Face the Facts

The sobering reality of fetal alcohol spectrum disorders

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"I used and I drank at the beginning of my pregnancy, before I found out I was pregnant. And then, I continued to drink wine during my pregnancy at my physician's OK. … And when my son was born, I thought I'd sort of dodged the bullet because he looked perfect and he had 10 fingers and 10 toes. And as he started getting a little bit older, I realized things just weren't quite right. So when I finally realized … what was going on, it was a relief, and it was horrifying almost. And I felt guilty and I felt ashamed, but mostly I felt relieved to know what was going on.

"Well I was not about to do anything unless my doctor said so. I mean that is what kind of pregnant person I was. And I went in and specifically asked, 'A friend of mine said that I could drink wine when I'm pregnant—red wine, specifically red wine,' and he said that was perfectly fine, that I could have … a glass at night with my dinner. And as a matter of fact, it may help me to relax and to [improve] circulation … so not only did I think that it was OK—and that's kind of what I wanted to hear—but I also thought that… it was possibly helping. … Even when I asked, 'Is it okay to drink wine when you're pregnant?' he didn't ask me if I had a drinking problem, or how many drinks I had a day, or … if I binge drink, or if I'd ever blacked out when I drank. There wasn't really any dialogue. I was angry because I'd been given wrong information about drinking and being pregnant."

—Melissa W., mother of a child with an FASD, and member of the NOFAS Circle of Hope[1]

Women of reproductive age receive conflicting messages about the dangers of drinking alcohol while pregnant from media, friends and family, and even their health care providers. Yet, the guidelines from medical associations, including the American Congress of Obstetricians and Gynecologists,[2] American Academy of Pediatrics,[3] and Centers for Disease Control and Prevention (CDC)[4] are clear: no amount or type of alcohol is safe to consume during any trimester of pregnancy or while trying to conceive.

Trouble on tap

Prenatal alcohol exposure is the sole cause of fetal alcohol spectrum disorders (FASDs), a term used to describe the continuum of disorders caused when a developing baby is exposed to alcohol before birth. These disorders may result in a range of effects, from mild intellectual and behavioral issues to profound disabilities or death.[4] Recent estimates indicate that 1 in 20 school-aged children in the United States have an FASD.[5]

To clarify, FASD is not a clinical diagnosis but a term that encompasses all of the conditions attributed to prenatal alcohol exposure.[4] Fetal alcohol syndrome (FAS), which includes certain identifying facial features, growth deficits, and brain abnormalities, is often considered the most severe and widely known diagnosis. Other conditions that fall under the umbrella of FASDs include partial FAS, alcohol-related birth defects (ARBD), alcohol-related neurodevelopmental disorder (ARND), and neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE).[6] Fetal alcohol spectrum disorders that do not have identifying physical characteristics can be difficult to diagnose and may not manifest until a child is older.[6] Unfortunately, the effects of FASDs last a lifetime and although there is no cure, there are substantial benefits to a child's development from early diagnosis and intervention treatment.[4]

Although FASDs are completely preventable if there is no prenatal exposure to alcohol, many women still report drinking during pregnancy. For instance, a CDC analysis of 2011–2013 data showed that 10.2 percent of pregnant women reported drinking alcohol within the previous 30 days and 3.1 percent reported drinking more than three drinks on any one occasion, which is defined as binge drinking.[7]

Alcohol is a known teratogen and, when used during pregnancy, can affect the unborn baby's development. Although the placenta acts as a barrier for many toxins, alcohol is water-soluble and easily passes by diffusion from maternal to fetal blood.[6] Once alcohol is absorbed into the developing baby's circulation, it is distributed throughout the fetal tissues and cells, and reaches blood alcohol concentrations similar to that of the mother.[6] In addition, the developing baby lacks liver function and enzymes to metabolize the ethanol in alcohol, and can only eliminate the ethanol through diffusion back into the mother. This prolonged process of eliminating alcohol from the fetal circulation means that alcohol levels in the developing baby might be higher than those in the mother and present for a longer period of time.[6]

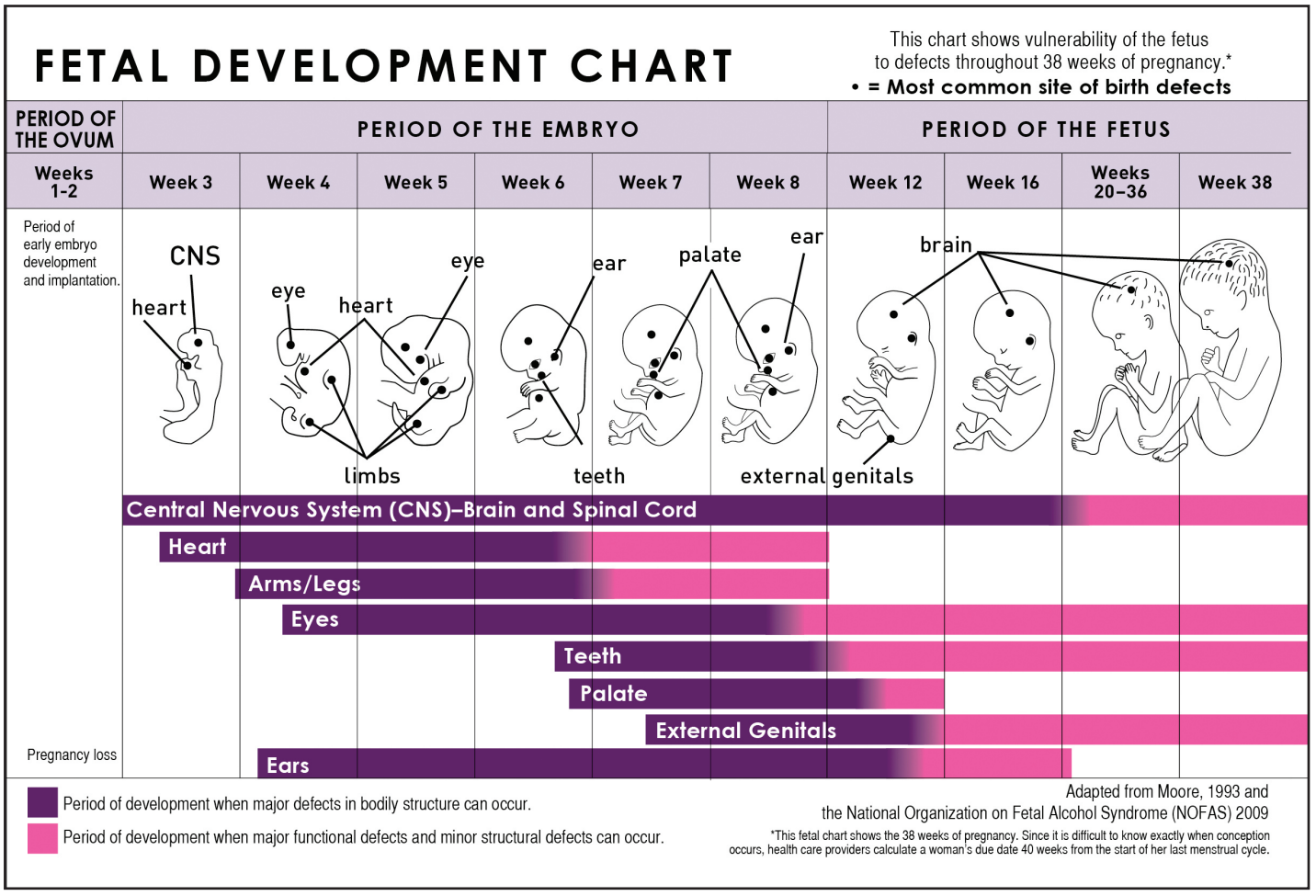
All of these factors—the easy diffusion of alcohol from mother to developing baby, its distribution throughout fetal tissues, and the prolongation of the alcohol concentration and time of exposure—help explain why the effects on the fetus are so pronounced.[6,8]

There is no safe time or known safe amount of alcohol to drink during pregnancy. All types of alcohol—beer, wine, wine coolers, and hard liquor—have the same impact, and the timing, frequency, and pattern of alcohol exposure influence the effect on the fetus. For example, significant exposure to alcohol in the first two weeks post-conception can cause pregnancy loss. Exposures later in the first trimester are associated with structural birth defects and the abnormal facial features characteristic of FAS. Second- and third-trimester exposures can be associated with pregnancy loss, brain anomalies, and impaired growth.[6] Studies have shown that even a single drink per day while pregnant can affect the baby's growth.[3] Although the effects of prenatal alcohol exposure are irreversible, they can be lessened by decreasing the dose and duration. Consequently, it is never too late for a pregnant woman to stop drinking.

A spectrum of signs

There is no single test that can diagnose an FASD. When identifying an individual who may have been exposed to alcohol in utero, health care professionals are concerned with four major signs and symptoms[6,9]:

1. Central nervous system abnormalities
   - Structural
     - Abnormally small head size for a person's height and weight
     - Structural changes in the brain as seen through magnetic resonance imaging (MRI) or computed tomography (CT) scans
   - Neurologic
     - Poor muscle control or coordination
     - Problem sucking as a baby
   - Functional
     - Cognitive deficits (e.g., low IQ) or developmental delays
     - Executive functioning deficits (e.g., poor organization, lack of inhibitions)
     - Motor functioning delays (e.g., balance problems, difficulty writing or drawing)
     - Attention problems or hyperactivity (e.g., easily distracted, difficult to calm)
     - Problems with social skills (e.g., lack of empathy, no fear of strangers)



- Other problems (e.g., sensitivity to taste or touch, difficulty reading facial expressions)

2. Distinct facial features associated with prenatal alcohol exposure
   - Smooth philtrum, or area between the upper lip and nose
   - Thin upper lip
   - Small palpebral fissures (i.e., short distance between the inner and outer corner of the eyes)
3. Growth deficiencies at or below the 10th percentile for height, weight, or head circumference prenatally or postnatally
4. A history of confirmed or suspected prenatal alcohol exposure affecting the suspected patient

If one or more of these signs or symptoms are present, a referral for further assessment and diagnosis could be made by the health care provider.

Other co-occurring psychiatric, emotional, and behavioral problems frequently coincide with an FASD. Individuals with FASDs have a 95 percent lifetime likelihood of experiencing mental health issues, including anxiety and mood disorders, particularly depression, suicide, attention-deficit hyperactivity disorder (ADHD), substance use, and addiction.[10] Individuals with an FASD often have problems in school or with the law, and may have difficulty finding and keeping a job.

Catherine Flores, CMA (AAMA), BHS, MLT(ASCP), has intimate experience with the effects of prenatal alcohol exposure, because her adopted sister Joann has an FASD. "Joann is now 31. She has a very low IQ, which is fortunate in some ways because she can receive services. She is easily influenced. She cannot handle transitions or change. She has detachment disorder. She cannot do math—it makes no sense to her. Her reading level is 2nd and 3rd grade. She basically cannot self-discipline, she doesn't understand consequences. She has tantrums like she's two years old. Her main issue is that she's very aggressive, both physically and verbally."

These issues are just the tip of the iceberg with Joann, notes Flores. "We respect her, we know her, and we know her challenges, but the community doesn't understand. They don't understand how you could prevent this. This child didn't have to be this way."

A timely diagnosis and the early provision of support services (e.g., developmental intervention) can significantly help children with an FASD, particularly those with developmental and learning problems, adds David Wargowski, MD, professor within the department of pediatrics and chief of the Division of Genetics and Metabolism at the University of Wisconsin School of Medicine and Public Health in Madison. "This depends on early identification, ideally before 3 years of age. Early developmental and behavioral intervention and support also help reduce the risk of problems later in life; delayed or misdiagnosis contributes to a higher risk of co-occurring consequences of deficits in adaptive skills that can impair an individual's ability to function well in school, at home, or in the community. Early diagnosis helps by enabling families affected by FASDs to access needed support and services, which include counseling, medical specialty care, and peer and community programs," says Dr. Wargowski. "Although FASDs have no cure, individuals with FASDs benefit from ongoing interventions, particularly those that build capacity in identified strengths and provide parenting strategies, social support, and developmental or educational interventions that address the neurological, developmental, and behavioral problems related to FASDs," he says.

Stigma inhibits diagnosis

Diagnosis of an FASD can be complicated by the wide variety of symptoms that often overlap with other health conditions. Mothers can help their children receive a timely diagnosis and services if they tell their health care providers about their alcohol use during pregnancy, but many are reluctant to disclose this information to health care providers for fear of stigma and judgment. "Stigma prevents many physicians from asking women about their alcohol use. Doctors have told me that it feels too personal, and they just would not know how to refer or help someone that drank too much anyway," says Kathleen Mitchell, vice president and spokesperson for the National Organization on Fetal Alcohol Syndrome (NOFAS). For more than 20 years, she has worked to support families of children with FASDs and teach health care providers about the importance of addressing alcohol use with patients.

Stigma is a barrier to diagnosis, continues Mitchell. "Some doctors have reported that they won't diagnose a child with an FASD, even when they believe that it is an accurate diagnosis. They don't want to stigmatize the birth mother, her family, or her child. Stigma is a major reason that FASDs are substantially underdiagnosed and helps explain why FASDs remain a largely hidden disability," she says.

Health care professionals can help decrease stigma by asking about alcohol use in a nonjudgmental manner and avoiding accusatory language. For example, referring to FASDs as "a continuum of dis-

Here's to you

Medical assistants can help reduce risky drinking and prevent alcohol-exposed pregnancies in several ways:

1. Remind patients that alcohol should be avoided while trying to become pregnant.
2. If a woman self-discloses about drinking during pregnancy, help her discuss this with her provider.
3. Hone communication skills by practicing a nonjudgmental approach to patient education and avoiding accusatory language.
4. Take advantage of teachable moments when discussing family planning, nutrition, or pregnancy to talk to patients about preventing alcohol-exposed pregnancies.
5. Ask supervisors about opportunities to screen patients for alcohol use.
6. Place literature on tables or walls in the waiting room and in the exam rooms.

orders caused by prenatal alcohol exposure" assigns less blame than stating that FASDs are "caused when a woman drinks alcohol while pregnant." Stigma is also reduced when health care professionals avoid assumptions and biases about who may or may not be at risk for an alcohol-exposed pregnancy.

Health care professionals can also reduce barriers for those seeking help and increase their level of comfort discussing their patients' alcohol use by asking women about alcohol use at every encounter, including primary care visits, prenatal visits, and well-child visits. Mitchell's advice to health care professionals is simple: "Never doubt the power of the gift of giving just two minutes of your undivided attention to your female patients who you suspect may be experiencing problems with alcohol or other drugs. Making that human connection is the best intervention of all. Listen with compassion, tell her you believe in her, and help her to make the call."

The right influence

There are two key ways to prevent an alcohol-exposed pregnancy:

1. Eliminate alcohol consumption for pregnant women
2. Prevent pregnancy, for example, by using birth control effectively

To achieve the first of these prevention goals, women of reproductive age should undergo screening to assess their drinking levels. Screening procedures gauge the possible severity of an individual's alcohol use based on the number of standard drinks consumed. To accurately assess whether a person is consuming alcohol at a risky level, there must be a shared understanding of what constitutes a standard drink. The National Institute on Alcohol Abuse and Alcoholism defines a standard drink as "any drink that contains approximately 14 grams (about 0.6 fluid ounces) of pure alcohol," which is the amount contained in 12 fluid ounces of beer or wine cooler, 8.5 fluid ounces of malt liquor, 5 fluid ounces of wine, or 1.5 fluid ounces of 80-proof distilled spirits.[11]

These figures are estimates because the actual amount of alcohol varies based on the brand and type of beverage, as well as the size of the beverage container. For example, many malt liquors are sold in 40-ounce containers, which is the equivalent of 4.5 standard drinks. Likewise, a typical 25-ounce bottle of table wine holds five standard drinks. Packaging of alcoholic beverages can be unclear or misleading, so it is essential

that patients be asked about the number of drinks they consume and the size of the container they use.[6,11]

Addressing risky drinking requires knowing which patients are consuming alcohol at harmful levels. There are many readily available, research-based screening tools that health care professionals can use to assess drinking levels. For nonpregnant women, excessive alcohol use means more than three standard drinks on any one occasion or more than seven standard drinks in a week. For men, excessive use is more than four drinks on any one occasion or more than 14 drinks per week.[11] Drinking more than these amounts places the individual at risk for a variety of negative health and social effects, such as cirrhosis, certain cancers, depression, motor vehicle crashes, and violence.[6] Yet for pregnant women, no amount of alcohol should be considered safe to consume at any point during pregnancy or while trying to get pregnant.[2-4]

The second key way to avoid an alcohol-exposed pregnancy is for women to avoid alcohol if they are sexually active and do not use birth control effectively. Almost half of all pregnancies in the United States are unplanned and alcohol exposure can affect the baby's development even before the pregnancy is recognized.[4,12] Following the screening, women who indicate alcohol use during pregnancy or who are engaging in any risky or hazardous alcohol use, even outside of pregnancy, should receive a brief intervention from a health care professional to help them understand the risks associated with drinking and identify strategies to reduce or eliminate alcohol use. This process of screening for alcohol use and then providing feedback to assist the patient in taking steps to reduce alcohol use is called *alcohol screening and brief intervention*, or alcohol SBI.

Alcohol SBI has been shown to be an effective, low-cost option to address risky drinking and prevent alcohol-related harms, including alcohol-exposed pregnancies.[6] Brief interventions are evidence-based procedures for working with individuals who are not alcohol dependent but need to reduce alcohol use to lower the chances of health risks; they are not designed to treat patients with moderate to severe alcohol use disorders.[13] Women who indicate high levels of alcohol consumption should be referred to an alcohol use disorder specialist.

The U.S. Preventive Services Task Force recommends alcohol SBIs in primary care settings for persons 18 years and older, including pregnant women.[7] Alcohol SBIs can be implemented in many clinical settings[14,15]:

- Hospitals
- Emergency departments
- Primary care outpatient offices
- Trauma centers
- Ob-gyn and other office- or clinic-based practices
- Other community health settings (e.g., schools, dental offices, veterans centers, and pharmacies)

Screening and brief interventions can also be flexibly administered by individuals without special medical training or experience with substance-use counseling.[16]

Despite the pervasiveness of alcohol consumption in the United States, only approximately 1 in 6 adults report ever talking with a health care professional about their drinking.[15] This finding represents countless missed opportunities to help individuals who drink too much understand the health benefits of reducing their drinking. Studies have shown that when health care professionals talk with patients who drink too much about their alcohol use, the amount of alcohol consumed can be reduced by 25 percent.[15]

Health care professionals can adopt techniques that facilitate conversations about alcohol as another method to help ease discomfort. For example, questions about alcohol use during pregnancy can be embedded within a series of questions about general pregnancy topics.[6] Conversations about nutrition during pregnancy or use of potential teratogens, such as medications or nicotine, are an opportunity to also introduce the topic of alcohol. Then, to ease into a conversation about alcohol use patterns, providers can ask a patient about their alcohol use before pregnancy and then ask about their alcohol use during pregnancy. Questions presented in a routine, nonjudgmental manner typically produce the most reliable answers. For example, asking "Have you had a drink since you found out you were pregnant?" rather than "You haven't had any drinks while pregnant, have you?" may lead to a more open conversation.[6]

For pregnant women or women who may become pregnant, the brief intervention generally involves motivating a woman who is drinking at risky levels to identify mechanisms for lowering the risks of an alcohol-exposed pregnancy. This may include lowering drinking levels or increasing use of effective contraception, or both. Health care professionals can engage a patient who drinks moderately in a brief intervention by reinforcing the benefits of an alcohol-free pregnancy and assisting the patient with ways to maintain motivation to reduce or eliminate drinking. Following up with the patient who received a brief intervention is essential to ensuring that the patient is not putting herself or her developing baby at risk.

Keeping tabs

Find more information on preventing alcohol-exposed pregnancy through these sources:

Centers for Disease Control and Prevention
http://www.cdc.gov/fasd

National Organization on Fetal Alcohol Syndrome
http://www.nofas.org

Tender care

In clinical practice, alcohol SBI to reduce alcohol-exposed pregnancy comprises many parts, from universal screening of all women of reproductive age, to brief intervention for those who are drinking at risky levels, to referral to substance use treatment for those who have an alcohol use disorder. These many parts of alcohol SBI are best kept in motion when a team-based approach is used, particularly one that includes medical assistants. Medical assistants who are certified by the Certifying Board of the American Association

of Medical Assistants (AAMA) with the CMA (AAMA) credential have demonstrated skills and knowledge in providing patient education and interventions to promote preventive care and are prepared to be active members of the health care team.

"An [alcohol] SBI is a quick and powerful way for a health care team to reach out to and help their patients who are drinking at risky levels even before their drinking causes problems, such as alcohol-exposed pregnancies," says Alicia Kowalchuk, DO, FASAM, assistant professor in the department of family and community medicine at the Baylor College of Medicine.

"Medical assistants are key to the success of [alcohol] SBI in a practice, ensuring patients are routinely screened for risky drinking in an open, nonjudgmental way. Evidence-based screening is often just one question, easily incorporated into other routine health screening questions, and many patients expect their medical providers to ask about their use of alcohol as a routine part of their care," she says.

Many characteristics of medical assistants' administrative and clinical roles support their involvement in alcohol SBI. Medical assistants have the potential to support FASD prevention and intervention because of their frequent interaction with patients, their role as liaison between patient and provider, their familiarity with the technology of electronic health records (EHRs) and the details of patient health histories, and in many cases, because they are more culturally and linguistically attuned to the patient population compared with providers.

Screening can be done by medical assistants as part of the routine intake visit by incorporating screening questions into health history forms or EHRs.[17] This allows for continual screening throughout pregnancy or during other health care visits, rather than one-time screening as part of a discrete intervention. Ongoing screening not only increases the chances of identifying behaviors that may not be present at the initial visit but also allows patients time to develop trust in the health care team.

Through established alcohol SBI protocols, medical assistants may be the first on a health care team to identify patients at risk for an alcohol-exposed pregnancy and have the opportunity to flag these patients for further assessment. If patient education or health coaching is needed, medical assistants are well-positioned to provide specific, concise messaging that reinforces advice provided by other members of the health care team.[18] Patients are more likely to change behavior if they hear consistent messages from two or more types of health professionals.[19]

Flores understands the significant role medical assistants can play in preventing FASDs. "As medical assistants, it's critical to be able to do this intervention, this screening. This is a larger issue than any of us can ever imagine." Flores notes that medical assistants and other health care and social service providers cannot fully understand the impact of an FASD "until you live one day in somebody's shoes that has to fight for services, fight for somewhere for someone to live, fight for their medical care."

As health care reform continues to shift the focus of care from acute services to primary prevention, medical assistants will play an important part in extending preventive services and enhancing interdisciplinary teams to meet patients' needs. ✦

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