[Archived] FAE/FAS: Prevention, Intervention and Support Services Commentary on Burd and Juelson, Coles, and O'Malley and Streissguth

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Community-based screening for fetal alcohol syndrome. Commentary on Burd and Juelson[a]

Introduction

Dr. Larry Burd is the Director, North Dakota Fetal Alcohol Syndrome Center and an Associate Professor in the Department of Pediatrics at the University of North Dakota School of Medicine. He has worked in the fetal alcohol syndrome (FAS) field since the mid-1980s and has published extensively in this area, most recently on the use of community screening for detecting FAS. He is also part of the Four State FAS Consortium funded by the Center for Substance Abuse Prevention, a project aimed at determining and reducing risk factors associated with FAS in the

states of Minnesota, Montana, North Dakota and South Dakota. Tim Juelson is a medical student at the University of North Dakota School of Medicine.

Research and Conclusions

In his article, Dr. Burd makes a case for the effectiveness of community screening for FAS, using a kindergarten-screening program conducted between 1992 and 2000 as an example of this approach. Over 1,300 children were screened and seven cases of FAS identified. Currently, as Dr. Burd points out, the published prevalence rates of FAS vary tremendously and screening data give us a much better picture of the true extent of FAS/FAE in our communities. But perhaps more importantly, early screening would ensure that affected individuals were appropriately identified, so that early intervention could be implemented. Other work[1] indicates that intervention can make a vital difference in terms of outcomes for affected individuals and families. Dr. Burd makes the excellent point that FAS is a lifelong condition and there is a need for ongoing assessments as individuals meet certain benchmarks in their development.

Implications for Development and Policy Perspectives

There have been few attempts at community screening for FAS, and obviously more work is needed in this area. Different methodologies and screening tools testing these programs need to be evaluated before their widespread use can be implemented. The value of such community screening programs may depend upon the population being assessed, the screening instrument and the community where the screening is done. For example, in one assessment of community screening in the first grade in two counties in Washington, one county had basically all students screened, while in the other only about 25% participated. Another serious limitation was that only about half of the children who screened positive were seen in the specialty clinic for possible FAS diagnosis.[2] Screening without effective follow-up is of limited utility. However, it must be pointed out that this screening did detect previously undiagnosed cases of FAS.

Obviously, the success of a screening program depends to a large extent on the willingness of the community to participate fully, the type of screen and how it is employed and the follow-up evaluation. More research is needed to establish how these programs can best be utilized and how the success of these programs can be enhanced.

Another concern about the usefulness of community-based screening is the need to assess communities in which there is a high knowledge of FAS among health-care professionals.

Screening may be only minimally effective in utility-detecting undiagnosed cases of FAS if those who come into contact with the pregnant woman and her offspring are aware of the full spectrum of problems caused by prenatal alcohol and can identify “high-risk” pregnancies or children under school age. Obviously, this has the advantage of earlier identification, as well as providing a means for FAS prevention. Educating health-care providers and individuals who are in contact with children about FAS is a high priority to enhance early identification.

The case for the cost-effectiveness of community screenings is also made in this paper. In previous work, the cost per identified FAS case was estimated to be about $4,000.[3] Given the financial burden of dealing with the problems that can result from a lack of services to an undiagnosed case of FAS, this certainly seems like a smart investment. However, it has to be considered that the estimated cost of screening was $13 per child,[3] which many communities, even under the best of circumstances, could not afford. One compromise might be to do screening in populations thought to be at increased risk for FAS/FAE, such as children in the foster-care system or adopted children. For example, in a screening of children in foster care, the rates of FAS were 10 to 15 times greater than in the general population.[4]

Community screening can be an effective way to increase the accuracy of prevalence statistics for FAS and identify high-risk cases that might otherwise go undetected. However, additional work is needed to determine the best methodologies to use before these programs are implemented on a wide-scale basis.

Individuals Affected by Fetal Alcohol Spectrum Disorder and Their Families: Prevention, Intervention and Support. Commentary on Coles

Introduction

Claire Coles is the Director of the Fetal Alcohol Center at the Marcus Institute at Emory University, as well as an Associate Professor in the Departments of Pediatrics and Psychiatry and Behavioral Sciences at the Emory University School of Medicine. She has been publishing in the area of FAS since the early 1980s and brings the perspective of a developmental psychologist to the field. She is widely cited for her work on attention problems associated with prenatal alcohol exposure and on comparing outcomes in children seen in the clinic situation with those prospectively identified.

Research and Conclusions

This extremely perceptive article points out limitations in our current knowledge, gaps that exist in services, opportunities for additional research and implications for policy and planning. Dr. Coles makes some excellent points: 1) The necessity to identify services needed to deal with individuals with a fetal alcohol spectrum disorder (FASD) and their families, and whether these differ from those required by individuals with other developmental disabilities. Certainly, issues related to diagnosis are pertinent here, and it is essential to develop a standard of care. In line with this, we need to assess interventions designed for individuals with FASD, as many of these individuals do not seem to obtain effective interventions in the current climate. 2) Dr. Coles raises a question that is frequently not addressed in assessing the problems faced by individuals with FASD. Many of these individuals have been raised in situations filled with stress and less than optimal environmental conditions (e.g., an alcoholic home, foster care). I agree that more attention needs to be paid to the effects of these stressors and most importantly, to how they interact with the impact of prenatal alcohol exposure.

Dr. Coles also provides a reasoned discussion of research needs that should be addressed so that adequate, appropriate services can be provided with the realization that resources are not unlimited.

Implications for Development and Policy Perspectives

Dr. Coles makes several recommendations regarding the implications of her proposal: the usefulness of a needs assessment, comparing individuals with FASD to others with different disabilities, developing unique services where required and the necessity for program evaluation. I agree that these are an excellent starting point for policy planning. In terms of the needs assessment, this information is currently being gathered by the FAS Center for Excellence through a series of “stakeholders’” meetings, and common themes are emerging. However, in my opinion we need to obtain this information from a wider range of individuals affected by prenatal alcohol exposure. We do need to compare and contrast FASD with other disorders so that we do not reinvent the wheel, but we can utilize best practices already ascertained from the study of other developmental disabilities. Furthermore, this comparison might assist in the diagnosis of cases where the obvious dysmorphic signs of prenatal alcohol exposure are not apparent, as behavioural profiles of FASD might emerge, differentiating them from other disorders. Unique services need to be developed where appropriate. Furthermore, health-care providers and educators need to be trained in the consequences of prenatal alcohol exposure so that they can request services at the first signs of a problem in a particular area. For example, motor and

social skills can be affected by such exposure, and training can be implemented quickly if these appear to be problems, rather than waiting until the problem becomes so obvious that intervention may not be as successful. All too often, we hear that an individual's problem is simply a developmental delay that he or she will outgrow, or the problem is not serious enough to warrant intervention. If providers understood the long-term consequences of prenatal alcohol exposure, they might provide services sooner.

I believe that Dr. Coles' point that there is not enough information to provide specific treatment recommendations based upon scientific data is well taken. She is certainly not recommending that we do nothing at present, but rather that we provide services based on our best knowledge and collect data to enhance and improve those services. Information gathered from parents, educators and others who deal with individuals with FASD that appears to describe effective intervention needs to be put into practice and most importantly, evaluated. Research-based interventions from other areas of developmental disabilities need to be evaluated for their usefulness in the treatment of FASD. There is much that can be done with what we know, but it is extremely important that research be conducted to improve and focus these services. Interventions need to be evaluated so that we can develop programs based upon sound research.

Clinical Intervention and Support for Children Aged Zero to 5 years with Fetal Alcohol Spectrum Disorder and Their Parents/Caregivers. Commentary on O'Malley and Streissguth[b]

Introduction

Dr. Kieran D. O'Malley is an Assistant Professor in the Department of Psychiatry and Behavioral Sciences, University of Washington. One of the few psychiatrists actively conducting research on FASD, he brings a unique perspective to the study of this disorder. He has been working in this area since the mid-1990s and has primarily been involved in studies on the treatment of children with FASD and the occurrence of psychiatric disorders in these children. Dr. Ann Streissguth is a Professor in the same department and the Director of the Fetal Alcohol and Drug Unit at the University. She was one of the authors of the paper that originally identified fetal alcohol syndrome in 1973 and FAS has been her major area of study since that time. She is the author of over 200 papers on numerous aspects related to prenatal alcohol exposure and of the book "Fetal Alcohol Syndrome: A Guide for Families and Communities."[5]

Research and Conclusions

This article touches on a number of topics pertaining to FASD, particularly as it relates to younger children, and highlights several of these. The authors accurately recognize two problems: 1) That there are no science-based intervention studies and 2) that studies of support for families with FASD are lacking. The authors examine intervention studies from four conceptual views: preconception, prenatal, birth/infancy and toddler/young child.

Since FASD results from alcohol consumption during pregnancy, it is imperative to provide treatment to pregnant women who cannot stop drinking on their own. Even simple measures such as brief motivational interventions can be effective, but a range of treatments have to be available on demand, and these services have to take into account the special needs of pregnant women who may have other children in their care. Treatment services for alcohol-abusing women who may also have disabilities or psychiatric conditions have to be available.

As self-reported data on alcohol consumption are always suspect, obtaining objective measures of such exposure would be important and worthwhile. However, there are problems with the current measures available, although recent work on assaying fatty acid ethyl esters (FAEE) in meconium has produced some interesting results and if costs for this assay can be brought down, it may prove useful when alcohol use is in question. The authors also bring up the prevalence of various conditions related to prenatal alcohol exposure in younger children and I agree that more work is needed in this area. Certainly, we know that certain physical, cognitive and behavioural effects often result from prenatal alcohol exposure and that these can frequently be identified early in life. However, more work is needed on the frequency with which these effects occur and what factors play a role in their etiology (e.g. dose, timing or pattern of exposure; genetic factors). As Dr. Coles points out, we need to acknowledge the possible interactive effects of psychosocial stressors such as sub-optimal living conditions.

The authors note the lack of studies on interventions with infants and young children. I agree that this is an area in which further investigation is needed and that interventions demonstrated to be effective need to be implemented. The authors also point out the need for parent education and the necessity to support the entire family dealing with an FAS individual.

Implications for Development and Policy Perspectives

The authors imply that several things could be done to enhance the prevention and treatment of FASD. There is certainly a need for reliable biomarkers for maternal alcohol consumption. Several potential biomarkers have been proposed, although all have limitations that make their

current use in wide-spread screening problematic. However, it is hoped that within a relatively short time, the cost of such assays will be reduced and the limitations of the assays will be overcome and may therefore be more appealing for screening. Recently, the possibility of assaying FAEE through a hair sample was examined, and if this is confirmed and found to be reliable, such an assay might be useful.

I would also endorse the continued evaluation of infants and young children exposed prenatally to alcohol. The use of the Zero to Three diagnostic schemas might be one way to do this. This methodology, which offers a comprehensive framework for diagnosing emotional and developmental problems, may prove very useful in the assessment of infants and young children with FASD. Certainly, other methods of assessing newborns for FASD may prove useful. A better knowledge of the range of effects of prenatal alcohol exposure would certainly increase our understanding of the disorder, and might also allow for better diagnosis when obvious physical signs of alcohol exposure are not apparent or when the history of prenatal alcohol exposure is vague or unknown.

In the introduction to their concluding remarks, the authors note that there is a paucity of research on interventions with children with FASD and their families. I could not agree more, and this really needs to be corrected. These children are in need of interventions and caregivers are seeking out potential therapies. Unfortunately, the efficacy of most of these interventions has never been tested scientifically. Caregivers talk of success with various therapies (e.g. neurofeedback or hyperbaric oxygen therapy), but until these are tested in controlled studies, their real value will remain unknown. There are certainly difficulties in doing evaluation studies of various potential therapies, but their importance cannot be overstated. A decision on what types of therapies to evaluate can be based upon anecdotal reports of success, but in the end we need to provide a standard of care based upon good objective data, not anecdotal reports.

Another aspect mentioned by the authors deserves serious attention. They point out that that FASD involves the whole family unit – not just the affected individual in need of support and intervention. Interventions should take into account the family unit, the need for respite and the need to deal with other co-morbid conditions. I am also in agreement with providing a more coordinated “system of care” for substance-abusing women. The greatest risk factor for having a child with FAS is having a previous child with the disorder. Therefore, a coordinated system of care could identify which women are at greatest risk for having affected children. Intensive intervention could help them quit drinking or use effective family planning strategies. This would

have a major impact on reducing the number of new cases of FASD.

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[a] Comments on original paper published by Larry Burd & Tim Juelson in 2003. To have access to this article, contact us at cedje-ceecd@umontreal.ca

[b] Comments on original paper published by Kieran O'Malley & Ann Streissguth in 2003. To have access to this article, contact us at cedje-ceecd@umontreal.ca