[Archived] Fetal Alcohol Syndrome/Effect and its Impact on Psychosocial Child Development Comments on Sandra and Joseph Jacobson and Susan Astley

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FAS/FAE and Its Impact on Psychosocial Child Development. Commentary on the review conducted by Joseph and Sandra Jacobson

Introduction

Since the initial description of fetal alcohol syndrome (FAS) in 1973,[1] a great deal has been learned about its physical manifestations. However, much less attention has been given to the psychosocial outcomes of affected children and adults — an unfortunate oversight since the major problems arising from FAS are behavioural rather than physical. In their paper, Joseph and Sandra Jacobson review the current body of knowledge on the behavioural outcomes of

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affected FAS children.

As the physical manifestations of FAS are understood, there is increasing recognition that many individuals with the behavioural manifestations of prenatal exposure to alcohol do not manifest all of the physical characteristics of the syndrome.[2] A variety of terms have been used to describe affected individuals with fewer physical markers of exposure. The term that the Jacobsons have chosen to use is Fetal Alcohol Effect (FAE). Other terms used to describe FAE include partial Fetal Alcohol Syndrome (pFAS),[3] alcohol-related neurodevelopmental disorder (ARND),[3] and fetal alcohol spectrum disorder (FASD).[4]

The authors note that, unlike many other syndromes (such as Down syndrome), individuals affected by FAS are not necessarily intellectually impaired, and that many (particularly those with FAE), function at normal or near-normal IQ levels. The studies that they have reviewed delineate the deficits that are common across all ability levels in FAS/FAE — the most common deficits being detected in arithmetic and attentional functions.

Research and Conclusions

The authors reviewed a series of studies that have documented attentional deficits in affected children[5-8] as well as a series by Coles[9,10] which did not find as many problems in attention as other researchers have found. They noted that the children in Coles' studies came from a cohort that is being followed from birth because of high levels of exposure, whereas many of the studies that have found attentional deficits have used clinically referred children. Such an approach introduces the possibility that attentional deficits arise from an interaction of prenatal alcohol exposure and postnatal environmental factors, such as dysfunctional family situations. The authors also reported on studies that have found deficits during executive functioning, learning, and memory in clinic–referred children.[11-19]

The research on the psychosocial functioning is more limited. The Jacobsons reviewed two studies of clinic-referred adolescents in which deficits in adaptive behaviour, cognitive functioning, and delinquency were found. They noted that aggressive and antisocial behaviour tended to increase during adolescence in affected children.[7,20,21]

Research on the psychosocial outcomes of FAS/FAE is limited by the methodologies used to described the difficulties in affected children. Some studies have followed a large cohort of children known to have been exposed to variable amounts of alcohol in utero, and who have been

followed longitudinally.[9,10,12,22-28] Most of the children in these studies do not have FAS/FAE. Such studies have been useful in determining the dose-dependent relationship between exposure and outcome, but do not describe the children who experience major deficits attributable to prenatal alcohol exposure. The exception has been Coles' studies,[9,10] which have included affected children followed since birth, and compared them to both normal controls and children with attentional problems who were not prenatally exposed to alcohol.

Other studies have used data on children referred to clinics to address functional concerns and subsequently diagnosed as having FAS/FAE.[5,6,8,11-16,18-20,29-34] This method of subject selection only included children for whom some type of clinical concern had been noted, and weighted the study towards finding adverse psychosocial outcomes.

One of the major issues in psychosocial research is the selection of adequate contrast or control groups. Research that implements carefully selected controls also allows for the identification of differences between groups of children facing psychosocial adversity and is useful in describing the deficits of exposed children relative to normative standards. Children with attentional problems who are not exposed to alcohol in utero have constituted a very useful control group in describing the unique effects of prenatal alcohol exposure on attention.[5,8,9]

Another major issue in the psychosocial research into FAS/FAE is the lack of attention paid to postnatal environmental variables, such as multiple out-of-home placements, recurrent illness, and child abuse. Several authors[33,35] have reported high rates of child abuse in affected children, particularly sexual abuse. To date, none of the research has attempted to assess the impact that these adverse postnatal events may have on affected children's behavioural and social outcomes.

Implications for Policy and Services

The Jacobsons note that the offspring of both alcoholics and recreational drinkers may present with cognitive and behavioural manifestations of prenatal alcohol exposure that will require educational intervention. In addition, they note the importance of prevention programs to limit the extent to which children are prenatally exposed to alcohol.

FAS is a common disorder, occurring at similar rates to Down syndrome and spina bifida. When all manifestations of FAS/FAE are considered together, the incidence is likely much higher than that of other common syndromes. Thus, children with FAS/FAE are likely to be found in a variety of educational settings, from mainstream classrooms to special education placements. Because

aggression and antisocial behaviour increase in adolescence, FAS/FAE is likely to be a common problem for youth in trouble with the law and those in a variety of treatment facilities.

Greater understanding of the behavioural manifestations of FAS/FAE may lead to more appropriate school programs, which may reduce school failure and high drop-out rates in affected individuals. It is likely that the high drop-out rates in some communities reflect the failure of schools to provide programming that engages adolescents with these disabilities. Treatment facilities for adolescents, both within the youth justice system and within more traditional health care systems, need to make allowance for the psychosocial needs of affected individuals so that programming can be tailored to their strengths and weaknesses.

Prevention of drinking during pregnancy is the only way to reduce the incidence of this disorder. As more is known about the subtle yet serious manifestations that accompany even recreational use of alcohol during pregnancy, the pressure will increase to provide public education programs designed to reduce drinking among pregnant women, aimed at many targets, including affected youth, in order to prevent multigenerational FAS/FAE.

FAS/FAE: Their Impact on Psychosocial Child Development with a View to Diagnosis. Commentary on the review conducted by Susan Astley

Introduction

FAS/FAE is an umbrella term used to describe individuals who present with the physical and behavioural manifestations of exposure to excessive amounts of alcohol in utero. When first reported in the English-speaking medical literature,[3] fetal alcohol syndrome (FAS) referred to a collection of abnormalities found in the infants of severe, chronic alcoholics. These infants presented with indications of growth retardation, unusual facial features, and evidence of central nervous system abnormalities. Many had other abnormalities as well, such as heart and skeletal defects. As the complete spectrum of difficulties caused by prenatal alcohol exposure was revealed through prospective studies of alcohol-exposed children, other terms were developed to describe individuals with lesser manifestations of the syndrome.[36,38]

Research and Conclusions

In this paper, Astley has reviewed diagnostic systems for FAS/FAE. Although the diagnostic criteria for FAS have been fairly well accepted, the diagnostic criteria applied to individuals with

some but not all of the manifestations of FAS have been much more controversial.[38] Astley points out that a number of terms have been used to designate diagnoses, including fetal alcohol effect (FAE)[38] and alcohol-related neurodevelopmental disorder (ARND).[3] Unfortunately, there has been little agreement among researchers and clinicians about the boundaries of FAE, leading to diagnostic confusion, misdiagnosis and underdiagnosis. The use of several poorly defined terms has also lead to an inability to compare incidence and prevalence findings across studies.

It was the Institute of Medicine (IOM)[3] that proposed a diagnostic schema involving five separate diagnostic groups to encompass all affected individuals. The terms proposed were FAS with and without an exposure history, partial fetal alcohol syndrome, alcohol related birth defect and alcohol-related neurodevelopmental disorder. Unfortunately, this system has not come into wide spread use and such as non-specific terms, such FAE, continue to be used.

In order to improve the accuracy and reliability of diagnoses, a four-digit code has been developed in which each of the four cardinal diagnostic features is rated from 1 to 4.[39-44] These features include maternal history of exposure, growth deficiency, facial features, and central nervous system dysfunction. Clinicians, primarily physicians, are trained to rank each feature, using specific objective criteria. These criteria have been developed from the clinical population followed at the University of Washington.

Astley has reviewed a series of studies showing that physicians may be trained to use the system with a high degree of accuracy and reliability,[39,43] leading thereby to more consistent diagnosis across diagnostic clinics — so long as those clinics use the four-digit code. She notes that many clinics in the US and — Canada now use this system.

A diagnosis serves many functions. It helps clinicians to communicate quickly, it allows data on incidence and prevalence to be collected and compared, and it frequently allows individuals to access services, such as special education and specialized health care, which are based on a specific diagnosis.

Although there is no doubt that the four-digit code leads to more reliable diagnosis, its major liability is that it is not helpful for other care providers (such as teachers, social workers, parole offices) to understand or treat affected children. Knowing that a child is a **4-4-4-4** or a **3-2-1-3** will not help to access resources for the child. In addition, the four-digit code theoretically yields 96 possible separate diagnostic groups, which tends to obfuscate rather than enhance diagnostic

clarity. As a result, most clinicians using the four-digit code find it necessary to translate the four-digit code back into terms such as FAS or FAE in order to obtain services for children. Thus, the diagnostic confusion that the four-digit code was designed to prevent remains unresolved.

In addition a diagnostic term that includes the word “alcohol” aids in prevention efforts since it is prenatal exposure to alcohol that must be prevented in order to reduce the incidence of this condition. Moreover, a numeric diagnostic system does not fulfill with the need to prevent at-risk drinking during pregnancy.

It was recently proposed that the term fetal alcohol spectrum disorder (FASD)[45] be used to encompass all manifestations of prenatal alcohol exposure, including FAS, FAE and ARND. This proposal has been warmly welcomed by the parents of affected children, who have been denied services because their children were diagnosed with FAE rather than FAS. The clinical utility of the term remains to be determined.

Implications for Policy and Services

Astley points out that the two critical pubic policy issues in FAS/FAE are preventing the birth of affected children through prevention programs, and reducing the difficulties that affected children have by providing appropriate supports to them. Both of these policy initiatives must be based on accurate diagnostic information. Therefore, improving the diagnostic criteria for FAS/FAE can lead to more targeted prevention programs and better educational and treatment programs for affected children and their families.

The four-digit code can improve diagnostic accuracy, but needs to be paired with a simpler, more descriptive set of terms for use in public policy initiatives. Indeed, the public is not likely to associate programs to prevent **4-4-4-4** and prenatal exposure to alcohol, even though this code represents an individual with all of the features of FAS.

In addition, most physicians require specialized training to reliably use the four-digit code. This diagnostic code is therefore limited in its usefulness, as many physicians cannot take the time to receive such training. A major concern among parents and other care providers is the shortage of diagnostic facilities, particularly in rural and remote communities, and the long waiting lists where facilities that do exist. Training physicians to use the four-digit code is likely to increase diagnostic accuracy, at the expense of further limiting access to diagnostic resources by reducing the pool of physicians will to make a diagnosis.

Prenatal alcohol exposure is a major public health issue in all industrialized nations and in many developing nations where alcohol abuse by women of childbearing age is common. Confusion over diagnostic criteria has hindered the development of accurate measurements that can reveal the scope of the problem. The four-digit diagnostic code is therefore useful for physician training, but needs to be paired with a universally accepted, descriptive terminology that service providers can use, such as the IOM criteria.

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