

The consequences of alcohol use in pregnancy

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Introduction

The foundations for our lifelong health and well-being are established during pregnancy. Fetal alcohol spectrum disorder (FASD) is the term used to describe the spectrum of adverse effects that alcohol consumption during pregnancy can have on the fetus.^{1,2} FASD places a huge burden on the individual, their whanau and society. However, FASD is entirely preventable.¹ This article will discuss the teratogenic effects of alcohol, the epidemiology and impact of FASD, and current FASD related interventions, with reference to developments in New Zealand.

Epidemiology

The true extent of FASD is unknown and likely underestimated. In New Zealand FASD is likely to be the leading cause of preventable, non-genetic intellectual disability. In New Zealand, approximately 600–3000 babies are born with FASD each year, which equated to 1–5% of all live births in 2015. International studies estimate up to 5% of the general population will have a diagnosis of FASD, with the prevalence being higher in disadvantaged groups including indigenous populations, adopted children, children in state care, individuals involved in the justice system and those with mental-health issues.⁴

Teratogenic impact of alcohol and diagnostic criteria

Alcohol is a teratogen and freely crosses the placenta. When alcohol is consumed, the fetus is exposed to similar concentrations of alcohol as the mother, but the fetus cannot process the alcohol as fast or efficiently, making the fetus particularly vulnerable.⁵ Alcohol exposure has variable effects. Not all fetuses exposed to alcohol will be born with teratogenic birth defects.⁶ The amount and pattern of alcohol consumption are significant predictors of the severity of teratogenic outcomes. The more alcohol is consumed, the more likely it is that teratogenic outcomes will eventuate. Binge drinking is associated with more damage than frequent drinking at lower doses. ⁶ The gestational period also influences the outcome. Alcohol consumption during the first trimester is most likely to result in structural defects and organ damage. Miscarriage is more likely to be induced by alcohol in the first and second trimester, while intrauterine growth is most restricted in the third trimester.⁶ Genetic variability influences the susceptibility of the fetus. Some women metabolise alcohol faster, decreasing the risk of FASD in their offspring.⁶ Twin studies have shown the genotype of the fetus also influences its vulnerability. Alcohol exposure needs to be considered in context as

poverty, other drug use, a lack of prenatal care, and poor maternal health can increase the likelihood of teratogenic effects. 67

Only 10% of individuals with FASD have identifiable physical features, meaning FASD is a largely invisible disability. Therefore, individuals with FASD often go undiagnosed or are misdiagnosed with other disorders such as attention deficit hyperactivity disorder, autism, or other mood and behavioural disorders. The internationally recognised Canadian Guidelines in Table 1 highlights the features required for a diagnosis of FASD.

As highlighted in Table I, to make a diagnosis of FASD there must have been alcohol exposure prenatally. Individuals must have severe impairment in at least three areas of neurodevelopmental functioning. There are two types of FASD: FASD with less than three sentinel facial features and FASD with three sentinel facial features. It should be emphasised that FASD is a spectrum; some individuals are more affected than others and each individual has a unique set of strengths and weaknesses.⁹

The consequences of FASD

In terms of economic costs, FASD-associated morbidity and premature mortality contributed to an aggregate loss of \$49–200 million NZD in 2013. An estimated \$690 million NZD is spent annually on supports and services for those effected by FASD. This equates to \$15,000 NZD annually for every individual affected by FASD. These figures do not take into consideration the opportunity costs experienced by caregivers of those with FASD. Nor do they take into account the extra educational, legal, medical and interventional costs associated with FASD. §

There is also a huge psychological and social cost. Raising a child with FASD results in additional stressors for caregivers. A study of caregivers raising children with FASD reported that: 50% needed regular supervision; 58% had mental health issues; 70% were violent; 75% had attempted theft; and 96% had anger problems. Individuals with FASD exhibit a range of behavioural issues and antisocial traits, and this places a burden on the justice system and social supports. It is estimated that 50% of children in Oranga Tamariki care are affected by FASD and individuals with FASD are over-represented in the justice system. In the education system, the behavioural and neurodevelopmental challenges faced by children with FASD means they required additional educational support. This

Table I The Canadian Guidelines for a diagnosis of Fetal Alcohol Spectrum Disorder.9		
Diagnostic criteria	Diagnostic Categories	
	FASD with < 3 Sentinel Facial Features	FASD with 3 Sentinel Facial Features
Prenatal alcohol consumption	Confirmed	Confirmed
 Neurodevelopmental Domains: Adaptive Behaviour, Social Skills or Social Communication Affect Regulation Executive Functioning, including impulse control and hyperactivity Attention Memory Academic Achievement Language Cognition Motor Skills Brain Structure/Neurology 	Severe impairment in at least three of these neurodevelopmental domains	Severe impairment in at least three of these neurodevelopmental domains
Sentinel facial features: 1. Smooth Philtrum 2. Short Palpebral Fissure 3. Thin Upper Lip	Presence of all three features	Presence of <3 of these features

constrains already stretched educational resources and placement in special educational facilities may be necessary.\(^{1}\) In terms of future outlook, individuals with FASD may have decreased potential for employment and independent living.\(^{6}\)

The recently publicised case of Teina Pora highlights consequences of FASD. Teina Pora was wrongly convicted of the murder of Susan Burdett in 1994 and subsequently spent 21 years in prison. The diagnosis of FASD was pivotal in his conviction being quashed, as due to the neurodevelopmental deficits associated with FASD, his confession was not deemed reliable. Without a reliable confession there was little evidence that could uphold his conviction. II

Alcohol consumption during pregnancy

FASD is entirely preventable if women abstain from alcohol during pregnancy.6 Despite this, a nationwide study reported that 29% of women in New Zealand consume alcohol while pregnant.¹² Drinking after pregnancy recognition is especially worrying, as an unborn child is knowingly put at risk. A New Zealand study published in 2018 involving 4823 women who consumed alcohol before pregnancy found that 32% of women who consumed alcohol before pregnancy (or awareness of pregnancy) continued to drink, after becoming aware of pregnancy, in the first trimester. A further 19% of women continued to drink throughout their pregnancy.3 As unplanned pregnancy occurs in two in five pregnancies in New Zealand, this increases the chance of alcohol consumption before awareness of pregnancy. Rates of drinking in the first trimester were highest for European and Maori women with no secondary qualifications and who had an unplanned and/or first pregnancy. Rates of drinking in the second or third trimester were highest for European or Maori women in their first pregnancy and aged 30 or over.3 Other risk factors for alcohol consumption in pregnancy include: low socioeconomic status, poor educational attainment, paternal alcohol consumption, poor nutrition, poor access to health care and women experiencing neglect and abuse.13

When retrospectively assessing alcohol consumption in pregnancy, just asking 'did you drink during pregnancy' is unlikely to gain meaningful information, and this question may come across as stigmatising. Instead an understanding should be sought regarding alcohol consumption and a woman's relationship with alcohol. For example, it is useful to discuss life stressors — when they found out they were pregnant, if the pregnancy was planned, their drinking habits prior to pregnancy, and their partners drinking habits — and then lead this on to alcohol consumption during pregnancy. Clear documentation regarding the amount of alcohol consumed, the pattern of drinking and at what stage during the pregnancy alcohol was consumed will allow a more in-depth assessment regarding the potential impact on the fetus.^{6,14}

Interventions

The Dahlgren-Whitehead model shown in figure I highlights that multiple factors at different levels influence alcohol consumption in pregnancy, the diagnosis of FASD and access to support services. Therefore, interventions must target both upstream and downstream factors. ^{10,15}

The 'Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019, an action plan' is a comprehensive cross-agency plan written by the Ministry of Health with the aims of: prevention, early identification, support services and increasing evidence.\(^1\) There has been targeted work from this action plan and some examples will be discussed.\(^1\) A major downfall of this plan is that only \$12 million NZD has been allocated to implementing this plan over the next four years. This is disappointing, considering the government levies almost \$1\) billion NZD annually from the alcohol industry and Alberta, Canada (with a similar population to New Zealand) allocates \$18\) million CAD annually towards FASD related interventions.\(^1\)

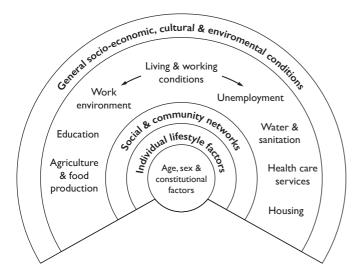


Figure 1 The Dahlgren-Whitehead Framework highlighting the multi-level determinants of health.

Table 2 Assessing alcohol consumption in pregnancy. 14		
Step I	Ask about and assess levels of alcohol consumption. Try to understand the context of drinking, for example, stressors, drinking patterns, and ideas regarding alcohol consumption in pregnancy. 14	
Step 2	Advise against alcohol consumption if planning a pregnancy or if already pregnant. Justify this advice by explaining the adverse outcomes of drinking while pregnant and evidence-based guidelines supporting an abstinence approach. ¹⁴	
Step 3	Assist women to stop drinking through brief interventions when necessary. Extra support and referrals may be needed for those finding it difficult to abstain. ¹⁴	

Prevention

The only way to prevent FASD is to avoid alcohol consumption during pregnancy.6 As mentioned earlier, rates of alcohol consumption during pregnancy are still alarmingly high. At the most upstream level, a cultural shift is needed in New Zealand's drinking culture, as drinking is shaped by the environmental, social, and cultural contexts. Women who drink heavily and frequently prior to pregnancy are more likely to drink during pregnancy and in a more hazardous way. Shifting New Zealand's drinking culture is going to take time and a multi-sector approach. Monthly meetings have been held by a cross-agency working group for over a year. This group has been coordinating interventions aimed at reducing harmful alcohol consumption and shifting drinking culture. Social media campaigns have been initiated, for example, the 'Say Yeah Nah' campaign, which has won awards. In September 2018 the 'Don't Know?, Don't Drink' campaign was launched, encouraging women of child bearing age to abstain from alcohol if there is any chance they could be pregnant. A specific emphasis has been placed on not drinking before awareness of pregnancy and the clear message delivered is that no amount of alcohol is safe.1

Alcohol abstinence while pregnant or planning a pregnancy is advocated by The Alcohol Health Watch, The Ministry of Health, The Health Promotion Agency, health professionals and professional groups.8 Therefore, it is concerning that women often receive conflicting and inconsistent advice regarding alcohol consumption in pregnancy. In a national study, 32% of women received no advice to abstain from alcohol during pregnancy.¹⁷ Consistent, clear, and unambiguous messages are needed from health professionals, public health campaigns, retailers, the alcohol industry, friends and whanau – messages that advise women to abstain from all alcohol if planning a pregnancy or pregnant. 1,14 Alcohol abstinence should be recommended, as there is no known safe level of exposure. Alcohol exposure at levels as low as one drink per week has been associated with adverse outcomes. Alcohol has variable effects on different fetuses due to maternal health, genetic and contextual factors. Alcohol has adverse effects throughout pregnancy, therefore, there is no safe time to consume alcohol.^{6,14} Proposed interventions to achieve abstinence include extension of public health campaigns, education in schools and mandatory warning labels on all alcoholic beverages regarding the risk of drinking in pregnancy. Table 2 provides guidance on how to assess alcohol consumption in pregnancy.

For the majority of women, steps I and 2 will provide enough impetus for the adoption of alcohol abstinence. ¹² For women who are anxious about their drinking prior to pregnancy recognition, advice such as

'stopping drinking at any stage reduces the risk' may allay fears. ¹⁴ However, some women will require step 3 to abstain from alcohol. Women who have a previous history of heavy drinking, an unplanned pregnancy, have children with FASD or have FASD themselves, are at increased risk of not abstaining from alcohol. ^{1,13} It is essential to increase access to responsive and flexible support for women with pre-existing alcohol and drug issues. For some women, an abstinence approach will be infeasible so a harm reduction strategy, where alcohol consumption is reduced, is more appropriate. ⁶ The Waitemata pregnancy and parenting service programme that provides alcohol and drug services for pregnant women and women with small children has been extended to include Tairāwhiti, Northland, and Hawkes Bay. ¹⁶

Health care also needs to be accessible and culturally appropriate with a focus on reducing barriers to access, as engagement with health services improves outcomes. A focus on Maori and Pacific women and those with complex needs is especially important. Access to sexual health services is imperative so women can access contraception and preconception advice, which reduces rates of FASD. The Sexual Health and Reproductive Action Plan aims to increase access to culturally competent and equitable sexual health services. At a more downstream level health professionals need to be supported with educational material so clear, consistent, and up-to-date advice and brief interventions can be provided. Table 3 highlights how interventions can be tailored to different population subgroups.

Early identification

Over the last ten years, New Zealand has begun to diagnose FASD in a more accurate and systematic way.¹³ Making a diagnosis of FASD is complex due to the assessment of multiple domains and the need for a multidisciplinary approach. Due to this complexity, diagnosing FASD is estimated at \$8000 NZD.¹¹ Surveys of health professionals have identified a lack of confidence in diagnosing FASD. Reasons cited for this include a lack of education and training around FASD, the often invisible nature of FASD, the stigma of FASD, and inconsistency in the use of diagnostic criteria.¹

In 2011 the capacity of New Zealand health professionals to diagnose FASD was enabled after clinicians travelled to Canada and the United States for diagnostic training. The Canadian Guidelines in table 1 are the most widely used diagnostic criteria in New Zealand. ¹³ There needs to be more emphasis getting all District Health Boards in New Zealand to

Table 3 Tailoring interventions to different population subgroups. ¹⁸		
Population subgroup	Intervention strategy	
Educated, older, and career-driven women who continue to drink after pregnancy recognition.	Changing drinking culture and social norms. Non-alcoholic beverages should be provided at functions. ^{1,18}	
Unemployed, younger women with low self-esteem, who continue drinking after pregnancy recognition.	Community based programmes involving multi-disciplinary, hands-on approaches. Counselling and motivational speakers help motivate and reinforce abstinence. This is one of the most effective abstinence strategies. ^{1,18}	
Women who drink as they are unaware they are pregnant.	Media campaigns and warning labels on alcohol that warn of the adverse effects of alcohol consumption during pregnancy. This will increase the likelihood of abstinence after pregnancy recognition. ^{1,18}	
Adolescents at risk of pregnancy	School-based educational campaigns, mass media campaigns, and warning labels on alcohol. These help to change social norms. Good access to sexual and reproductive health care enabling the utilisation of effective contraception. 1.18	
Partners of pregnant women	Mass media campaigns to increase awareness of the adverse outcomes associated with prenatal alcohol consumption. Encouragement should be given to abstain from alcohol. ^{1,18}	

implement the Canadian Guidelines and to ensure staff are adequately trained and confident in the use of this diagnostic tool. 13 The Hawkes Bay is one of the most advanced FASD diagnostic centres in New Zealand, with a specialist diagnostic team comprising consultant paediatricians, social workers, speech and language therapists, occupational therapists and psychologists. These teams have shared education, beliefs and values, and thus can provide consistent and appropriate care tailored to the needs of individuals with FASD. 10 There are now seven of these specialist FASD diagnostic teams throughout the North Island, with two under development in the South Island.⁸ The Ministry of Health is supporting training to further build the capacity of clinicians to diagnose and support individuals with FASD. Matua Raki, the national centre for addiction workforce, has been contracted to help design resources for health professionals to correctly identify and diagnose individuals with neurodevelopmental impairments. The lived experiences of individuals with FASD will guide the development of these resources.¹⁶

Ideally, all children in New Zealand should be screened for FASD, for example a brief screen could be implemented as part of the 'B4 School Check'. But as aforementioned, there are logistical challenges associated with a diagnosis of FASD, as a diagnosis is time consuming and requires multidisciplinary input.\(^1\) Other professionals who engage with individuals with FASD also need education and tools. Teachers have a key role in identifying and supporting students with FASD. The Ministry of Education has developed FASD resources on their Inclusive Education website. Despite these great resources, there has been no money, time or initiatives devoted to getting teachers to use these resources, and it

is assumed teachers will access these materials on their own volition, in their own time. $^{\rm 19}$

Support

One of the biggest challenges after diagnosis is providing post-diagnostic support and interventions.⁸ Research alludes to the importance of having the individual and their whānau at the centre of decision making. Support services should build on an individual's strengths, be culturally appropriate and fit within the context of an individual and their whānau. A cross-agency, collaborative and consistent approach including input from the education sector, health professionals, social workers and whānau, will improve service delivery.¹⁰ A few examples of New Zealand-based support interventions will be discussed.

The neurodevelopmental consequences of FASD result in primary problems. However, some of the greatest harms come from the secondary problems that are inflicted by society in terms of intolerance, stigma, exclusion and a failure to be accommodated in medical, education and legal systems due to misinterpreting primary problems as 'bad behaviour'. Therefore, training is necessary to educate individuals that this behaviour is not bad, but rather the result of a neurodevelopmental disability, as no child chooses to be impaired with FASD. 8.10

The key worker role has been instrumental in supporting individuals and their whanau. The key worker adopts a family-centred approach that is consistent, collaborative and non-judgmental. They engage with

individuals and their whanau to provide education and support and to help navigate across different services. Key workers involved in FASD have the additional role of educating mainstream service providers about FASD, enabling the provision of appropriate care. ¹⁰

Parent-led initiatives in New Zealand have been developed, incorporating advocacy and mentoring. A parent-led initiative in Dunedin has established a seven-week course for parents and caregivers of children with FASD. This course aims to empower, advocate and mentor. Resilience is developed and strategies are taught to help caregivers and parents navigate support services and parenting approaches tailored to children with FASD. There is also a monthly peer support group that parents are encouraged to attend. The Ministry of Health has supported the organisation Fetal Alcohol Spectrum Disorder Care Action Network, which aims to help parents and caregivers learn tailored parenting strategies and to reduce the incidence of secondary problems developing. 16

Conclusion

FASD is entirely preventable through alcohol abstinence in pregnancy. New Zealand has relatively high rates of FASD and the costs to the individual, their whānau and the wider society are immense. Collaborative interventions on multiple levels are necessary to prevent FASD and to ensure those that do have FASD are diagnosed in a timely and appropriate manner. Comprehensive support services should be provided to ensure individuals with FASD are able to achieve their full potential. As this is an under-diagnosed and often stigmatised condition, more research is necessary to accurately estimate the true prevalence of this condition. Further research is also required to identify inequities, which will help to guide resource allocation and ultimately to reduce the devastating burden of FASD.

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