EDITORIAL

Implications of Higher Than Expected Prevalence of Fetal Alcohol Spectrum Disorders

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Fetal alcohol spectrum disorders are a group of serious, chronic, systemic diseases that are caused by prenatal alcohol exposure and characterized by central nervous system damage and physical deficits that subsequently lead to a wide range of permanent and lifelong health consequences. Individuals exposed to alcohol prenatally are at greater risk of having comorbid conditions[1] and premature mortality[2] than individuals who have not been exposed to alcohol prenatally. The financial burden associated with fetal alcohol spectrum disorders is substantial, estimated to cost (Can) $1.8 billion to Canadian society in 2013.[3]

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In this issue of *JAMA*, May and colleagues[4] report new prevalence estimates among 13 146 children enrolled in first grade between 2010 and 2016 from 4 diverse communities in the Rocky Mountain, Midwestern, Southeastern, and Pacific Southwestern regions of the United States. This study reports the prevalence of fetal alcohol spectrum disorders to be between 1% to 5% (using a conservative approach to estimation) and 3% to 10% (using a less conservative approach). Although the different approaches reflect the uncertainty about the actual prevalence, these new estimates are up to 10 times higher than those previously reported using similar methods from 2 single-site studies,[5,6] and up to 5 times higher than a recent meta-analysis of 6 studies from the United States with a pooled prevalence of 2%.[7] The authors cautioned that their findings may not be generalizable to all US communities but also suggested that their estimates are likely more accurate than previously reported estimates for the United States.

In this study, May and colleagues[4] used active-case ascertainment, which is the most reliable approach for estimating the prevalence of fetal alcohol spectrum disorders. Active-case ascertainment has 3 primary advantages over other approaches, including the (local) representativeness of data obtained by assessing an entire community or population; a high likelihood of accurate diagnosis by clinical specialists; and elimination of self-selection biases, which are characteristic of passive surveillance or clinic-based methods.[8] Accordingly, this study[4] could prompt other countries to perform such active-case ascertainment studies to obtain their own prevalence data, both among the general population and among high-risk populations such as those in the child protection and criminal justice systems and Aboriginal and psychiatric populations, in which the prevalence is suspected to be much higher.[7] An example of such an endeavor is the project currently under way by the World Health Organization, with the support of the National Institute on Alcohol Abuse and Alcoholism, on the estimation of the prevalence of fetal alcohol spectrum disorders in several countries of Central and Eastern Europe, Africa, and Canada. (The WHO International Collaborative Research Project on Child Development and Prenatal Risk Factors With a Focus on Fetal Alcohol Spectrum Disorders is available by request from WHO Department of Mental Health and Substance Abuse, Management of Substance Abuse).

The finding of May and colleagues[4] that fetal alcohol spectrum disorders is not a rare condition among the general US population has substantial implications for clinicians and researchers, including that many cases are either missed or misdiagnosed; additional supports should be made available for affected children and adults; surveillance systems for affected children and for prenatal alcohol exposure are needed; and improved prevention efforts targeting prenatal alcohol use are clearly required.

Many cases of fetal alcohol spectrum disorders remain unrecognized or have been misdiagnosed.[9] In the study by May and colleagues, only 2 of 222 children had been previously diagnosed.[4] There are likely a number of contributing factors, such as unknown or unconfirmed prenatal alcohol exposure, overlapping diagnostic criteria with other neurodevelopmental disorders,[10] and high rates of comorbidity.[2] This problem is further exacerbated because there are a number of clinical diagnostic guidelines, and although the current criteria considerably overlap with one another, they lack diagnostic reliability due to low convergent validity.[11] Thus, a universal diagnostic approach needs to be accepted or developed.[12] Ideally, novel and reliable biomarkers for detecting fetal alcohol effects will be identified,[12] which could have significant implications for intervention and therapeutic services.

Many individuals with fetal alcohol spectrum disorders will require the support of different services and service systems throughout their lives, partly due to co-occurring secondary disabilities (eg, mental health problems, poor academic achievement and school failure, and involvement with the law).[13] As such, provision of appropriate diagnosis, interventions, and support services early in life and maintained throughout the life span is essential. Such supports and interventions can significantly improve an affected individual's quality of life and long-term prognosis.[14] Accurate prevalence estimates are crucial for effectively prioritizing, planning, and delivering the numerous required services.

The harmful effects of alcohol on a fetus result in many cases of preventable long-term disability and must be recognized globally as a public health problem. The prevalence

estimates reported by May and colleagues[4] demonstrate the need to establish a national fetal alcohol spectrum disorders surveillance system to monitor its prevalence, as well as the prevalence of its main indicator—alcohol use during pregnancy—regularly and systematically over time. Measuring the prevalence of fetal alcohol spectrum disorders and rates of prenatal alcohol exposure and monitoring the respective rates and trends over time in the general population as well as population subgroups are necessary for understanding and identifying vulnerable populations, targeting prevention and treatment resources, and establishing baselines to evaluate the effectiveness and cost-effectiveness of prevention and treatment strategies. A comprehensive surveillance system is needed not only in the United States but also throughout the world. Such surveillance systems could allow for a better understanding not only of the prevalence of the disorder and rates of prenatal alcohol exposure but also of the associated morbidity and mortality rates, quality-of-life indicators, and service utilization rates of affected individuals. A comprehensive surveillance system is currently being established for select provinces and territories of Canada with the support of the Public Health Agency of Canada.[15]

The high prevalence of fetal alcohol spectrum disorders in the United States[4] suggests better education of girls and women of childbearing age about the detrimental consequences of alcohol use during pregnancy on the fetus is needed. Efforts should be made to provide education on alcohol use in general as early as possible to both girls and boys, and the school system would be an ideal venue for such efforts to take place.

As the first point of contact, physicians and other health care professionals have an important role in prevention and identification. Special attention should be paid to young women who may engage in binge drinking because it can lead to unprotected sex[16] and unplanned pregnancies. Prepregnancy drinking behavior is known to affect the likelihood of prenatal drinking to a great extent.[17] Primary care clinicians should routinely include appropriate screening for alcohol use among all women of childbearing age, preconceptual health promotion, contraceptive counseling, and referral to substance abuse programs for those identified to have an alcohol use disorder. For women for whom it is not possible to ascertain prepregnancy drinking habits, identification of prenatal alcohol use should be a priority because reducing or eliminating alcohol use during pregnancy can potentially reduce the severity of the effects on the fetus. In addition, fetal alcohol spectrum disorders are an intergenerational issue with a high rate of recurrence within families; as such, families of affected children should be provided with ongoing support to reduce the likelihood of bearing additional children with fetal alcohol spectrum disorders.

As suggested by the American Academy of Pediatrics,[18] the message about alcohol use during pregnancy to the public should be clear and consistent: there is no safe amount, time, or type of alcohol to drink during pregnancy or when trying to get pregnant.

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