Fetal Alcohol Spectrum Disorders: A Whole Body Diagnosis

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Outline of Presentation

- International View
- Brief Overview of Diagnosis
- Behavioural Problems by Age
- Physical Problems
- Transgenerational Aspects
Pooled prevalence of alcohol use during pregnancy in general population for select countries
(Any amount of alcohol consumed and at any point during pregnancy)

*The prevalence for countries with an asterisk are based on actual data

<table>
<thead>
<tr>
<th>Country</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ireland</td>
<td>60.4%</td>
</tr>
<tr>
<td>Denmark</td>
<td>45.8%</td>
</tr>
<tr>
<td>Russian Federation</td>
<td>41.3%</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>36.5%</td>
</tr>
<tr>
<td>Republic Australia</td>
<td>36.3%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>35.6%</td>
</tr>
<tr>
<td>Italy</td>
<td>34.0%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>33.1%</td>
</tr>
<tr>
<td>Hungary</td>
<td>32.7%</td>
</tr>
<tr>
<td>Portugal</td>
<td>30.5%</td>
</tr>
<tr>
<td>Romania</td>
<td>28.3%</td>
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<tr>
<td>France</td>
<td>27.0%</td>
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<tr>
<td>New Zealand</td>
<td>26.7%</td>
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<tr>
<td>Germany</td>
<td>25.8%</td>
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<tr>
<td>Lithuania</td>
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<tr>
<td>Poland</td>
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<tr>
<td>Norway</td>
<td>22.6%</td>
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<tr>
<td>Greece</td>
<td>21.1%</td>
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<tr>
<td>Zambia</td>
<td>18.5%</td>
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<tr>
<td>Netherlands</td>
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<tr>
<td>Brazil</td>
<td>15.2%</td>
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<tr>
<td>Spain</td>
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<tr>
<td>South Africa</td>
<td>14.8%</td>
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<tr>
<td>Ghana</td>
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<td>Croatia</td>
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<tr>
<td>Chile</td>
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<tr>
<td>Canada</td>
<td>10.6%</td>
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<tr>
<td>Venezuela</td>
<td>10.0%</td>
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<tr>
<td>Sweden</td>
<td>10.0%</td>
</tr>
<tr>
<td>Nigeria</td>
<td>8.1%</td>
</tr>
</tbody>
</table>

With kind permission Popova et al., submitted
Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: systematic review and meta-analysis

Popova et al 2017  The Lancet Global Health Open Access article
Global prevalence (per 10 000 people) of FAS among the general population in 2012

Popova et al 2017 The Lancet Global Health Open Access article
Diagnostic Criteria

Based on four measures;

1) Growth
   - Short in length
   - Light in weight
   - Smaller than normal head circumference

2) Facial features

3) Brain

4) Maternal Drinking History

www.cdc.gov/fasd
FAS FACIAL FEATURES

Discriminating Features
- short palpebral fissures
- flat midface
- short nose
- indistinct philtrum
- thin upper lip

Associated Features
- epicanthal folds
- low nasal bridge
- minor ear anomalies
- micrognathia

Streissguth, 1994
**Bad news** Neuro-Developmental Disorders Pre-natal Alcohol Exposure (ND-PAE) failed to be listed in the DSM-5.

**Good news** It is included in the appendix as “conditions needing further study” (page 798).

**Good news** is that ND-PAE is used as an example for “Other Specified Neurodevelopmental Disorder,” code 315.8 (page 86).
Simple View of Causation

An individual child’s risks of FASD are influenced by:

- **Quantity** of alcohol consumed by mother during pregnancy.
- **Pattern** of alcohol consumption.
- **Frequency** (how often) the mother drinks.
- **Timing** of drinking in relation to period of gestation.

(Goodlet Horn and Zhou 2005)
Critical Periods of Human Development

Moore et al 1988
Behavioural Aspects by Age
Birth to 36 months

- May have been diagnosed as “failure to thrive” (one of many diagnoses given over time).
- Difficulties with feeding.
- Difficulties in establishing a regular sleeping pattern.
- Irritability very active/hyperactive.
- Frequent bouts of illness.
- Delay in reaching milestones.
- Indiscriminate, people are interchangeable.
Failure to grasp cause and effect
Three to Five Years

- Easily overwhelmed.
- Frequent lengthy temper tantrums.
- May be physically aggressive.
- Reacts badly to and resists change.
- Unable to learn from experience.
- Accident prone.
- Fearless/unable to comprehend danger.
Six to Ten

- Visual memory better than auditory memory.

- Information seems to “slip in and out” Remembers today, forgets tomorrow and remembers again next week. Interpreted by teachers?

- Difficulty separating fact from fantasy.
Eight to Ten Years

- Mood swings
- Difficulty with self-regulation
- Problems with planning and the sequencing needed in a lot of tasks
- Needing constant reminders for basic living tasks
- Confabulating

Ten to Fourteen

- Initially may be seen as intelligent based on language skills.
- Lots of words but quantity masks quality.
- Speech problems e.g. stammering.
- Gets lost quickly in conversation and loses interest.
- Trouble following directions.
- Little understanding of social norms.
- Increased risk of drink/drug use.
Fourteen to Eighteen

- No sense of personal space or boundaries.
- May be sexually inappropriate/does not understand risks.
- Overly affectionate with people s/he does not know well.
- May be teased or bullied by other adolescents.
- May bully or frighten others.
- Moves through extremes of behaviour in a short space of time.
- May be diagnosed as “Conduct Disorder”.
- Burns people out.

FAS/FAE Support Network
Vancouver
Adult

- Judgement and critical thinking are poor
- Lacks social skills either aggressive or withdrawn
- Blames others for own mistakes
- Involved in criminal activity
- Difficulty in keeping a job
- Abusive relationships
- Mental health problems Counselling?
  - Depressed/ suicide attempts
  - Anxious
Dear mum & dad

Nov. 22, 94

I'm having the best time of my life in NYC. you're not going to try and help me, because I don't have a drug and alcohol problem. The only problems I had started at home, I would just like to clear this for the record you're not my real parents and I'm not your real daughter, OK.

I'm never coming back, NEVER.
I hate you both and you can rot in HELL for all I care.

Love, Yr. Stu

[Signature]

PS. Please write back.
Comorbidity of Fetal Alcohol Spectrum Disorders: Physical Problems
Comorbidity of Fetal Alcohol Spectrum Disorders

Two studies;

- Systematic search for studies reporting comorbid conditions in individuals with one or more of the conditions included under the umbrella term FASD.

- A Canadian study describing a survey of adolescents and adults with a diagnosis of pre-natal alcohol exposure.
The objectives of the study were to:

1) Identify the comorbid conditions that occur among individuals with FASD.

2) Estimate the pooled prevalence of comorbid conditions found to occur among individuals with FAS

A group of young people began to talk amongst themselves about the physical problems they had.

Being young people they thought the best way to do this was using the internet.

With the help of colleagues Profs Joanne Weinberg and Ed Riley designed a questionnaire.

Their aim was to develop the idea of FASD being a "whole body diagnosis"
Preliminary Results of a Health Survey of Adults with an FASD

- The survey includes over 260 items in 26 areas including:
  - Auto-immune Disorders.
  - Immune Problems.
  - Heart Problems.
  - Problems with Bones, Muscles and Joints.
  - Vision/Hearing.
  - Endocrine Disorders
    - Thyroid

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results of a Health Survey of Adults with an FASD

- Sensory Problems.
- Seizures.
- Sleep Disorders.
- Problems with Executive Function.
- Mental Health.

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results of a Health Survey of Adults with an FASD

**Number of respondents** = 356

<table>
<thead>
<tr>
<th>Ages</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>16-19</td>
<td>24.4%</td>
</tr>
<tr>
<td>20-30</td>
<td>41.6%</td>
</tr>
<tr>
<td>31-40</td>
<td>20.9%</td>
</tr>
<tr>
<td>41-50</td>
<td>7.6%</td>
</tr>
<tr>
<td>51-59</td>
<td>3.9%</td>
</tr>
<tr>
<td>Over 60</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results Of A Health Survey Of Adults With An FASD

Gender

- Female: 53.7%
- Male: 44.1%
- Other: 1.1%
- Rather not say: 1.1%

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results Of A Health Survey Of Adults With An FASD

Diagnosis

FAS  48.6%
pFAS  9.7%
ARND  22.4%
FAE  9.7%
Static  9.7%
Encephalopathy

Each respondent was asked and supplied the name of physician and/or clinic where the diagnosis was made.

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results of a Health Survey of Adults with an FASD

Auto-Immune Disorders

- Rheumatoid Arthritis: 12 x higher than general population.
- Celiac Disease: 4 x higher than general population.
- Crohn’s Disease: 4 x higher than general population.

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Preliminary Results of a Health Survey of Adults with an FASD

Immune Problems

- Asthma 4 x higher than general population
- Allergies (any) 1 x higher than general population
- Carrying an Epi-pen 4 x higher than general population

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Preliminary Results of a Health Survey of Adults with an FASD

Immune Problems

- **Chronic Sinusitis:** 3 x higher than general population.

- **Chest Infections:** 2 x higher than general population.

- **Chronic Ear Infections (adults):** 142 x higher than general population.

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Preliminary Results of a Health Survey of Adults with an FASD

Heart Problems

- Congenital Heart Defects: 23 x higher than general population.
- Child Heart Surgery: 15 x higher than general population.
- Hypertension (ages 18-44 years) 2 x higher than general population.
- Supraventricular Tachycardia  27 x higher than general population.

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Preliminary Results of a Health Survey of Adults with an FASD

Bones, Muscles, Joints

- Scoliosis: 7 x higher than general population.
- Joints always hurt, “make a noise”: 3 x higher than general population.
- Osteoarthritis: 4 x higher than general population.
- Gout: 10 x higher than general population.

With kind permission of Himmelreich, Lutke & Travis 2016
Preliminary Results of a Health Survey of Adults with an FASD

Problems with Hearing

Hearing Loss as Children: 75 x higher than general population

Often leading to problems at school

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Preliminary Results of a Health Survey of Adults with an FASD

**Thyroid Disorder**

- **Hypothyroidism (clinically evident):** 160 x higher than general population.

- **Hyperthyroidism:** 4 x higher than general population.

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Preliminary Results of a Health Survey of Adults with an FASD

Sensory Problem

- Acute Sense of Smell: 55 x higher than general population.
- No sense of smell: 9 x higher than general population.
- Doesn’t like the texture of food: 54.2%
- Do not feel hunger: 35.2%

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Preliminary Results of a Health Survey of Adults with an FASD

Seizures Disorders: 21 x times higher than the general population

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Preliminary Results of a Health Survey of Adults with an FASD

Sleep Disorders

- Problems Falling Asleep: 7-14 x higher than general population.
- Problems Staying Asleep: 6-11 x higher than general population.
- Sleep Apnoea: 6 x higher than general population.

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Preliminary Results of a Health Survey of Adults with an FASD

Executive Function

- Problems with Short Term Memory: 79.80%
- Problems with Long Term Memory: 69.30%
- Problems Paying Attention: 88.30%
- Problems Making Decisions: 86.0%

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Preliminary Results of a Health Survey of Adults with an FASD

Executive Function

- Difficulty with judgement 80.7%
- Difficulty understanding what people say to you 68.80%
- Difficulty understanding what you read 68.30%

With kind permission of Himmelreich, Lutke & Travis 2016
Sensitivity

Emotionally loaded
Carries with it

• Moral judgements
• A view of women as nothing more than vehicle for the next generation

WOMEN DO NOT GET PREGNANT ALONE!!!!!!!
• The egg that made you was developing in your mother when she was a 6 weeks old embryo in your grandmother.

• Not only does prenatal experience count but pre pre natal experience counts.

Courtesy of Dr Chris Loocke
Contact Details:

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