

To Test or Not to Test and That is the Question

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The article from Yan and colleagues summarizes the discussions from the NeuroDevNet Brain Development Conference in September 2012 that included scientists who developed the test for detection of fatty acid ethyl esters (FAEE) in meconium as a marker for prenatal exposure to alcohol, a risk factor for fetal alcohol spectrum disorder (FASD).¹ The other respondents were from law and ethics but there was neither an expert on women's issues nor clinical experts on diagnosis of FASD and the lifespan trajectory in FASD. Fetal alcohol spectrum disorder is a life-long disability with impairments in learning ability, cognitive, social and adaptive functions and behavioral regulation that requires extensive and costly (\$1.8 million annually in Canada) services from many sectors including health, mental health, education, social services, justice and ultimately supports for dependent living.

As pointed out by Yan *et al*, there are still challenges in screening using FAEE in meconium.¹ Fatty acid ethyl esters in meconium identifies alcohol exposure in the second and third trimesters of pregnancy but not the first 13 weeks of the pregnancy which is a critical time in fetal brain development.²⁻⁵ Many women, especially with an unplanned pregnancy will have that early exposure but then abstain once the pregnancy is identified. These cases will be negative by FAEE but still at risk for brain damage as there are no known safe amounts of alcohol in pregnancy. However, with a negative FAEE these children might not be targeted for developmental follow-up. If the child has developmental challenges, there might be no consideration of an FASD diagnosis because of the negative test. On the other hand, a positive FAEE identifies a pregnancy in which the mother would be aware of the pregnancy in the second and third trimesters but for complex reasons continues to expose the fetus to alcohol. Is that a failure of prevention messaging to the general public or appropriate advice for her health care provider or related to her own personal issues rooted in the psychosocial determinants of health, a major public health question? There can be false positives from collection sampling that could result in family stress and have legal implications.⁶

The ethical questions raised in this article are still being debated in medical, legal and ethical arenas.^{2,4} At recent conferences by the Alberta Government Institute of Health Economics on FASD and the Law and FASD Prevention from an international perspective, held in September 2013, there was discussion on FAEE meconium testing as a screening tool as part of broader issues in FASD. This was a consensus conference of a group of legal, social and medical experts. The final reports will be available on the Institute of Health Economics website www.ihe.ca.⁷ The conclusion was that more research is needed with respect to informed consent, privacy and ensuring appropriate follow-up of results. There was also the recommendation that this needs to be done without a punitive approach to the mother by apprehension of her child into the

child welfare system but with provision of support programs for women who continue to drink in pregnancy that is most often grounded in the biopsychosocial determinants of health. The need for developmental follow-up of the child identified at risk is essential by a multidisciplinary team trained in assessment of FASD. Most children with prenatal exposure to alcohol, unless full FAS, do not show specific impairments until after the age of six years to assign a definite diagnosis of FASD.^{5,8,9} This can be a period of considerable anxiety for caregivers who have the knowledge that their birth, adopted or foster child had a positive FAEE. Ethically all young children who show delays in development should have access to early intervention services, the most important of which is a stable environment that promotes development of attachment and opportunities for appropriate stimulation and prevention of post natal neglect and abuse. There needs to be a longitudinal study of children with positive FAEE in the neonatal period into at least their middle school years to determine how predictive it is of FASD. Currently in well established FASD diagnostic clinics, about 10 to 30% of children with positive prenatal exposure to alcohol by maternal self report or other reliable sources do not meet criteria for the diagnosis of FASD. The protective or compounding factors are not known but there is much ongoing research on genetics, epigenetics, nutritional factors and impact of stress in pregnancy.

On a population basis, FAEE is a good tool to identify alcohol use in pregnancy in the last two trimesters of pregnancy. This is very important data to determine if prevention messaging is having an impact. However, it will not identify which groups or individuals who will need more supports to stop use of alcohol in pregnancy. This will not get to the personal level. If there are identifying factors, that mother can be referred to programs that have good research evidence to support her to avoid the next pregnancy exposed to alcohol and to help her achieve positive changes in her own life. The neonate at risk can be referred for developmental monitoring with the key message that a positive FAEE is not a diagnosis nor is it a reason for legal authorities to remove her child from her care. The issue of informed consent or implied consent and how information is then used is still under debate in the legal community when it is not just a population study.^{4,7}

Another question is the diagnostic capacity for FASD after a positive screen and recognizing that it may be six or more years before a definite diagnosis of FASD can be made. There has been an increase in diagnostic clinics in some areas of Canada but not sufficient to meet current demands. Based on FASD being reported as 1% of the population and that 11 to 15 % of women continue to drink in pregnancy by a recent report, there will need to be a significant increase in capacity and consistency in the diagnostic process. This is a challenge within Canada being addressed by many leaders including the Diagnostic

Network of the Canada FASD Research Network and the Public Health Agency of Canada with the revision of the Canadian Guidelines for FASD Diagnosis.

In summary, meconium FAEE is an excellent tool for population estimate of prenatal alcohol exposure in the second and third trimesters of pregnancy and a proxy measure for effectiveness of primary prevention programs. The question of use to inform individual case exposure with consent is still in legal debate. The need for longitudinal follow-up of those infants who screen positive to determine the percentage who do meet criteria for an FASD diagnosis is critical. Programs to support birth mothers and infants that screen positive will need to be provided. Removing the infant to the child welfare system is not the solution.

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