Prevalence of Fetal Alcohol Spectrum Disorders in an American Indian Reservation-based Sample

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The 8th International Conference on FASD Research: Research, Results and Relevance, Vancouver, BC, Canada March 7th, 2019
Disclosure

- Presenter has nothing to disclose
Learning Objectives

- Estimate the prevalence of FASD among Southern California American Indians
- Compare and contrast with national estimates
- Recognize the possibility of cultural bias in prevalence estimates of FASD
Why we wanted to do this study

- FASD status awareness required for ongoing project
  - Healthy Women
  - Healthy Native Nation (previous talk)
- The NIH-NIAAA Collaboration on FASD Prevalence (CoFASP) study

Source: Museum of Man, Kumeyaay, made by basketmaker Carmalita LaChappa
Initial Steps

- Approved by UCSD and Southern California Tribal Health Clinic IRBs
- Local Native community members hired and trained
  - Recruitment including consent and assent
  - All scheduling and participant transportation
  - Surveys and interviews
  - Neurobehavioral exams
- Experts from San Diego County CoFASP sample study enlisted
Methods

- **Eligibility criteria**
  - 5-7 year old community members and parent/guardian
  - Consent and assents obtained

- **Recruitment**
  - Letters to families with eligible children, flyers, newsletter blurb, and presentations at community events

- **Logistics**
  - Research sites
  - Transportation
    - Non-Native team members (ex. dysmorphologists) brought to reservation sites
    - Participants
Methods

- **Evaluations**
  - Physical exam by developmental pediatrician
  - Neurobehavioral exam: DASII, NEPSY, VMI, Bracken
  - Child related Interviews: VABS, CBCL
  - Pregnancy and mother related interview including prenatal alcohol exposure

- **Criteria for maternal alcohol consumption**
  - ≥3 drinks on ≥2 occasions during pregnancy
  - ≥6 drinks per week on ≥2 weeks during pregnancy

- **Diagnostic classification based on Institute of Medicine and Hoyme criteria**
Ready, Set, Go!

488 eligible

119 consented (24.4%)

113 sufficiently complete to reach case conference (23.2%)
<table>
<thead>
<tr>
<th></th>
<th>% or mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Sex, Female</td>
<td>53.8</td>
</tr>
<tr>
<td>Child Age (months)</td>
<td>77.0 ± 10.8</td>
</tr>
<tr>
<td>Caregiver Age (years)</td>
<td>35.8 ± 10.1</td>
</tr>
<tr>
<td>Bio-Mom Interviews</td>
<td>82.6</td>
</tr>
<tr>
<td>Mothers consumed any alcohol in pregnancy</td>
<td>33.6</td>
</tr>
<tr>
<td>Mothers met CoFASP criteria for alcohol in pregnancy</td>
<td>25.2</td>
</tr>
</tbody>
</table>
### Results

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>Crude Prevalence Estimate (% of Eligible Children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARND</td>
<td>14</td>
<td>2.90</td>
</tr>
<tr>
<td>PFAS</td>
<td>6</td>
<td>1.20</td>
</tr>
<tr>
<td>FAS</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total FASD</strong></td>
<td><strong>20</strong></td>
<td><strong>4.10</strong></td>
</tr>
</tbody>
</table>

Total FASD prevalence was estimated at 4.1%

Not different from non-Native San Diego or National samples
Limitations

- Less than a quarter of eligible children participated
  - Self-selected
- Small numbers: participants in total and cases in each category
- Single assessments as opposed to repeated
- Deficits may be caused by something other than prenatal alcohol exposure
- Not all validated measures had been validated among Native populations much less this Native population
- Unknown contribution of culture
Strengths

- Community support
- Recruitment by trusted community members
- Study broadly publicized using culturally congruent methods
- Transportation and culturally expected food provided
- Active case-ascertainment
- Standardized protocol and measures allow comparison with other communities
Local Relevance

- Identified need within the community for FASD related services, treatment, and support
- Identified families affected by FASD to facilitate Health Native Nation (HNN) goals
- Linked families and children to needed services
- Raised awareness of FASD, HNN, and currently available support
- Provided opportunities to decrease stigma
- Increased capacity of local clinic and community
Conclusions

- The estimated minimum prevalence of FASD among a sample of reservation-based American Indians in Southern California was 4.1%.
- The estimate was consistent with estimates from the national CoFASP study.
- No cases of FAS were identified.
- No cases had been previously identified.
- May not be generalizable to all Native communities given the heterogeneity of Native communities.
Grateful for Support!

Ready, Set, Go! research was supported by the NIAAA Co-FASP grant #U01AA019879/05S2

Artist: Tiffany Wolfe
Questions?
A classification of fetal alcohol syndrome requires all features specified in points A through D.

A. A characteristic pattern of minor facial anomalies, including 2 or more of the following:
   1. Short palpebral fissures (≤10th percentile)
   2. Thin vermilion border of the upper lip (rank 4 or 5 on lip-philtrum guide)
   3. Smooth philtrum (rank 4 or 5 on lip-philtrum guide)

B. Growth deficiency
   1. Height, weight, or both at or below the 10th percentile

C. Deficient brain growth
   1. Head circumference at or below the 10th percentile

D. Neurobehavioral impairments
   1. Point a, b, or both
      a. with cognitive impairment
         Evidence of global impairment (general conceptual ability ≥1.5 SD below the mean, or performance IQ or verbal IQ or spatial IQ ≥1.5 SD below the mean) or
         Cognitive deficit in at least 1 neurobehavioral domain of 1.5 or more SD below the mean (executive functioning, memory impairment, or visual-spatial impairment or 1.0 or more SD below the mean for specific learning impairment)
      b. with behavioral impairment without cognitive impairment
         Evidence of behavioral deficit in at least 1 domain 1.5 SD or more below the mean in impairments of self-regulation (mood or behavioral regulation impairment, attention deficit, or impulse control)

FAS

pFAS

W/ PAE: A and D
W/o PAE: A and D, plus B or C

ARND

Requires PAE
W/ cognitive impairment: D.a.
   but with cognitive deficits in at least 2 domains
W/o cognitive impairment: D.b.
   but with behavioral deficits in at least 2 domains
California

- Largest number of Native Americans & most distinct tribes today
- ~1/3 of all Native Americans in U.S. pre-contact
- ~100 languages and >300 dialects pre-contact
- San Diego County has more tribes than any other county in the U.S.
Both the intervention and control groups significantly reduced risky drinking, but were not different from each other in the total sample. Among depressed, the intervention group decreased risky drinking to a greater extent than the control group.