

THE LILILWAN PROJECT: NEURODEVELOPMENTAL OUTCOMES AND FETAL ALCOHOL SPECTRUM DISORDERS (FASD) IN REMOTE AUSTRALIAN ABORIGINAL CHILDREN

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Introduction and Aims: Aboriginal leaders in remote Western Australian communities, concerned about the impact of high levels of alcohol consumption in pregnancy, invited researchers to collaborate in The Lililwan Project with the objective to determine prevalence of FASD.

Design and Methods: Using active ascertainment, children born in 2002/2003, living in the Fitzroy Valley in 2010/2011, were identified (n=134). In interviews, 127 (95%) consenting caregivers provided social, biomedical and antenatal data including alcohol use, with birth outcomes derived from medical records. Interdisciplinary assessments were conducted for 108 (81%) children. Prenatal alcohol exposure was objectively quantified. Conditions on the FASD spectrum (Fetal Alcohol Syndrome (FAS), partial FAS, and Neurodevelopmental Disorder – Alcohol Exposed (ND-AE)) were diagnosed using Canadian FASD Diagnostic guidelines with slight modification. Management plans were prepared for each child.

Results: Alcohol was used in 55% of 127 index pregnancies. Of women who drank, 87% drank at high-risk levels and 88% drank in the first trimester. In 108 children assessed, FAS or pFAS was diagnosed in 13 (120 per 1000 (95% CI 70-196), all with confirmed prenatal alcohol exposure. Of these, 69% had microcephaly, 85% had growth deficiency, and all had facial dysmorphism and CNS impairment in 3-8 domains. Using conservative diagnostic criteria, 8 more children were diagnosed with ND-AE. Overall FASD prevalence was 194 per 1000 (95% CI 130-280). Additional children considered at high risk for neurodevelopmental difficulties were referred for future evaluation.

Discussion and Conclusions: FASD prevalence was higher than reported previously in Australia and amongst the highest worldwide. Alcohol use in pregnancy remains a major public health challenge throughout Australia, particularly in remote communities with high rates of alcohol consumption. Aboriginal community-led initiatives for FASD prevention and FASD intervention must be supported.

Disclosure of Interest Statement:

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Data on The Lililwan Project FASD prevalence is not yet published in the scientific literature. The community consultation process requires that these data not be communicated outside the abstract review panel prior to the 2015 Conference.