Clinical Intervention and Support for Children Aged Zero to Five Years with Fetal Alcohol Spectrum Disorder and Their Parents/Caregivers

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Topic
Fetal alcohol syndrome

Introduction
Recently, the United States Surgeon General’s Report on Mental Health\(^1\) included a section on Children and Mental Health that commented, citing Rutter,\(^2\) “it seems likely that the roots of most mental disorders lie in some combination of genetic and environmental factors,” and that the environmental factors could be biological or psychosocial. Prenatal alcohol exposure offers an example of a common biological environmental factor.

Subject
This paper will deal with clinical interventions involving the zero to five-year-old population of children with Fetal Alcohol Spectrum Disorder (FASD), diagnosed Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE) or Alcohol Related Neurodevelopmental Disorder (ARND).\(^3\) These children can present with immediate physical, developmental, social-emotional and behavioural problems, but are often not diagnosed because they may not show the classical facial dysmorphology, or because they fail to test out as developmentally delayed on standardized tests of mental and motor development. This paper will also discuss the importance of parental/caregiver support for managing these infants and young children with FASD.

Problems
1. There are almost no science-based early intervention studies performed on the zero to five-year-old population of infants and young children with FASD.

2. The support studies for children (zero to five) with FASD and their parents or caregivers have been more of an anecdotal than of a scientific nature.
Early Intervention Studies

These can be conceptualized at four stages: pre-conception, prenatal, birth/infancy, toddler/young child:

A. Pre-conception
This concept acknowledges the “transgenerational” aspect to the condition by using interventions to discourage alcohol consumption in the current generation of pregnant women and to decrease the occurrence of FASD in the coming generation. The Centers for Disease Control (CDC) reported that drinking by women of childbearing age decreased in the 1980s but steadily increased in the 1990s, especially binge drinking of five or more drinks per occasion.

The Parent Child Assistance Program (PCAP) is an intervention for substance abusing mothers and their children aged zero to three years. The three-year program provides a paraprofessional advocate for each mother whether or not the child remains with the mother. The goal is to prevent future alcohol-affected pregnancies. This intervention model uses the concept of intensive, relational and long-term advocacy. The program has had success decreasing the mother’s alcohol and substance abuse, increasing her active birth control and increasing health visits for her infant. It has been replicated in four centres in Washington State, 10 in the USA and Canada, including Alberta and Manitoba. This program also serves to protect birth to three-year-old infants from the child abuse and neglect that often occurs in the homes of alcoholic mothers. For mothers with Child Protective Service (CPS), contracts for care can be written between the mother, the advocate and CPS when the mother wants to retain custody. For other mothers, safety of the young child is maintained by placing the child with a relative or foster family. While maternal sobriety would be expected to have a positive effect on the emotional development of the young child, the program has not specifically addressed this factor.

There should be a greater recognition of the co-morbid psychiatric disorders in pregnant women who drink heavily. These include bipolar disorder, depressive disorder, post traumatic stress disorder or even psychotic disorder. Some of these women may also have a co-morbid developmental disorder, not uncommonly FASD itself. The FASD in the adolescent or adult can affect organizational skills, attention, impulsivity and judgment: all essential skills for parenting. A recent study of 44 adult women with FASD found that 49% were drinking during a pregnancy. Both male and female FASD parents had significant problems caring for their children.

B. Prenatal
This includes 1) comprehensive clinical treatment programs for pregnant alcohol-dependent women, 2) identification of infants at risk from biomarkers for alcohol consumption or maternal self-report screening tools of alcohol consumption during pregnancy, and 3) the introduction of neuroprotective agents to protect the developing alcohol-exposed fetus.
1) **Comprehensive clinical treatment programs for pregnant alcohol-dependent women.**

These programs are generally broad with multimodal interventions, incorporating medical and obstetric services to address the complex problems of this patient population.\(^1\) However, there is good evidence for the effectiveness of comparatively low-cost, brief treatment approaches such as motivational interviewing for the treatment of alcohol abuse and dependence.\(^12\)\(^-\)\(^14\) Cognitive behavioural interventions based on learning theory and aiming to develop coping skills have been used to reduce drinking and related problems in pregnant women.\(^15\)

2) **Identification of infants at risk using biomarkers of alcohol consumption or maternal self-report screening tools of alcohol during pregnancy.** There are a number of blood test biomarkers for detecting alcohol consumption and abuse. They include gamma glutamyl transferase (GGT), mean corpuscular volume (MCV), and carbohydrate-deficient transferrin (CDT).\(^15\) As well, haemoglobin acetaldehyde adduct (HbAA) levels were studied in 19 alcohol-abusing pregnant women and the levels were elevated in 68% of the women with alcohol-affected infants (eight infants diagnosed as having fetal alcohol effects), whereas only 28% of the alcohol abusing pregnant women had elevated HbAA levels when they had non-affected infants.\(^16\) Recent work has focused on fatty acid ethyl esters (FAEE), detected in many animal tissues, including fetuses and placentas following maternal ethanol consumption.\(^17\),\(^18\) The FAEE has also been detected in both cord blood and meconium in humans.\(^19\) Other research on prenatal alcohol biomarkers has explored the use of prenatal ultrasound and the movement of developing fetuses. Waas and colleagues\(^20\) studied the frontal cortex development, finding 46% of heavy alcohol exposed fetuses to have a length below 25th percentile, whereas McLeod and colleagues\(^21\) found that maternal alcohol drinking for 15 minutes abolished fetal breathing movements. Certain maternal self-report screening tools such as the T-ACE (tolerance, annoyed, cut down, eye opener) and TWEAK (tolerance, worried, eye opener, amnesia, cut down)\(^22\) could be used to identify “at-risk” infants. The 10-question drinking history questionnaire has also proven to be useful.\(^23\) Recent research suggests that the Binge Alcohol Rating Criteria (BARC) and the Frequency–Binge Aggregate Score (F–BAS) may offer good specificity for identifying mothers at risk of having alcohol-affected offspring.\(^24\)

3) **The introduction of neuroprotective agents to protect the developing alcohol exposed fetus.** These are agents that protect the developing fetal brain from the teratogenic and neurotoxic effects of prenatal alcohol; of these, folic acid has the most documentation.\(^25\) Studies on ASA and indomethacin, which inhibit the alcohol-induced high prostaglandin levels in uterine and embryonic tissue, have been shown to reduce perinatal mortality and decrease the incidence of ARBD in animal models.\(^26\),\(^27\) In humans, alcohol use in pregnancy has been shown to decrease a number of important nutrients, including: thiamin, folate, pyridoxine, vitamin A, vitamin D, magnesium and zinc.\(^28\) Zinc supplementation has also been studied as a neuroprotective agent during alcohol-exposed pregnancies.\(^29\) Finally, the protective effect of a long-chain fatty acid supplementation diet in mice has been evaluated, but reports are mixed.\(^30\)
C. Birth/infancy
Infant interventions such as infant massage, with tactile and kinesthetic stimulation of the infant\textsuperscript{15} and infant sensory integration techniques have been used by occupational therapists for many years in infants with neurological disorders. They have recently been applied to infants and young children with FASD, but no science-based evaluations have been performed.\textsuperscript{31} Specialized infant feeding techniques have addressed the severe feeding problems experienced by some infants with FASD.\textsuperscript{31,32} Educational demonstrations of the infant’s capabilities to the parent in the course of administering an infant examination (such as the Brazelton Scale) have proven to be a particularly effective technique.\textsuperscript{15} Also, coaching the parents’ interactions with the infant (e.g. teaching the parents specific techniques for slowing down and modulating their response to correspond with the infants’ tempo) has shown to enhance parent sensitivity.\textsuperscript{34-36}

D. Toddler/young child
General enrichment programming, early assessment and programming for hearing impairment have been studied.\textsuperscript{37,38} Recent studies in rat pups exposed to alcohol have shown efficacious effects of specific motor training programs contrasted with generalized enriched or non-enriched environments.\textsuperscript{39} A study using the Bayley scale evaluations of one- and three-year-old children whose mothers were in the three-year PCAP program\textsuperscript{6,7} revealed that although the mothers made substantial progress in sobriety and bringing order to their lives, the mental, motor, and behaviour scores of their children were indistinguishable from children of controls.\textsuperscript{40}

Family Supports
Studies of USA families affected by substance abuse have highlighted the potential for infant or child maltreatment and its subsequent clinical sequellae.\textsuperscript{41} The care-giving stress of parenting birth or adoptive infants and young children with complex medical disorders or developmental disabilities has also been studied.\textsuperscript{42-44} In families with FASD, this stress is compounded by the adoptive family being unaware of the infant/child’s exposure history or being unable to obtain a diagnosis. Currently, 80% of infants and young children with FASD are not living in their birth home and many are in adoptive or foster homes.\textsuperscript{43,45}

Family supports that have been helpful include in-home support with a community social worker or trained aide, respite care, instrumental family therapy or dyadic therapy to address relationship issues between parent/caregiver and infant or young child.\textsuperscript{46} Family caregiver stress is a product of the medical needs, mental health needs, economic impact and compassion fatigue of managing the child with FASD.\textsuperscript{45} No systematic research has addressed family support for infants/young children with FASD.

Conclusions and Implications
There is a pressing need for scientific studies of interventions in infants and young children aged zero to five years with FASD and support studies for their parents/caregivers. These interventions should be culturally sensitive, infant/young child focused and family or caregiver-centred.\textsuperscript{47} They should acknowledge the
“transgenerational” aspect to FASD and begin with the Preconception Period, but also include the Prenatal, Birth/Infancy and Toddler/Young Child time periods.

There needs to be a more coordinated “system of care” for alcohol- or substance-abusing pregnant women, as they are often excluded from treatment. Obstetric, psychiatric, addiction and developmental services are currently disconnected and so are unable to intervene properly to prevent or treat the next infant with FASD.
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