EXPANDING RESEARCH AND CLINICAL PRACTICE IN YOUNG CHILDREN WITH PRENATAL EXPOSURE TO ALCOHOL

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Aim: This symposium brings together recent findings from the assessment and diagnosis of young children with prenatal alcohol exposure. The clinical implications of early assessment, the complexity of measuring domains of functioning in young children and the comorbidity difficulties that include disrupted sleep patterns are discussed.

PRESENTATION 1: Clinical Characteristics and diagnostic outcomes of young children with prenatal alcohol exposure (PAE)

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Introduction: The consequences for children born with birth defects and developmental disabilities encompassed by Fetal Alcohol Spectrum Disorder (FASD) are profound, affecting all areas of social, behavioural and cognitive functioning. The current project aimed to develop a diagnosis process for young children (aged 3 – 7 years).

Approach: A protocol for the assessment of the ten brain domains required under the Australian Diagnostic Guidelines was used to assess children referred to a designated FASD Clinic. All children were required to have confirmed prenatal alcohol exposure.

Results: Data on the first 90 children will be presented. The majority met diagnosis for FASD, either with 3 sentinel facial features (13, 14%) or FASD with < 3 sentinel facial features (46; 50%). Eighteen (20%) were considered at risk of FASD and 13 (14%) received no diagnosis. High rates of comorbidity were found; impairment on multiple domains of functioning were observed (45% had impairment on four or more domains). Most children were not living with biological parents and two thirds had current or previous contact with child protection.

Discussions and Conclusions: Young children with confirmed PAE demonstrate multiple impairments across ten domains, highlighting the importance of ensuring early diagnosis and support is provided. The clinical utility of this diagnostic process will be considered with reference to (i) the value held in communicating among practitioners, families and teachers (ii) the ease of use and time required (iii) its usefulness in selecting interventions and making recommendations. Issues with potential diagnostic problems will be discussed.

PRESENTATION 2: Interventions for improving executive functions in children with Fetal Alcohol Spectrum Disorder (FASD): Systematic review and meta-analysis

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Introduction: There is a growing focus on the development of interventions that enhance or support the development of executive functions (EFs). This systematic review and meta-analysis synthesises evidence in children (aged 3 – 16 years).

Method: Studies were included in the review if they reported a psychological intervention aiming to improve EF in children 3-16 years who had either confirmed PAE or a diagnosis relating to FASD. Eligible study designs included RCTs, quasi-experimental, and single-group pre-post designs with either no treatment, wait list control, or an alternative treatment as a comparison condition.

Results: The systematic search identified 3,747 records, 11 unique studies met inclusion criteria: 6 RCTs, 1 quasi-experimental, and 4 pre-post intervention designs.

For RCT and quasi-experimental studies, the overall effect of EF interventions generally favored the experimental condition, but was not statistically significant for all but one EF domain. For pre-post single group designs, there was evidence for small to medium sized improvements in EF. However, these results must be interpreted with caution due to high risk of bias.

Discussion and Conclusions: This review found limited and uncertain evidence for the effectiveness of interventions for improving EF in children with FASD.

Implications for Further Research: Only a small number of eligible comparison group studies are included in the present analyses, and it is likely that relatively small sample sizes hinder detection of effects across outcomes. These findings underscore the need for a greater number of high-quality comparison studies with larger sample sizes. This will allow for more definitive conclusions to be drawn regarding the overall effectiveness of interventions for EF in children with FASD.

PRESENTATION 3: Understanding sleep problems in children with PAE: Implications for a clinical trial.

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Introduction: There is growing recognition that a significant number of children with FASD experience marked difficulties with regulating their sleep, in part due to abnormal circadian rhythms. Melatonin has been proposed as a potential pharmacological treatment but has not been evaluated in this population.

Design and Methods: We have designed a randomised double-blind, cross-over study of melatonin and placebo in young children aged 5 – 12 years. Following a 4-week sleep hygiene intervention, children who fail to show improvement are eligible to enter the melatonin/placebo or placebo/melatonin phase of the trial.

Key Findings: The trial has commenced and recruitment and retention will be reported. Adherence to the treatment regime has been good. Qualitative interviews from carers post trial indicate enduring difficulties pre-trial in children's sleep behaviours, and some challenges in adhering to a complex trial process that requires recording of sleep using sleep diaries and wearing of actigraphy watches.

Discussion and Conclusions: Preliminary findings suggest that this trial is feasible. Recruitment of children meeting study inclusion criteria is challenging but retention to date suggests that this trial will be able to recruit an adequate sample size.

Implications for Practice: Children with FASD are routinely prescribed melatonin and other medications to assist with sleep. There has been no systematic evaluation of this and thus this trial has an important role in evaluating the efficacy of this treatment. The link between sleep and executive functioning, a key area of challenge for children with FASD, is critical as poor sleep may be contributing to their social academic and functioning difficulties.

PRESENTATION 4: CHALLENGES IN ASSESSING YOUNG CHILDREN FOR FASD: AND A PROPOSED SOLUTION

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Introduction: Current diagnostic assessment for FASD is time and resource intensive. And further complicated by the paucity of neuropsychological instruments designed and normed for young children. These factors have contributed to a widely held clinical view that young children should not be assessed for FASD, thereby missing an opportunity for tailored intervention during early critical developmental periods.

Method: Twelve children (age 3 – 5 years) with confirmed prenatal exposure to alcohol were assessed using the Australian Guide to the Diagnosis of FASD requiring extensive and individualized assessment using psychometrically validated assessments across 3 – 4 days. This "gold standard" assessment process is compared to a diagnosis obtained on the basis of the Griffiths Scales of Child Development (Edition III), a single assessment instrument that takes 3 hours to administer.

Key Findings: The diagnostic profile indicates significant delay across multiple domains of functioning. The following diagnostic profiles: 2- FASD with 3 sentinel facial features, 7- FASD with < 3 SFF; 3- "At Risk of FASD" on gold standard assessment. Concordance with diagnosis, arrived at using Griffiths Scales, was >90%.

Discussion and Conclusions: These data suggest that the Griffiths shows sensitivity and specificity compared to gold standard assessment. Further work is required to test this more robustly.

Implications for Practice: The utility of adopting an assessment process that has both sensitivity and specificity is essential given the scope of the problem (eg estimates 15-22% of high-risk populations such as children-in-care having FASD). The Griffiths holds promise as an effective assessment process that can be taken to scale and provide opportunities for timelier assessment and tailored intervention support.

Discussion Section: This discussion will focus on the way in which increasing opportunities for tailored support and early intervention can be provided in the context of complex presentation, high rates of comorbidity and difficult assessment processes. The potential for NDIS funding is discussed and how existing early intervention approaches may be tailored to this highly vulnerable population of young children reviewed.

Discussant: Associate Professor Doug Shelton, MB BS, Dip Paed, FRACP. Churchill Fellow and Pre-Eminent Staff Specialist. Clinical Director, Women's & Children's Health Services, Gold Coast Health

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