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

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Introduction

The 1999 United States Surgeon General's report on Mental Health[1] in its Children and Mental Health section quoted Michael 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 is a common biological environmental factor.

Subject

©2005-2026 ABILIO | FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

This paper updates information on clinical interventions involving the zero- to five-year population of children with Fetal Alcohol Spectrum Disorders (FASD), diagnosed either Fetal Alcohol Syndrome (FAS) or Alcohol Related Neurodevelopmental Disorder (ARND) (old term Fetal Alcohol Effects (FAE).[3,4] These infants and young children can present physical, developmental, social-emotional and behavioral 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 motor or mental development. The paper will discuss the importance of early diagnosis, early interventions and parent/caregiver support programs.

Problems

1. There are still no science-based diagnostic studies of the zero- to five-year-old population of infants and children with FASD.
2. 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.
3. 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.

Research: Context, Key Questions, Recent Results

1. 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.[5] The Centers for Disease Control (CDC) reported that drinking by women of childbearing age decreased in the 1980s, but steadily increased in the 1990s,[6] especially binge drinking five or more drinks per occasion.

The Parent Child Assistance Program (PCAP)[7,8] 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. In 2005, it has been replicated in five centres in Washington State, 14 in the USA and Canada.[7,8] 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. Bayley scale evaluations of one- and three-year-olds whose mothers were in the three-year PCAP program revealed that, although the mothers made substantial progress in sobriety and ordering their lives, the mental, motor, and behaviour scores of their children were indistinguishable from control children.[9]

Co-morbid psychiatric disorders in pregnant women who drink heavily are an important issue. These include, depression, post traumatic stress disorder, anxiety with or without panic attacks, bipolar disorder and even psychotic disorder.[10,11] Some of these women may also have a co-morbid developmental disorder, not uncommonly FAS or ARND.[12,13] FAS or ARND in the adolescent or adult can affect organizational skills, attention, impulsivity and judgment: all essential skills for parenting.[13] A study found that both male and female parents with either FAS or ARND had significant problems caring for their children.[14] Co-morbid addiction problems may exist with FASD.[13] This same study of 44 women found that 49% were drinking during a pregnancy.[14]

B. Prenatal

This includes 1) comprehensive clinical treatment programs for pregnant alcohol-dependent women; 2) identification of infants at risk from maternal and fetal 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) Clinical treatment programs for pregnant alcohol-dependent women.

The comprehensive programs are generally broad-based with multimodal interventions, incorporating medical and obstetric services to address the complex problems of this patient population.[15] Cognitive behavioural interventions have been used to help pregnant women develop coping skills in order to reduce their drinking and alcohol-related problems.[4,16,17] Lastly, there is some evidence for effectiveness of brief treatment approaches such as motivational interviewing, couple and/or family therapy.[17,18]

2) Identification of mothers and infants at risk using biomarkers of alcohol consumption or maternal self-report screening tools of alcohol during pregnancy.

Maternal blood biomarkers include: Blood tests such as gamma glutamyl transferase (GGT), mean corpuscular volume (MCV), and carbohydrate-deficient transferrin (CDT) indicating maternal alcohol consumption.[4] As well, haemoglobin acetaldehyde adduct (HbAA) levels have been studied in 19 alcohol-abusing pregnant women showing elevated levels in 68% of the women with alcohol-affected infants (eight infants diagnosed as having fetal alcohol syndrome or ARND), whereas only 28% of the alcohol-abusing pregnant women with non-affected infants had elevated HbAA levels.[19]

Infant biomarkers include: Fatty acid ethyl esters (FAEE), which have been detected in animal tissues, including fetuses and placentas following maternal ethanol consumption.[20] Recently, FAEE has been detected in both human cord blood and meconium.[21] Prenatal cranial ultrasound and fetal breathing or movements have also been studied as potential prenatal biomarkers. Waas and colleagues[22] studied the fetal frontal cortex development, finding 46% of heavy alcohol exposed fetuses to have a length below 25th percentile. Alternatively, McLeod *et al.*[23] found suppression of fetal breathing movements after 15 minutes of maternal alcohol drinking. Hepper and colleagues[24] have described a delayed maturation of the spontaneous startle behaviour in the fetus exposed to alcohol.

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)[25] could be used to identify ‘at risk’ infants. The 10-question drinking history questionnaire has proven to be useful.[26] Recent research suggests that 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.[27]

3) The introduction of neuroprotective agents to protect the developing alcohol-exposed fetus.

These are agents which protect the developing fetal brain from the teratogenic and neurotoxic effects of prenatal alcohol. Folic acid supplementation is the most researched.[28] Studies on ASA and indomethicin, 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 Alcohol Related Birth Defects (ARBD) in animal models.[29,30] In humans, alcohol in pregnancy has been shown to decrease a number of important nutrients including: thiamin, folate, pyridoxine, vitamin A, vitamin D, magnesium and zinc.[31] Zinc supplementation has neuroprotective properties.[32] Finally, long-chain fatty acid supplementation diet may help maintain brain integrity.[33,34]

C. Birth/infancy

Postnatal biomarker: Neonatal cranial ultrasound may quantify the developmental changes in the corpus callosum due to prenatal alcohol.[35] Breast feeding increases Essential Fatty Acids (EFA) critical for brain development. Interventions such as infant massage and sensory integration techniques have been used by nurses and OTs for many years in preterm infants.[4,36] Swaddling has been compared favourably to massage in infants with cerebral injury.[37] Specialized infant feeding techniques have addressed issues such as poor suck and long latency to suck experienced by some infants with FASD.[38,39] Parents have benefited from educational demonstrations of the infant's capabilities shown in the course of administering a Brazelton Scale examination.[4] Coaching the parents' interactions with the infant (i.e. teaching the parents specific techniques for slowing down and modulating their response to correspond with the infants' tempo) enhances parent sensivity.[40] Finally, neonatal choline may have an ameliorating effect.[41]

D. Toddler/young child

The PCAP intervention with the substance-abusing mothers has not proved of sustained value for the development of their children.[9] Early toddler assessment, and enriched home or pre-school environments are beneficial.[42,43] The benefits of specific motor training programs contrasted with generalized enriched or non-enriched environments have been shown in rat pups exposed to alcohol.[44] Motor training has probable utility in infants/ toddlers with FASD. Nevertheless, at this age it is essential to screen for both Post Traumatic Stress Disorder (PTSD) frequently present as

a result of physical and/or sexual abuse, and/or Reactive Attachment Disorder related to multiple foster home placements with an emotional disconnection from birth parents. These co-occurring disorders respond to play therapy or mother/toddler dyadic therapy.[13]

2. Family supports

Studies of USA families affected by substance abuse have highlighted the potential for infant or child maltreatment and its subsequent clinical sequelae especially PTSD.[45] The care-giving stress of parenting birth or adoptive infants and young children with developmental disabilities and/or complex medical disorders has also been studied.[12,46] The stress in FASD is compounded by the parents' inability to obtain a diagnosis under five-years-old, leading to increased adverse life outcomes.[47] Currently 80% of infants and young children with FASD are not living with their birth parent and are in adoptive or foster homes, sometimes with added uncertainty related to the alcohol exposure history.[12]

Helpful family support programs include instrumental family therapy or dyadic therapy to address relationship issues between parent /caregiver and infant or young child, in home support with a child aide, nurse, OT, PT or speech therapist, and planned respite care. Family caregiver stress is a product of the medical needs, the mental health needs, the economic impact, and compassion fatigue of managing the child with a FASD.[12,42,48] No systematic research has addressed FASD family support programs.

Conclusions and Implications

There is a need for scientific diagnostic studies of infants and toddlers using standardized instruments such as the recently updated Zero to Three diagnostic nomenclature.[49] Specialist clinical observations show that infants and toddlers with FAS or ARND often fulfill the diagnostic categories of Regulatory Disorder, Type I, (Hypersensitive) Type II (Under-reactive), and Type III (Motor Processing- Impulsive, Motorically Disorganized). Studies need to quantify the effect of prenatal alcohol on developing brain neurotransmitters and phospholipids relating this to clinical presentation (i.e. Regulatory Disorder in infancy followed by early onset ADHD).[34,50] Brain phospholipids, such as EFA's, are fundamental to neuronal function, and are already being studied in developmental neuropsychiatric disorders such as ADHD and Schizophrenia.[34] More focus is needed on research and utilization of prenatal/postnatal biomarkers and neuroprotective agents.[19-35] Research should consider the role of maternal frontal lobe EEG

asymmetry in pregnant alcohol-abusing depressed mothers and its effect on their infants' sleep and circadian rhythms.[51,52] Multi-modal interventions in properly diagnosed infants and young children aged zero to five years with FAS or ARND are needed including studies of specialized support programs for their parents/caregivers. These interventions should be culturally sensitive, infant/young child focused and family or caregiver-centred.[53] Already the American Academy of Child and Adolescent Psychiatry is addressing service provision and intensity in this population by developing and field-testing a standardized assessment and service intensity instrument, ESCII.[54]

Interventions should acknowledge the 'transgenerational' aspect to FASD beginning with the Preconception Period but including Prenatal, Birth/Infancy and Toddler/Young Child periods. Thus, there needs to be a more coordinated "system of care" for alcohol or substance-abusing pregnant women, as they are often excluded from treatment.[13,52] The obstetric, psychiatric, addiction and developmental services are currently disconnected and so are unable to intervene properly to prevent, or treat the next infant at risk for either FAS or ARND.

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