Introduction to Fetal Alcohol Spectrum Disorders: The Medical Assistant’s Role
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OVERALL LEARNING OBJECTIVES
By the end of this training, you will be able to:

1. Discuss the lifelong effects of FASDs.

2. Become familiar with how FASDs are diagnosed and why early intervention is important.

3. Describe screening techniques used to determine who is at risk for an alcohol-exposed pregnancy.

4. Identify ways to improve communication with patients about their alcohol use.
The MA Scope of Work

Always refer to your state and/or employer's scope of practice regulations for the role of the MA.
SECTION 1

The lifelong effects of FASDs
What are FASDs?
Are they preventable?
How common are they?
What are the societal costs?
Fetal Alcohol Spectrum Disorders (FASDs)

• a continuum of disorders ranging from mild intellectual & behavioral issues to extreme issues that may lead to profound disabilities or premature death

• caused solely by prenatal alcohol exposure and are NOT hereditary

• last a lifetime, but there are benefits from early diagnosis, support, & services

(NCBDDD, 2015b)
Associated conditions encompassing a range of effects in an individual prenatally exposed to alcohol:

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (pFAS)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)
- Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)

(Hartje et al., 2015a; Pierce-Bulger, 2011; Senturias et al., 2015)
Not all prenatal alcohol-related conditions show the identifying physical characteristics

(Bertrand et al., 2004)
FASDs are COMPLETELY PREVENTABLE with NO ALCOHOL USE DURING PREGNANCY
10.2% of pregnant women aged 18 to 44 years report current alcohol use

(CDC, 2015a)
ALCOHOL IS A TERATOGEN
(a substance that causes malformation to the developing baby)

(Bertrand et al., 2004)
The impact of alcohol on the developing baby is **NOT** reversible.
This chart shows vulnerability of the fetus to defects throughout 38 weeks of pregnancy. *Most common site of birth defects*

Central Nervous System (CNS)-Brain and Spinal Cord:
- Heart
- Arms/Legs
- Eyes
- Teeth
- Palate
- External Genitals

Period of development when major defects in bodily structure can occur.

Period of development when major functional defects and minor structural defects can occur.

Adapted from Moore, 1993 and the National Organization on Fetal Alcohol Syndrome (NOFAS) 2009.
Patient Question: I just found out I am pregnant. I have stopped drinking, but was drinking in the first few weeks of my pregnancy, before I knew I was pregnant. What should I do now?
**Answer:** The most important thing is that you have completely stopped drinking since learning of your pregnancy. It is never too late to stop drinking. Because brain growth takes place throughout pregnancy, the sooner you stop the safer it will be for you and your baby. **Talk with your health care provider** as soon as possible and share your concerns. Make sure you get regular prenatal checkups.

(NCBDDD, 2014a)
The prevalence of FASDs in the United States is estimated to be as high as 2-5% of school-age children, a rate similar to that of autism spectrum disorders.

(May et al., 2014; Astley et al., 2002; Fast et al., 1999)
The Societal Costs of FASDs
Living with FASDs Video

(NOAFS, 2012b)
What are they?

Are they preventable?

How common are they?

What are the societal costs?

FASDs REVIEW
SECTION 2
Diagnostic resources for FASDs
How are they diagnosed?

What concerns in a patient might lead to a referral for FASD assessment?

Why is early diagnosis important?
Characteristics associated with prenatal alcohol exposure

1. Specific facial features
2. Growth deficiency
3. Central nervous system problems
1. Specific Facial Features

- Small palpebral fissures
- Small eyes (distance from A to B)
- Smooth philtrum
- Thin upper lip

(Astley & Clarren, 2001; Bertrand et al., 2004)
Child Not Exposed to Alcohol | Child Exposed to Alcohol

CONTROL | FAS

Source:
2. Growth deficiency

(CDC, 2001; Module 10K: Fetal Alcohol Exposure, n.d.)
3. Central Nervous System (CNS)

Categories of CNS problems:

1. Structural Problems
   - Small head size
2. Neurologic
   - Poor coordination
   - Poor muscle control
   - Problems sucking as a baby
3. Functional
   - Cognitive deficits
   - Executive functioning deficits

(NCBDDD, 2014c)
Non-alcohol affected vs. Profoundly alcohol-affected brain

(Streissguth & Little, 1994)
Patient Question: I drank wine during my last pregnancy and my baby turned out fine. Why shouldn't I drink again during this pregnancy?
Answer: Every pregnancy is different. Drinking alcohol might affect one baby more than another. You could have one child who is born healthy and another child who is born with problems. Sometimes, alcohol-related effects don’t appear until later in life, so if you drank during your first pregnancy, you should speak with your child’s healthcare provider.

(NCBDDD, 2014a)
Possible Effects of Prenatal Alcohol Exposure on Behavior and Cognition
Cognitive or developmental deficits
Executive functioning deficits
Motor functioning delays
Attention deficit or hyperactivity
Poor social skills
Co-Occurring Behavioral/Mental Health Issues

- Anxiety and mood disorders, particularly depression
- Attention-deficit/hyperactivity disorder
- Substance use
- Trouble with the law
- High risk sex behaviors and sexual abuse
- Homelessness or transiency

(Streissguth et al., 1996; Williams & Smith, 2015)
5 types of concerns that may lead to an assessment for an FASD

1. Developmental or behavioral concerns
2. Specific facial features associated with prenatal alcohol exposure (PAE)
3. Growth deficiency at or below 10\textsuperscript{th} percentile for head circumference, height, weight at any time, including prenatally
4. History of confirmed or suspected PAE
5. Self-reported or family concern about possible FASD

(AAP, 2016)
Importance of early identification

- Early identification, before six years of age when possible, helps reduce risk of later life problems.
- Early diagnosis works by helping families affected by FASDs to get the support and services they need which can include counseling, medical specialty care, peer and community programs.

(Streissguth, 1997; Williams & Smith, 2015)
Patient Question: I suspect my child might have an FASD. What should I do?
Answer: If you think your child might have an FASD, talk to your child's doctor and share your concerns. Don't wait. If a problem is suspected, ask the doctor for a referral to a specialist who knows about FASDs, such as a developmental pediatrician, child psychologist, or clinical geneticist. To find doctors and clinics in your area, visit the National and State Resource Directory from the National Organization on Fetal Alcohol Syndrome (NOFAS). Also call your state’s public early childhood system to request a free evaluation to find out if your child qualifies for intervention services. This is sometimes called a Child Find evaluation. You do not need to wait for a doctor’s referral or a medical diagnosis to make this call.

(NCBDDD, 2014a)
How are they diagnosed?

Why is early diagnosis important?

What concerns in a patient might lead to a referral for FASD assessment?
SECTION 3

Screening techniques to determine who is at risk for an alcohol-exposed pregnancy
What is risky drinking?

What is the guidance on alcohol use during pregnancy?

What is SBI?

Who should be screened to prevent alcohol-exposed pregnancies?

Screening
What Is Considered A Standard Drink?

12 fl oz of regular beer  =  8–9 fl oz of malt liquor (shown in a 12 oz glass)  =  5 fl oz of table wine  =  1.5 fl oz shot of 80-proof spirits ("hard liquor"—whiskey, gin, rum, vodka, tequila, etc.)

about 5% alcohol
about 7% alcohol
about 12% alcohol
about 40% alcohol

The percent of "pure" alcohol, expressed here as alcohol by volume (alc/vol), varies by beverage.

(NIAAA, 2005, n.d.b)
EXCESSIVE DRINKING INCLUDES:

- For women, binge drinking is 4 or more drinks consumed on one occasion.*
- For men, binge drinking is 5 or more drinks consumed on one occasion.*
- Any alcohol use by those under age 21.
- Any alcohol use by pregnant women.
- For women, heavy drinking is 8 drinks or more per week.
- For men, heavy drinking is 15 drinks or more per week.

*One occasion = 2-3 hours
Guidelines on alcohol use during pregnancy are clear.
The 2005 U.S. Surgeon General Advisory stressed that

- A woman should not drink any alcohol during pregnancy.
- A pregnant woman who has already consumed alcohol during her pregnancy should stop in order to minimize further risk.
- A woman who is considering becoming pregnant should abstain from alcohol.

(U.S. Department of Health and Human Services, 2005)
American College of OB-GYNs
American Academy of Pediatrics
Centers for Disease Control and Prevention

NO alcohol use during pregnancy
OR while trying to conceive

(ACOG, 2008; AAP, 2015a; NCBDDD, 2014b)
Patient Question: Why should I worry about alcohol use if I am not pregnant and not trying to get pregnant.
Answer: Nearly half of all pregnancies in the United States are unplanned. If you drink alcohol and do not use contraception (birth control) when you have sex, you might get pregnant and expose your baby to alcohol before you know you are pregnant. So, if you are not trying to get pregnant but you are having sex, talk to your health care provider about using contraception consistently.

(NCBDDD, 2014a)
2 ways to prevent alcohol exposed pregnancies

1. Reduce risky drinking
2. Use birth control effectively

Optimal outcome – Women choose to do both.

(Balachova et al., 2013; Floyd et al., 2007; Wilton, et al., 2013)
Alcohol Screening and Brief Intervention (aSBI)
SBI Concept

- uses a public health approach to universal screening for alcohol use

- provides
  - immediate rule out of non-problem users
  - identification of levels of risk
  - identification of patients who would benefit from brief advice
  - identification of patients who would benefit from further assessment

(Aiello et al., n.d.)
The Drinkers Pyramid

- 16% at-risk or hazardous use
- 4% harmful or dependent use
- 80% lower-risk use, including abstinence

(Babor, Higgins-Biddle, & Robaina, 2016)
Screen ALL women of childbearing age
Simple Screening Questions

✓ **Non-Pregnant:** “On any single occasion during the past 3 months, have you had more than 3 drinks containing alcohol?”

✓ **Pregnant:** “Have you had a drink since you found out you were pregnant?”

If the response to this one question is “yes”, follow clinic protocol such as using another set of screening questions or deferring to the healthcare provider.

(CDC, 2014a)
Brief Interventions
Examples of Brief Interventions

• Advise a woman who drinks moderately and is pregnant or who is contemplating a pregnancy to abstain from alcohol in order to prevent an FASD

• Help a woman weigh the costs/benefits of reducing alcohol use before or during pregnancy

• Help a woman maintain motivation to reduce/eliminate drinking by reinforcing the benefits of an alcohol-free pregnancy
What is risky drinking?

What is the guidance on alcohol use during pregnancy?

What is SBI?

Who should be screened to prevent alcohol-exposed pregnancies?

Screening REVIEW
Improve communication with patients about alcohol use and pregnancy
What is it?

How does it relate to women’s alcohol use?

Why is it a barrier to preventing & identifying FASDs?

How can MAs avoid reinforcing it when talking to patients?
Stigma is a powerful, complex social and cognitive process that leads to the discrediting, devaluing or excluding of a person or group of people based on a real or perceived difference.
Stigma Leads to Missed Opportunities

The highest alcohol use during pregnancy is among ... ????
Women Aged 35-44 years (18.6%)
College graduates (13.0%)
If medical professionals ASSUME certain populations are less likely to engage in risky drinking, OPPORTUNITIES for screening, identification of risky use, and prevention of FASDs may be LOST.
Patient Question: Why are you asking about my alcohol use?
**Answer:** We ask every patient about their alcohol use. Just like knowing your blood pressure can help with making decisions about your care, knowing your drinking levels can also help us provide you with better care. It is important when caring for women of childbearing age to assess their alcohol consumption as this is a key time to prevent alcohol exposed pregnancy.
Stigma Prevents Healthcare Providers from Asking about Alcohol

• Many myths and biases towards people with alcohol and substance use disorders (AUDs/SUDs)

• Women with AUDs/SUDs are often stereotyped

• Many healthcare professionals do not receive comprehensive education about AUDs/SUDs
Stigma is a barrier to diagnosing FASDs

- Stigma can prevent concerned parents from discussing their alcohol use during pregnancy
- Providers may fear that diagnosing a child or adult with an FASD will be “labeling” them with a stigmatizing condition

(Van Boekel et al., 2013; Rojmahamongkol et al., 2015; NOFAS, n.d.)
Words Matter
FASDs are caused when a woman drinks alcohol during pregnancy.

FASDs are caused by prenatal alcohol exposure.
Shame on you for drinking while pregnant.
FASDs are caused by women who drink alcohol.
no woman drinks because she wants to hurt her baby
Role of the MA

• Avoid assumptions and biases about who is at risk for an alcohol-exposed pregnancy
• Ask at EVERY visit – Screening for alcohol misuse can be as common as a blood pressure
• Have resources available to help women that need support to stop drinking
• Have culturally relevant material available for families
Words can perpetuate **STIGMA**

- Avoid blaming language
  - FASD occurs when a fetus is exposed to alcohol **NOT** FASD occurs when a pregnant woman drinks
  - A child who has an FASD versus an FASD child (person first language)
Melissa: Birth mother of a child with FASD
What is it?

How does it relate to women’s alcohol use?

Stigma

Why is it a barrier to preventing & identifying FASDs?

How can MAs avoid reinforcing it when talking to patients?

REVIEW
Take Home Messages
FASD is an umbrella term that covers multiple diagnoses related to prenatal exposure to alcohol.
Alcohol affects multiple organ systems throughout pregnancy, particularly the baby’s brain.
NO SAFE
TIME
NO SAFE
TYPE
NO KNOWN
SAFE
AMOUNT
NO
PREVENTION IS BETTER THAN CURE
Screen ALL women of childbearing age
HELP women talk about their alcohol consumption
Thank you!!

Contact: