COMMENTARY

Ethical challenges in FASD prevention: Scientific uncertainty, stigma, and respect for women's autonomy

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ABSTRACT

Fetal alcohol spectrum disorder (FASD) is a leading form of neurodevelopmental delay in Canada, affecting an estimated 3000 babies per year. FASD involves a range of disabilities that entail significant costs to affected individuals, families, and society. Exposure to alcohol in utero is a necessary factor for FASD development, and this has led to FASD being described as "completely preventable". However, there are significant ethical challenges associated with FASD prevention. These challenges revolve around 1) what should be communicated about the risks of alcohol consumption during pregnancy, given some ongoing scientific uncertainty about the effects of prenatal alcohol exposure, and 2) how to communicate these risks, given the potential for stigma against women who give birth to children with FASD as well as against children and adults with FASD. In this paper, we share initial thoughts on how primary care physicians can tackle this complex challenge. First, we recommend honest disclosure of scientific evidence to women and the tailoring of information offered to pregnant women. Second, we propose a contextualized, patient-centred, compassionate approach to ensure that appropriate advice is given to patients in a supportive, non-stigmatizing way.

KEY WORDS: Fetal alcohol spectrum disorders; ethics; women's health; preventive health services; personal autonomy

La traduction du résumé se trouve à la fin de l'article.

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Fetal alcohol spectrum disorder (FASD) is a leading form of neurodevelopmental delay in Canada, affecting an estimated 3000 babies per year (9 out of 1000 births).[1] FASD involves a range of disabilities that entail significant costs to affected individuals, families, and society.[2,3] Primary disabilities associated with FASD include birth defects and cognitive and behavioural deficits. Secondary consequences consist of mental health problems, alcohol and substance abuse, and involvement with the criminal justice system.[1]

FASD is viewed as preventable, since exposure to alcohol in utero is a necessary factor for its development.[4] Consequently, much attention has been paid by health authorities to raising awareness about the risks of drinking during pregnancy. Prevention efforts are crucial to raising awareness about FASD and reducing its incidence, but whether FASD is *completely* preventable is contested (e.g., some women drink before they know they are pregnant; addiction poses significant challenges to cessation of alcohol consumption). Moreover, it has been argued that prevention efforts have led to a "moral panic".[5]

Recently, the Canadian Medical Association highlighted the importance of FASD prevention but also the need to avoid stigma within prevention.[6,7] Indeed, FASD prevention strategies face significant ethical challenges. These challenges revolve around 1) what should be communicated about the risks of alcohol consumption during pregnancy, given some ongoing scientific uncertainty about the effects of prenatal alcohol exposure,[6] and 2) how to communicate these risks, given the potential for stigma against women who give birth to children with FASD as well as against individuals with FASD.[7] We share initial thoughts on appropriate messaging given these challenges.[8]

ONGOING UNCERTAINTY SURROUNDING THE EFFECTS OF LOW TO MODERATE ALCOHOL CONSUMPTION DURING PREGNANCY

High levels of alcohol consumption during pregnancy can lead to significant deleterious effects for the child[9,10] and, although a dose-dependent progression of risks seems supported,[7,10,11] the effects of low to moderate consumption are less clear. To further complicate the assessment of the evidence, there are no standard definitions of what constitutes low to moderate levels of alcohol consumption, and most studies on the subject are observational.[7,12] Despite the uncertainty surrounding the effects of low to moderate consumption, the prudent public health message that there is "no safe amount, and no safe time, to drink alcohol during pregnancy" is common and officially endorsed by Health Canada.[1] However, this message of abstinence faces some criticism, as 1) it can be unrealistic for some; 2) it ignores the uncertainties discussed above; and 3) it can present an obstacle to informed choice for

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women as it fails to acknowledge the complexity of the evidence about the effects of prenatal alcohol exposure.[5] Recently, the Centers for Disease Control and Prevention (CDC) endorsed a stronger public health message that extended the need for alcohol abstinence to all women who could become pregnant (i.e., sexually active women not using birth control).[13] This message was heavily criticized by many, especially in the media.[14–16] In addition to facing the same criticisms as other abstinence campaigns, the CDC's message was criticized for its paternalism, its assumptions about heterosexual norms, and its neglect of the potential effects of men's alcohol drinking patterns on fetal outcomes.[17] These are all valid criticisms that must be considered when developing strategies for FASD prevention.

STIGMA AND BLAME CREATE BARRIERS TO CARE

Although FASD is a leading form of developmental delay,[1] it is mired in stigma. The stigma can be felt by many, including children and adults who have FASD, their families, and especially their mothers.[18] Paradoxically, well-intentioned prevention messages that stress the preventability of FASD or focus exclusively on the mother's behaviour or role in the development of FASD can inadvertently contribute to blame and shame. Prevention messaging thus risks perpetuating stigma and promoting the idea that women who give birth to children with FASD are irresponsible and careless mothers who are at fault.[5,18–20] The risk of perpetuating stigma is heightened when prevention messaging neglects both the factors that may lead a woman to drink while pregnant (e.g., social pressures, being unaware of or not wanting to reveal the pregnancy, coping strategies)[21] and other factors that can modulate the susceptibility to the development of an FASD (e.g., nutrition, smoking, and socio-economic effects).[12,22] Although stigma may be an effective tool in some public health prevention efforts,[23,24] it can run *counter* to FASD prevention efforts, as it may result in a reluctance to admit to alcohol use and lead to apprehension in accessing prenatal care.[19,20] Worse, in some states, prevention efforts have extended to criminalizing the use of alcohol or drugs during pregnancy, which can have further deleterious effects on access to prenatal care and can increase the stigma associated with FASD.[25,26]

Thus, in FASD prevention, there is a tension between on the one hand promoting strong messages that are convincing and on the other minimizing harmful and judgemental messages that can propagate stigma. Unfortunately, examples of overly strong and blameful messages can be found both in the Canadian[27] and international media,[28–36] as well as in public health campaigns both here[37] and abroad.[38–40] How to communicate in light of the risk of stigmatizing individuals is an important challenge that public health must face. Public health prevention efforts can address affected communities directly or indirectly through service providers. Here we discuss the types of messages primary care physicians should be encouraged to communicate to individuals and communities.

WHAT TO COMMUNICATE GIVEN SOME SCIENTIFIC UNCERTAINTIES AND RESPECT FOR AUTONOMY?

In the face of uncertainty about the effects of low to moderate alcohol consumption on fetal development, it is generally understood that the safest message is one of abstinence.[20,41,42] While this prudent message may be appropriate from a population-level public health perspective, important ethical concerns voiced in academic and public discussions suggest that it may be inappropriate from a primary care perspective. A strict message of abstinence has been described as paternalistic and counter to respect for pregnant women's autonomy, since informed choices require the complicated truth of uncertainty.[43,44] Analogously, women regularly make other kinds of decisions that involve some uncertain risks during their pregnancy (e.g., decisions regarding physical activity, consumption of certain foods) without fear of reprisal or litigation. However, some in the public domain[43–45] fear that a more lenient stance may be viewed as a "licence to drink", a behaviour that would run counter to preventive efforts.[46,47]

Fortunately, in the clinical realm, there is more flexibility to tailor the message regarding alcohol and pregnancy to individual patients; this is in line with recommendations from the Canadian Society of Obstetrics and Gynaecology.[20] For example, abstinence may be impossible for some women who struggle with addiction. In these situations, physicians should be encouraged to adopt a harm reduction strategy to promote the safety of their patients and minimize risks to them.[20] In other instances, pregnant women may consume alcohol to cope with stress; here the physician should be encouraged to counsel patients on alternative coping strategies, provide support, and reiterate the known and unknown risks. If a woman drank before she knew she was pregnant, it may be appropriate to encourage physicians to assuage patient fears of having harmed their child by communicating that low levels of consumption are unlikely to lead to birth defects while discouraging them from further consumption.[20] Thus, primary care physicians who treat pregnant women should be encouraged to communicate that there are serious potential outcomes to consumption of alcohol during pregnancy, acknowledge the limits of knowledge on risk, and tailor messages to individuals appropriately.

HOW TO COMMUNICATE PREVENTION MESSAGES GIVEN THE POTENTIAL FOR STIGMA?

Stigma against women who give birth to children with FASD and against children and adults with FASD is pervasive.[18] Indeed, stigmatizing attitudes and behaviours from health care practitioners have been identified as a prevalent problem in the provision of care to pregnant women who use licit and illicit drugs.[19,48] Thus, it is essential that health care practitioners refrain from exhibiting these attitudes and behaviours and adopt a non-judgemental approach. Public health can assist in this matter by improving clinicians' understanding of the complex factors that can lead women to drink while pregnant. A contextualized, patient-centred, compassionate approach can ensure that appropriate advice is given to patients in a supportive, non-stigmatizing way. Being proactive in discussions of alcohol use with male and non-pregnant female patients of all backgrounds is also important to reducing the many potential harms of alcohol consumption, and this universal approach may reduce feelings of being targeted or stigmatized.[49]

MOVING FORWARD WITH FASD PREVENTION

Given the consequences for individuals and families affected by FASD, FASD prevention must remain a public health priority.

However, the "what" and "how" of prevention raise important ethical challenges. These challenges call attention to the need to balance both respect for autonomy and the principle of beneficence. Both of these can be further achieved by empowering women with accurate and up-to-date information, as well as providing compassionate patient-centred care and support in decision-making. Family physicians are in the important position of being able to tailor messages to future mothers (and fathers) to ensure that the best balance between ethical principles is struck.

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RÉSUMÉ

L'ensemble des troubles causés par l'alcoolisation fœtale (ETCAF) est une forme prépondérante de retard de développement neurologique au Canada, touchant environ 3 000 bébés par année. L'ETCAF induit une gamme d'incapacités qui entraînent des coûts importants pour les personnes touchées, les familles et la société. L'exposition à l'alcool in utero est une condition nécessaire au développement de l'ETCAF, ce qui a conduit à la description que l'ETCAF s'avère « complètement évitable ». Cependant, il existe d'importants défis éthiques associés à la prévention de l'ETCAF. Ces défis portent sur ce qui devrait être communiqué au sujet des risques de la consommation d'alcool pendant la grossesse, compte tenu de l'incertitude scientifique persistante sur les effets de l'exposition prénatale à l'alcool, et la manière de communiquer ces risques compte tenu du risque de stigmatisation chez les femmes qui donnent naissance à des enfants avec un trouble causé par l'alcoolisation fœtale ainsi que chez les enfants et les adultes atteints par l'ETCAF. Dans cet article, nous partageons de premières réflexions sur la façon dont les médecins de première ligne peuvent aborder ce défi complexe. Premièrement, nous recommandons la divulgation des preuves scientifiques aux femmes et l'adaptation de l'information offerte aux femmes enceintes. Deuxièmement, nous proposons une approche contextuelle, axée sur le patient et la compassion pour assurer que des conseils appropriés soient donné aux patients d'une manière favorable et non stigmatisante.

MOTS CLÉS : ensemble des troubles causés par l'alcoolisation fœtale; ethique; santé des femmes; soins de santé préventifs; autonomie personnelle