Fetal Alcohol Syndrome (FAS)

In 1714, about two million gallons of gin were reportedly consumed in England. By 1750, the annual alcohol consumption rate had grown to 11 million gallons. A letter was written to Parliament voicing concerns about the gin problem and stating that, "too often the cause of weak, feeble, and distempered children, who must be, instead of an advantage and strength, [become] a charge to their country." Medically, it has been reported, there was very little appreciation of alcohol's influence on the fetus during the gin epidemic.

By the middle of the 19th century, Dr. E. Lanceraux, a French physician, seemed to have described some of the significant characteristics of FAS when he stated:

"As an infant, he dies of convulsions or other nervous disorders; if he lives, he becomes idiotic or imbecile, and in adult life bears the special characteristics: the head is small..., his physiognomy vacant [peculiar facial features], a nervous susceptibility more or less accentuated, a state of nervousness bordering on hysteria, convulsions, epilepsy...are the sorrowful inheritance,...a great number of individuals given to drink bequeath their children." (Lanceraux, 1865; quoted by Gustafson, 1885)

Fetal Alcohol Syndrome (FAS) is a disorder characterized by growth retardation, facial abnormalities, and central nervous system dysfunction (CNS). These characteristics affect the child for their entire life. FAS is not a genetic disease, it is caused by a woman's use of alcohol during pregnancy. Fetal Alcohol Syndrome is 100% preventable. A woman only needs to abstain from alcohol during pregnancy to prevent her child from developing FAS.

Babies affected by alcohol can have some or all of the clinical signs of FAS. The term Fetal Alcohol Effects (FAE) had been used to describe children who have some, but not all, of the clinical signs of FAS. Experts in the field were unable to agree on the case definition for FAE so the Institute of Medicine (IOM) coined two terms that separately described disabilities and central nervous system abnormalities associated with prenatal alcohol exposure: alcohol-related neurodevelopmental disabilities (ARND); and alcohol-related birth defects (ARBD).

Criteria

A diagnosis of Fetal Alcohol Syndrome (FAS) is based on four separate criteria; prenatal alcohol exposure (whether confirmed or not), growth retardation, facial characteristics, and neurodevelopmental problems. These criteria are expanded in the chart below. Not all children adversely affected by maternal alcohol use meet all four of the criteria. These children may have an isolated physical abnormality and be classified as having an Alcohol-Related Birth Defect (ARBD). Other children may just have neurodevelopmental abnormalities, such as problems with communication skills, memory, learning ability, visual/spatial skills, intelligence, and motor skills. These children are classified as having an Alcohol-Related Neurodevelopmental Disorder (ARND).

Identification of FAS, ARBD and ARND

1. Fetal Alcohol Exposure - required for diagnosis (see below).

2. Fetal Alcohol Syndrome (FAS) - Fetal Alcohol Exposure and Criteria I, II and III (see below).

3. Alcohol-Related Neurodevelopmental Disorder (ARND) - Fetal Alcohol Exposure and Criteria III (see below).

4. Alcohol-Related Birth Defects (ARBD) - Fetal Alcohol Exposure and Criteria IV (see below).

Maternal Alcohol Use (confirmed or unconfirmed)

- Abstainer (No alcohol or less than 1 drink per month)
- Low-risk drinker (3-6 drinks a week. None before driving, when pregnant, or on medication)
- At-risk drinker (7-21 drinks a week. Drink in high risk situations)
- Problem drinker (More that 21 drinks per week)
- Dependent drinker (Cannot stop drinking once started)
- Criteria I: Growth Retardation
- Weight less than tenth percentile
- Length/height less than tenth percentile

Criteria I: Growth Retardation

- Weight less than tenth percentile
- Length/height less than tenth percentile

Criteria II: Facial malformation

- Short palpebral fissures
- Thin upper lip
- Long, flat philtrum
- Hypoplastic midface

Criteria III: Neurodevelopmental Disorder

- Head circumference less than tenth percentile
- Sleep disturbances
- Attention deficits
- Decreased response to noise
- Decreased visual focus
- Increased activity
- Delayed speech development
- Altered motor skills
- Learning deficits
- Increased activity

Criteria IV: Other Physical Abnormalities

- Ophthalmologic (problems related to the eyes)
- Otologic (problems related to the ears)
- Cardiac (problems related to the heart)
- Limb

It needs to be emphasized that a definitive diagnosis of neurodevelopmental behaviors cannot be made in infants and preschoolers. Clinicians can generally make a diagnosis and distinguish causes only when medical findings exist. These can be microcephaly (abnormally small skull), seizures, or severe delays due to brain damage. In most children, the causes of observed neurodevelopmental behaviors will not be identified until the child can be given psychometric testing. Some behaviors may not be diagnosable until the child is almost ten years old. But it is very important for the child's development that alcohol related damage be identified early in life. Children identified prior to age 5 have a greatly improved chance of home and school intervention maximizing the child's potential. No treatments exist that can reverse the effects of Fetal Alcohol Syndrome.

Alcohol-Related Neurodevelopmental Disorder (ARND)

Children with ARND do not have full FAS, but may demonstrate learning and behavioral problems caused by prenatal exposure to alcohol. Alcohol related problems can manifest as changes in behavior, poor fine motor skills, difficulties with attachment, poor attention span, difficulty developing language skills, and reduced cognitive function.

Alcohol-Related Birth Defects (ARBD)

Alcohol-related birth defects can include a variety of abnormalities to the face, eyes, ears, heart, brain, kidneys, and limbs of an affected child.

- Heart -- Atrial or ventral septal defect (a hole in the heart between the atria or ventricles), truncus abnormalities (defects in the division between the ventricles), other deformities in the heart muscle
- Eyes -- Retinal vessel abnormalities, lens flaws, cornea deformities, ptosis (drooping eyelids)
- Ears -- Conductive hearing loss, low-set backward-rotated ears, auditory nerve defects
- Kidneys -- aplastic (defective function), dysplastic (abnormal growth), hypoplastic (underdeveloped)
- Skeletal -- fused bones in forearms, fingers, toes, hands

Effects

"The U.S. Public Health Service has indicated that there is no safe level of alcohol use during pregnancy. If a woman drinks while pregnant, she puts her developing fetus at risk for a wide spectrum of adverse effects including spontaneous abortion; growth retardation; physical, mental, and behavioral abnormalities; facial abnormalities; and CNS impairment, such as developmental delay, speech or language delay, lower IQ, and decreased head circumference. In the worst cases, prenatal exposure to alcohol may result in fetal death." (Centers for Disease Control and Prevention)

The exact mechanism by which alcohol damages the fetus and critical times of exposure are not known. Some studies have shown that exposure during the first trimester results in the structural defects (i.e., facial changes) characteristic of FAS. But the growth and central nervous system disturbances could occur from alcohol use during any time in pregnancy. It must also be noted that not all women who drink alcohol during pregnancy deliver a child with FAS or ARND.

While the specific mechanisms are not known, their results can be seen. Fetal brain analysis has shown that the cerebral cortex (area of the brain which coordinates sensory and motor information) in exposed children contains abnormal patterns of neuron and neurotransmitter distributions. The hippocampus (memory forming area) and cerebellum (coordinates muscles and the maintenance of bodily equilibrium) have been shown to have decreased cell numbers and altered neurochemical activity.

Studies that followed FAS children into adulthood have shown that the majority of them have difficulty leading independent lives. Many have difficulty maintaining employment and establishing stable relationships with family and friends. As the FAS children grow to adulthood, they still retain their motor skills problems, hyperactivity, and problems with learning and retention. While intervention at an early age may help the children develop coping skills and ways to work around some of their problems, there are no cures. They will always have the physical and structural damage caused by alcohol exposure while in the uterus.

Treatment

Fetal Alcohol Syndrome is an irreversible, lifelong condition that affects every aspect of a child's life and the lives of his or her family members. FAS is the only birth defect that can be completely prevented. If a woman does not consume any alcohol during pregnancy, her child will not develop FAS. With early identification and diagnosis, a child with FAS can receive services that can help maximize his or her potential but will never be cured.

There is no known safe amount of alcohol that can be consumed during pregnancy. Any amount of alcohol is potentially dangerous to an unborn baby. However, if a pregnant woman is drinking during pregnancy, it is never too late for her to stop. The sooner a woman quits drinking, the better it will be for both her and her baby. This does not mean that some damage can heal, but the severity of the damage may be minimized.

Early intervention at home and school is very important for a child's quality of life. Intervention should begin at least by the time a child is 5 years old. Children who screen positive for, whether or not they subsequently are diagnosed with FAS, ARND, or ARBD often come from very unstable families and may be at greater risk for abuse and neglect. As many as 85 percent of these children are not being raised by their parents, but by relatives, foster parents, or adoptive parents. These children have life-long learning and behavioral problems as a result of the damage to their brain. Raising a child affected by FAS can be extremely stressful and overwhelming for the caregivers.

Treatment options are rather limited. Some of the physical birth defects can be repaired with surgery; several procedures may be required though before the damage is repaired. Many of the defects cannot be treated and will be a permanent part of the child's life. Specialized social, educational, and legal services may also be necessary. As you can see in the Associated Traits section, many problems will persist throughout the child's entire life. By getting the child into intervention programs early, some of the negative social and educational effects can be minimized before they can impact other areas of the child's development. The services available may also be limited to what the local community has to offer a family raising a FAS child. These options are not guaranteed to work but they do attempt to improve the child's life, as well as the child's outlook on life. Unfortunately, nothing has yet been discovered to repair the damage alcohol causes to the brain of a developing fetus.

Associated Traits

There are several personality and learning traits associated with children exposed to alcohol in utero. People have documented the traits in babies and children as far back as the early 1700's. Parents, teachers, and doctors can observe similar traits in the children they work with and live with, but alcohol being a direct cause has not been proven. Many factors (socioeconomic status, abuse, neglect, chemical exposure, nutrition, etc.) have also been shown to be associated with similar behavior patterns. With early intervention some of these behaviors can be improved or even reversed, but many others will be a permanent part of the child's life.

Kindergarten - Sixth Grade

- Gullible, easily influenced by others
- Memory loss and retrieval problems. Needs things repeated multiple times and still may not retain information.
- Lying, stealing, or disobedient
- Problems separating fantasy from reality, having a different perception of reality
- Temper tantrums
- Impulsive
- Delayed physical, academic, and/or social development
- Silence, retreating from situations
- Inappropriate social behavior

Middle School / Junior High

- Self-centered
- Criminal activity
- Poor reasoning skills
- Cognitive problems from previous section do not improve (memory, recall, reality, etc.)
- Poor motivation, low self-esteem, depression
- Academically tops out in one or more subjects
- Sexually active, drug or alcohol use

- Lacks time management skills, no concept of time

High School

- Same traits as Middle School
- Difficulty maintaining living quarters, homeless
- Poor sequencing
- High level of frustration, easily frustrated

Post High School / Early Adulthood

- Same problems as in High School
- Inability to sort information and set priorities
- Poor financial management skills
- No concept of cause and effect
- Suicidal

Is FAS a Significant Problem?

FAS is the leading known cause of mental retardation. In the United States:

- Prevalence of FAS is estimated to be between 0.5 and 2 per 1,000 births.
- Prevalence of FAS, ARND, and ARBD combined is at least 10 per 1,000, or 1 percent of all births.
- Based on the above rates of FAS, ARBD, and ARND, FAS affects at least 40,000 newborns each year.
- the cost to the nation of FAS alone may be up to $6 billion each year.
- For one individual with FAS, the lifetime cost is at least $2 million

Drinking Among Pregnant Women

In the United States:

- 1 in 30 pregnant women reports high-risk drinking (7 or more drinks per week, or 5 or more drinks on any one occasion).
- 1 in 9 pregnant women binge drinks in the first 3 months of her pregnancy.
- 1 in 30 pregnant women drinks at levels that increase the risk of FAS.
- More than 1 in 5 pregnant women report alcohol use in the first trimester, 1 in 14 in the second trimester, and 1 in 20 in the third trimester.
- Those who are unmarried and over 30 tend to have the highest rates of alcohol use in pregnancy. However, in 2004, the rate of past month binge drinking among pregnant women age 15 to 17 (8.8%) was more than twice that of pregnant women age 26 to 44 (3.8%).
- Among women of childbearing age entering substance abuse treatment, 4% were pregnant. Eighteen percent of pregnant women entering treatment say that alcohol is their primary substance of abuse Alcohol use during pregnancy varies by race.

Identified Risk Factors

A profile of 80 women in Washington State who have given birth to a child with FAS reveals several risk factors for drinking during pregnancy:

- 96% had at least one mental illness.
- 95% had a history of sexual or physical abuse.
- 61% had less than a high school education.
- 77% had an unplanned pregnancy, 81% had no birth control, and 92% wanted some form of birth control.
- 59% had an annual gross household income less than $10,000.

The study also identified factors that had helped pregnant women avoid alcohol. These included mental illness treatment and large social support networks.

What Problems Do People With FAS Face?

People with FAS are vulnerable to a range of difficulties, such as failure in school, substance abuse, mental illness, and involvement in the criminal justice system. A University of Washington study shows the percentage of people age 6 to 51 with FAS who had difficulties in the following areas:

- 94% had mental health problems.
- 23% had received inpatient care for mental illness.
- 83% of adults experienced dependent living.
- 79% of adults had employment problems.
- 60% of those age 12 and older had trouble with the law.
- 35% of adults and adolescents had been in prison for a crime.
- 45% engaged in inappropriate sexual behavior.
- 43% had disrupted school experiences (e.g., dropped out).
- 24% of adolescents, 46% of adults, and 35% overall had alcohol and drug problems.

Can FAS Be Prevented?

The most important statistic to remember about FAS is that it is 100% preventable. The only cause of FAS is prenatal exposure to alcohol. If a woman does not drink during pregnancy, her baby will not have FAS. Individuals who already have FAS should receive an accurate diagnosis and appropriate treatment, prevention, and support services. FAS prevention and treatment strategies present an opportunity to address FAS, raising hope for families everywhere.
