[Archived] A Strategy for Community-Based Screening for Fetal Alcohol Syndrome

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Introduction

Prenatal exposure to ethanol is the causal factor in fetal alcohol spectrum disorders (FASD). FASD is comprised of a highly variable phenotype, often accompanied by various neurological deficits and/or mental retardation.[1,2,3] The most severe manifestations of FASD include growth impairments (both in height and weight), characteristic facial features and neurologic impairment (fetal alcohol syndrome [FAS]). Published prevalence estimates for FASD vary by nearly 100 fold, with current estimates suggesting a rate of 9.1 per 1,000 live births.[1,4,5] The adult outcome of FASD may be poor.[6]

Subject

A critical review of prevalence studies found that prevalence estimates developed with screening to identify at-risk populations almost always produced higher prevalence estimates than did studies without a screening step.[7] Screening for FAS can also enhance efficiency in the use of diagnostic resources and can be a low-cost strategy in identifying high-risk children.[8,9]

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Research Context

Several screening strategies have been suggested.[7] To examine the process of community-based screening, we utilized the FAS Screen, a rapid tool for the community-based screening of FAS.[8] The FAS Screen is a brief screening test that screens out low-risk children while screening in high-risk subjects.

Problem

Strategies for the Development of Community-Based Screening for FAS

Prior to screening, a four-hour screening training session should be completed in each community setting. The process and purpose of screening is discussed. Each item on the screening tool is reviewed and the consent process is discussed. The issue of how to obtain informed consent to participate is thoroughly contemplated.

The actual screening process takes about 8 to 11 minutes per child.[8,10] Since the performance characteristics of the screening tool are of interest to communities, all children are screened, even if they have already been diagnosed with FAS.

Research Results

Example of a Screening Project[10]

During a nine-year period, over 98% of the children enrolled in kindergarten were screened (see Table 1). Of the 1,384 children screened, 69 (5%) had a positive screen score (20 or above). These children were then referred to a diagnostic clinic for evaluation. In this group, seven (11%) were diagnosed with FAS and one with partial FAS. Each child diagnosed with FAS also met the criteria for category 1, 2, or 3 from the Institute of Medicine; FAS with confirmed maternal exposure (n=6) and partial FAS with confirmed maternal exposure (n=1).5 The prevalence of FAS in this community was about one per 230 kindergarten students or 4.4 per 1,000.

Table 2 presents the performance characteristics of the FAS Screen in this community setting.

Steps After Screening

Diagnosis

Children with a positive screen were then referred for diagnosis. If a community did not have access to an FAS Clinic for evaluation, a referral to a local genetics dysmorphology clinic provided access to the necessary diagnostic services. Each child was seen for an individualized evaluation. A standardized examination was used to record the signs of FAS or other genetic or dysmorphic syndromes.[2] The checklist used in our program produced a weighted severity score for FASD, utilizing the diagnostic criteria reported in our previous studies.[11] The reports were then sent to each child's physician, and, with the consent of a parent or guardian, were shared with the school to facilitate educational planning.

We have outreach diagnostic clinics 1 to 2 times per year and an ongoing FASD clinic. Children who had a positive screen scores above the screening cut-off and missed the clinic appointment, were seen at the next available clinic.

Management

A second important outcome resulting from the screening and diagnostic assessment was recommendations for management of the child.[11,12] Since FASD is a lifelong problem, ongoing follow-up is crucial. Many current diagnostic systems are limited by the fact that they use a one-shot approach ending with diagnosis, occasionally with management recommendations made based on the one time assessment. Many children with FASD have major developmental disabilities requiring ongoing assessment and treatment planning.[12] Our intervention strategy is strongly oriented to a management strategy emphasizing anticipatory training and intervention. The strategy encourages parent training to prevent secondary disabilities and to provide parents and schools with skills and planning prior to the development of behaviour disorders. We also have a strong commitment to development of system change before the person with FASD needs the services. The use of a ten-year prospective plan can be helpful. At each evaluation, parents and teachers thereby discuss where a child is likely to be in 10 years. This is especially helpful in anticipating the problems likely to be encountered as a result of developmental transitions (school entry, middle school, graduation from high school, etc.).

Conclusions

In some communities, screening programs can take two to three years to develop properly. We have found that a one-year program can also produce useful results. In a one-year period public

health nurses compiled screening in the Early Periodic Screening Diagnostic Testing Program (designed for low-income families) in North Dakota. n = 2,800 children. The result was the identification of 28 cases of previously undiagnosed FASD (Fetal Alcohol Spectrum Disorder).

Policy Implications

Should communities screen for FASD and related disorders? Many communities would benefit from a screening program.[7] The cost is low, the time commitment is modest, and the screening program facilitates early recognition and entry into intervention programs.[10] When a child is diagnosed with FASD, his or her siblings should also be evaluated since their risk is very high. Screening also provides a systematic step to encourage communities to develop services for the mother who is at high risk of drinking while pregnant. If a mother continues to drink, the risk of a second child with FASD exceeds 75%. Having a child diagnosed with FASD is also a marker for a very serious health condition in the mother. Her mortality risk during the ensuing 10 years exceeds 5%.

Policy development must be driven by evidence and need. FASD is a serious disorder, which provides compelling evidence of the need for action. Screening in communities is an important first step to diagnosis, appropriate, timely intervention and prevention. The potential for cost savings from prevention is high.[13,14]

References

1. Abel EL, Sokol RJ. A revised conservative estimate of the incidence of FAS and its economic impact. *Alcoholism: Clinical and Experimental Research* 1991;15(3):514-524.
2. Burd L, Martsolf JT. Fetal alcohol syndrome: diagnosis and syndromal variability. *Physiology and Behavior* 1989;46(1):39-43.
3. Abel EL. *Fetal alcohol abuse syndrome*. New York, NY: Plenum Press; 1998.
4. Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM. Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology* 1997;56(5):317-326.
5. Stratton KR, Howe CJ, Battaglia FC, eds; Committee to study Fetal Alcohol Syndrome, Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine. *Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment.* Washington, DC: National Academy Press; 1996.
6. Streissguth AP, Barr HM, Koga J, Bookstein FL. *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): Final report for the Centers for Disease Control and Prevention.* Seattle, WA: University of Washington Fetal Alcohol and Drug Unit, University of Washington Publications services; 1996.
7. Burd L, Cox C, Fjelstad K, McCulloch K. Screening for fetal alcohol syndrome: is it feasible and necessary? *Addiction Biology* 2000;5(2):127-139.

8. Burd L, Cox C, Poitra B, Ebertowski M, Martsolf JT, Kerbeshian J, Klug MG. The FAS screen: a rapid screening tool for fetal alcohol syndrome. *Addiction Biology* 1999;4(3):329-336.

9. Sokol RJ, Clarren SK. Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring. *Alcoholism: Clinical and Experimental Research* 1989;13(4):597-598.

10. Poitra BA, Marion S, Dionne M, Wilkie E, Dauphinais P, Wilkie-Pepion M, Martsolf JT, Klug MG, Burd L. A school-based screening program for fetal alcohol syndrome. *Neurotoxicology and Teratology* 2003;25(6):725-729.

11. Burd L, Cotsonas-Hassler TM, Martsolf JT, Kerbeshian J. Recognition and management of fetal alcohol syndrome. *Neurotoxicology and Teratology* 2003;25(6):681-688.

12. Burd L, Klug MG, Martsolf JT, Kerbeshian J. Fetal alcohol syndrome: Neuropsychiatric Phenomics. *Neurotoxicology and Teratology* 2003;25(6):697-705.

13. Klug MG, Burd L. Fetal alcohol syndrome prevention: Annual and cumulative cost savings. *Neurotoxicology and Teratology* 2003;25(6):763-765.

14. Lupton C, Burd L, Harwood R. The cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics Part C-Seminars in Medical Genetic*s 2004;127C(1):42-50.