



Ord Valley Aboriginal Health Service's fetal alcohol spectrum disorders program: Big steps, solid outcome

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Abstract

Objective: Over the past four decades the international community has sought to clarify the risks associated with maternal alcohol use and the associated disability of Fetal Alcohol Spectrum Disorders (FASD). Until recently, Australia has done little to raise awareness of FASD, study prevalence or assist individuals born with these disorders. A prevention program was initiated in 2008 in the East Kimberley region of Western Australia through the Ord Valley Aboriginal Health Service (OVAHS) in response to the local Aboriginal community's concerns about the risks of maternal alcohol use.

Method: Antenatal clients were assessed three times during their pregnancy. Information was gathered on their alcohol use pre and post pregnancy awareness and knowledge of FASD. FASD education was also provided to the wider community and feedback was evaluated.

Findings: Assessment outcomes in the first year showed that the majority of women reported drinking alcohol at some point during their pregnancy. Over half reported nil further consumption post FASD

education. In addition to these promising findings, the insight gained into the reasons behind alcohol consumption proved to be of equal importance to program development and delivery. Client evaluation of community based education indicated that many found the education sessions useful and transferable to their own family and community.

Implications: Assessment results indicating high levels of maternal alcohol use supported the need for raising awareness of the risks of prenatal alcohol exposure. Following a twelve month evaluation of the program, the findings demonstrated the effectiveness of a consultative, whole-of-community approach as a strategy to address this significant health issue.

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CORE FUNDING



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Background

Alcohol and FASD

Current international research indicates that alcohol is the most commonly ingested substance responsible for inducing birth defects in developed countries [1, 2]. Although it is difficult to definitively determine the effect of alcohol on the developing brain, any alcohol consumed during pregnancy may have consequences for the fetus and potentially result in one of the Fetal Alcohol Spectrum Disorders (FASD) [2, 3]. This is an umbrella term used to describe separate diagnoses, including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), Alcohol Related Birth Defects (ARBD) and Alcohol Related Neurodevelopmental Disorder (ARND) [4, 5]. These disorders can result in a range of primary disabilities including neurobehavioral problems, learning, cognitive and developmental impairment, along with various physical impairments from subtle facial anomalies to organ damage [4]. The secondary disabilities associated with FASD are life-long and include, for instance, mental health problems, disrupted schooling, inappropriate sexual behaviour and a high incidence of involvement with the criminal justice system [1].

Alcohol use and pregnancy in Australia

Recent Australian data indicates that not only have the drinking patterns of women shown an increased use of alcohol generally, but that alcohol use in pregnancy is also common [3]. For instance, one study has revealed that almost 59% of pregnant women drank alcohol at some stage during their pregnancy [3, 6]. Similarly, a 2006 study of 1103 women of childbearing age indicated that 24% of those surveyed indicated they would continue to drink alcohol during their pregnancy [3].

The link between moderate to high levels of pre-natal alcohol exposure and the risk of FASD is well recognised [7]. Although it is clear that continual heavy drinking and/or binge drinking poses the greatest risk to fetal development, there remains much debate regarding the risks resulting from low levels of alcohol consumption during pregnancy [7, 8]. Despite this, there is agreement that the timing, pattern and dose of any alcohol consumed during pregnancy, plus numerous socio-behavioural influences and maternal and fetal genetics, all play a part in determining detrimental outcomes for the fetus [3, 4, 9].

Alcohol guidelines

The National Health and Medical Research Council (NHMRC) 2009 released revised guidelines on the safe levels of alcohol consumption in pregnancy [3]. While the guidelines acknowledged the limitations of existing research, including the lack of conclusive evidence as to the risks associated with low to moderate alcohol

consumption, they recommend that there is no absolute safe level of alcohol a woman can consume during pregnancy and as such no alcohol in pregnancy is the safest option [3, 7].

The message is not out there

Although the guidelines leave no room for ambiguity they remain poorly communicated in both the clinical setting and to the general public in Australia [7, 10, 11]. Indeed, some health professionals argue that because of the recent changes to the recommendations, the message is confusing for health practitioners and in turn women [7]. Recent Australian studies also show that less than half of health professionals routinely enquire about alcohol use in pregnancy [12]. Another study showed that only 12% of health professionals surveyed were able to identify the essential diagnostic features of FAS [11]. This study also indicated that only 13% of professionals surveyed gave information and advice to their clients that were consistent with NHMRC guidelines on safe levels of alcohol in pregnancy [11]. As a consequence, many women continue to drink throughout the gestation period, unaware of the possible consequences for their children [3]. In addition, comprehensive education, diagnosis and management of FASD in Australia are virtually non-existent. At present there are no national standards for accurately assessing and identifying children with FASD [13]. Furthermore, some health professionals argue that the recommendation's hardline approach only acts to further marginalise and alienate women who are drinking, particularly those at risk [7]. Although avoiding alcohol is optimal, some believe a harm minimisation approach is an option for women unable or unwilling to stop drinking during pregnancy [9].

What is the problem in the Kimberley?

Although there is no way of knowing the number of children affected by FASD locally, we do know that many women are drinking alcohol while pregnant [14]. In an effort to address this problem at a local level, a prevention program was initiated in August 2009 through the Ord Valley Aboriginal Health Service (OVAHS). This is a comprehensive primary health care (PHC) facility servicing Aboriginal people in the remote township of Kununurra and the surrounding communities. Kununurra is situated in the far north east Kimberley region of Western Australia. The town has a population of approximately 7,500 people, and of those, approximately 50% are Aboriginal. The program was developed in response to the high incidence of alcohol consumption locally [14], in particular maternal alcohol use and the resultant suspected incidence of FASD [9]. Although alcohol use in pregnancy is not confined to Indigenous populations [3], high levels of alcohol use in pregnancy were identified by the local Aboriginal community as of great concern and the local traditional owners, the Miriwung and Gajerrong peoples agreed to provide initial funding for the OVAHS FASD program.

What is OVAHS doing about this?

The preliminary aim of the OVAHS program was to gain an understanding of the situation locally, namely local drinking patterns among antenatal clients and the perceived needs of these women and their families. Following this, the OVAHS program endeavoured to develop and deliver strategies aimed at meeting those needs by supporting both the individual and the family to make informed choices regarding alcohol and pregnancy. Given the connection between the individual, families, community, environment and alcohol, the FASD program took a broad, holistic approach when working with women and their families. There was also a clear recognition locally that prenatal alcohol use, other drug taking behaviours and teenage sex were often linked and were key causative factors. The reasons why a person drinks at levels that are harmful are invariably complex, with a number of contributing factors involving poverty, isolation, stress, domestic violence, poor mental health, addiction, low self esteem, learned behaviours and fear [3]. In fact, one researcher suggests that poverty is the major contributing determinate to maternal alcohol use [7]. It is also recognised that women who live in poverty and drink alcohol at harmful levels often do so as a coping mechanism to deal with despair, trauma, abuse and stress [9]. Young women are of particular concern here as they are more likely to be consuming alcohol at risky levels and are also at greater risk of unplanned pregnancy [6, 9].

OVAHS 5-Point Plan

Within this context, strategies aimed at preventing maternal alcohol use and in turn FASD were put in place by OVAHS in 2008 and then further developed into the FASD program in August 2009. A 5-point plan was developed targeting five main groups, with priority given to all Aboriginal antenatal women presenting at OVAHS. The remaining groups include all Aboriginal women between the ages of 13 to 45, OVAHS staff, local Aboriginal men and finally local, national and international interest groups and organisations.

Target group 1

As mentioned, the principal target group for the program is all antenatal clients attending OVAHS. The program primarily provides FASD education, AOD (alcohol and other drug) assessment and one-to-one counseling to each antenatal client, extending these interventions to include partners, families and the community as a whole. Brief intervention, motivational interviewing and a three part antenatal assessment are key features of the program. Furthermore, all FASD education during this period incorporates contraception education and advice, which is then followed up during the postnatal period. The FASD program, and indeed OVAHS, view contraception as a significant way for women, and in particular young teenage women, to gain greater ownership of decisions around pregnancy.

Target group 2

In addition to the primary target group, the OVAHS FASD program targets all women of child-bearing age. This is done through local services such as the schools, the crisis centre and weekly community stalls and events, all of which form a significant part of the team's out-reach program. The age range in this group is 13 to 45 years, as some local Aboriginal women start families as young as 13 years of age and may continue having children into their 40s. Given the link between unplanned pregnancy, high levels of alcohol consumption (in particular binge drinking) and FASD [13], raising contraceptive awareness is central to decreasing the incidence of FASD. Special emphasis is placed on at-risk women who may not readily access community, education or health services. Sharing information about FASD with the elderly women also provides an important means of support for the younger women. Given cultural and family ties and inter-generational maternal alcohol use this indirect strategy complements the prevention efforts directly targeting at risk young women [7].

Target group 3

The third target group is all OVAHS staff with an aim to provide education and training on alcohol awareness, FASD and contraception. Developing skills in providing brief intervention in alcohol use and contraception are key aspects of this process

for OVAHS clinic staff. Particular emphasis is placed on recognising the important role of the Aboriginal staff at OVAHS. They are vital links to communicating knowledge to the community and are key contributors to raising public awareness of FASD and ensuring the cultural appropriateness of all aspects of the program. Education is pitched at various levels to accommodate the experience and knowledge of employees, ranging from reception to allied health and medical staff. In an effort to increase the capacity of OVAHS employees to identify the causative factors of FASD and reflect on the true extent of the diagnostic process, a number of nursing and medical staff have completed an internationally recognised FASD diagnostic training course through Washington University in the USA (4-Digit Diagnostic Code Training) [15].

Target group 4

The fourth target group is local Aboriginal men. While appreciating that traditionally Aboriginal men are not involved in the antenatal process, they are viewed as key players in supporting their partners to make alcohol-free choices throughout pregnancy. The majority of men who have received FASD education have welcomed this information, with feedback indicating recognition that the responsibility of fatherhood begins from conception, not delivery. The men also believe that Aboriginal culture, knowledge and stories rely heavily on oral tradition, and therefore memory, and that this is potentially lost if many of the next generation suffer neurological damage as a result of pre-natal alcohol exposure [16]. Men within the local community are also aware that too many of their young men are leaving school early and with only basic education, and that rates of imprisonment are high among Aboriginal men. As such the local men have voiced concern that FASD could be a contributing factor, especially as Aboriginal people currently make up 21% of the total number of Australian prisoners, yet only comprise 2.5% of Australia's population [17, 18].

Target group 5

Lastly, continual broad community consultation and the development of links with the local Aboriginal population and the organisations that provide a service to them are important to the success of the program. Similarly, developing links with national and international FASD networks has been vital in establishing the FASD program, especially as the bulk of experience, knowledge and research has occurred overseas. Through this there has been a strong recognition of the importance of a unified and consistent approach at all levels of health promotion, research and policy development.

What were the challenges and how were they addressed?

As the program's first year draws to a close, there have been many encouraging outcomes, as well as a number of challenges. Each has acted to both strengthen the founding goals and objectives and to help direct and formulate changes. This continual assessment and evaluation of the FASD program has ensured it remains responsive to the needs of the community and retains local support and sustainability.

The culture of alcohol use

A significant challenge for the FASD program has been the social acceptance of heavy alcohol use in both Indigenous and non-Indigenous Australian culture, which in turn adversely impacts on the health choices women make in their pregnancies [7]. Despite studies that show more non-Aboriginal women drink alcohol, compared with Aboriginal women, those that do drink consume more [7, 9]. The social, economic and historical factors known to contribute to excessive alcohol use similarly affect the Aboriginal population of Kununurra [14]. Consequently, the program takes into account these factors and has thus adopted a broad holistic approach in its program delivery. Fortunately, OVAHS has the capacity to readily engage with clients and their families on a needs basis, either through the FASD team or following referral to OVAHS AOD support counsellors.

Engaging with at-risk clients

Engaging with pregnant women who attend the OVAHS clinic is often straight forward, and FASD assessment and brief intervention is now an accepted part of routine antenatal care. However, for a variety of reasons, engaging with at-risk antenatal clients is sometimes a challenge for the FASD team. It is these women, in particular teenage women, who are most vulnerable to alcohol use in pregnancy and in turn predisposing their child to FASD [6]. To encourage these women to access the program the FASD team endeavours to be non-threatening or judgemental, yet engaging at all times. One of the main strategies in achieving this is to create a relaxed and welcoming place for women during the brief intervention and assessment process. Visiting women where appropriate in the community or in their homes is also carried out by the FASD team. Follow up in the context of the client's home often allows the team to gain an understanding of some of the client's broader concerns. There is, however, always recognition that there may be sensitivities around home or community visits. For instance the client may not have revealed her pregnancy to a partner or other family members. There may also be issues of shame and fear, particularly if the client is very young. On a practical level, out-reach visits may not always be appropriate due to distractions such as children or other family members. In all instances, confidentiality is paramount and all interventions are directed by the client's own preference.

The antenatal assessment process

The development of a routine antenatal assessment survey at the outset of the OVAHS FASD program has been, among other things, a useful tool for engaging with the majority of women in the primary target group and has also remained the key performance indicator essential for program evaluation. The assessment is conducted in three parts throughout the course of the pregnancy. It aims to determine drinking patterns (pre and post pregnancy awareness), base knowledge of FASD and the risks associated with prenatal alcohol exposure. The same questions are asked of each of the antenatal clients, whether they drink alcohol or not. This is seen as important as it standardises the assessment process, thus helping reduce any perceived shame or stigma some women may feel [7]. All questions are embedded in general conversation within the context of maternal and fetal health. Where appropriate the FASD team encourage and involve partners and/or family in the assessment process as this is likely to improve client outcomes [7]. FASD information provided is accurate and informative, yet sensitive to the needs of each client. Above all it is culturally appropriate, with the Aboriginal FASD team worker invariably conducting each session. Any barriers to ceasing or reducing alcohol consumption identified by clients are explored and the opportunity for clients to receive further support and counselling is offered through the staff at OVAHS Social Support Unit (SSU) and/or the clinic.

Assessment limitations and outcomes

One of the challenges of collecting client information lies in the accuracy of information provided during each assessment. All responses rely on self-reporting and thus inaccuracies based on poor recollection or under-reporting are possible. To date the outcome of the 78 assessments conducted show that 15.3% did not consume alcohol, while 84.7 % reported alcohol use at some point during their pregnancy, often inadvertently prior to pregnancy awareness. Despite this high percentage of reported maternal alcohol use, 56.4% of the women reported to have abstained from alcohol use following initial FASD education, 14.1% reported to have cut down while 1.2% reported to have continued to drink alcohol at follow-up sessions during their pregnancy either weeks or months following initial assessment. Only 2 clients refused FASD education and for 10.2% it was not possible to follow-up an outcome as they had moved away to another location. For the purpose of the assessment, even one episode of alcohol use from initial FASD education to delivery of the baby was recorded as cutting down rather than abstinence. Presenting to OVAHS late in pregnancy and the transient lifestyles of some of the clients meant that only 4 of the 78 women surveyed completed all three assessments. Despite this, the opportunity to assess 74 clients more than once, plus conducting frequent follow-up as needed was sufficient for general evaluation purposes. Although obtaining 100% abstinence is a primary objective of the program, the outcomes of the assessments have been encouraging and

invaluable in providing greater insight into the drinking patterns and social circumstances of the pregnant Aboriginal women seen at OVAHS. In addition, beneficial outcomes have been achieved through many of the women making alcohol-free choices in pregnancy following FASD education.

Promoting contraception as a cornerstone of FASD prevention

The early onset of sexual activity in some Aboriginal adolescents [19] and the relative lack of contraception awareness among many young women in the community have also been of great concern. Research nationally indicates that 50% of all pregnancies are unplanned [9, 20], with recent Australian statistics show Aboriginal women, as a group, having babies younger than non-Aboriginal women [18]. Certainly these statistics were reflected in the FASD program findings that indicated of the 78 antenatal women assessed, 70.5% of the pregnancies were reported to be un-planned.

Dialogue with young women in the community revealed that their knowledge of puberty, menstruation, pregnancy and contraception varied, with a significant number reporting little knowledge of contraception in particular. Given the incidence of early alcohol use among young women (and its resultant impairment of judgement), and their attitudes and norms around consumption, the program has placed considerable emphasis on the promotion of alcohol awareness, contraception and safe sexual practices as part of all brief interventions. Parental monitoring is also addressed separately [18]. In an effort to encourage safer sex, female OVAHS clinic staff routinely ask female clients about their contraception use. A comprehensive puberty and contraception brief intervention resource and interactive contraception workshop was developed with input gained through OVAHS staff and community consultation with the local Aboriginal adolescent women. In addition, a brief intervention flow chart resource was developed and is used as part of all clinic consultations where appropriate. This opportunistic education is viewed as critical to raising awareness in the community and encouraging higher levels of contraception use.

Engaging with women in the 13-45 age brackets has been central to raising community awareness of FASD and has largely been achieved through regular community stalls and education workshops. For instance, of the 770 local Aboriginal women aged 13-45, 56% have so far received FASD brief intervention either at OVAHS or in the community, including 33 female only workshops. Evaluation of FASD education by the women has provided the program with positive feedback, with over 95% indicating that the information given was very useful to both themselves and their families.

Challenge of educating clients about FASD

Informing the clients of potential risks associated with prenatal alcohol exposure was also a challenge for the program. Infants born with FASD often display no obvious sign of disability in the early years, with many looking, sounding and behaving in a way that does not necessarily set them apart from other children [1, 7]. For instance, a 24 year old client said 'I drank for the other kids and there's nothing wrong with them'. In addition, there is often great variability in outcome for the child exposed to alcohol prenatally due to the many contributing mechanisms impacting on fetal development [1, 5]. Predicting the outcome for each child is often difficult and it can take a number of years before any obvious neurological deficit in an affected child is evident [5, 9]. Consequently, the team must rely on providing consistent, clear and accurate information on the potential effects of alcohol to the unborn child. The use of visual aids, audiovisual and other locally generated resources, along with clear explanation of the often hidden nature of this disability has been an effective means of getting the message across.

The role of men in determining maternal alcohol free choices

An additional challenge has been the role of men in the community. In some families, women report that men hold the power-base and as such strongly influence the choices made regarding alcohol use in their pregnancies. Through conversation with antenatal clients, a number of women identified pressure from their partners as being significant in determining drinking behaviours during pregnancy. The women reported they would like to stop drinking, but were often pressured to stay with their partners in the 'drinking circle' as a show of family loyalty and their commitment and faithfulness to the relationship. Some female clients also report that to remove themselves from this social circle and 'sit' with non-drinking family members or friends, or spend time doing activities such as fishing potentially results in relationship problems, arguments or even violence. The role men play in the decision making of some clients was not initially anticipated, but it was recognised early on that the success of the program lay in part in the inclusion and education of men.

Overcoming the perception that pregnancy, and in turn prenatal alcohol exposure, was 'Women's Business' was challenging in the early stages of the OVAHS FASD program. Fortunately, following the request for FASD education by many male elders in the community, along with efforts to include men in program design and resource generation, the involvement of men in the program has greatly increased. Male focused FASD education workshops and outreach brief intervention is now a regular activity of the program. To date, 6 male only workshops and 23 mixed gender

workshops or presentations have been conducted locally. Like feedback gained from the women, the majority of men indicated that the FASD information was of great value to themselves, their families and the community. Along with the support of the male SSU staff, the program fosters FASD awareness and promotes fathering responsibility from conception. Men are also encouraged to take an active role in supporting their partners throughout the pregnancy by cutting down or abstaining from alcohol.

Starting from scratch

The absence of an existing FASD program, specific to the needs of a similar local community, to draw upon for knowledge and experience was identified as an additional challenge. However, there have been opportunities to draw on other initiatives nationally and internationally, in particular work done in Indigenous communities overseas that share similar socio-economic concerns and high levels of alcohol abuse. In addition, the lack of FASD resources appropriate to this community and suitable for both men and women were initially barriers to raising awareness. With community input from various gender and age groups, two logos were designed; one targeting men and the other targeting women. Using colloquial language ('No Grog for Nine') and visuals pertinent to the local population (for instance a VB beer can), a range of resources were developed. In addition, an audiovisual DVD using local images and voice-overs from local Aboriginal people has been developed.

Generating interest nationally

Generating national interest in the FASD program has been an important means of raising the profile of FASD and in turn attracting funds for future sustainability of the program, capacity building and implementing long term processes. This has been achieved through lobbying by the OVAHS Committee and CEO, national conference presentations and publication of reports and articles in Indigenous websites and magazines.

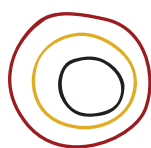
It has been encouraging to see a strong level of interest in what is a grass roots program that could potentially be adapted and implemented by other health services across Australia. It is these efforts, along with the production of culturally appropriate FASD and contraception resources, clear directives, assessment tools and most importantly wide community acceptance that has seen the program secure Commonwealth funding for a further four years.

Conclusion

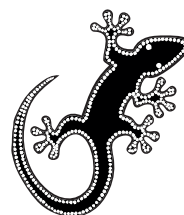
Decades after the effects of alcohol on the unborn child were identified; FASD continues to present a number of significant challenges in Australia. Despite this, OVAHS, an Aboriginal controlled PHC service in remote north Western Australia, has taken steps to tackle the suspected problem of FASD locally. The FASD program was founded on the principles of community control and self-determination and as such has successfully responded to the concerns of prenatal alcohol use raised by the community over a year ago. Identifying the obstacles and developing innovative ways to minimise or overcome these have clearly been challenging, but the outcomes in its first 12 months are encouraging. The success of the program to date can be attributed to both community investment and ownership and the willingness of the Aboriginal community of Kununurra to take control and embrace change.

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