Incidence and Prevalence of FASD in Alberta and Canada

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Overview

• Definition of Incidence and Prevalence
• Considerations in Data Interpretation
• What We Know in General
• What We Know about Subpopulations
• Gaps in the Data
• Opportunities and Next Steps
Rates

<table>
<thead>
<tr>
<th>Incidence</th>
<th>Prevalence</th>
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</table>
| • New cases occurring as a proportion of a population  
  – # per 1000 live births  
• Requires a defined population and a defined criteria for diagnosis | • All new and existing cases  
  – # per 1000 people  
• Important for providing resources and support  
• More commonly reported than incidence for FAS/FASD |
Considerations

• When is FAS/FASD a new case?

Conception | Exposure to alcohol | Onset of FAS(D) | Birth | Diagnosis
Considerations

- Different diagnostic definitions

  **Broader**
  
  FASD  FAS  FASD
  FASD  FAS  FASD
  FASD  FAS  FASD

  **Narrower**
  
  FASD  FAS  FASD
  FASD  FAS  FASD
  FASD  FAS  FASD

- 2005 Canadian guidelines for diagnosis of FASD
  - Comprehensive multidisciplinary diagnosis
  - Limited capacity & expertise → low identification

Chudley et al., 2005
Considerations

• Low incidence and prevalence rates could mean:
  - Prevention is working.
  - OR
  - There is low identification of the disease.

• Methodology limitations and consequences
  – Different ways of studying FASD incidence and prevalence → different rates
### Considerations

<table>
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<tr>
<th>Methodology</th>
<th>Advantage</th>
<th>Disadvantage</th>
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</table>
| **Passive Surveillance**   | • Use of existing resources  
                          • Costs less  
                          • Easy to conduct                                     | • Difficult to diagnose at birth   
                          • Relies on non-specialist physicians                        |
| **Clinic-Based Studies**   | • Maternal history  
                          • Large # of pregnancies  
                          • More control and rigor                                      | • Self-selection bias   
                          • Reflects clientele of clinic                                 |
| **Active Case Ascertainment** | • Diagnose at suitable age  
                          • More likely to uncover children with FAS  
                          • Wide representation                                         | • High cost (labour) & time   
                          • Need community support   
                          • Often study high-risk populations                             |
Considerations

• Sub populations and generalizability
  – Generalizing is difficult due to variation:
    • between subpopulations and methodologies
    • in reporting and diagnosis
    • in prevalence and detection of alcohol use
Search Strategy

• Known and accessible papers and reports
• Medline search
  
  Any of:
  • f(o)etal alcohol syndrome
  • f(o)etal alcohol spectrum disorder
  • f(o)etal alcohol effects

  Either of:
  • prevalence
  • incidence

  Any of:
  • Canada, BC, AB, SK, MB, ON, QC, PE, NS, NB, NL, NT, YT, NU

• Searching reference lists
• Provincial/Territorial government web sources
Incidence Rates

Canada

No official statistics

- Estimates 1 - 3 per 1000 live births
- Estimates 9 per 1000 live births
Incidence Rates

Alberta

No official statistics

- Estimates 1 - 3 per 1000 live births
- Estimates 2 - 9 per 1000 live births

Children and Youth Services Ministry

A new information system will provide the ability to gather information on FASD on children in care in a systematic way.
Incidence Rates

FAS in other provinces

per 1000 live births

- Birth Defects Registry
  - 0.25
- All cases known to FAS clinic and clinicians
  - 4.7
- Thompson General Hospital, MB (1994)
  - 7.2
-SK (1988-1992)
  - 0.589

- Mostly Aboriginal population
- Small sample

Wong, 1983 (in Williams et al., 1999)
Habbick et al., 1996
Williams et al., 1999
BC, non-Aboriginals (1972-80)
BC, Aboriginals (1972-80)
Prevalence Rates: Children in Care
(Manitoba, 2004/05)

FASD per 1000 children in care

Fuchs et al., 2005
Prevalence Rates: Corrections Systems

per 1000 people

Canadian corrections system (2001/02)

Known cases only as reported by corrections systems

0.087

Youth remanded to a psychiatric inpatient assessment unit (BC, 1995/96)

Burd et al., 2003
Fast et al., 1999

0 100 200 300

FAS

10

233

FAS  FASD
Prevalence Rates: Aboriginal Children

per 1000 children

Ranges
FAS: 31-62
FASD: 51 -101

Referrals after extensive awareness programs in
36 communities

Kowlessar, 1997; Robinson et al., 1987;
Asante et al., 1985 (in May et al., 2009)
Prenatal Alcohol Use

- Risk of FASD is related to an exposure
- May need information on the rate of exposure in the population to interpret the incidence

50% of first-time Alberta mothers reported drinking some alcohol before they knew they were pregnant

- Low risk drinking: 73%
- Binge drinking: 22%
- High-risk, no binge: 5%

Sampson et al., 1997
Tough et al., 2006
Complexities of FASD

- Development of FASD is a complex interaction between maternal alcohol ingestion, fetal susceptibility, maternal biology including nutrition and pattern of alcohol use.
Gaps

- Absence of actual rates
  - Canada
  - some provinces
  - cities and subpopulations
- Statistics are often dated
- Inconsistent diagnostic and reporting criteria
- Variation in study methodologies
## Summary

<table>
<thead>
<tr>
<th></th>
<th>FAS</th>
<th>FASD</th>
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<tbody>
<tr>
<td><strong>Incidence</strong></td>
<td>0.25 to 7.2</td>
<td>Estimates 2 to 9</td>
</tr>
<tr>
<td>(per 1000 births)</td>
<td></td>
<td></td>
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<tr>
<td><strong>Prevalence</strong></td>
<td>0.087 to 121</td>
<td>25 to 233</td>
</tr>
<tr>
<td>(per 1000 people)</td>
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*Interpret with caution*
The Future

• Low incidence and prevalence rates could mean:
  
  Prevention is working. OR There is low identification of the disease.
References


References


Cited in published papers but unable to retrieve:
