Fetal Alcohol Spectrum Disorder:
A Healthcare Provider’s Role

By Pamela Gillen, ND, RN, CSN, Sharon Langendoerfer, MD and Karen Fehringer, PhD, OTR

Learning Objectives

After reading this article, the reader will be able to:

- Discuss the importance of screening all women of childbearing age for alcohol use prior to conception, during pregnancy and after birth.
- Identify a fetus/neonate that has been prenatally exposed to alcohol.
- Describe nursing’s role in screening for alcohol use, identify a neonate with an FASD and work with the infant’s family.

One of the most troubling complaints of families raising a child with Fetal Alcohol Spectrum Disorder (FASD) is that the professionals they look to for help lack knowledge about this disability. Nurses are the first healthcare professionals to have an opportunity to work with such families. A nurse’s knowledge base about FASD is critical to helping the mother-child dyad and to the long-term well-being of the family. Studies have shown that infants exposed to alcohol prenatally have the best outcomes when they get early interventions, receive quality care from professionals, are discharged to stable nurturing homes and are provided stimulating and stress-free environments by their parents.

What is FASD?
The adverse effects of women drinking alcohol during pregnancy have been noted since ancient times but the message has been forgotten repeatedly. The teratogenic effects of alcohol exposure on the developing fetus result in a continuum of symptoms and disabilities that is referred to as Fetal Alcohol Spectrum Disorder (FASD). The most devastating of these effects are brain injury and neurobehavioral deficits. The term FASD is descriptive not diagnostic. Its use was agreed upon by the National Task Force on Fetal Alcohol Syndrome.
and Fetal Alcohol Effect (FAE) and the federal Interagency Coordinating Committee on Fetal Alcohol Syndrome in April 2004. FASD includes a wide range of disabilities from mild learning difficulties to fetal death. Usually, children who survive with FASD must deal with lifelong sequelae, including physical, mental and behavioral disabilities.

In the U.S. Fetal Alcohol Syndrome (FAS) was first described in 1973 as a cluster of effects observed in a Native American child with known prenatal alcohol exposure. FAS is now known to be a birth defect with a group of characteristic signs and symptoms caused by maternal alcohol consumption during pregnancy. The specific types and severity of these effects depend on several factors: the dose and timing of alcohol exposure relative to the stage of fetal development; the nutritional status of the mother; and the genetic makeup of the parents.

The diagnosis of FAS requires the presence of three features: (1) dysmorphic facial features (2) small body and head size and (3) cognitive disorder, listed in Box 1. Figure 1 shows the most common facial features associated with FAS, although these features may be poorly defined at birth and become more apparent in the next few months or years of life. Table 1 outlines other syndromes which can present with some of the same facial features as FAS and should be considered when assessing an infant for possible FAS.

A variety of terms have been used to characterize the effects of less-than-full FAS. Common diagnostic terms within this spectrum are Fetal Alcohol Spectrum Disorder (FASD), Alcohol Related Birth Defects, Alcohol Related Neurodevelopmental Disorder (ARND) and Partial Fetal Alcohol Syndrome.

The term Fetal Alcohol Effect (FAE), first used in 1978, described a range of effects caused by prenatal alcohol exposure that did not result in a diagnosis of FAS because of a lack of various aspects of the syndrome. Concerned about the validity of the term FAE, the Institute of Medicine (IOM) developed new diagnostic criteria in 1996, and the term FAE is no longer used. The IOM describes Partial FAS as a diagnostic classification that includes: (1) growth deficiency—whether due to low birth weight, decelerating weight over time unrelated to nutrition, or disproportionate height to weight, (2) some evidence of the facial features of FAS and (3) central nervous system damage, such as decreased cranial size at birth, structural abnormalities, neurological hard or soft signs, cognitive/functional impairment and evidence of prenatal alcohol exposure.

Alcohol Related Neurodevelopmental Disorders (ARND) is a diagnostic classification in which no physical signs are present. The diagnosis of ARND depends on signs of CNS damage (structural, neurological, and/or functional impairment), knowledge of prenatal alcohol exposure and exclusion of environmental causal factors. A consensus work group to determine if there is sufficient research evidence to encourage screening and diagnosis for ARND in primary care settings was convened in the fall of 2011. The results of the work group are available at http://www.niaaa.nih.gov/AboutNIAAA/Interagency/Pages/default.aspx.

Incidence

FAS has an estimated prevalence rate of 2.0 to 7.0 cases per 1,000 live births in the U.S. FAS is the leading known preventable cause of mental retardation and developmental disabilities. FASD, which includes FAS and the other conditions within the spectrum, have prevalence rates estimated at 9-10 per 1000, and are known to be higher than those of Down syndrome or autism spectrum disorder. Each year, as many as 40,000 babies are born with FASD. It is the most expensive birth defect in the U.S. costing the nation about $4 billion per year.

The Behavioral Risk Factor Surveillance System has shown that drinking rates among women of childbearing age have not changed significantly since the early 1990s. In 2011, 2.2% of women of childbearing age reported binge drinking in the two weeks prior to the survey. Binge drinking is defined as five or more drinks on an occasion for women. In 2011, 21.5% of women of childbearing age reported having at least one drink in the previous year.

**Box 1: Three Requirements for the Diagnosis of FAS**

All three facial abnormalities (see Figure 1)

- Smooth philtrum — Based on the University of Washington
- Thin vermilion border — Lip: Philtrum
- Guide rank 4 or 5
- Small palpebral fissures: at or below 10th percentile.

Growth deficits with height or weight <10th percentile. CNS abnormalities (structural, neurological and/or functional) with or without confirmed maternal alcohol exposure.


**Figure 1: Facial characteristics associated with fetal alcohol exposure**

changed for the past 20 years. Data from 1991 through 2005 showed that at least 12% of pregnant women had reported some alcohol use in the past 30 days. In one study 45% of pregnant women reported drinking alcohol in the month prior to pregnancy, and almost half of pregnant women had consumed some alcohol during pregnancy. These are alarming rates, considering that there is no known safe level of alcohol on the fetus.\textsuperscript{18} Many women will stop drinking once they find out they are pregnant, but many will have consumed alcohol early in the pregnancy, prior to knowing they were pregnant.

| Table 1: Differential diagnosis of individual features associated with FAS |
|-----------------------------|-----------------------------|
| Feature                     | Syndromes                   |
| Smooth philtrum             | • Cornelia de Lange syndrome |
|                             | • Floating-Harbor syndrome  |
|                             | • Geleophysic dysplasia      |
|                             | • Opitz syndrome             |
|                             | • Toluene embryopathy        |
| Thin vermillion border      | • Miller-Dieker (Lissencephaly) syndrome |
|                             | • Fetal Valproate syndrome   |
|                             | • Geleophysic dysplasia      |
|                             | • Cornelia de Lange syndrome |
|                             | • Toluene embryopathy        |
| Small palpebral fissures    | • Campomelic dysplasia       |
|                             | • DiGeorge sequence          |
|                             | • Dubowitz syndrome          |
|                             | • Duplication 10q sequence   |
|                             | • Duplication 15q sequence   |
|                             | • FG syndrome                |
|                             | • Maternal phenylketonuria (PKU) fetal effects |
|                             | • Oculodentodigital syndrome |
|                             | • Opitz syndrome             |
|                             | • Trisomy 18 syndrome        |
|                             | • Williams syndrome          |
|                             | • Velocardiofacial syndrome  |
|                             | • Toluene embryopathy        |

Note: Features that discriminate these disorders from FAS can be found in Jones, 1997. (Source from Bertrand J, Floyd RL, Weber MK, O’Connor M, Riley EP, Johnson KA, Cohen DE, National Task Force on FAS/FAE. Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis. Atlanta, GA: Centers for Disease Control and Prevention; 2004).\textsuperscript{45}

Affected individuals who do not have the physical features of full-blown FAS may remain undiagnosed, and the cause of their unacceptable behavior may also remain unidentified and untreated. In many cases the affected individual reaches adulthood unable to live independently.\textsuperscript{3}

Why are FASD infants not identified in healthcare settings?
Studies show that primary pediatric providers often do not recognize FASD, or even the full syndrome of FAS. Diagnosis of infants is even more difficult than diagnosing young children because of: (1) a lack of knowledge by neonatal medical and nursing staff about FASD, (2) inadequate information about the mother’s prenatal drinking patterns and (3) the fact that not all of the features typically used for diagnosis are present at birth.\textsuperscript{20}

Obtaining the information about mothers’ drinking patterns during pregnancy is often the only way to confirm the diagnosis of ARND as the cause of later neurodevelopmental, cognitive and/or behavioral problems. Nurses typically have the earliest and best communication with the newborn’s parents. Nurses are often in a position to obtain vital information about the mother’s drinking patterns during pregnancy. It is critically important that this information be thoroughly documented in the infant’s medical record and then shared with other team members who can garner the necessary resources to assist the infant and family. Social workers remind us that mothers are much more likely to reveal sensitive information to the baby’s nurses than to a social worker, who is often regarded with suspicion.

The barriers to obtaining a reliable history include not only lack of skills and preparation by nurses but patients’ fear of the consequences of completely honest communication. Use of standardized assessment tools, proven communication techniques (such as Motivational Interviewing [MI]—see Sidebar), and keeping an open, positive attitude, facilitate communication with patients. In working with an at-risk population, it is beneficial to understand your own beliefs and prejudices about alcohol and drug abuse and how they might affect your interactions with

What disabilities are encountered by children and adults who were exposed to alcohol in utero?
Children and adults affected by prenatal alcohol exposure most commonly exhibit neurobehavioral deficits, particularly in the area of executive function (EF).\textsuperscript{19} Impairment of EF causes significant deficits in planning ability, flexible thinking and problem-solving. These difficulties result from an impaired ability to predict the consequences of one’s actions. Disability in EF often leads to conflicts with both peers and adults during childhood. By adolescence it sometimes results in involvement with the criminal justice system.
parents. Nurses facilitate a positive communication when the patient is approached non-judgmentally, empathetically and with an intention to be of assistance. An opinionated, condemning or aloof manner aborts effective communication and a therapeutic relationship with the family.

Fifty percent of the female population enjoys social alcohol consumption from time to time. However, 20% of these same women “risk drink” or overindulge. Risk drinking for women is defined as more than 3 drinks at a setting or more than 7 drinks in a week. A standard drink is considered a 12 ounce can of beer, a 5 ounce glass of wine or one and one-half ounces of hard liquor (see Figure 2). While social alcohol consumption is acceptable to most people, alcohol used in excess (especially for a woman), during pregnancy, or around young children, is often stigmatized. Many believe that such a mother doesn’t care about her child or about the effect the alcohol is having on the developing fetus. But in fact, a woman who continues to drink well into her pregnancy or throughout the pregnancy is likely suffering from a substance use disorder and is simply unable to quit on her own.

### Screening Tools

Discussing the volume of a standard drink is important to insure that you and the patient are both talking about the same amount of alcohol. Standard screening tools include helpful questions nurses can ask in simple conversations with mothers at the bedside. Using MI can help improve the communication, as well as provide a strategy for a brief intervention, if warranted.

Screening tools should be used prior to asking any other questions about alcohol use. There are several reliable screening tools that are both sensitive (do not miss “risk drinkers”) and specific (do not over-identify too many low-risk drinkers). The gold standard for gathering information on how much a woman is actually drinking is the Timeline Follow-back typically used in research. For clinical settings, the following screening tools are both sensitive and specific. Some tools are more appropriate for adults than for adolescents and some are more reliable in determining all risk drinking during pregnancy. The CAGE (see Table 2) was initially developed for males, and became the foundation for many of the other screening tools in use today. However, the CAGE was not found to be “sensitive to risk drinking at any cut point.”

The T-ACE and the TWEAK are two screening tools designed specifically for pregnant women, and have been shown to be both sensitive and specific for women of childbearing age. TWEAK (see Table 3) is similar to the CAGE but omits the question related to guilt, and adds the tolerance question. However, note that a positive for the tolerance question, regarding how many drinks the subject can have before passing out (amnesia or black outs) requires an answer of 5+. Since significantly less alcohol use has been shown to be harmful to the fetus, this screen will miss the mothers who can hold up to 4 drinks before passing out.

The T-ACE (see Table 4) also was derived from the CAGE, and was developed for use in OB/GYN clinics. It has been shown to be a brief, efficient screen for risk drinking, out-performs clinical assessment alone, and is the most sensitive instrument in detecting current alcohol consumption. T-ACE also

### Table 2: CAGE Screening Tool

<table>
<thead>
<tr>
<th>C</th>
<th>Have you ever felt you ought to cut down on your drinking?</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Have people annoyed you by criticizing your drinking?</td>
</tr>
<tr>
<td>G</td>
<td>Have you ever felt bad or guilty about your drinking?</td>
</tr>
<tr>
<td>E</td>
<td>Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover? Eye opener?</td>
</tr>
</tbody>
</table>

**Scoring**

Each question score positive is one point, 2 or more points is a positive screen.

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replaces the question about feeling guilty with a question about tolerance. However, in this screen, a “positive” for the tolerance questions requires the patient to feel high after only 2+ drinks, thus setting a lower threshold to screen a risk drinker. Because the current research is quite clear that even small amounts of alcohol might be damaging to the fetus, choosing a tool that is both sensitive and specific for this population is critical. Asking: “How many drinks make you feel high?”, rather than “How many drinks can you hold?” might lead to different answers based on social expectations. Another screening tool that identifies risk drinkers is the AUDIT-C (See Table 5), which contains the first 3 questions of the World Health Organization’s screening tool: The AUDIT Alcohol Use and Pregnancy: Improving Identification.28,29 Working with adolescent mothers requires the use of a tool designed for the adolescent population. CRAFFT (see Table 6) is a validated screening tool that was tested on 14-18 year olds. The tool’s validity is dependent on asking the questions in private, away from the adolescent’s parents.30

Screening for risk of an alcohol-exposed pregnancy must be done systematically to ensure efficacy. Asking frequency and quantity of alcohol consumption questions prior to

<table>
<thead>
<tr>
<th>Table 3: TWEAK Screening Tool</th>
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<tbody>
<tr>
<td>T</td>
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<tr>
<td>W</td>
</tr>
<tr>
<td>E</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>C</td>
</tr>
</tbody>
</table>

Scoring: Tolerance: 2 pts if she can hold more than 5 drinks w/o falling asleep or passing out. Worry: positive is 2 pts. All other questions: 1 pt

<table>
<thead>
<tr>
<th>Table 4: T-ACE Screening Tool</th>
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<tbody>
<tr>
<td>T</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>C</td>
</tr>
<tr>
<td>E</td>
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</tbody>
</table>

Scoring: A Positive Screen is a score of 2 pts or more. Answer of 2 or more on tolerance is a positive 2 points. A positive on A, C, E each score one point.

<table>
<thead>
<tr>
<th>Table 5: AUDIT-C Screening Tool</th>
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<tbody>
<tr>
<td>1. How often do you have a drink containing alcohol?</td>
</tr>
<tr>
<td>a. Never</td>
</tr>
<tr>
<td>b. Monthly or less</td>
</tr>
<tr>
<td>c. 2-4 times a month</td>
</tr>
<tr>
<td>d. 2-3 times a week</td>
</tr>
<tr>
<td>e. 4 or more times a week</td>
</tr>
<tr>
<td>2. How many standard drinks containing alcohol do you have on a typical day?</td>
</tr>
<tr>
<td>a. 1 or 2</td>
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<tr>
<td>b. 3 or 4</td>
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<tr>
<td>c. 5 or 6</td>
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<tr>
<td>d. 7 to 9</td>
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<tr>
<td>e. 10 or more</td>
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<tr>
<td>3. How often do you have six or more drinks on one occasion?</td>
</tr>
<tr>
<td>a. Never</td>
</tr>
<tr>
<td>b. Less than monthly</td>
</tr>
<tr>
<td>c. Monthly</td>
</tr>
<tr>
<td>d. Weekly</td>
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<tr>
<td>e. Daily or almost daily</td>
</tr>
</tbody>
</table>

Scoring: The AUDIT-C is scored on a scale of 0-12 points.

a=0 
b=1 
c=2 
d=3 
e=4

In men, a score of 4 or more is considered positive. In women, a score of 3 or more is considered positive.

Positive score: Optimal for indentifying hazardous drinking or active alcohol use disorders.

However, when the points are all from Questions 1 alone (#2 and #3 are zero), it can be assumed that the patient is drinking below recommended limits and it is suggested that the provider review the patient’s alcohol intake over the past few months to confirm accuracy.34
to screening questions decreases sensitivity of the screen by 95% to 32%. If the screening test is positive, more detailed questions about quantity and frequency are necessary and can be facilitated by using the AUDIT-C (see Table 5).

Nurses in the NICU, nursery and/or pediatrician’s office will be screening women who have been pregnant. These mothers may not have consumed alcohol during pregnancy or may have stopped drinking once the pregnancy is discovered and indicate that no alcohol was consumed. To determine alcohol-exposure in early pregnancy and to identify more accurate measurement of drinking patterns prior to pregnancy, ask questions on the AUDIT-C tool with the caveat: “Prior to pregnancy…” Then ask, “When did you realize you were pregnant?” which may give you a window into alcohol-exposure during pregnancy.

**Table 6: CRAFFT Screening Tool**

<table>
<thead>
<tr>
<th>C</th>
<th>Have you ever ridden in a car driven by someone (including yourself) who was “high” or had been using alcohol or drugs?</th>
</tr>
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<tbody>
<tr>
<td>R</td>
<td>Do you ever use alcohol or drugs to relax, feel better about yourself, or fit in?</td>
</tr>
<tr>
<td>A</td>
<td>Do you ever use alcohol or drugs while you are by yourself, alone?</td>
</tr>
<tr>
<td>F</td>
<td>Do you ever forget things you did while using alcohol or drugs?</td>
</tr>
<tr>
<td>F</td>
<td>Does your family or friends ever tell you that you should cut down on your drinking or drug use?</td>
</tr>
<tr>
<td>T</td>
<td>Have you ever gotten into trouble while you were using alcohol or drugs?</td>
</tr>
</tbody>
</table>

**SCORE:** Each yes answer is counted as one point. A total of 2 points is considered positive and needs further assessment.

**Box 2: Risk Drinking: Consuming More Alcohol Than is Safe**

- **Quantity of Alcohol Consumption on a Single Occasion: Binge Drinking**
  - Female (non-pregnant): >3 drinks
  - Male: >4 drinks

- **Frequency of Drinking: Risk Drinking**
  - Female (non-pregnant): >7 drinks/week
  - Male: >14 drinks/week

**Benefits of early identification and diagnosis**

Once a woman gives birth, knowing her drinking patterns during pregnancy is important for early identification and interventions for the neonate as well as to prevent future alcohol-exposed pregnancies. Many infants exposed to alcohol and other drugs are cared for in well-baby nurseries and are never admitted to the NICU. For these infants, critical information may be obtained by the Mother-Baby nurse caring for the couplet during short hospital stays.

Challenging or arguing with a mother who denies alcohol use during pregnancy is counter-productive and may compromise the therapeutic relationship. If alcohol use is suspected, asking the father or other family member may provide a more accurate history. It may help to tell the family member that you are concerned because the baby is small for size, hypertonic or has difficulty with self-regulation. While these findings may be due to many causes other than alcohol intake, this tactic may assist in obtaining the needed information. The conversation should be held in private, noting to the family member that it is often hard to acknowledge alcohol use because of feeling responsible for something being wrong with the infant. Help the mothers and their families understand that there are many women who drink prior to knowing they are pregnant, and many women who continue drinking during pregnancy often don’t know how to stop drinking. Whichever of these scenarios resulted in an alcohol-exposed fetus, mothers need to be supported rather than blamed.

Early identification and subsequent early intervention are critical to improving the affected individual’s entire life. Identifying a mother who needs treatment for her substance abuse significantly benefits the child’s growth, development and behavior. Early diagnosis, before the age of six, is a protective factor for the development of secondary disabilities (i.e., school failure, trouble with the law, job failure and inability to live independently) later in life. Being identified as alcohol-exposed at a young age enables children to receive not only increased amounts, but also appropriate types of interventions and
Many infants are not recognized as being prenatally exposed at birth.1,34 Heavy prenatal alcohol exposure causes a continuum of neurocognitive, behavioral and developmental delays.35-38 Unfortunately, testing for alcohol is not included in routine meconium testing, must be ordered separately, and is expensive. Moreover, it is currently available in only a few labs.

Intrauterine growth restriction, marginal postnatal growth, borderline small head for body size, fussiness and feeding difficulties may have been caused by alcohol-exposure but are not diagnostic. Usually they are attributed to the condition that led to admission to the NICU. A small number of infants with less severe effects than full-blown FAS may have congenital physical anomalies which were, in fact, caused by alcohol exposure. Nevertheless, the amount of exposure that might significantly affect cognitive ability and behavior is not considered an indication for testing to search for internal organ anomalies, unless there were clues on the fetal ultrasound or physical findings suggestive of such problems, e.g. a significant heart murmur.

Early intervention matters
Alcohol-exposed infants need closer than normal monitoring of feeding, growth and development. Through Part C of the Individuals with Disabilities Education Act, all states have some system of early intervention developmental resources for high-risk children aged birth to 3 years. Alcohol or drug-exposed infants are eligible for evaluation by each state’s Early Intervention Program. At birth these infants may not demonstrate special needs; however, they are at-risk and require continual monitoring and timely referral if problems develop. Either the family or medical provider can access the Part C program. Early therapies can significantly improve the child’s cognitive and behavioral readiness for school and prevent what might otherwise become early failure.
Parent attachment and caretaking are pivotal development features that are influenced by alcohol exposure.1 When mothers are able to provide a high level of emotional support, their children show strong signs of attachment and have better coping skills.1,40 There is also a direct relationship between caregiver stress and depression, neonatal nurses should assess parents using tools like the Parenting Stress Index and the BECKS Depression Scale.42 Referral for a home visiting program after discharge can be beneficial for both parenting success and child development.43

Once parents understand the risks – and the availability of resources to prevent or minimize their child’s possible future challenges, they become Partners-in-Care. Because parents are experts about their child they can partner with the healthcare team to monitor for signs and symptoms needing intervention. Knowing that a child is at high risk, parents are prepared to advocate for their child by seeking evaluation and therapy at the first sign of problems, rather than waiting to see if he/she will “grow out of it.”

The Child Abuse and Prevention Treatment Act (CAPTA) Reauthorization Act of 2010 is a source of funding for child welfare with specific

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Post-Test: Fetal Alcohol Spectrum Disorder

Complete the quiz on line at www.anhi.org at no charge. Please note online questions or answers are randomized and may not appear in the sequence below. Do not assume that the “letter” preceding the correct response will be identical to the online version.

1. The following terms are all diagnostic terms except one.
   a. ARND
   b. Static Encephalopathy
   c. FASD
   d. FG Syndrome

2. Which of the following tools to identify women’s drinking patterns is considered the gold standard in terms of sensitivity and specificity?
   a. TWEAK
   b. Follow-back timeline
   c. T-ACE
   d. AUDIT-C

3. What are the authors’ recommendations for screening tools that are both sensitive and specific within a busy clinic?
   a. TWEAK
   b. TLFB
   c. T-ACE
   d. Audit

4. What is the screening tool for adolescents that is described in the article?
   a. CRAFFT
   b. Audit-C
   c. TWEAK
   d. CAGE

5. When screening women at risk for an Alcohol Exposed Pregnancy (AEP), what are the two key components of the screen?
   a. Valid long screen such as the TLFB and drinking history during last pregnancy
   b. Screening for risk drinking and effective contraception use
   c. Screening for risk drinking and past pregnancy drinking
   d. Screening the women and her partner for drinking histories

6. Studies have shown that infants exposed to alcohol prenatally require:
   a. A stimulating and stress-free environment
   b. Quality care given by professional and parent.
   c. Early interventions
   d. Stable, nurturing home environment
   e. All of the above

7. What is considered the most devastating effect of prenatal alcohol exposure?
   a. Facial dysmorphology
   b. Small stature
   c. Brain injury and neurobehavioral deficits
   d. Hypotonia

8. Which of the following diagnosis terms deals only with damage to the central nervous system?
   a. FASD
   b. ARND
   c. FAS
   d. (pFAS)

9. The acronym DARN stands for which of the following?
   a. Develop, Able, Reason, Notice
   b. Desire, Ability, Reason, Need
   c. Desire, Able, Reason, Notice
   d. Develop, Ability, Regard, Need

10. What is not a key component of Motivational Interviewing (MI)?
   a. Developing equal partnerships
   b. Providing appropriate advice
   c. Exploring the topic rather than advising
   d. Use of rulers to assess confidence and importance in making desired behavior change

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Abbott Nutrition Health Institute is an approved provider of continuing nursing education by the California Board of Registered Nursing, Provider #CEP 11213.
eligibility requirements. One new area of the legislation states that healthcare providers must make appropriate referrals to Child Protective Services (CPS) for the development of service plans to ensure the safe care of newborns affected by prenatal drug exposure or diagnosed with an FASD. A positive alcohol screen during pregnancy requires a more thorough medical workup of the infant prior to referral to CPS. However, if a formal diagnosis is made after screening a new mother for prenatal alcohol use, a healthcare provider needs to be aware of the law.

ABOUT THE AUTHORS

Pamela Gillen, ND, RN, CSN, is assistant professor of research in the Department of Nursing and the project director for the University of Colorado Denver, Anschutz Medical Campus Colorado Fetal Alcohol Prevention Outreach Project (COFAS-POP). She has over 30 years experience in the Health and Human Services field, as a public health nurse, nurse coordinator and nurse case manager for at-risk pregnancies working with high-risk women of childbearing age to help prevent Fetal Alcohol Spectrum Disorder/Alcohol Tobacco and Other Drugs (FASD/ATOD) affected infants. Dr. Gillen will be the co-chair of the National FASD Center for Excellence Expert panel for the next 5 years. She has lectured nationally on issues that relate to the prevention of fetal alcohol spectrum disorder.

Sharon Langendoerfer, MD, has been a practicing neonatologist and pediatrician for high-risk infants at Denver Health and Hospitals for the past 35 years. She has been a member of Colorado Fetal Alcohol and Substance Abuse Coalition for the past 20 years and is currently an appointed member of the Colorado State Commission on FASD. Dr. Langendoerfer has also been a volunteer at the March of Dimes for 35 years.

Karen Fehringer, PhD, OTR, is assistant clinical professor at the University of Colorado Anschutz Medical Campus, Colorado School of Public Health, where she is a researcher in infancy, child development, and oral health care. She is a practicing occupational therapist at the University of Colorado Hospital Neonatal Intensive Care Unit. Dr. Fehringer has more than 35 years of experience in neonatal intensive care units, pediatric in- and out-patient settings, birth to three-year and school district programs. She is a former special education coordinator and specializes in assessment and management of FASD. Dr. Fehringer is an appointed member of the Colorado State Commission on FASD.
**Feature: Fetal Alcohol Spectrum Disorder**

**REFERENCES**


Evidence-Based Treatment of Gastroesophageal Reflux in Neonates

By Susan Pfister, RN, CNNP, MA

Premature infants are at risk for many health problems including gastroesophageal reflux (GER), which is very distressing to parents and caregivers. Infants with GER experience symptoms such as regurgitation, crying, irritability and arching within 30 minutes of feeding. The purpose of this article is to examine GER in neonates and review research evidence to support effective interventions. Common interventions such as elevating the head of the bed, holding the infant upright, using prone or left-lateral positioning, thickening feedings and use of medications will all be discussed. In addition, research evidence about the supposed relationship of GER to apnea in preterm infants will be presented.

“Show Me the Evidence”
It is estimated that only 85% of healthcare practice has been scientifically validated. Ideas become habits, and these habits become established practice, without any research to support them. Several neonatal nursing texts recommend interventions for neonatal GER such as elevating the head of the bed, holding the infant upright after feeds, and prone positioning with the head of the bed elevated, without sufficient supporting evidence. For example, many caregivers in neonatal intensive care units (NICUs) position infants with the head of the bed elevated, an anecdotal remedy, upon the recommendations of outdated reference books that offer conflicting advice, or they place the infant in a prone position despite the recommendation of the American Academy of Pediatrics against the practice after 37 weeks.

LEARNING OBJECTIVES
After reading this article, the reader will be able to:
• Identify predisposing factors for GER in neonates.
• Recognize non evidence-based interventions for GER in neonates.
• Identify evidence-based interventions for GER in neonates.
• Understand the relationship between GER and apnea.
Of the various methods to evaluate research, the most accepted is to classify a study by how it was performed (study method), the number of subjects studied, and whether the results can be reproduced by others. Many professionals believe this model does not allow for the incorporation of clinical expertise. However, history has shown that numerous examples of healthcare interventions that seem to work and benefit individuals, are actually found to have no benefit and/or to be harmful in randomized controlled trials (RCTs). Some examples of non-evidence-based practice in neonatal care are unrestricted oxygen use, resulting in retinopathy; restriction of oxygen use, resulting in CNS damage or death; postnatal steroids and resuscitation with 100% oxygen. In contrast, surfactant therapy in preterms is an example of a well-studied, evidence-based intervention.

While the majority of daily nursing decisions do not emerge from RCTs, best practice encourages professionals to thoughtfully examine the literature in order to validate new practices and re-evaluate established ones. Some authors have taken the different classifications of research and created a pyramid that puts more reliable evidence near the top and more opinionated evidence near the bottom. The pyramid model takes evidence and weights it based upon established criteria:

A. Level I: systematic reviews from RCTs, or clinical guidelines based on systematic reviews of RCTs.
B. Level II: evidence from a single, well-designed RCT.
C. Level III: evidence from a well-designed study without randomization.
D. Level IV: evidence from case-controlled and cohort studies.
E. Level V: evidence from the opinion of an established authority or committee.

Using this type of classification helps determine the reliability and validity of a study, and allows one to apply the information to clinical practice.

An extensive literature search for studies that discussed GER and positioning was undertaken and reviewed. The databases searched were the Cumulative Index to Nursing and Allied Health Literature (CINHAL), the Cochrane library, Medline, PubMed and Google Scholar. As the articles were read, cited articles were noted and retrieved. Keywords were: gastric esophageal reflux, gastric-esophageal reflux, head of bed elevation, positioning, neonate, infant and baby. Eight articles, including one Cochrane review, were chosen to review and critique for this analysis.

Definitions and Incidence

After ingestion, food passes through the esophagus into the stomach via the lower esophageal sphincter, which opens and allows the food to enter the stomach. The sphincter then closes to prevent reflux of food and stomach acid back into the esophagus. Factors predisposing infants to GER include gastric emptying time, all feeding as liquid, and positioning after feeding. In late preterm infants the mean time to half emptying of the stomach varied from 34.9 to 75.3 minutes depending on positioning. Enterally-fed infants take up to 180 milliliters per kilogram per day, a volume comparable to an adult ingestion of about 14 liters of fluid per day. Additionally, as soon as the infant completes the feeding he or she is often laid down to sleep. Some 67% of normal 4-month-old infants regurgitate at least one time per day.

GER is a developmental condition of young infants and older adults. In neonates the reflux of stomach contents into the mouth (spit up) is quite common and usually not accompanied by any evidence of distress. GER of this degree typically decreases with age and is uncommon by about 10 months of age. If reflux into the esophagus or mouth is accompanied by distress, the infant may be said to have gastroesophageal reflux disease (GERD). Symptoms of GERD include: regurgitation, irritability, excessive crying, disturbed sleep, impaired feeding tolerance, poor weight gain and respiratory complications. GERD that is more than minimally symptomatic may require more extensive diagnosis and treatment.

There is a widespread belief that GER either causes or exacerbates apneic episodes in preterm infants. Apnea, a cessation of respirations for more than 20 seconds, is common in preterm infants and may be either primary (apnea of prematurity) or secondary, due to other causes such as position, temperature, sepsis etc. Most apneic episodes are central (inspiratory efforts are absent) or mixed (airway obstruction with central apnea) and do occur frequently in premature infants. The younger the gestational age, the greater the frequency of apneic episodes.

However, both an RCT and a pH-probe study of 102 infants could establish no relationship between GER and apnea. In the RCT, researchers concluded that GER does not cause, prolong or exacerbate apnea. Apnea of prematurity usually resolves as the infant reaches 40 weeks corrected gestational age, whereas GER symptoms often are seen in infants up to age 10 to 12 months. Caregivers who understand the physiology, pathophysiology and timing of each condition can avoid causal conclusions when data do not support a relationship.

Knowledgeable caregivers are also able to provide interventions for each condition, independent of the other.

Interventions for GER

When an infant has symptoms of GER, caregivers and parents will attempt a number of approaches to alleviate the infant's distress. Following are commonly used interventions and the research evidence for each.

Elevating the Head of the Bed

Because of anecdotal practice and unit history, head-of-the-bed elevation is the first treatment used for many infants with symptoms of GER. This treatment is suggested in many nursing texts and articles but has not been validated. Some texts cite a 2002 review of the literature that discusses the problem of GER in neonates; however, the author of the review notes that the information and recommendations for neonates are an extrapolation of research performed on older infants. This article cites factors that may contribute to GER: (1) increased intra-abdominal pressure; (2) excessive crying; (3) delayed gastric emptying and (4) sluggish esophageal motility. The researcher also notes that supine, right lateral and elevated positioning in a
car seat exacerbate the symptoms of GER. Although prone positioning with 30 degree elevation, and left lateral positioning lessen the symptoms of GER, the author points out that the prone position is associated with SIDS and is therefore not recommended. The articles referenced in the review are the same as those used for this critique and do not list any studies that support head of the bed elevation.

Two articles in 1983 evaluated positioning for the relief of GER in infants. Placing an infant upright in a car seat at a 60 degree angle had been used to treat GER — without evidence to support the practice. When studied, using a car seat did not decrease, but rather increased, GER symptoms because the lower esophageal sphincter is more likely to be submerged in the 60 degree head-elevated position. In two prospective controlled comparisons, one of 9, the other of 15 infants with GER symptoms, each infant had a pH probe and continuous pH monitoring for 24 hours while positioned in either a car seat or prone, with head of the bed elevated. The studies monitored the percentage of time with esophageal pH below 4, number of episodes when pH was less than 4, the number of low pH episodes lasting longer than 5 minutes and the duration of the longest episode. Both studies showed that infants in car seats had longer exposure to GER, for a longer period of time, and had more episodes. These studies did not look at either of the positions compared to any other sleeping position.

In 1990, another study by the same researchers compared the efficacy of 30 degree head-of-the-bed elevation to prone positioning in 100 infants younger than six months of age, 90 of whom had suspected GER. Using pH probes, the researchers monitored esophageal pH continuously for 24 hours. Recordings were assessed for number of minutes with a pH less than 4, mean duration of each episode, number of episodes with pH less than 4, and number of episodes of less than 5 minutes duration. Each infant was randomly placed in one position and then, half way through the study, changed to the other position. The results revealed “no measure of reflux that was significantly better in the head-elevated position than in the prone position.” The study concluded that positioning infants in head-elevated positions was not worth the effort. Although the first study in 1983 showed head-of-bed elevation of 30 degrees was superior to car seat sitting at 60 degrees, the 1990 study showed that head-of-bed elevation of 30 degrees was, in fact, not superior to the prone position for the relief of GER symptoms.

Elevation of the head of the bed came from the supposition that infants lying flat may be more susceptible to GER symptoms. Caregivers have elevated the head of the bed with wedges and created cloth slings to hold the infant in place once the head is elevated. Some crib companies now manufacture and sell cribs that allow the head of the bed to be elevated. Advice and recommendations for parents are readily available on multiple internet sites. Some of these interventions seem benign, but may increase the length of hospital stay and be costly to parents. Parents may be encouraged to buy a special crib, wedges and/or slings for an existing crib at home. Worse, the interventions can lead to unsafe sleeping conditions for the infant. For example, the use of pillows or blankets contributes to an increased risk of suffocation. Elevation of the head of a normal crib may make the infant vulnerable to a fall.

**Left Lateral Position**

In 1997, 24 infants with symptoms of GER were randomly assigned to one of four positioning groups: prone, supine, right lateral or left lateral. In addition, there was a comparison of infants placed horizontally to those positioned with the head of the bed elevated 20 degrees. After 24 hours, infants were randomly assigned to another group. All infants had a pH probe to monitor acid levels in the esophagus. Reflux index (i.e., percent of time with a pH less than 4), number of episodes with a pH less than 4 during 24 hours, number of episodes lasting more than 5 minutes, and the duration of the longest episode were monitored. Table 1 shows the reflux index in various study positions. There was a significant difference between right lateral position and supine position compared to left lateral and prone position. There was no significant difference between horizontal and head-of-bed elevation. Therefore, these researchers concluded that “in this study no benefit for head elevation was noted.”

In 1999 another investigation using the reflux index reproduced the same results in a sample of 18 infants in a NICU. Left lateral, right lateral and prone positions were investigated with 24 hour pH probes. The number and severity of reflux episodes for infants in the right lateral position exceeded those of the infants in the left lateral and prone positions. Because the least frequent and least severe symptoms occurred in infants placed in the prone or left lateral position, the study concluded that the left lateral position be adapted as a position for infants with symptoms of GER.

In 2009, a Cochrane Review analyzed five different studies regarding head-of-bed elevation. A 1999 study by Bagucka found that the head-elevated position was not helpful in decreasing GER. Other research covered in the Cochrane Review includes the previously listed articles by Tobin and Orenstein. The Cochrane Review authors classified the quality of the analyzed studies as good. Each study used pH probe monitoring for 24 hours.

**Table 1: Reflux Index Related to Infant Position**

<table>
<thead>
<tr>
<th>Infant Position</th>
<th>Reflux Index*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supine</td>
<td>15.3</td>
</tr>
<tr>
<td>Right Lateral</td>
<td>12.0</td>
</tr>
<tr>
<td>Left Lateral</td>
<td>7.7</td>
</tr>
<tr>
<td>Prone</td>
<td>6.7</td>
</tr>
<tr>
<td>Horizontal</td>
<td>10.7</td>
</tr>
<tr>
<td>Elevated Head of Bed</td>
<td>10.1</td>
</tr>
</tbody>
</table>

*Normal average index is 10 for infants <12 months of age*
as a determination of severity of symptoms. Some research compared infants with head-of-bed elevated to those positioned in an elevated car seat, some compared infants placed prone to those placed supine; some compared left lateral to right lateral positioning.\(^{19,20}\) Of the five different investigations reviewed, none found any significant decrease in GER symptoms for infants with head-of-bed elevation. Elevated pH in the esophagus was the same for infants positioned flat as with the head of bed elevated.\(^{19-23}\) Prone and left lateral positioning was significantly superior to supine or right lateral positioning. In fact, research that analyzed positioning greater than 30 degrees (i.e., in car seat or using positioning aids) found that prone and left lateral positioning were superior to elevation. Due to the risk of sudden infant death syndrome (SIDS), the prone position is not recommended by the study authors or the review authors. It should be noted that the studies evaluated in the Cochrane Review were of small sample size and, due to the nature of the research, blind randomization was not achieved.

In 2007, a randomized controlled trial of 22 preterm infants with GER symptoms assessed whether left side lying position was effective in decreasing non-acid GER, as well as acid GER. The infants were monitored by pH probes for 24 hours to assess the number and length of GER occurrences.\(^{24}\) Liquid versus air reflux was differentiated in the study using modern impedance equipment. Each patient was randomly positioned in right lateral, left lateral, prone and supine positions. Findings were similar to previous studies showing the least GER occurrences in prone position, the next fewest in the left lateral position, then right lateral, with the most occurrences in the supine position. Results were the same for liquid reflux and air reflux. The authors concluded

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**Post-Test: Evidence-Based Treatment of Gastroesophageal Reflux in Neonates**

Complete the quiz on line at www.anhi.org at no charge. Please note online questions or answers are randomized and may not appear in the sequence below. Do not assume that the “letter” preceding the correct response will be identical to the online version.

1. The opinion of an established authority/expert committee carries more weight when evaluating evidence than a systematic review of randomized-controlled studies.
   a. True
   b. False

2. The gold standard of research evidence is the randomized controlled trial and/or meta-analysis of randomized controlled trials.
   a. True
   b. False

3. “We’ve always done it this way and we’ve never had any problems” justifies using anecdotal clinical interventions.
   a. True
   b. False

4. GER is a common condition in neonates and young infants.
   a. True
   b. False

5. Factors that predispose neonates to GER do not include:
   a. relaxed lower esophageal sphincter
   b. liquid feedings
   c. gastric emptying time
   d. being held upright by mother for 30 minutes after feeding

6. The mean gastric emptying time for a neonate is:
   a. less than 30 minutes
   b. 30 to 90 minutes
   c. 3 hours

7. GER and GERD are the same syndrome.
   a. True
   b. False

8. Thickening feedings decreases GER and has no adverse effects.
   a. True
   b. False

9. Anti-reflux medications have been thoroughly studied in neonates, are safe and recommended to treat GER.
   a. True
   b. False

10. Research shows that GER causes, prolongs the duration of, and exacerbates apnea in preterm infants.
    a. True
    b. False

11. Apnea of prematurity is a complication of GER.
    a. True
    b. False

12. According to the research reviewed in this article, the position that decreases the frequency, duration and severity of GER symptoms is:
    a. supine with head of bed elevated
    b. right lateral position
    c. left lateral position
    d. none of the above
that there was no statistical difference between prone and left lateral positions because only 1.9 episodes occurred in left lateral position and 1.1 episodes in prone position. The authors also stated that the “findings do not provide any information on clinical improvement” but rather a “simple way to limit GER.”

Therefore, this review of the literature shows that head-of-bed elevation is not supported by research. The recommended positions for infants who are experiencing symptoms of GER are either prone or left lateral side lying.

Other Interventions for GER

More invasive interventions, such as thickening feeds and medication, have been used for GER. Evidence does not support the safety or efficacy of these modalities. Caregivers have postulated that thickened feedings alter stomach contents from fluid to a more solid consistency, decreasing the occurrence of regurgitation into the esophagus. But no reduction of GER has been noted from thickening breast milk with a starch additive. Moreover, a possible relationship between thickened feedings and necrotizing enterocolitis was noted. In term infants fed formula however, there is some evidence that thickened formula can reduce the number of regurgitation episodes.

There is widespread use of anti-reflux medications to treat GER in neonates—with a lack of efficacy noted in clinical studies. Off-label use (without approval by the Food and Drug Administration for use in neonates) of metoclopramide and ranitidine is so common that they are ranked first and fourth, respectively, among medications most frequently used in the NICU. Adverse effects of these medications in preterms include an increased risk of hospital-acquired sepsis and a higher incidence of necrotizing enterocolitis. Although clinical studies demonstrate no statistical benefit in the reduction of GER symptoms from medications and/or thickening of breast milk, these interventions continue to be prescribed in NICUs.

Implications and Recommendations

Based on the research reviewed here, infants with symptoms of GER should be placed flat to sleep in a prone position or left lateral position until they are 37 weeks corrected gestational age, after which the prone position should be avoided. Elevating the head of the bed, thickening feedings, and use of medications have not been shown to be effective in decreasing the duration or severity of GER symptoms.

When an infant presents with symptoms of GER, “a stepwise approach, based mainly on conservative interventions is the best therapeutic choice.” Other causes for the symptoms should be eliminated with a thorough review of perinatal history and a physical assessment. While considering differential diagnoses, interventions to diminish symptoms of GER can be initiated. Holding the infant upright after feedings helps eliminate air from the stomach with burping. Holding the infant for 30 minutes after feeding, the usual time when acid reflux occurs, diminishes symptoms, enables the caregiver to comfort the infant, and helps transition to a sleep state. Placing the sleeping infant in a left lateral position for at least 30 minutes and then repositioning onto the back for sleep, relieves symptoms and complies with AAP “Back to Sleep” guidelines. More research is required to give long-term recommendations.

Conclusion

An evaluation of the literature has shown that some of the most often applied positional interventions: head of bed elevation, slings and wedges, do not have evidence-based origins and do not stand up to physiological testing. Preconceived ideas withhold the relief that could be available by recommended interventions, such as horizontal prone and horizontal left lateral positions. This critical review of the literature shows the efficacy of the prone and left-lateral positions and reveals the need for evidence-based practice.

ABOUT THE AUTHOR

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