NABCA RESEARCH

The Public Health Considerations of Fetal Alcohol Spectrum Disorders

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Alcohol use during pregnancy is a major public health problem with 1 in 10 pregnant women reporting alcohol use in the past 30 days and 1 in 5 report binge drinking (defined as four or more drinks on at least one occasion in the past 30 days).[i] Consuming alcohol while pregnant can lead to physical and mental problems known as Fetal Alcohol Spectrum Disorders (FASD) for a developing baby. The Centers for Disease Control and Prevention (CDC) defines FASD as "a group of conditions that can occur in an individual who is prenatally exposed to alcohol." Alcohol consumption during pregnancy is the leading preventable cause of birth defects.[ii] Abstaining from alcohol during pregnancy is the best strategy to prevent FASD.

Under the FASD umbrella, three primary conditions exist, differentiated by the visibility and type of disabilities:

- Fetal Alcohol Syndrome (FAS) – the most visible result of drinking during pregnancy, FAS was named and defined in a 1973 article in *The Lancet* medical journal after doctors observed a pattern of medical issues in infants born to alcoholic mothers. The initial 11 cases produced the same fundamental definition used today, with refinements made due to additional research and case studies. FAS symptoms cover three areas: growth difficulties, central nervous system issues, and atypical facial features.

- Alcohol-Related Neurodevelopmental Disorder (ARND) – those individuals diagnosed with ARND do not have atypical facial features but may have growth difficulties and central nervous system issues related to alcohol consumption by an expectant mother. This may lead to behavioral and learning issues including but not limited to trouble with memory, impulse control, judgment, and attention deficit concerns.

- Alcohol-Related Birth Defects (ARBD) – ARBDs describe physical issues related to alcohol consumption during pregnancy. These defects may include problems with the heart, kidneys, and bones.[iii]

The prevalence of FASD in the United States is similar to the rates found in other parts of the world where studies have been conducted. Data suggests FASD in the United States is more common than originally thought, and these conditions are underreported or underdiagnosed.

Previously, figures indicated that the United States had less than two FASD cases per 1000 births while a country such as South Africa has over 60 FASD cases per 1000 births.

A 2013 study that used a Midwestern town as a national representative surveyed 70 percent of parents of first-grade students and reported six to nine cases per every 1000 births for Fetal Alcohol Syndrome and 11 to 17 cases per every 1000 births for other FASD.[iv]

More recently, a 2018 study featured in the *Journal of the American Medical Association* found a significant number of children in the U.S. have FASD, representing a more accurate prevalence estimate than prior research. Researchers collected data from over 6,000 children in four geographic regions of the United States from 2010-2016 and found that up to five percent of American children may have FASD.[v] The study was the first school-based assessment, a method considered to be the "gold standard" for public health surveillance.[vi]

Prevention

No doubt exists as to the fundamental cause of FASD – fetal alcohol exposure. Depending on the source, there is some debate as to the risk small amounts of alcohol consumption can have on a developing fetus.

Reports suggest that a pregnant woman drinking over two standard drinks per day puts her unborn child at the most risk for FASD; more than four standard drinks per day creates a greater risk for Fetal Alcohol Syndrome.[vii] The harm from a pregnant woman consuming less than two drinks per day is not definitive although CDC recommends no alcohol consumption by pregnant women. A 1981 U.S. Surgeon General's report suggested pregnant women limit their alcohol intake but did not provide any guidelines or specific limits; this was updated by a new advisory document in 2005 with the following recommendations:

- Complete abstinence from alcohol consumption during pregnancy
- Immediate cessation of alcohol consumption by women who have already drank during pregnancy
- Inquiries by doctors and other health care authorities of women of a childbearing age as to their alcohol consumption
- Education about the risks of alcohol consumption while expecting to women of a childbearing age by doctors and other health care authorities
- Intervention by doctors and other health care authorities including referral to alcohol treatment programs[viii]

An International Charter on Prevention of FASD – also known as the "Edmonton Charter" - was endorsed at the First International Conference on the Prevention of FASD in 2013 and later featured in the medical journal, *The Lancet*. The Charter notes that:

> *Although maternal alcohol consumption during pregnancy is the direct cause of fetal alcohol spectrum disorder, many underlying causes exist for drinking during pregnancy. Reasons include women having little information about the risks of drinking while pregnant, drinking before pregnancy is recognized, dependence on alcohol, untreated mental health disorders, and social pressures to drink. The complex biological and social determinants of health, including genetics, poverty, malnutrition, and poor social support networks and personal autonomy, also affect drinking behavior and the severity of its results to the fetus. The risk of alcohol-exposed pregnancy increases with adverse life events, gender-based violence, trauma, stress, and social isolation.*[ix]

Interventions

There are two strategies endorsed by the CDC to reduce the number of alcohol-exposed pregnancies: alcohol screening and brief intervention (SBI) and CHOICES. Both interventions are evidence based and use motivational interviewing, a proven technique used in clinical settings to help an individual find motivation to make positive decisions to accomplish a desired goal. CHOICES, a program for women who are not pregnant, but at risk of an alcohol-exposed pregnancy, also provide counseling sessions to encourage contraceptive use.

Diagnosis

There has been substantial progress in developing criteria for defining and diagnosing FASD since the conditions were first referenced in the medical literature in 1973.[x] Diagnosing FASD can be challenging as it requires expertise to conduct the assessment and detect the symptoms that are often similar to other disorders. The CDC has developed guidelines about diagnosing FAS, the most visible form of FASD, and efforts to create diagnostic criteria for other FASDs are underway.

Recognizing that early diagnosis and services can help improve a child's ability to function, the American Academy of Pediatrics developed a FASD Toolkit to help raise awareness and promote surveillance and screening, and to ensure that all affected children receive appropriate and timely interventions.[xi]

Resources

The National Organization on Fetal Alcohol Syndrome is the only organization committed solely to FASD prevention, support, and advocacy with an affiliate network of over 30 member organizations.[xii] For the past 28 years, NOFAS has served as a clearinghouse for resources for anyone impacted by FASD including medical professionals, parents, and adults diagnosed with a FASD. NOFAS' resources include fact sheets, legislative tracking, and access to the National Institute on Alcohol Abuse and Alcoholism's Alcohol Treatment Navigator.[xiii]

NOFAS also sponsors the Circle of Hope program designed to support women struggling with addiction and find appropriate treatment. Stigma and blame towards women and their families have hindered both prevention and treatment of FASDs. The NOFAS Stamp Out Stigma campaign seeks to "stop the stigma of birth mothers of children with FASD and all children, adults, and families touched by Fetal Alcohol Spectrum Disorders." The NOFAS Affiliate

Network exists as an "international coalition for the purpose of preventing FASD and meeting the needs of people living with the disorders, while each member organization maintains its identity and autonomy."

A number of states have their own FASD-related organizations and programs and serve as active members of the NOFAS Affiliate Network.

North Carolina

The North Carolina Fetal Alcohol Prevention Program (FASDinNC) provides training, education, and resources to women of childbearing age and the professionals that serve them in order to prevent alcohol exposed pregnancies. Its events and programs have reached over 40,000 people since 2010, including a 2016 expansion through a grant from the state's Department of Health and Human Services to help underserved portions of eastern North Carolina.

FASDinNC's website provides health care advice and information for women prior to conception as well as alcohol-free alternatives to cocktails for expectant mothers to "celebrate an alcohol-free pregnancy." They also partner with Mother to Baby, a program in North Carolina that provides information confidentially regarding the potential impact of drugs and alcohol on a baby during pregnancy and breastfeeding.[xiv]

Michigan

The Michigan Coalition for Fetal Alcohol Resources, Education, and Support started in 2003.[xv] In addition to its involvement in NOFAS, MCFARES actively participates in the state FASD Task Force; a group out of Wayne State University's Michigan Developmental Disabilities Institute, focused on providing knowledge to medical professionals and parents.

MCFARES provides similar resources and support as other organizations affiliated with NOFAS in addition to supplying information on FASD's impact on the criminal justice system.

Individuals diagnosed with a FASD possess a higher rate of involvement with the criminal justice system. To this end, MCFARES provides resources from academic reports to publications from the American Bar Association and the Royal Canadian Mounted Police (FASD Guidebook for Police Officers) to assist members of the criminal justice system.

Minnesota

MOFAS, the Minnesota Organization on Fetal Alcohol Syndrome, provides some of the most comprehensive resources.[xvi] Among these resources includes the MOFAS Diagnostic Clinic, where families can receive support through the FASD evaluation process. The Clinic provides literature on the evaluation process, a Family Support Packet, and financial assistance in the diagnosis process. MOFAS also sponsors several events on FASD education and support throughout the year.

In 2017, MOFAS launched the Center for FASD Justice & Equity project. With funding from the American Legion Child Welfare Foundation, the project intends to "establish a national center and clearinghouse for issues related to the intersection between FASD and justice and equity issues." Its plan includes holding conferences among FASD stakeholders, sponsoring surveys and focus groups, and spotlighting new practices that are showing promising results.

Conclusion

Reducing the rates of FASD will come from a number of interventions focused on both the direct causes of FASD and the underlying factors that lead to alcohol consumption by pregnant women. Despite the overwhelming evidence that consuming alcohol while pregnant causes FASD, nearly 40,000 infants are born with FASD each year in the United States costing an estimated $4 billion annually for FAS alone, the most visible form of FASD. However, stigma

associated with FASD for birth mothers in addition to individuals and families living with FASD remain a significant barrier to progress.

National and state programs that support millions of Americans dealing with this preventable cause of birth defects are critical partners in the advancement of research, education, and advocacy efforts for the prevention, detection, and treatment of FASD.

Endnotes:

[i] Alcohol Use and Binge Drinking Among Women of Childbearing Age — United States, 2011–2013. Morbidity and Mortality Weekly Report, September 25, 2015. Centers for Disease Control and Prevention. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6437a3.htm?s_cid=mm6437a3_w

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[iv] May, Philip A., et al. Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders. Pediatrics. November 2014.

[v] Lange S, Rehm J, Popova S. Implications of Higher Than Expected Prevalence of Fetal Alcohol Spectrum Disorders. JAMA. 2018;319

[vi] Honein MA, Paulozzi LJ. Birth defects surveillance: assessing the "gold standard" Am J Public Health. August 1999

[vii] Yaffe, Sumner J. Drugs in pregnancy and lactation: a reference guide to fetal and neonatal risk (9 ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins, 2011.

[viii] Fetal Alcohol Spectrum Disorders. National Institutes of Health Fact Sheets. https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=27

[ix] International Charter on Prevention of FASD. https://www.lawnow.org/international-charter-prevention-fasd/

[x] Chudley, Albert E., et al. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal. March 2005.

[xi] Fetal Alcohol Spectrum Disorder Toolkit. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/The-Toolkit.aspx

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

[xiii] National Institute on Alcohol Abuse and Alcoholism's Alcohol Treatment Navigator. https://alcoholtreatment.niaaa.nih.gov/

[xiv] North Carolina Fetal Alcohol Prevention Program. http://www.fasdinnc.org

[xv] Michigan Coalition for Fetal Alcohol Resources, Education, and Support. https://www.mcfares.org/

[xvi] Minnnesota Organization on Fetal Alcohol Syndrome. https://www.mofas.org/