Fetal Alcohol Syndrome: The Dilemma for Adoptive Families

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Introduction

Over the last several decades, progress has been slow in determining just how many children both in this country and abroad are affected by prenatal exposure to alcohol. A combination of legal, social, and attitudinal barriers has restrained communication on every level, starting with the health care provider and patient. Physicians, whether they are based in the United States or abroad, rarely ask a pregnant woman about her alcohol intake, leaving prospective adoptive parents without any sound information about the child’s risk status. Unfortunately, fetal alcohol syndrome (FAS) remains the most common cause of diagnosable mental retardation in the United States, as well as one of the leading causes of behavioral problems in children.

The prevalence of FAS is estimated to range from 0.2 to two cases per 1,000 live births, depending on ethnic, cultural, and regional factors. But the problem is even worse than these statistics suggest. A recent study of 4,800 women from a wide range of social and economic classes found that 22 percent of the women had used alcohol in early pregnancy, and 11 percent continued drinking even though they knew they were pregnant. Thus, about one million children across the United States may be exposed prenatally to alcohol each year.1

1 Please see the references at the end of this chapter for sources on prevalence rates.

Children available for adoption are at highest risk for prenatal exposure to alcohol. Several studies have estimated that 70 to 80 percent of children in the U.S. child welfare system who are available for adoption have been removed from their homes because of alcohol abuse in the family, and about 50 percent of children available for adoption through a private agency have been prenatally exposed to alcohol. Rates of prenatal exposure to alcohol among children available for international adoption are extraordinarily high, especially among children from the former Soviet Union, Eastern Bloc nations, South Korea, and South Africa. Thus, it is important for prospective adoptive parents to have a thorough understanding of the impact alcohol can have on the developing fetus and the long-term implications for children who have been exposed.

Criteria for Diagnosis

Fetal alcohol syndrome is the original name given to a cluster of physical and mental defects present from birth that is the direct result of a woman’s consuming alcoholic beverages while pregnant. Infants with FAS have signs in three categories: (1) growth deficiencies, (2) facial dysmorphology, and (3) central nervous system impairment.

Growth Deficiencies

In the United States, the average birth weight of babies born at full term (37 to 42 weeks gestation) is seven pounds, eight ounces, with a normal range down to five pounds, eight ounces. Babies
born to mothers who use alcohol have an average birth weight of around six pounds, and are more likely than babies born to mothers who abstained from alcohol to weigh less than five pounds, eight ounces. As children with fetal alcohol syndrome grow older, they tend to continue to be small for their age—that is, short and underweight. To meet the FAS diagnostic guidelines set for growth criteria, a child must have either reduced weight or height (at or below 10th percentile on standard growth charts) at birth or at any point in time after birth.

**Changes in Facial Features**

Facial features associated with prenatal alcohol exposure are consistent with overall flattening of the middle portion of the face. As a result, children with FAS exhibit:

- Epicanthal folds (extra skin folds coming down around the inner angle of the eye)
- Short palpebral fissures (small eye openings)
- A flattened elongated philtrum (no groove or crease running from the bottom of the nose to the top of the lip)
- Thin upper lip
- Small mouth with high arched palate (roof of the mouth)
- Small teeth with poor enamel coating
- Low-set ears

**Facies in Fetal Alcohol Syndrome**

These changes can vary in severity, but they usually persist over the life of the individual. Most people will not recognize any differences when they see the child, but physicians and other practitioners with experience in working with children prenatally exposed to alcohol will be able to detect the changes.

A problem arises when clinicians rely too heavily on changes in facial structure to recognize the child affected by prenatal alcohol exposure. In animal studies, pregnant rats given alcohol on days seven or eight after conception had newborns with facial features typical of FAS. However, giving the pregnant rats alcohol on days one through six, or on day nine or any time beyond, did not affect the facial features in any way. Thus, there appears to be a very narrow window of alcohol exposure that can affect children’s facial features.

**Central Nervous System Impairment**

Problems in the central nervous system can be manifest through structural, neurological, or functional changes. Structurally, a small head circumference (at or below tenth percentile) at birth or at any time thereafter indicates poor brain growth. For example, the average head size of term infants at birth is 35 centimeters, while the head size of a baby with FAS often is less than 33 centimeters. Neurological damage can be manifest as seizures, problems in coordination, difficulty with motor control, or a number of “soft” neurological deficits.

Functionally, the average IQ in children with FAS is about 68, compared to the general population, in which the average IQ is 100. Alcohol-exposed children, with or without the characteristic facial features or growth retardation, have consistently lower IQ scores than nonexposed children. Importantly, even alcohol-exposed children with a “normal IQ” demonstrate difficulty with behavioral regulation, impulsivity, social deficits, and poor judgment, causing problems in day-to-day management in the classroom and home.
From a brain structure perspective, prenatal alcohol exposure can not only cause the child to have a small brain overall, it can also stunt the growth of individual parts of the brain. This damaged growth may be present regardless of the child’s facial features. Problems in the formation and development of different parts of the brain can result in a wide range of behavioral and learning deficits. Many children with prenatal alcohol exposure have trouble moving information between different brain regions; they cannot effectively use information to self-direct their behavior or to think in the abstract. They may have trouble learning new information and recording it in the brain—and then have even more difficulty retrieving the information they’ve already learned.

Other parts of the brain also can be affected, impairing the child’s ability to coordinate planned motor movements and resulting in impulsive movement and clumsiness. Reduction in the size of the cerebellum in the back part of the brain, for example, produces difficulties with balance and arousal, and may be a source of sleep problems. Again, it is important to remember that such problems occur not only in children with the abnormal facial features associated with full expression of FAS, but also in many alcohol-exposed children who “look normal.”

More recently, research has demonstrated that children with FAE may have significant structural and functional changes in the brain, even though they lack overt physical manifestation of the alcohol exposure. Currently, the preferred terminology for children who have been exposed to alcohol but who do not meet criteria in all three diagnostic categories is alcohol-related neurodevelopmental disorder (ARND) or alcohol-related birth defects (ARBD). In April 2004, a group of federal agencies developed a consensus definition of fetal alcohol spectrum disorders (FASD):

> [A]n umbrella term describing the range of effects that can occur in an individual whose mother drank during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications (Bertrand et al., 2004).

Diagnostic terminology in daily use mainly focuses on FAS or ARND, both of which fall within the larger continuum of effects seen in children with FASD. FASD is not meant to serve as a diagnostic term, but rather a unifying one to help us appreciate the many ways in which prenatal alcohol exposure can become manifest in the affected individual.

**The Dilemma for Adoptive Families**

Diagnosis of alcohol-affected children is not nearly as easy as the terminology implies; the truth is, there is great controversy as to how and when to diagnose children whose mothers drank alcohol during pregnancy. The key barrier to diagnosis is the lack of information regarding maternal alcohol use during pregnancy. But the most important practical problem adoptive parents face relates to the lack of physical sequelae among the majority of alcohol-exposed children. Through the history of work with FAS, facial changes have been recognized as an essential component of diagnosis. However, at the same time, new
research demonstrates the primary role growth status (height and weight) has in recognizing children at risk from prenatal alcohol exposure.

In a recent study at Children’s Research Triangle, among 78 foster and adopted children with a confirmed history of prenatal alcohol exposure, the children’s current growth patterns, as opposed to facial changes, provided the strongest correlations with poor neurodevelopmental functioning. In this same study, by restricting the diagnosis of FAS to children with growth below the third percentile rather than the tenth percentile for chronological age, we were able to demonstrate neurodevelopmental differences between children with FAS versus those with ARND.

The clarification of these diagnostic issues is important for all families considering adopting a child with prenatal exposure to alcohol, especially in light of the necessity to recognize, early, those children who may be at risk from prenatal exposure, as well as the need for parents to advocate for the child to ensure access to early intervention programs. Without a diagnosis of alcohol-related risk, many children will not be deemed eligible for early intervention and school-based treatment programs, nor will insurance companies pay for related health care interventions. Parents and caregivers thus find themselves in a position of advocating for children not deemed “sick enough” to receive services.

In October 2005, the Centers for Disease Control and Prevention (CDC) published guidelines for the identification and referral of persons with fetal alcohol syndrome. The underlying goal of their report was to clarify the diagnosis of FAS, so as to enhance practicing clinicians’ ability to recognize and refer patients who may have been negatively affected by prenatal alcohol exposure. However, for practicing clinicians, the CDC’s guidelines contain many confusing features. The recommendation that substantial prenatal alcohol use must be confirmed runs counter to published data that document the impact of relatively small amounts of alcohol use in pregnancy. Further, any thresholds for safe use have not been empirically validated, and as the authors of the CDC article acknowledge, it is extremely difficult to confirm prenatal alcohol use because denial, minimization, and inaccurate memories are common among birthparents.

In addition, the collection of some of the data recommended in the CDC guidelines lies outside the practice of a general pediatric office. While it is relatively straightforward to evaluate more evident changes in the midface (nose, lip), it is extremely difficult to measure palpebral fissure size (size of the eye) without special equipment and facilities. From a practical perspective, many of the recommendations are overly broad: referring all children proposed in the CDC’s 2005 published guidelines—those with alcoholic parents, a history of abuse or neglect, involvement with the child welfare system, or a history of foster or adoptive placements—simply is not viable. Presently, further research is necessary to develop a more practical and clinically appropriate approach for the recognition and diagnosis of the spectrum of alcohol-related sequelae in children. Most importantly, eligibility criteria for the various federal- and state-funded treatment programs must be expanded to include all children at-risk from prenatal alcohol exposure.

The most important things adoptive parents can do in this regard are to:

- gather as much information as possible about maternal drinking behaviors during pregnancy
- seek a comprehensive evaluation of the child from a professional who has expertise in the area of prenatal alcohol exposure
- advocate for their child so that he or she will receive the most appropriate early and ongoing interventions, and thus enhance long-term outcomes
References on prevalence of prenatal exposure to alcohol and FAS


References on diagnosis of fetal alcohol syndrome


