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This month, FASD in Review examines the article recently published by Philip A. May, et al., in Pediatrics, titled “Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders,” Volume 134, Number 5, November 2014.

Prevalence of FASD – Background

The link between prenatal alcohol exposure (PAE) and Fetal Alcohol Spectrum Disorders (FASD), and the estimated prevalence and incidence of FASD in the United States, are ongoing topics of interest among researchers, practitioners, and policymakers. The recently published Treatment Improvement Protocol (TIP) #58, Addressing Fetal Alcohol Spectrum Disorders (Center for Substance Abuse Prevention, 2014), is a new resource available to behavioral health providers and administrators to help increase awareness about FASD and develop or improve prevention and treatment programs to address FASD. TIP 58 also includes a detailed history on FASD prevalence, and describes how the contemporary history on the recognition of facial features and other symptoms among infants with PAE began with the early research of Lemoine and colleagues in France (1968), and Ulleland and colleagues at the University of Washington (Ulleland et al., 1970; Ulleland, 1972). The latter work would eventually lead to a seminal article describing a pattern of outcomes associated with PAE (Jones, Smith, Ulleland, & Streissguth, 1973), as well as the publication that coined the term Fetal Alcohol Syndrome, or FAS (Jones & Smith, 1973).

Although subsequent research has clearly identified PAE as the cause of FASD, and public health policy messaging has asserted for nearly a decade that there is no known ‘safe’ level of alcohol consumption during pregnancy (Office of the Surgeon General, 2005; Hicks & Tough, 2009; Feldman et al., 2012), FASD remains a complex issue for women who drink while pregnant and for many primary care and behavioral health providers. Further study is underway to better understand the specific interactions and implications of dose of alcohol, pattern and timing of exposure, genetics, maternal use of other drugs and tobacco, general health and nutrition of the mother, stress and trauma during pregnancy, age, and other factors. Efforts to measure FASD prevalence have also been challenging for a variety of reasons, including the lack of consistently defined and applied referral criteria, passive surveillance methods that required diagnosis at birth and entry into birth defects registries (often requiring identification before the age of one or two), and an overall lack of diagnostic capacity.

Perhaps because of this complexity, there continues to be a range of views about the use of alcohol during pregnancy. Researchers, physicians, and women themselves debate the issue and question the view that abstinence is necessary for FASD prevention. As a recent example, an online article in Cosmopolitan reflected the author’s view that drinking in moderation is not a risk during pregnancy, and that many women and physicians share this view, at least privately.

1 Incidence generally refers to something measured within a set number of people and in a given time period (Rothman, 2002); for instance, newly occurring cases of a disease over a specific year. Prevalence speaks to something measured within a specific population at a given point in time, and not necessarily commencing at that point (Shields & Twycross, 2003). In other words, the condition may already be existing. The difference between the two can be summarized as: Prevalence answers "How many people have this disease right now?" Incidence answers "How many people per year newly acquire this disease?"
Findings continue to emerge that demonstrate the risks of this kind of thinking, and support the need for continued efforts to better understand and address FASD. International research on FASD has provided valuable approaches for assessing prevalence, based on active case ascertainment in schools. The effectiveness of these studies has influenced methodologies used in the United States, including those described in “Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders,” a new article by Philip A. May, Ph.D., and colleagues published in the November 2014 issue of *Pediatrics*. The next section summarizes this important new publication, which strongly indicates that FASD prevalence is much higher than previously believed.


The prevalence study authored by Dr. May and colleagues utilized a school-based sample to examine prevalence among first graders in a representative Midwestern U.S. city. The study community involved 160,000 residents; 87% were Caucasian. The community demographic indicators were very similar to U.S. averages, except for poverty level (slightly lower in this community) and racial diversity (community in study is not as diverse as typical American cities). Per capita alcohol consumption in the study community was higher than the overall state average, but the alcohol-related mortality index was less than the state as a whole.

The study team chose to oversample children with dysmorphic features in the population, based on the clear correlation between dysmorphic features and PAE. The study population involved all children enrolled in the first grade (n=2,033) across 32 public and private schools. All children were measured for height, weight, and head circumference at the beginning of the school year. Consent forms were sent to parents/guardians, with a 70.5% participation consent rate. A random sample of children was used to provide representative, normative controls.

**Content Highlights Existing Knowledge**

This study contributes to the FASD prevalence findings in the general population of the United States. The study found that:

- No significant differences were found for age or race across diagnostic categories or controls.
- Total dysmorphology scores showed significant differences between FAS and partial FAS (PFAS), and between FAS and PFAS and other controls.
- Alcohol-related neurodevelopmental disorder (ARND) did not show significant differences in dysmorphology scores from other controls.
- Cognitive and behavioral test performances were significantly lower for children who had an FASD than for controls.
- Significant maternal risk factors of mothers of children who had an FASD included:
  - First recognition of pregnancy further into pregnancy than controls;
  - More drinks per drinking day 3 months before pregnancy than controls; and
  - Husbands/partners consumed more drinks per drinking day during pregnancy than controls.

Using three techniques to estimate prevalence among these first graders, findings showed:

- Estimated prevalence of FAS was between 6-9 per 1,000;
- Estimated prevalence of FAS and PFAS combined was between 17-26 per 1,000; and
• Estimated prevalence of the overall FASD spectrum was between 24-48 per 1,000, or 2.4% - 4.8% (3.6% midpoint).

New or Notable Information

Previous prevalence estimates for FAS, one diagnosis along the FASD spectrum, have ranged from .2 to 1.5 per 1,000 children (CDC, 1995; 1997) to .5 to 3 per 1,000 children (Stratton et al., 1996). Prevalence of FAS among high risk populations, including children in foster care, has been estimated as high as 10 to 15 per 1,000 (Astley et al., 2002; Astley, 2004). The prevalence of the full spectrum of FASD in the general population has been estimated at 9.1 per 1,000 children (May et al., 2009).

This new study suggests that diagnosable cases within the FASD spectrum may be far more common. These include May and colleagues’ own previous findings (2009), which suggested that the overall prevalence of FASD in the general population was approximately 1%. If the new data are suggestive of changes in the overall FASD case rates, prevalence may be closer to 4%.

Implications of the New Research

The prevalence rates identified in this latest report, combined with so many unplanned pregnancies and many women not recognizing when they first become pregnant, hold significant implications for renewed federal commitment to FASD research, training, prevention, and treatment. The research findings suggest the importance of active case ascertainment for estimating prevalence vs. the more commonly used passive methods of surveillance or clinic-based studies, as these appear to underestimate the rates of FASD. The research also leaves an important question related to incidence unanswered: Until we have more consistent, longitudinal data on the prevalence of FASD, and increased diagnostic capacity, it will be difficult to measure changes in incidence over time and to allocate necessary resources appropriately.

The data also suggest important implications for FASD program and policy development. As TIP 58 suggests in its summary on the historical background of FASD, federal mandates have been instrumental in establishing key national resources for guiding research and program priorities to prevent and address FASD, including the Interagency Coordinating Committee on FASD (ICCFASD, funded by the National Institute on Alcohol Abuse and Alcoholism [NIAAA]); the National Task Force on FAS and FAE (the Centers for Disease Control and Prevention [CDC]; no longer active), and SAMHSA’s FASD Center for Excellence.

These mandates have been and continue to be instrumental in establishing the knowledge base about FASD. However, as that knowledge base has grown, so has need, which includes more intensive and personalized services, and early diagnosis and intervention to improve outcomes and decrease adverse life issues for those with an FASD and their families. The need for increased prevention services also seems clear, both in light of the increased prevalence reported and the perceptions of some, like the author of the Cosmopolitan article, that suggest little understanding of the health risks to the developing fetus when alcohol is consumed during pregnancy.
References


