



Fetal Alcohol Spectrum Disorders (FASD)

Systematic reviews of prevention, diagnosis and management

FASD Systematic Review – Key Findings

Elliott, L., Coleman, K., Suebwongpat, A., Norris, S. **Fetal Alcohol Spectrum Disorders (FASD): systematic reviews of prevention, diagnosis and management. HSAC Report 2008; 1(9)**

This report contains a systematic review of interventions that aim to reduce the burden of FASD, and a top-level review of FASD diagnosis and management strategies. In addition, there is a brief overview of the literature on the economics of FASD. This summary lists the predefined research questions and a summary of the key findings.

Prevention and Prenatal Screening

- Do primary, secondary or tertiary prevention strategies aimed at reducing FASD reduce the incidence of FASD?

The literature search did not identify any publications that directly addressed this question.

- Do primary, secondary or tertiary prevention strategies aimed at reducing FASD result in a reduction of the amount of alcohol consumed by women during pregnancy?

Primary prevention strategies aim to educate the general public. The search identified literature related to three primary prevention programs: warning labels on alcohol bottles, a multi-dimensional educational campaign and an alcohol ban. An additional paper assessed the impact of multiple sources of information. The only strategy that reduced alcohol consumption during pregnancy was alcohol prohibition.

Secondary prevention strategies are aimed at pregnant women. The literature search identified 13 publications evaluating a variety of secondary prevention strategies, all of which

can be broadly characterised as one-on-one, education-based interventions. Three programs statistically significantly reduced alcohol compared to a control group: an education session plus self-help manual, an assessment of alcohol use with a booklet for the subject to complete, and pooled results from multiple drug treatment programs. It is difficult to identify factors critical to the success of these three interventions as many of the features of these interventions were also present in studies which reported no benefit from the intervention.

Tertiary prevention strategies are targeted to women considered to be at a higher risk of having a child with FASD. The literature search identified 13 publications evaluating a variety of tertiary prevention strategies. Only one intervention, an intensive drug and alcohol prevention program, statistically significantly reduced prenatal alcohol consumption relative to the control group.

Many of the secondary and tertiary prevention studies did not detect a significant difference between the intervention and control group (the control group were typically given information about drinking during pregnancy). However a reduction in alcohol consumption was commonly observed in women in both groups. It may be that simple interventions are effective, but that more intensive interventions do not necessarily add to that effectiveness.

The simple interventions described in the literature involved the women being told about the effects of alcohol during pregnancy by their health care provider or via a letter or pamphlet.

- Do secondary or tertiary prevention strategies aimed at reducing FASD result in a decreased number of pregnancies in groups

or individual women known to be high users of alcohol?

The literature search did not identify any publications which directly addressed this question.

- Are screening tools able to identify women at increased risk of having a child with FASD?

The TWEAK and T-ACE are screening tools that were specifically designed to detect the lower levels of alcohol consumption that may affect fetal development. All publications identified in the literature search reported that the T-ACE and TWEAK were at least as effective as other general screening tools and were generally shorter and easier to administer. There was consensus in the literature that these are the most appropriate screening tools to use in the clinical setting.

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Visit HSAC's website

www.healthsac.net

Health Services Assessment
Collaboration

University of Canterbury

Private Bag 4800

Christchurch 8140

New Zealand

Phone: +64 3 345 8147

Fax: + 64 3 345 8191

E-mail: hsac@canterbury.ac.nz

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Postnatal Screening and Diagnosis

- Are postnatal screening tools (aimed at an individual or the mother of an individual suspected of having FASD) effective at identifying individuals who should undergo a full diagnostic FASD evaluation?
- Do diagnostic tools increase the accuracy of FASD identification?

The literature search did not identify any publications which directly addressed either of these clinical questions. However the literature search did identify three articles describing FASD or FAS postnatal diagnostic criteria and three diagnostic guidelines. The literature recommended that a full diagnostic evaluation only be performed by a trained specialist and preferably by a multidisciplinary team. The diagnostic approaches were broadly similar, evaluating prenatal alcohol exposure, characteristic facial abnormalities, growth retardation and CNS abnormalities. All publications discussed the significant problems associated with diagnosing the less severe forms of FASD. The diagnostic criteria and guidelines are widely used internationally, however there is no consensus on which criteria are the most appropriate. This is not surprising given the absence of a reference standard for FAS or FASD. The 4-Digit Diagnostic code was the most commonly used diagnostic criteria worldwide.

Management

- Do management strategies improve clinical outcomes in individuals with FASD?

The literature search identified three guidelines, and two review articles which discussed the importance of early intervention and effective management strategies to minimise the effect

of primary disabilities and prevent secondary disabilities. The specific disabilities experienced by individuals with FASD can vary significantly and management plans need to be tailored to each individual. Individuals need access to multiple services (eg physical, occupational, speech, behavioural, mental health). Older children need practical interventions, such as improving skills of daily living, specific job skills and money management. There was insufficient evidence in the literature to recommend any specific management strategies.

Economics

FASD does not only create burden on the healthcare system, but also on social services, the education system, the judicial system, and the family.

Three studies assessed the economic burden of FASD. One estimated the average adjusted annual costs associated with FASD as CA\$14,342 (NZ\$20,059) per child. A second reported the costs associated with FASD as ranging from US\$3.6 billion to US\$11 billion (NZ\$5.9-17.9 billion). The third study examined the potential cost saving if a case of FAS was prevented. Based on estimated annual direct healthcare costs of a child with FAS (US\$2,840 [NZ\$4,628]) and without (US\$500 [NZ\$815]), the cost saving was estimated to be US\$2,340 (NZ\$3,813) per annum.

Two studies costed specific strategies aimed at reducing the burden of FASD. A comprehensive program that included public education, professional training, a telephone helpline, adult treatment and education services, and child assessment services cost an average of US\$2,429 (NZ\$3,958) per child. The cost of a paper-based questionnaire, used as a screening tool to identify early cases of FAS who may need intervention services was US\$13 (NZ\$21) per child and US\$4,100 (NZ\$6,681) per case identified.

Conclusions

The interventions assessed varied widely, and the studies were generally of poor to fair methodological quality. While a small number of prevention strategies appear to have shown a beneficial effect on the reduction of alcohol consumption in pregnant women (eg alcohol prohibition and intensive alcohol rehabilitation), there are issues surrounding the interpretation of these results with regards to potential biases and the implementation of these strategies in the New Zealand setting.

A limited review of high-level evidence was carried out for postnatal screening and diagnosis, and management of FASD. There was very little high-level evidence available for these strategies and as such it was not possible to identify which may be suitable for implementation in New Zealand. There was broad agreement in the literature of the need for a multidisciplinary team (comprising of paediatricians, psychologists, psychiatrists, occupational therapists, speech therapists etc) in order to ensure optimal, personalised management of individuals with FASD.

The assessment of the published economic evidence suggests that FASD represents a significant economic burden (NZ\$1.6-2.4 million per child over their lifetime). Given the extent of the economic burden of FASD, it is more than likely that simple, relatively low-cost prevention strategies would represent significant value for money from a societal perspective.

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