Fetal Alcohol Spectrum Disorder: An Overview

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Conflicts of interest - none
Overview:

• Definition of FASD
• Epidemiology
  - Prevalence
  - Risk factors
• Diagnosis of FAS
• Presentation of FASD
  - Neurobehavioural effects
• Intervention and prevention
Fetal Alcohol Spectrum Disorder (FASD)
(Bertrand 2005, Sokol 2003)

- Is the umbrella term used to describe damage to the developing fetus from drinking of alcohol by a pregnant woman, as well as the wider social and educational impact

- It is a permanent, irreversible*, lifelong condition

- Is recognised as the commonest preventable cause of intellectual disability worldwide

- Is a major public health problem in an increasing number of countries
Fetal Alcohol Spectrum Disorder

- Effects on individual can be physical, mental or behavioural – all with life long implications

- The term FASD is not a diagnosis
Fetal Alcohol Spectrum Disorder

Represents a diagnostic spectrum:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Alcohol Related Birth Defect (ARBD)
Fetal Alcohol Syndrome

- Specific pattern of facial features
- Pre and/or post natal growth deficit
- Evidence of CNS dysfunction
- Positive history of maternal drinking
- FAS is most clinically recognisable diagnosis on the spectrum but represents the ‘tip of the iceberg’
Epidemiology

Prevalence of FASD (FAS, PFAS, ARND)

South Africa, Western Cape Province: school entry aged children (May et al)

2007  FASD: 69 - 89 per 1000
2011  FASD: 94 - 130 per 1000
2013  FASD: 135 - 207 per 1000 (included ARND for the first time)
2016  **FASD: 182 - 259 per 1000 or 18-26%**

FAS occurs in 93-128 per 1000 children
PFAS in 58-86,
ARND in 32-46 per 1000.

Northern Cape Prov.  FASD: 74 -119 per 1000
(Urban et al, 2008)

USA:  FAS  20-50 per 1000 or 2-5%
Italy:  FAS  4-12 per 1000;  FASD  23-63 per 1000 or % 2.3-6.3%
(May et al, 2006,2011)
Risk Factors for effects of alcohol exposure on the developing fetus

- No prenatal exposure to alcohol
  - = no FASD
- Any woman of child bearing age, anywhere, is at potential risk
Risk Factors for effects of alcohol exposure on the developing fetus

**Maternal** (Western Cape SA, May et al., 2008, 2013, 2016).

- higher age, gravidity and parity
- lower education and income*; rural residence
- timing: drinks consumed daily, weekly, drinking in all trimesters; and pattern: binge drinking pattern
- partner’s alcohol consumption during pregnancy
- use of tobacco during pregnancy.
- nutrition
- metabolism of mother and unborn child
Binge drinking pattern
(a common pattern throughout Africa and elsewhere)

- Higher peak blood alcohol concentration (BAC) than in continuous drinking
- High BAC critical factor in producing fetal brain injury
- High BAC causes prolonged alcohol exposure
- Withdrawal between binges exacerbates injury
- Binge-like alcohol consumption prevalent in reproductive age group (abuse vs. dependence)
- Strong association with binge drinking and unplanned / unprotected sexual activity
Risk Factors for FASD

- Genetic susceptibility of exposed individual
- Poor home environment / low socio-economic status
- Adoption / fostering
  - 47,000 children adopted from Russia in past 10yrs
  - Sweden 52% of 71 adoptees ex E. Europe FASD, 30% FAS (Landgren et al., 2010)
When are the critical times of prenatal alcohol exposure in fetal development?
Figure 1 Vulnerability of the fetus to defects during different periods of development. The red portion of the bars represents the most sensitive periods of development, during which teratogenic effects on the sites listed would result in major structural abnormalities in the child. The yellow portion of the bars represents periods of development during which physiological defects and minor structural abnormalities would occur.

SOURCE: Adapted from Moore 1993.
2nd trimester 16, 20, 24 wks
3\textsuperscript{rd} trimester: 34, 36 wks
Central nervous system (CNS) Effects: Face and Brain

CNS effects have the most significant manifestations.
Face and brain effects of FASD

- Specific alcohol related changes in brain structure and function
- Children with histories of moderate to heavy prenatal alcohol exposure show significant behavioural, cognitive and psychopathological effects
Facies in Fetal Alcohol Syndrome

Discriminating Features
- Microcephaly
- Short palpebral fissure
- Indistinct philtrum
- Thin upper lip

Associated Features
- Epicanthal folds
- Low nasal bridge
- Minor ear anomalies
- Micrognathia

In the young child

Adapted from Streissguth et al., 1994
Figure 1  Similarities of facial defects found in (A) humans and (B) mice exposed prenatally to alcohol. Panel C shows a control mouse fetus not exposed to alcohol. Photograph courtesy of Kathy K. Sulik.
Clinical Diagnosis

- CDC 4-Digit code
- IOM criteria
- Both use Lip-Philtrum guide (Clarren, Astley 1999)
Brain morphology changes

- Reduced brain size (microcephaly)
- Selective alcohol effects on different brain regions with volumetric reductions and alterations in shape in specific areas (Riley et al. 2005)
- Confirmed on newer techniques such as brain mapping (Sowell et al. 2010)
- White matter microstructure connective changes in frontal and occipital lobes on DTI (Fryer et al. 2010)
Figure 2  (A) MRI showing the side view of a 14-year-old control subject with a normal corpus callosum, (B) a 12-year-old with FAS and a thin corpus callosum, and (C) a 14-year-old with FAS and agenesis (i.e., absence due to abnormal development) of the corpus callosum. MRI’s courtesy of the authors.
Neurobehavioural deficits in FASD
Data from South Africa shows a correlation with brain changes on MRI and socio-economic status

(Gautem et al, 2016)
Effects of prenatal alcohol exposure on neurobehavioural function

- continuum of effects
- degree, duration of exposure
- longer, higher more severe impairment
- individual susceptibility
Cognitive-behavioural deficits in FASD

- IQ (most borderline, mild intellectual disability)
- Sustained and focused attention
- Planning and executive function
  (Ability to maintain appropriate problem solving for the attainment of goals: includes judgement, decision making and social conduct)
  - inhibition
  - working memory
  - integrating information over time, space
- Learning and general memory
- Visuo-spatial
- Language
- Number processing
- Behaviour
Cognitive-behavioural phenotype in FASD can be described as generalised deficit in complex (higher order) information processing. *(Kodituwakku 2007)*

- Some deficits are independent of intelligence (IQ). (so-called ‘core’ deficits)

- Behaviourally can look similar to ADHD; both have social difficulties
Impact of low SES on child development

Relations between poverty, stunting, child development and school achievement

- Poverty
  - Nutritional deficiencies / infections
  - Stunting

- Primary caretaker
  - Stress / depression
  - Low responsibility
  - Low education

- Poor care and home stimulation

- Poor school achievement

- Poor cognitive, motor, socio-emotional development

Fig. 1. A neuropsychological model of cognitive and behavioural outcomes of prenatal alcohol exposure.
## Measurements of intelligence in a low SES population

<table>
<thead>
<tr>
<th>Intelligence Scales Measure</th>
<th>FASD Mean score (SD)</th>
<th>CONTROL Mean score (SD)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEITER (age 10yr) Non-verbal</td>
<td>67.6 (10.3)</td>
<td>79.8 (11.3)</td>
<td>.000 **</td>
</tr>
<tr>
<td>WISC-IV FULL SCALE (age 14.6yr)</td>
<td>54.1 (2.13)</td>
<td>69.3 (12.1)</td>
<td>.000 **</td>
</tr>
<tr>
<td>WISC-IV VERBAL</td>
<td>54.7 (11.23)</td>
<td>67.1 (13.3)</td>
<td>.000 **</td>
</tr>
<tr>
<td>WISC-IV PERCEPTUAL REASONING</td>
<td>64.7 (12.84)</td>
<td>78.4 (12.11)</td>
<td>.000 **</td>
</tr>
</tbody>
</table>
In children with FASD in South Africa, the impact of maternal education and SES on child educational performance is greater than the effect of prenatal alcohol exposure alone.
Adaptive and social skills

Significantly poorer than non exposed controls

- Self-efficacy
- Adaptive classroom behaviours
- Poorer socio-emotional development, and moral reasoning than children of similar IQ

(Thomas, Carmichael, 1998)
Mental Health and FASD

- Increased behavioural, mental health problems and psychiatric illness across the lifespan (secondary disabilities)

Childhood to adolescence

- Increase in emotional disorders (anxiety, depression), executive planning and conduct disorders
- Persistence of executive function deficits
DSM-oriented behavioural and mental health problems: Achenbach Scale Teacher Reports (TRF) Age 10.0yr

**p<0.01  *p<0.05  

Adnams et al, 2011
Adolescence and Adulthood

“predictable long-term progression
...into adulthood in which
maladaptive behaviours present
the greatest challenge to management”

(Streissguth, Aase et al, 1991)
Adults with FASD

- Have life-long limitations in cognitive skills
- Are less likely to participate in the labour force
- Are more likely to be the victims of violence
- Are vulnerable to cycle between prisons or institutions – or at least to live in substandard conditions

- Face the dual challenge of parenting and living with FASD.
- Parents with FASD require appropriate support and service in a number of areas e.g. child care, support of their own children’s learning and education, acquiring social benefits etc.
- It is difficult to accurately diagnose adults with FASD and therefore this is a barrier to access of appropriate services
• Is there evidence for neuro-behavioural effects from prenatal exposure to low levels of alcohol?

• What level of alcohol exposure is safe?
Animal studies

- Mice exposed to light to moderate levels of alcohol prenatally show deficits in learning and memory when challenged on demanding tasks *(Savage et al 2002)*

- Ethanol exposed mice showed enhanced preference for taste and smell of ethanol and drank significantly more alcohol than non-exposed mice up to adulthood *(Willenz et al 2007)*.
Human studies

- Recent studies show that light to moderate prenatal alcohol exposure can lead to behavioural (attention / hyperactivity) deficits in young children aged 4-7 years and cognitive deficits in school aged children at 10 years.
The Maternal Interview

- Should be done at any opportunity where you are in contact with women
- The interview allows identification of women at risk
- The interview forms an integral part of communicating and caring for the mother (and family)
- Sensitive screening instruments are available (T-ACE, AUDIT, CAGE, TWEAK etc)
- Retrospective history may be as accurate as present drinking history
Maternal history: considerations

- Non-judgemental
- Consider the reason / context in which a mother drinks / misuses alcohol
- ‘Very few women drink to harm their baby’ *
- Role of doctor is to provide information - give the facts
Volumes of alcohol intake

- Beer - 300 ml = 1 drink
- Wine - 150 ml = 1 drink
- Spirits - 50 ml = 1 drink
- Home brewed alcohol = concentration varies
Volumes of alcohol intake

- Light drinking = up to 2 drinks per day or occasion

- Moderate drinking = more than 2 and up to 5 drinks per day or on one occasion *

- Heavy drinking = more than 5 drinks per day or occasion (binge) *

* definitions may differ
T-ACE  (Sokol et al 1989)

**T**  
**Tolerance:** How many drinks does it take to make you feel high?

**A**  
Have people **Annoyed** you by criticizing your drinking?

**C**  
Have you ever felt you ought to **Cut down** on your drinking?

**E**  
**Eye opener:** Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover

**Score:**  
T > 2 drinks = 2 points  
A,C,E affirmative = 1 point  
Total of **2 or more** indicates pregnancy risk drinking *******
FASD: Implications for Health* and other Systems

- High burden in children on health system and society *(Crede et al, S. Africa 2010)*
  - Median no. of annual visits to public health care facilities per child = 8 (range 4- 14).
  - Total average annual cost per child was about AUD 800
  - Total annual societal cost for the Western Cape was AUD 56,000,000.

- Cost of diagnosis of FASD in Canada Ca$ 3000-4700 per person *(Svetlana 2013)*

- High burden of mental health illness in FASD

- Not all FASD and intellectual disability recognisable (implications for training and service planning)

- High burden also placed on other service systems such as social services, education and criminal justice

- Implications for general economy
Interventions in FASD
Interventions in FASD

Aim for primary prevention

Secondary prevention:

Evidence for efficacy of interventions:

- community interventions for women and families
- Educational, cognitive and behavioural for children
- Without an evidence base it is difficult to argue for targeted interventions
What is being done about primary prevention of FASD

- Warning notice on liquor bottles / containers
- Banning of advertising
- Prohibition of sale of liquor to pregnant women
- Various policies
Interventions in FASD (35 published)

Neurobehavioural:
- Maths skills
- Literacy
- Working memory
- Attentional skills
- Neurocognitive rehabilitation
- Self-regulation (Cognitive control therapy)
- Social skills
- Safety skills
- Parent-child interaction therapy
- Behavioural consultation

Other
- Pharmacological – variable response
- Dietary
Classroom Adaptations

- Basic adaptations can support FASD neurobehavioural and learning difficulties needs profile
Language and literacy Intervention in FASD
(Adnams et al 2007)

- Sufficient information on areas of strengths and weaknesses to base appropriate interventions
- Measured deficits include language
- Language and literacy provide a key to further learning and autonomy
Addressing practice through research: Identifying effective interventions in intellectual disability.

Mean PAELT score change

T1 - T2 = Baseline to 9 months  T2 - T3 = 9 months to 18 months

* P=0.000  LLT vs FASD-C
* P=0.000  LLT vs NONEXP-C

(Adnams et al, 2007)
Indicated interventions

- *De Vries et al, South Africa:* Indicated Prevention of Fetal Alcohol Spectrum Disorders in South Africa: Effectiveness of Case Management.

- Case management (CM) was delivered as a method of indicated prevention to empower heavy drinking pregnant women to achieve cessation or a reduction in drinking.

- CM activities incorporated life management, Motivational Interviewing techniques and the Community Reinforcement Approach.

- Alcohol consumption dropped significantly from before pregnancy to the second and third trimesters. AUDIT scores indicated that problematic drinking decreases significantly even after the vulnerable fetus/baby was born. CM significantly increases client happiness, which correlates with reduced weekend drinking.

- CM was successful for women with high-risk drinking behaviour, and was effective in helping women stop drinking, or drink less, while pregnant, reducing the risk of FASD.
Recommendations from research studies

1. We can adapt existing methods that have been shown to be effective

2. Intervention can be provided within existing services

3. Involving caregivers promotes improvements
   - Parent as the focus of intervention
   - Improving parental knowledge of FASD
   - Providing “tools” to support behavioral changes

4. Explicit Instruction (targeted interventions) are more effective

Bertrand (for the FASD Intervention Consortium, 2009) Adapted from Coles IASSIDD WC2016
Recent reviews on Interventions for FASD


Challenges in responding to neuro-behavioural problems in children with FASD

- Limited number of clinicians trained to diagnose FASD spectrum (under-recognised)
- The mild end of the spectrum may be clinically difficult to recognise and diagnose
- Lack of multidisciplinary teams and services in resource low settings
- Information about effective interventions and intervention resources may not be available (children are ‘written off’)
Conclusions

- Early (even antenatal) prevention* and detection is key to facilitation of appropriate supports, interventions and treatments to optimise life function.

- The development of effective, universally accessible identification, assessment and comprehensive and targeted approaches across the lifespan is essential.
Because of the multidimensional nature of FASDs, identification, assessment and interventions must be *integrated* to provide seamless services across the lifespan to affected individuals, families and communities.

- multisectoral *
- multidisciplinary *
• Thank you

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