Fetal Alcohol Spectrum Disorders

Louise Kodituwakku, Ph.D.
P.W. Kodituwakku, Ph.D.
UNM - Department of Pediatrics
Center for Development and Disability
History of FASD

• It has been known for centuries that alcohol causes problems for the fetus

• Late 1800s mothers, who were inmates in the UK, were observed drinking and had poor pregnancy outcomes

• Lemoine (France -1968): described 127 babies born to drinking mothers

• Jones & Smith(1973): coined the term FAS
Epidemiology

• CDC (2005) reports 50 to 60% of women in North America drink alcohol during the child bearing years

• 10 – 12% of women binge drink during child bearing years (4 or more drinks at any one time)

• 10% of pregnant women continue drinking with 2% continuing to binge drink

• Given 50% of all pregnancies are unplanned, it is important to educate women about the effect of alcohol on the fetus – there is no safe amount
Alcohol Use Among Women Aged 18–44, 1991–2005*

*Behavioral Risk Factor Surveillance System (BRFSS) surveys, United States.
†Binge drinking is defined as having five or more drinks on at least one occasion in the past 30 days.
Epidemiology

• It is not known what percentage of babies will be born with FASD if the mother drinks alcohol during pregnancy.

• Sampson et al (1997): Incidence of FASD: 9.1 per 1000 – this is the hardest to document

• In some communities this rate may be as higher (South Africa)

• The CDC estimates that up to 1.5 cases of FAS occur for every 1000 births.

• Unlike genetic disorders, it is 100% preventable.
# Fetal Development Chart

<table>
<thead>
<tr>
<th>Period of the Ovum</th>
<th>Period of the Embryo (in weeks)</th>
<th>Period of the Fetus (in weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
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<td>4</td>
<td>16</td>
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<tr>
<td></td>
<td>5</td>
<td>20-36</td>
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<tr>
<td></td>
<td>6</td>
<td>38</td>
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<td>7</td>
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<td>8</td>
<td></td>
</tr>
</tbody>
</table>

- **Central Nervous System (CNS)**
  - Heart
  - Arms
  - Eyes
  - Legs
- **Teeth**
- **Palate**
- **External Genitalia**

Under 2 Weeks:
- Nervous system
  - Brain

1-2 Weeks:
- Heart
  - CNS

3-4 Weeks:
- CNS
- Heart
- Arms

4-5 Weeks:
- CNS
- Heart
- Arms
- Eyes

5-6 Weeks:
- CNS
- Heart
- Arms
- Eyes
- Legs

6-7 Weeks:
- CNS
- Heart
- Arms
- Eyes
- Legs
- Teeth

7-8 Weeks:
- CNS
- Heart
- Arms
- Eyes
- Legs
- Teeth
- Palate

8-12 Weeks:
- CNS
- Heart
- Arms
- Eyes
- Legs
- Teeth
- Palate
- External Genitalia

Vulnerability of the fetus to defects during different periods of development. The dark blue 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 light blue portion of the bars represents periods of development during which physiological defects and minor structural abnormalities would occur.

*SOURCE: Adapted from Moore 1993.*

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**National Organization on Fetal Alcohol Syndrome**

Helping children & families by advocating for the prevention and intervention of Fetal Alcohol Spectrum Disorders, the leading known cause of mental retardation & birth defects in the United States.
FAS Can Happen to Any Child

Fetal Alcohol Syndrome in different races

American Indian  Black  White
RISK FACTORS FOR FASD

- Quantity of alcohol consumed
- Pattern of exposure (binge vs. chronic)
- Developmental timing of exposure
- Genetic variation
- Maternal characteristics - age, weight, etc.
- Socioeconomic status
- Interaction with nutritional variables
- Synergistic interactions with other drugs
- Stress level in the mother (cortisol)
FASD

• Mothers who have one affected child AND continue to drink usually have all subsequent children affected

• These subsequent children are affected more severely than the previous children

• Epigenetics – raises the question of the contribution from the father and previous generations (animal models are showing effects into the 4th generation, RSA 2009)
Kathleen Sulik’s Research
Fetal Alcohol Spectrum Disorder Includes:

- FAS – Fetal Alcohol Syndrome
- PFAS – Partial Fetal Alcohol Syndrome
- ARBD – Alcohol Related Birth Defects
- ARND – Alcohol Related Neuro-developmental Disorder
- *Key – Confirmation mother drank alcohol during pregnancy

Institute of Medicine
Diagnostic Code

• 315.8 – neurocognitive disorder due to prenatal alcohol exposure – DSM V

• 760.71 – ICD-9 Medical Diagnostic code for FASD
Characteristic facial anomalies

• Short palpebral fissures (less than or equal to the 10th percentile)

• Thin vermilion border of the upper lip (score 4 or 5 on the lip/philtrum guide)

• Smooth philtrum (score 4 or 5 on the lip/philtrum guide)
Palpebral Fissure

endocanthion

exocanthion
Philtrum Guide
Caudate in two 18-year olds

Normal  FAS
GROWTH PARAMETERS

- Restricted growth at birth or postnatally including:
  
  - Height – less than 10\textsuperscript{th} percentile on normal growth curves
  
  - Weight – less than 10\textsuperscript{th} percentile on normal growth curves
GROWTH DEFICIENCY IN FAS

- Weight
- Length
- Head Circ.

- BIRTH
- NORMAL
- FAS
Evidence of CNS Involvement

- Poor sucking reflex
- Hypotonia
- Growth restriction
- Fine motor delays
- Gross motor delays
- Language acquisition delays
- Delayed developmental milestones, rolling over, sitting up, walking, etc.
- Poor orienting responses – slower to respond, but higher levels of arousal (Kable & Coles, 2004)
Diagnostic Criteria for FAS

• Confirmed maternal alcohol consumption
  PLUS
• A. Evidence of a characteristic pattern of facial anomalies
• B. Evidence of growth retardation: low birth weight, decelerating weight over time not due to nutrition, disproportional low weight to height (<10\textsuperscript{th} percentile)
• C. Evidence of CNS neurodevelopmental abnormalities
• If A, B, and C present may diagnose without confirmed maternal alcohol consumption
Diagnostic Criteria for Partial- FAS

• Confirmed maternal alcohol consumption
  PLUS

• Evidence of some components of the characteristic facial anomalies.
  AND

• Either Evidence of growth retardation or Evidence of CNS abnormalities or Evidence of complex pattern of behavior or cognitive abnormalities.
FAS – Only the tip of the iceberg

- Alcohol Related Birth Defects
- Alcohol Related Neurodevelopmental Disorders
Diagnostic Criteria for Alcohol Related Birth Defects

Confirmed maternal alcohol consumption

AND

Evidence of the characteristic facial anomalies, including at least two of the following:

- short palpebral fissures
- thin vermilion border on upper lip
- smooth philtrum

PLUS
At least one of the following associated congenital anomalies, including malformations and dysplasias:

<table>
<thead>
<tr>
<th>Cardiac</th>
<th>ASD</th>
<th>Aberrant great vessels</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>VSD</td>
<td>Conotruncal heart defects</td>
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<tr>
<td>Skeletal</td>
<td>Hypoplastic nails</td>
<td>Clinodactyly of 5th fingers</td>
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<tr>
<td></td>
<td>Short 5th digits</td>
<td>Pectus carinatum/excavatum</td>
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<tr>
<td></td>
<td>Radioulnar synostosis</td>
<td>Vertebral segmentation defects</td>
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<tr>
<td></td>
<td>Lg joint contractures</td>
<td>Scoliosis</td>
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<tr>
<td></td>
<td>Camptodactyly</td>
<td>“Hockey stick” palmar creases</td>
</tr>
<tr>
<td>Renal</td>
<td>Aplastic/hypoplastic/</td>
<td>“Horseshoe” kidneys/</td>
</tr>
<tr>
<td></td>
<td>Dysplastic kidneys</td>
<td>Ureteral duplications</td>
</tr>
<tr>
<td>Eyes</td>
<td>Strabismus</td>
<td>Refractive errors</td>
</tr>
<tr>
<td></td>
<td>Retinal vascular anomalies</td>
<td>Optic nerve hypoplasia</td>
</tr>
<tr>
<td>Ears</td>
<td>“Railroad track” ears</td>
<td>Conductive/ neurosensory hearing loss</td>
</tr>
</tbody>
</table>
Hockey Stick Palmar Crease
Railroad Track Ears
Diagnostic Criteria for ARND

- Confirmed maternal alcohol consumption
  
  PLUS

- Evidence of CNS neurodevelopmental abnormalities
  
  including:

- Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be otherwise explained
The Effects of Alcohol on the Brain and Behavior

- Prenatal Alcohol Exposure
- Genetic Factors
- Adverse Postnatal Environment
- Abnormal Brain Development
- Neuropsychological Deficits
- Academic Difficulties
- Poor self-regulation
- Limitations of Adaptive Behavior
Neuroimaging Methods

- New neuroimaging methods allow visualizing brain structures in detail (MRI, DTI)
- Some other imaging methods allow looking at what is happening in the brain (function) while someone doing a task (fMRI, EEG, MEG)
Corpus Callosum

- The corpus callosum is the fiber tract that connects the two hemispheres.
- Anomalies in the corpus callosum can range from thinning in some regions to the total absence called agenesis.
- The integrity of corpus callosum is critical to the integration of information from two hemispheres.
Hippocampus

- The hippocampus is a structure located inside the medial temporal lobe
- The hippocampus plays a critical role in learning and memory
- It is a part of the limbic system
Magnetoencephalography
Slowness of eye movements;
Coffman et al. 201
Delayed neural responses to stimuli as revealed by magnetoencephalography; Stephen et al. (in press)
Summary

• At a behavioral level children with FASD show slow information processing and increased inattentiveness.
• At a neurocognitive level children with FASD display impaired performance on tasks that involve the integration and manipulation of information.
• At a neuronal level children with FASD show both structural and functional differences.
Interventions

• What helps maximize a child’s potential?
What does the research show?

• Difficulty in planning daily living tasks

• Attention difficulties interfere with learning ADHD/ADD

• Recognition memory is better than free recall – new information does not stay in memory, what is known one day is gone the next.

• Encode simple information better than complex - abstract information

• What is learned does not generalize to new situations
What does the research show? (cont.)

• Difficulty in learning from consequences – don’t anticipate consequences

• Poor reasoning and judgment - poor impulse control

• Have difficulty reading emotional cues in the face and voice

• Act younger than chronological age

• 25% have Intellectual Disabilities
Mother-Child Interaction

- Prenatal alcohol exposure impacts negatively on the infant’s affect – this influences the environmental stimulation needed for optimal cognitive development.

- Maternal postnatal drinking directly impacts the infant’s mental development (depression).

- Negative interactions or temperament mismatch between mother and infant may lead to attachment issues and/or abuse. (O’Connor, 1993, 2001)
Protective Factors that foster healthy development

• Stable, nurturing home
• Being diagnosed before the age of 6 years
• No physical or sexual abuse
• Not changing households
• Good quality of parenting in the home
• Early intervention services

Streissguth, et al, 1996
Ongoing Assessments

- Monitor vision and hearing
- Have child in speech and language therapy
- Physical therapy to help with gross motor
- Occupational therapy to help with fine motor
- Have child assessed for developmental delay
- Help parent find respite care, parenting support and advocacy
Adaptations for FASD Children

Offer services over a longer period of time

Expect slower progress

Use examples, modalities and treatment goals that are appropriate for children with FASD

Consider child’s sensory sensitivities and behavior regulation problems

Build on caregiver and child strengths while providing emotional support for caregivers
INTERVENTIONS

• Each child is unique and there are many ways to intervene

• Available information about intervention comes from:
  – Scientific Research
  – Reported Parent and Teacher Strategies

• Try suggested techniques until you find what works for a given child

• Case management is critical to assist mother (caregiver) and child get appropriate services
INTERVENTIONS

• Minimize change
  – Keep routines consistent with nap time, bedtime, meal time, bath time, etc.
  – Use the same babysitters and avoid changing caregivers
  – Repeat soothing language
  – Keep environment the same and introduce change slowly
Caregiver Strategies

– Provide a safe, stable, and structured home - visual schedules often help
– Avoid too much sensory stimulation
– Reduce distractions
– Use calming techniques like massage/warm bath
– Use simple, specific directions (1 step)
– Repeat directions frequently
– Keep rules simple and consistent
– Have immediate consequences for misbehavior
INFANTS with FASD:

- Irritability/Sleep Problems
  - Frequent holding/swaddling/consistency
  - Low light and sound levels
  - Soft clothing/no tags/soft smooth sheets
  - Calm colors/ limits objects in environment
  - Consider sleep study to help determine cause (monitor for sleep fragmentation)

- Feeding Problems/Weight Loss
  - Feeding Team/Nutritionist – often have sucking problems
  - Avoid stimulation during feeding/swaddle
  - Avoid hot/cold foods – room temperature
Toddler (ages 1 – 4)

Educational Strategies
- Enroll in a preschool that understands special needs use of play as the leading activity

- Teach self regulatory skills thru play (Simon Says)

- Working memory games, delay of gratification, response inhibition

- Use Multisensory approaches (see, hear, touch it)

- Repeat instructions frequently, simple rules, consistency
Strategies

- Multi-modal presentation may facilitate learning
- Example: learning the alphabet through seeing, speaking, touching, hearing, and tracing the letters
- Repeat – Repeat - Repeat
Possible Strategies: Low Intellectual Ability and Slow Information Processing

- Speak slowly and use simple and clear language at all times. Stop between ideas and allow for processing. Remember auditory processing may be slower than your rate of speech.
  
- Use concrete terms like “walk slowly” rather than “straighten up”

- Speak directly to the child and use their name

- Think younger

- Understanding (especially social/emotional) will be below chronological age
Possible Strategies: Low Intellectual Ability and Slow Information Processing

- Avoid using the negative terms like “stop running” instead say “thank you for walking slowly”
- Reinforce behaviors you want and use the same language each time
- Use visual cues to help with the explanations
- Break each task into small steps and teach through repetition
- Understand the child will have difficulty benefitting from feedback
Strategies for self regulation

• Teach self-regulation as early as possible (Tools of the Mind)
  Help develop language
  Language mediates self-regulation
  Develop self control
  Enhance parent-child relationship
  Use play as a method of teaching
Disabilities - Diagnosis - FASD toolbox
See do2learn.com website

If you get upset

Get teacher's attention
Go to quiet chair
Calm down
Go back to work
ADHD and FASD

- Many children with FASD also have ADHD which usually has early onset and is the inattentive type
  - Each child must be assessed individually to determine if he/she will benefit from stimulant medication
  - Often have comorbid psychiatric disorders (anxiety, mood, conduct) – neuroleptics may work better
  - Highly structured environment with predictable schedule and routine is critical
Strategies for Enhancing Early Developmental Success (SEEDS)

• Enhances child’s capacity to regulate emotions and behaviors and impacts multiple levels of the family system
  
  – Parent education and advocacy module
  – Attachment-based parenting skills group
  – Music-based parent-child play group

UCLA, O’Connor
Families Moving Forward

• Work with parents and schools for 9 to 11 months with biweekly sessions for the parents

• Uses a sustained model of supportive behavioral consultation with the ability to work on individual problems within the group

• Parents reported a decrease in the number of disruptive behaviors in their children when children were given explicit instruction rather than being required to learn by observation or a process of abstracting rules (Olson, et al, 2007)
Neurocognitive Habilitation

- Alert Program uses metaphor of a car engine to describe the concept of self-regulation
- Children are told they can make their engine run fast, slow or just right
- Behaviors are evaluated both at home and school
- Program teaches sensory self-awareness and helps child to select behaviors that match the environment
- Uses games and songs
  (Williams & Shellenberger, 1996)
Poor Social Skills

• Individuals with FASD have poorer social skills than unexposed children; especially difficulty in reading facial expressions

• Social Skills deficits continue into adolescents (delinquency) and adulthood (criminal activity)

• Important to address this issue early to reduce the number of problems later

• Teach scripts and role play Child Friendship Training (O’Connor, 2007) (Frankel)
Using Computer Games

Establishes clear rules
Sequences behaviors
Allows repeated presentations that are identical multisensory learning experience
Child learns at own rate
Provides immediate feedback for correct and incorrect responses (Simon Says)
For a specific purpose, i.e. fire and street safety
Strategies for memory problems

• Hands-on, experiential teaching methods
• Routines
• Memory aids
• Written schedules
• Communication with caregivers/social workers/supervisors
• Repeat, repeat, repeat
Adolescents with FASD:

- Poor judgment / poor social skills
- Poor problem solving skills
- Trouble applying knowledge and higher thinking
- No understanding of cause and effect
- Problems with time and money management
- Lack of common sense
Adolescents with FASD (continued)

• Impulsive/Antisocial behavior/Lying
• Aggression
• Substance abuse
• Sexual acting out
• Depression/low self esteem
• Lack of motivation
• Inappropriate response to other’s feelings
Adolescents with FASD (continued)

• Caregiver Strategies

  – Work out a plan of action for common problems (getting to work late, poor hygiene, etc.)
  – Provide quiet area for learning and downtime
  – Keep rules simple and consistent
  – Begin to think about plans for the adolescent / adult’s future
Adolescents with FASD (cont.)

• Structure educational program to build in teaching life skills (how do apply for a job, how to write checks, how to have interpersonal relationships, etc.

• Assess if the individual will be able to live independently or will need to have others close.

• Help establish a supportive environment that gives as much structure as needed.
Secondary Disabilities

• Mental health problems
• Dependent living
• Employment problems
• Disruptive school experience
• Trouble with law
• Confinement
• Inappropriate sexual behavior
• Alcohol/drug problems
Economic Costs of FASD

• Total cost in the US in 2003 for FAS was $5.4 billion and this has gone up.

• Lifetime cost for individual with FAS is $860,000 up to $4.2 million.
REMEMBER

• FASD is 100 % preventable

• Each individual woman must take responsibility for her own drinking and potential for having a child with FASD.

• The community must encourage abstinence for women of child bearing age.

• Education regarding the effect of alcohol on the unborn child should be available everywhere and starting in mid school.
References


• Carmichael-Olson,H & Montague, R (2010) An innovative Look at Early Intervention for Children Affected by Prenatal Alcohol Exposure
Contact Information

Fetal Alcohol Spectrum Disorder Clinic
Center for Development and Disability
2300 Menaul Blvd. NE
Albuquerque, NM  87107

Program Director—Louise Kodituwakku, Ph.D.
505-272-6157