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Importance of Fetal Alcohol Spectrum Disorders Prevention and Intervention

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Abstract

The consumption of alcohol and other substances during pregnancy can impair prenatal development. While scientifically informed public health measures have raised awareness of the risks of harmful prenatal substance exposures, the use of alcohol and other substances during pregnancy continues to rise. The successful dissemination of consistent messaging, health care professional education and training, and universal implementation of clinical interventions may help reduce drinking in pregnancy and prevent fetal alcohol spectrum disorders (FASDs), a constellation of developmental disabilities and birth defects caused by alcohol use during pregnancy. Alcohol screening and brief intervention (alcohol SBI) is an evidence-based preventive practice that enables early identification of excessive drinking and intervention prior to serious consequences. Routine clinical implementation of alcohol SBI has been shown to effectively reduce excessive alcohol consumption among adults, including pregnant people. Many barriers prevent widespread implementation of the practice: a lack of health care professional knowledge of the prevalence and implications of prenatal alcohol exposure, stigma surrounding individuals who use substances potentially harmful to their pregnancy, resistance to public health messages encouraging alcohol avoidance during pregnancy, and discomfort and hesitancy with alcohol SBI procedures among practitioners. The Centers for Disease Control and Prevention (CDC) leads the public health effort to prevent alcohol use during pregnancy and improve identification of and care for children living with FASDs. CDC partners with health systems, health care professional associations, universities, and community-based networks to promote alcohol SBI as an effective but underused preventive health service. This special section consisting of 6 articles including

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Authors' Contributions

TD obtained funding and directed the project. TD, ED, MPB, KM, and AK conceptualized the manuscript and provided content expertise. All authors contributed to writing the main body of the commentary and abstract, reviewed and edited the manuscript, and read and approved the final draft. TD and ED prepared the manuscript and Supplemental Material for submission.

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this introductory commentary represents the efforts of 11 CDC projects and their partners to demonstrate the rationale for FASD prevention and intervention, engage health care disciplines to expand prevention messaging and education for providers, develop practical approaches for implementing alcohol SBI in diverse clinical settings, and prevent alcohol use in pregnancy and FASDs.

Keywords

fetal alcohol spectrum disorders (FASDs); prenatal alcohol exposure; alcohol use disorder; substance use disorder; stigma; screening and brief intervention (SBI); public health; primary care; pregnancy

Background

Fetal alcohol spectrum disorders (FASDs) represent a constellation of developmental disabilities and birth defects that can occur when an embryo or fetus is exposed to alcohol during pregnancy. Alcohol can disrupt human development at any point during pregnancy. FASDs can include problems with behavior and learning as well as physical problems with lifelong implications.¹

Based on 2018 to 2020 data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System, researchers found that nearly 1 in 7 pregnant people reported consuming alcohol in the past 30 days at the time of the survey. About 1 in 20 pregnant people reported binge drinking in that same period.² Frequent mental distress among pregnant adults was associated with twice the rate of current drinking and more than 3 times the rate of binge drinking.² The articles in this special section refer to pregnancy-related or associated events. We acknowledge that not every person who can become pregnant identifies as a woman. Although we try to use gender-inclusive language whenever possible, much of the available research refers only to "women" when discussing the ability to become pregnant. When citing research, we refer to the language in the study.

As a result of prenatal alcohol exposure (PAE), as many as 1 in 20 school-age children in the United States might be affected by FASDs.³ Primary care practitioners and clinics trained to implement alcohol screening and brief intervention (SBI) represent an important opportunity to reduce the prevalence of PAE and FASDs. As described in CDC's alcohol SBI implementation guide, *Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices*, the abbreviation SBI originated in the 1990s to refer to research related to screening and brief intervention.⁴ In the early 2000s, the Substance Abuse and Mental Health Services Administration funded efforts to encourage the implementation of SBI, adding "and referral to treatment" to emphasize the role of treatment service agencies. This changes the acronym to SBIRT but can be misunderstood to mean that all patients who screen positive need a referral to treatment. Therefore, the traditional abbreviation of SBI is used here.

Historical Perspective on Alcohol and Pregnancy

First identified as fetal alcohol syndrome in medical literature in 1973,⁵ more than 50 years of research has established the risks associated with alcohol use during pregnancy and the consequences of FASDs.⁶ Alcohol use and misuse among women are increasing³ and rates of unintended pregnancy are higher among those who binge drink or who report heavy alcohol use.^{7,8} As a result, the need for enhanced health care professional awareness of risky drinking, the prevention of FASDs, and the implementation of clinical approaches such as alcohol SBI as part of routine clinical practice are essential.

While the majority of people reduce their alcohol consumption upon pregnancy awareness, women who are white, older, college-educated, have higher incomes, and are experiencing their first pregnancy are most likely to continue alcohol use when pregnant.⁹ Misconceptions among health care professionals about demographic risk factors for PAE can hinder prevention efforts.¹⁰ The prevention of PAE is dependent on consistent, nonjudgemental public education and widespread training of practitioners to communicate with people who can become pregnant about their alcohol use and to effectively screen for excessive alcohol use and intervene as appropriate.¹¹ Effective messages portray real-life examples of PAE and FASDs, avoid scare tactics or language that shames individuals for drinking before or during pregnancy, and direct consumers to knowledgeable and compassionate resources.¹² Because alcohol and substance misuse are highly stigmatized, people who are drinking could be hesitant or fearful when accessing health care, particularly if they feel responsible for their condition. Health care professionals who lack the skills to manage alcohol use disorder (AUD) and substance use disorder (SUD) or FASDs can unintentionally increase discrimination, bias the provision of care, and block diagnosis, treatment, and successful health outcomes.¹³

Public Health Guidance and Its Reception

The first government health advisory that informed the public that alcohol can interfere with embryonic and fetal development was published in 1977.¹⁴ The U.S. Surgeon General issued an advisory in 1981 recommending that women who were pregnant or considering pregnancy abstain from alcohol.¹⁵ The Surgeon General added that, “Health professionals are urged to inquire routinely about alcohol consumption by patients who are pregnant or considering pregnancy.”

CDC, the National Institute on Alcohol Abuse and Alcoholism, and the American College of Obstetricians and Gynecologists, among other health authorities, have consistently advised abstinence from alcohol during pregnancy.^{16,17} At times, public health advice to avoid alcohol during pregnancy has encountered resistance, including accusations of paternalism.¹⁸ These concerns touch on a variety of cultural and political issues including reproductive rights and the lasting backlash to prohibition, resulting in an instinctive resistance to perceived government interference.¹⁹ Public health messages may also trigger sensitivities around the historical depiction of women as unable to control their alcohol consumption.²⁰ Objection to public health messages also has occurred when alcohol

avoidance guidance is directed not only to people who are pregnant but to people who could become pregnant.

Major public health organizations have long recommended that pregnant people unable to avoid alcohol should have access to help and support within a medical and therapeutic context. Conversely, a segment of the public and some jurisdictions believe that pregnant people who drink alcohol have violated a social norm and should be criminally sanctioned.²¹ Prenatal substance use policies in the United States reflect both perspectives as some states grant pregnant people priority access to AUD and SUD treatment programs and other states define prenatal substance exposures as child abuse.²² Punitive measures are rooted in the moral model of AUD and SUD as a choice or voluntary behavior rather than the disease model that it is a chronic, progressive brain disease requiring therapeutic rehabilitative treatment.²³ To effectively address underlying AUD and SUD, when an individual is unable to abide by advice to abstain from alcohol during pregnancy, it may help that the response from practitioners and the public be compassionate and not punitive.

Stigma, Bias, and Discrimination and Their Effects

Stigma is a powerful, complex, social, and cognitive process that discredits, devalues, or excludes a person or group of people based on real or perceived differences.²⁴ In addition to race, ethnicity, age, and sexual orientation, people can be labeled, socially excluded, or discriminated against for their disability or health condition.²⁴ AUD and SUD, and other conditions improperly viewed as self-inflicted or due to immoral behavior such as PAE, are among the most stigmatized medical conditions.²⁵

Research findings suggest that the public discriminates against birth mothers of children with FASDs.²⁶ A qualitative study of interviews with biological mothers uncovered themes that mothers of children with FASDs are bad, FASDs occur because of poverty, and recovery from AUD and SUD is insurmountable.²⁷ A 1-year media analysis showed 2 themes reflecting FASD stigma: sympathy for the child and disdain for the biological mother.²⁸ In fact, researchers found that the public viewed mothers of children with FASDs with higher disdain, as more different, and as more responsible for their circumstance than women with SUD, mental health issues, and jail experience.²⁴

The discrimination associated with drinking during pregnancy is a barrier to the identification and management of FASDs.²⁹ Health care professionals have reported hesitancy to discuss, diagnose, or make a referral—even when they determine an FASD diagnosis is accurate—for fear of labeling the child or offending the mother. Practitioners have been found to harbor negative stereotypical attitudes that birth mothers of children with FASDs are neglectful and unfit parents.^{30,31}

The impact of stigma on health care is well documented and far reaching, contributing to health disparities through its negative effect on individual health status and as a barrier to access and delivery of quality health care services.²⁴ Assumptions and unconscious bias about who is at risk of having an alcohol-exposed pregnancy—or general discomfort discussing alcohol use—can interfere with the dialogue between health care professionals

and their patients.³² Few health care professionals in the United States receive adequate education on the neurobiology of AUD and SUD, and they might not ask about alcohol consumption because they lack confidence in their skills to support a patient with an AUD. Research has demonstrated that some practitioners believe patients with AUD and SUD never get better and that treatment options are not effective,³³ when in reality, relapse rates resemble those of other chronic diseases, such as diabetes, hypertension, and asthma.³⁴

Effective Interventions for Addressing Prenatal Alcohol and Other Substance Exposure and FASDs

More than 30 years of research has shown that alcohol SBI is effective at reducing excessive alcohol use. In 2018, the U.S. Preventive Services Task Force (USPSTF) examined the evidence on alcohol screening and behavioral counseling interventions and recommended universal implementation, saying, “The USPSTF recommends screening for unhealthy alcohol use in primary care settings in adults 18 years or older, including pregnant women, and providing persons engaged in risky or hazardous drinking with brief behavioral counseling interventions to reduce unhealthy alcohol use.”³⁵ Yet, alcohol SBI remains critically underutilized. A 2020 CDC report found that although 81% of US adults in 13 states and Washington, DC, reported being asked by their health care professionals about alcohol use, only 38% reported being asked about binge drinking during a routine checkup in the last 2 years. Among adults asked about their alcohol use in the past 2 years and who reported current binge drinking, 80% (or 4 of 5 persons) were not counseled to reduce their drinking.³⁶

Universal alcohol SBI utilizes one of several evidence-based screening tools—for example, Alcohol Use Disorders Identification Test (AUDIT)—combined with brief conversations with patients who screen positive to help them explore their pattern of alcohol use.³⁷ It is intended to capture a wide range of alcohol use behaviors in contrast to screening tools that focus on identifying AUD. Evidence-based screening practices also provide the benefit of reducing stigma through practitioner-patient conversations about alcohol use.

Standardized screening instruments include 3 to 5 initial questions that focus on an individual’s frequency and quantity of alcohol use.³⁸ The tools allow for calculation of a numerical score that can be used for future comparison purposes. If the initial screening indicates a score reflecting *at risk or high-risk* use, tools such as the AUDIT use additional questions that focus on how alcohol use might be impacting that person’s life. Depending on how the patient answers the additional questions, the health care professional can determine whether there is a need for additional intervention such as more extensive counseling or an offer of treatment referral. Primarily, the information can be used to frame and individualize the brief intervention conversation.³⁹ The AUDIT-C (Consumption), a three-question modified version of the AUDIT, has been found to be equally reliable, easier to use, and more suitable for routine doctor visits,³⁹ including for prenatal screenings.⁴⁰

Brief interventions are short conversations between a health care professional and patient to raise awareness on the part of the patient about their alcohol use and how it may present risks for their health or their pregnancy and to motivate behavior change.⁴¹⁻⁴³ The

interventions stimulate self-reflection and introduce realistic strategies to reduce drinking. The conversations also allow the practitioner to discuss a client's pregnancy intention and explore options such as contraception.

Alcohol is not the only substance of misuse that could harm a person's health or pregnancy, and patients may use multiple substances.⁴⁴ Use of other substances is common among pregnant women who report alcohol use—a recent study showed that about 40% of pregnant women who reported current alcohol use also reported the current use of one or more other substances.⁴⁵ Because polysubstance use is common, health care personnel can take a more comprehensive approach by screening for multiple substances using tools such as the NIDA (National Institute on Drug Abuse) Quick Screen, the ASSIST (Alcohol, Smoking and Substance Involvement Screening Test), or the PRO (Prenatal Risk Overview) for pregnant people, as suggested in the USPSTF recommendation statement on screening for unhealthy drug use. The 2020 statement reads, “The USPSTF recommends screening by asking questions about unhealthy drug use in adults aged 18 or older. Screening should be implemented when services for accurate diagnosis, effective treatment, and appropriate care can be offered or referred. (Screening refers to asking questions about unhealthy drug use, not testing biological specimens).”⁴⁶

Role of Health Care Professionals

Most people who screen positive for excessive alcohol use do not have an AUD. However, for those who do have a possible AUD, it is important for health care professionals to understand the barriers to treatment, what motivates women to enter treatment, and that treatment works.⁴¹ Like other chronic diseases, AUD can be managed successfully. Health care professionals educated about AUD and SUD, and who understand the manifestations of denial and the defense mechanisms that are common among those with AUD or SUD, are better equipped to identify individuals with excessive drinking patterns and respond with appropriate intervention and referral.⁴⁷ Health care practitioners trained to have open, nonjudgmental conversations with their patients can help assure patients that they do not need to live with pain or shame and that help is available. When primary care providers receive mental health and substance use training cofacilitated by individuals with mental illness and SUD, the direct social contact helps reduce stigma and improve the quality of care.⁴⁸⁻⁵⁰ Pregnant people with an AUD or SUD can be referred to a treatment specialist or facility for evaluation, a twelve-step recovery program, such as Alcoholics Anonymous or Recovering Mothers Anonymous, a virtual fellowship and mentoring program for people who have consumed potentially harmful substances during pregnancy, or an organization like FASD United, a public health nonprofit organization that supports both pregnant people unable to abstain from alcohol and children and adults living with FASDs. Founded in 1990, FASD United is a member of the CDC's national partner network that aims to reduce prenatal alcohol and other substance use, improve support services and access to care, and improve identification and health of children and families with FASDs.

Although surveys show health care professionals are the most common and trusted source for health information, three-quarters of Americans seek health advice from the Internet, including social media.⁵¹ Health information that cites scientific studies and government

advisories can be undermined by this growing trend. Few safeguards are in place to prevent health-related misinformation, claims that conflict with scientific evidence, or intentionally false information.⁵² Accordingly, health care professionals who implement alcohol SBI should be aware that they might encounter patients exposed to inaccurate beliefs about the risks associated with prenatal alcohol exposure.

CDC's Efforts to Reach Health Care Professionals

One of CDC's core strategies in promoting the prevention of PAE and the identification and care of children living with FASDs is to work with health care professional groups and systems. One of the early efforts in this area was to support centers to train medical and allied health students and professionals regarding the prevention, identification, and treatment of FASDs in academic settings and via continuing education events for practicing medical and allied health professionals. Recognizing that while training for health care professionals is one necessary aspect to initiate change, it is not sufficient by itself to result in lasting behavior change. Therefore, CDC initiated new efforts with the goals of more national coverage, stronger partnerships with professional organizations, more standardized curricula, more of an online presence, and increased focus on practice change. This shifted the program from training for individual health care professionals to capitalizing on prevention opportunities, the ability to impact health care at a systems level, and strengthening strategic partnerships with key national medical societies, professional organizations, and constituent groups, with a focus on reaching family medicine physicians, medical assistants, nurses, obstetrician-gynecologists, pediatricians, and social workers.

The CDC has also been working to promote alcohol SBI to health care professionals as an effective but underused preventive health service. Published in 2014, the CDC's SBI implementation guide⁴ provides detailed steps and resources to help staff in any primary care practice implement alcohol SBI.

In 2018, CDC recognized the need to continue reaching the critical audience of health care professionals as well as the need to continue the focus on implementation and disseminating existing resources to targeted disciplines. This led to funded efforts to (1) implement alcohol SBI in large systems of care providing women's health services; (2) promote the prevention of FASDs through health professional membership organizations relevant to settings serving pregnant people and people who can become pregnant; (3) raise awareness about the risks of prenatal alcohol exposure, improve understanding about individuals affected by FASDs, and promote the prevention of FASDs and care of affected individuals; and (4) improve the health and developmental outcomes of children with prenatal exposure to alcohol and other drugs by promoting identification, referral, appropriate diagnosis, documentation, and care in primary pediatric settings.

Introduction to Special Section

The articles in this special section describe the joint effort to meet the aims of the CDC-funded projects. This commentary provides background on the importance of FASD prevention and intervention, including strategies to address barriers such as stigma related to

this topic. It also describes the collaborative approach of CDC-funded efforts and discusses gaps in the field and implications for future work. Next, Townsel et al and Green et al describe approaches to reach health care providers, including strategies to target specific health care disciplines, in promoting FASD prevention and intervention.^{53,54} The articles assess various training and education approaches and practical modifications to content and delivery modality based on the needs of health care professionals, clinical setting, and patient and clinician perspectives. Finally, King et al, McRee et al, and Vendetti et al describe approaches for promoting the implementation of alcohol screening and brief intervention as an evidence-based strategy for the prevention of alcohol use during pregnancy and FASDs.⁵⁵⁻⁵⁷ The articles explore barriers to implementation, strategies to adapt workflows and systems, modifications to training content, logistics, and electronic health records systems, and the expansion of alcohol SBI services to include patients drinking at levels below AUD criteria. Lastly, the section considers the impact of alcohol SBI activities on system's level and provider-level outcomes to inform best-practice recommendations. Reflecting on what was learned as well as what gaps remain will help illuminate potential opportunities to advance the field and inform future directions.

Conclusions

Looking Ahead: Gaps and Opportunities

Alcohol SBI is the most promising public health approach for early identification of and intervention with patients whose alcohol use puts their health and pregnancy at risk. The work of CDC and its partners continues to strengthen the evidence base for alcohol SBI implementation. Exploring the use of technology to screen patients and deliver brief interventions offers an opportunity to reach rural and underserved populations, reduce health disparities, and overcome time constraints and competing priorities.⁵⁸ Among other barriers to the implementation of alcohol SBI are medical reimbursement, privacy concerns, lack of a clear pathway for referral, and health care professionals' reluctance to adopt the practice.⁵⁹ Electronic SBI combined with practitioner consultation and text messaging and follow-up holds the potential to increase contact with patients without overburdening health care professionals.⁶⁰ Clinicians should consider screening for the simultaneous use of alcohol, opioids, marijuana, and other substances, recognizing that the use of multiple substances known to be harmful to human development is common among pregnant people who report alcohol use.³⁸ The opportunity to identify and treat alcohol and substance use disorder, prevent alcohol-exposed pregnancies, and reduce the occurrence of FASDs makes successful and widespread implementation of alcohol SBI a worthwhile and essential aim.

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Highlights

- Despite public health measures, alcohol consumption during pregnancy and the risk of fetal alcohol spectrum disorders (FASDs) is increasing due to stigma surrounding alcohol and substance use disorder and a lack of knowledge among health care professionals.
- Alcohol screening and brief intervention (alcohol SBI) has been shown to reduce excessive alcohol use, including any use among pregnant persons.
- The Centers for Disease Control and Prevention (CDC) is promoting alcohol SBI to health care professionals as an effective preventive health service.
- This special section consisting of 6 articles represents the work of 11 CDC-funded projects to explore and describe the rationale, approaches, and challenges in implementing FASD prevention and intervention strategies and practices.