The changing face of FASD & the role of the paediatrician:

National case surveillance findings 2014-2017

Dr Marcel Zimmet on behalf of APSU FASD Investigators
What is Fetal Alcohol Spectrum Disorder (FASD)

Why is it important?

Tip of the iceberg: neurodevelopmental & physical effects of prenatal alcohol exposure

Acquired brain injury: severe neurodevelopment impairment
   +/- Physical features: facial, growth deficits, birth anomalies (biomarkers)

Preventable, common cause of neurodevelopmental disability
FASD epidemiology in Australia

Previous national surveillance
FAS/PFAS (2001-04) Elliott et al
92 cases, incidence rates considered underestimate

Prevalence studies
Lililwan: high risk community in WA - Fitzpatrick et al - FASD 20%
Youth in detention in WA (Banksia Hill Project) - Bower et al - FASD 36%

Important studies, yet not representative of national population
What this study adds

**Australian context**

The **first national** study to identify children across the **entire FASD spectrum** using updated criteria (2016)*

Includes FASD without physical features

Precursor to national registry (FASDAR)

**International context**

The **only national FASD surveillance study**

Comparison to Canadian FASD registry possible

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What data have we captured?

Diagnostic patterns
  • Clinical patterns
  • Who / where are children diagnosed?

Demographics

Changes over time
Methods: Case finding

**What?**
- Active surveillance
- Prospective national case-finding

**Who?**
- Children/adolescents < 15 years old
- Reporters: ~1500 paediatricians
  - %90 paed. in Australia
  - Monthly response rate 80-90%

**When?**
- December 2014 – Dec 2017

**How?**
- Paediatrician reporting case completes questionnaire
Verified cases: Dec 2014-Dec 2017

Notifications
N = 437

Qn/s received
N = 415

Verified Cases
N = 251

Age > 15y/diagnosis date n = 96
Criteria not met n = 10
Not yet classified n = 21
## Methods: Diagnostic Criteria

<table>
<thead>
<tr>
<th>FASD + 3SFF</th>
<th>Prenatal alcohol exposure (+/-)</th>
<th>Severe Neurodevel. impairment</th>
<th>3 Sentinel Facial features</th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD &lt; 3SFF</td>
<td>Prenatal alcohol exposure</td>
<td>Severe Neurodevel. impairment</td>
<td>0,1,2 Sentinel Facial features</td>
</tr>
<tr>
<td>FASD Classification (n=251)</td>
<td>Median age</td>
<td>Female:male</td>
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<tr>
<td><strong>FASD +3SFF</strong> 24 %</td>
<td>7.6y*</td>
<td>1 : 1.6**</td>
<td></td>
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<tr>
<td><strong>FASD &lt;3SFF</strong> 76 %</td>
<td>9.2y</td>
<td>1 : 1.9</td>
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</tbody>
</table>

* Significant difference (p<0.001)
** No significant difference (p = 0.59)
Prenatal alcohol exposure

19% used standardised tool (typically AUDIT-C)

High risk exposure

- 40% 7+ std drinks per week
- 32% 5+ std drinks on a single occasion

Risk level not reported in ~60% of cases

41% birth mothers reported to have alcohol use disorder
18% alcohol related health problems/injury
<table>
<thead>
<tr>
<th>Neurodevelopmental Domains</th>
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</thead>
<tbody>
<tr>
<td>Brain structure /neurology</td>
</tr>
<tr>
<td>Motor skills</td>
</tr>
<tr>
<td>Cognition</td>
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<tr>
<td>Language</td>
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<td>Academic Achievement</td>
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<tr>
<td>Memory</td>
</tr>
<tr>
<td>Attention</td>
</tr>
<tr>
<td>Executive function, Impulse control, Hyperactivity</td>
</tr>
<tr>
<td>Affect Regulation</td>
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<tr>
<td>Adaptive behaviour, Social skills, Social comm.</td>
</tr>
<tr>
<td>Brain structure /neurology</td>
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<td>---------------------------</td>
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<tr>
<td>Memory</td>
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</tbody>
</table>
Brain structure/Neurology Domain

24% **Microcephaly** (~correlates with rate of FAS with 3SFF)

14% **Structural brain anomaly** (e.g. thin corpus callosum, optic. N hypoplasia)

8% **Neurological abnormalities** (e.g. seizure disorder, cerebral palsy)

25% **Growth impairment** (correlates with neurodevelopmental outcomes)
Facial features

- 40% Short palpebral fissures
- 57% Smooth philtrum
- 47% Thin upper lip

*Photo analysis software used in 60%*
Demographics

Diagnostic patterns
## Demographics

<table>
<thead>
<tr>
<th>Category</th>
<th>FASD 2014-17</th>
<th>FAS 2001-04</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis (median)</td>
<td>8.6 y</td>
<td>3y</td>
</tr>
<tr>
<td>Male:female ratio</td>
<td>1.3:1</td>
<td>1:1</td>
</tr>
<tr>
<td>Child protection services (<em>current/past</em>)</td>
<td>75%</td>
<td>67%</td>
</tr>
<tr>
<td><strong>Out of home care (<em>foster/adoptive</em>)</strong></td>
<td>54%</td>
<td>38%</td>
</tr>
<tr>
<td>Biological parents’ care</td>
<td>18%</td>
<td>40%</td>
</tr>
<tr>
<td>Grandparents’ care</td>
<td>16%</td>
<td>21%</td>
</tr>
<tr>
<td>Sibling with FASD</td>
<td>15%</td>
<td>51%</td>
</tr>
<tr>
<td>Indigenous</td>
<td>57%</td>
<td>65%</td>
</tr>
<tr>
<td>WA 70%, 43% elsewhere</td>
<td></td>
<td>3% general population</td>
</tr>
</tbody>
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### Change since previous study 2001-2004

<table>
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<tbody>
<tr>
<td>Reporting rates</td>
<td>84 per year</td>
<td>23 per year</td>
</tr>
<tr>
<td>Incidence</td>
<td>1.79 per 100,000 children &lt; 15y</td>
<td>0.58 per 100,000 (FAS/PFAS only)</td>
</tr>
<tr>
<td>Similar ratio</td>
<td>1:3</td>
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<tr>
<td>3 SFF : &lt;3 SFF</td>
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*as expected given what we know about FASD*
Who is diagnosing FASD and how?

84% diagnosed in specialist FASD clinics / by FASD champions/experts (in MDT teams)

Specialist FASD clinicians more commonly diagnosing FASD with <3 SFF:

- 7 paediatricians
  - 18% (of 38 reporting paed/s for FASD)
  - 0.005% (of 1500 reporting paed/s to APSU overall)

- 82% vs 61%  
  \(p = .006\)
Where is FASD being diagnosed?

State/territory distribution

Gen population

FASD population
Reporting patterns: *Discussion*

**Possible reasons for regional variation**
- Differences in drinking patterns in different regions
- Real differences in prevalence
- Under vs over diagnoses
- Access to diagnostic services
- Interests and biases of paediatricians

? Other clinicians diagnosing e.g. geneticists, psychiatrists

*Assessment is challenging, time consuming – partic. for solo clinicians; developmental teams may be under-diagnosing*
A child diagnosed with FASD in Australia is most likely:

- Male
- 8 years old
- In foster/adoptive care
- Indigenous

To have:
- <3 sentinel facial features
- A history of nicotine/polydrug co-exposure

To be diagnosed in:
- A specialist FASD clinic
- WA, NSW, or QLD
The lived experience of this study
Key trends

FASD diagnosis by Australian paediatricians is increasing coinciding with:

- Establishment of specialised FASD diagnostic clinics
- Availability of national diagnostic guidelines
- Likely reflects better recognition of the FASD spectrum (neurodevelopmental impairment in the absence of facial and other physical features) – the changing face of FASD
Interpretation of key trends

FASD is likely *underdiagnosed* given:
  - High rates of drinking in pregnancy in Australia (40-60%)*
  - FASD prevalence internationally (0.8%+)**

Over-representation of children in out-of-home care and Indigenous children suggests *underdiagnosis* in:
  - Non-Indigenous children
  - Children living with their birth mother,

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## Limitations & challenges

<table>
<thead>
<tr>
<th>Reporting</th>
<th>Predominance of cases from small group of reporters</th>
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<tr>
<td></td>
<td>Variation in use of standardised tools could affect diagnosis: e.g. for facial features</td>
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<tr>
<td>Data gaps:</td>
<td>Diagnostic details: eg. psychometric test scores</td>
</tr>
<tr>
<td></td>
<td>Number of care placements, early life trauma, neglect/abuse</td>
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<td>Children’s strengths</td>
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</tbody>
</table>
Strengths

Novel national/international data set

Able to monitor diagnostic trends

Platform for national registry

Guides service provision, planning, policy & advocacy

Educative process for paeds re: FASD

Collection → Reporting

Dissemination & utilisation

Analysis & interpretation
Disruptive conversations

About who we are, or are not diagnosing, and why
About FASD as form of brain injury and reframing our understanding of children accordingly

About FASD as a common preventable neurodevelopmental disorder/disability, and opportunities for prevention (e.g. in future siblings) as well as better and early intervention

About the impact of alcohol on children in our society more broadly, in all rather than just some communities

FASD is not an Indigenous problem
And it doesn’t just occur in foster children

About understandable barriers, concerns, uncertainties and challenges with diagnosing FASD
As the face of FASD changes, so does the work of paediatricians.
A disruptive conversation, for a healthier future......

The onus is on us from a public health and ethical perspective to move the conversation forward, for the kids and families we are working for now, and those yet to be born...

– for a healthier future
Thank you
..and please diagnose & report FASD!

Questions?