in pregnant women.

We recommend that more sensitive and specific biomarkers of exposure among pregnant women be developed. These tools and actions would provide a means of gathering and validating more accurate alcohol information during pregnancy, and in research settings would contribute to more meaningful comparisons of these data across studies. Ultimately, these steps could improve the identification of women who are likely to deliver affected babies.

We recommend that strategies be developed to identify affected children early in life in order to direct those children into early intervention programs that can address developmental and behavioral problems at an age that can be of maximum help to them and to society.

IDENTIFYING NEUROBEHAVIORAL EFFECTS ASSOCIATED WITH PRENATAL EXPOSURE TO ALCOHOL

The most significant potential effect of prenatal alcohol exposure is on development of the central nervous system. Although neuropathologic data are based on a relatively small number of cases, a variety of structural defects have been described, including but not limited to defects of neuronal migration (Jones and Smith, '75), partial to complete absence of the corpus callosum (Clarren et al., '78; Kinney et al., '80; Coulter et al., '93), and cerebellar abnormalities including dysgenesis, heterotopies, and agenesis of the vermis (Clarren et al., '78; Peiffer et al., '79; Wisniewski et al., '83;

Coulter et al., '93). Magnetic resonance imaging (MRI) studies on living children exposed prenatally to alcohol have documented similar defects (Mattson et al., '92, '96b).

With respect to neurobehavioral effects, a number of abnormalities have been noted. At birth, irritability and sucking-related difficulties have been reported (Coles et al., '87). During childhood, FAS children exhibit deficits on tests of attention (Nanson and Hiscock, '90; Coles et al., '97), executive functioning (Mattson et al., '99), particular aspects of visual-spatial processing (Mattson et al., '96a), and new learning of both verbal and visual information (Mattson and Roebuck, '98). A mean IQ of 65 with a range of 20 to 120 has been documented in a review of individual FAS cases, while a mean IQ of 72 with a range of 47 to 98 has been reported in retrospective group studies (Mattson and Riley, '98). Unfortunately, outside of the research environment, it is not yet possible to be confident that a child's neurobehavioral problems are caused by prenatal alcohol exposure in the absence of the characteristic pattern of structural anomalies.

Recommendations

We recommend that research be focused on further attempts to delineate a behavioral phenotype characteristic of FAS. The identification of such a phenotype would support better estimates of the true public health impact of this disorder, even among children who do not have a sufficient number of structural features to meet the diagnostic criteria for FAS. This would allow neurobehaviorally affected children to receive specific and early intervention services that they might otherwise be denied.

DETERMINING RISKS OF HEAVY ALCOHOL CONSUMPTION DURING EARLY PREGNANCY

Since the minimum amount of alcohol that can adversely affect fetal development remains unclear, it is desirable that women abstain from drinking alcohol during pregnancy. However, a high proportion of pregnancies are unplanned and/or unrecognized in the early weeks of gestation (Floyd et al., '99a, '99b). Early inadvertent exposures of nonalcoholic women to significant quantities of alcohol prior to the recognition of pregnancy may frequently occur.

Recommendations

We recommend that research be focused on the specific risks for adverse pregnancy outcome in women with heavy alcohol consumption that is restricted exclusively to the first 6 to 8 weeks of pregnancy. These data could be valuable in providing more accurate risk assessments for pregnant women with this pattern of alcohol consumption and could also better define the potential benefit of prevention programs that target alcohol use in women prior to pregnancy.

RISK FACTORS FOR AND PREVENTION OF FETAL ALCOHOL SYNDROME

Despite the fact that FAS is the most common recognizable cause of mental retardation, no prevention program has yet successfully dealt with this problem. According to U.S. survey data comparing the prevalence of reported alcohol consumption among pregnant women between 1997 and 1999, it is clear that educational programs designed to decrease risky drinking by pregnant women do not appear to be working. In 1997, 11.4% of pregnant women reported any drinking versus 12.8% in 1999; and frequent drinking (defined as ≥ 7 drinks per week or ≥ 5 drinks on at least one occasion) increased from 2.1% to 3.3% over the same period (Morbidity and Mortality Weekly Report, '02).

While the reasons underlying the risky drinking behavior of women in this survey are unclear, among pregnant women who drink heavily, a number of factors that appear to confer susceptibility for having an FAS-affected child are beginning to emerge. These include maternal age over 30 (Jacobson et al., '96), low socioeconomic status (Abel, '95; Abel and Hannigan, '95), ethnic group (Native American and African American ethnicity) (Abel, '95; Abel and Hannigan, '95), alcohol dehydrogenase genotype (McCarver et al., '97; Jacobson et al., '00; Viljoen et al., '01), and having had a previous child with FAS (May, '95). Others have suggested that nutritional deficiencies that are associated with alcohol abuse may be important risk factors for FAS (Dreosti, '93; Carey et al., '01).

Recommendations

We recommend that prevention programs be developed that focus on high-risk women, including those who previously have given birth to an affected baby, who are older, or who are of lower socioeconomic status. These prevention programs must be culturally specific and culturally appropriate.

We recommend that research be focused on better understanding of the extent to which genetic factors play a role in the incidence of this disorder and poor nutrition confers susceptibility for FAS.

SOCIAL AND ECONOMIC FACTORS ASSOCIATED WITH PREVALENCE AND PREVENTION OF FAS

Social and economic factors can play a role in the prevalence of FAS and in the success of prevention programs. For example, in the United States, the prevalence of FAS is highest on some of the American Indian reservations, areas of this country where the percentage of the population with three or even four of the identified risk factors is high. It is not known if there are genetic factors unique to Native American Indians that confer additional susceptibility, if Native American women consume greater amounts of alcohol as a way to escape from their impoverished and in some cases hopeless situations, and/or if factors such as poor nutrition and smoking, both of which are associated

with lower socioeconomic status and with alcohol use, exacerbate the effects of heavy alcohol consumption on the fetus in such women. However, it is clear that the prevalence of FAS is high in areas where poverty is endemic and alcohol consumption is part of the culture (Bingol et al., '87; Abel, '95).

Another example of the potential influence of poverty on the prevalence of FAS is seen in many of the poorer communities in the Western Cape province of South Africa (Croxford and Viljoen, '99). In a recent study, 46 of 1,000 (4.6%) children in the normal first grade classes in a rural town in South Africa were documented to have FAS (May et al., '00), a rate 30 times higher than that found in industrialized nations in which it has been studied. In areas such as these, as in many of the Indian reservations throughout North America, people have traditionally looked for ways to escape from their impoverished situation. Alcohol has been one legal and inexpensive method of escape that is widely used.

Recommendations

We recommend that programs designed to prevent FAS take into consideration the underlying social and economic bases of problem drinking and incorporate components that address these issues over and above the education of pregnant women. Only by looking at this problem within a broad social and economic context will it be possible to understand the reasons for drinking alcohol during pregnancy and to begin developing strategies that could prevent fetal alcohol syndrome.

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