

FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

Early Intervention for Children with Fetal Alcohol Spectrum Disorders

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Introduction

First identified in the United States over 35 years ago,^{1,2} Fetal alcohol syndrome (FAS) is a major birth defect resulting from prenatal alcohol exposure (PAE) and is characterized by a distinct pattern of facial abnormalities, growth retardation and central nervous system dysfunction. The term fetal alcohol spectrum disorders (FASD)³ is used to reflect the full range of effects associated with PAE, and in addition to FAS, includes partial FAS, alcohol related neurodevelopmental disorder (ARND), and alcohol related birth defects (ARBD).⁴ FASD places a significant burden on both affected families and society. The lifetime cost for a person with FAS is estimated to be approximately \$2 million, most of which reflects special education and medical and mental health treatment.⁵

Subject

This paper reviews recent progress in developing early interventions for children with FASD, current challenges in providing services for this high-risk population, and possible directions for

future research.

Problems

The deleterious effects of PAE are evident from infancy among both animals^{6,7} and humans,⁸⁻¹⁰ with many studies highlighting impairments in self-regulation. In infants and toddlers, PAE is associated with poorer orientation^{9,11} and habituation,¹² problems with state¹² and autonomic¹¹ regulation, sleep abnormalities,¹³ and increased level of activity.¹⁴ Studies have also documented greater reactivity to stress,^{15,16} alterations in the pain regulatory systems,¹⁷ and increased negative affect and higher rates of insecure attachment behaviour¹⁸⁻²⁰ in these children.

Such problems do not appear to be transient. Significant behavioural, cognitive and emotional difficulties have been reported among individuals with FASD throughout life, including intellectual and learning disabilities, executive dysfunction, memory problems, speech and language delays, and internalizing and externalizing behaviour problems.²¹⁻²⁶ Moreover, such individuals are at increased risk for many secondary disabilities, including comorbid psychiatric conditions, school failure, alcohol and substance abuse problems, and delinquency.²⁷⁻³³ Despite these findings, many children may not be referred for screening until relatively late (if ever), thus missing out on the potential benefit of early intervention.³⁴ FASD appears to be under-recognized and under-treated, particularly in certain high-risk settings, including psychiatric populations, the child welfare system, and juvenile detention and correctional facilities.^{29,35,36} The importance of early identification is highlighted by findings that an early diagnosis is one of the strongest predictors of more positive outcomes for these individuals.³³

Research Context

In the last few years, some initial progress has been made in the development of treatments for individuals with FASD, but those focusing on young children have been extremely limited. Early intervention studies present significant methodological challenges with this population.

Recruitment of study participants can be challenging when children with FASD are often not identified until school-age.³⁴ Additionally, as many children with FASD are involved in the child welfare system, obtaining proper consent to enroll them in early intervention programs can be difficult. Selecting an appropriate control group can also be challenging. Given the dearth of services for this population, utilizing no-treatment control groups raises ethical issues, whereas utilizing standard of care control groups may work against finding any significant effects for

programs in their early stages of development.

Key Research Questions

Several key lines of inquiry are currently being addressed in research on early intervention for FASD. Such questions include:

1. How can animal models inform our development of interventions for young children with PAE?
2. To what extent can early intervention programs ameliorate some of the primary deficits seen in infants and young children affected by PAE?
3. What functional domains are appropriate targets of intervention?

Recent Research Results

1. Animal studies

Several lines of animal research suggest the promise of various prenatal and neonatal interventions. For example, recent studies suggest that lithium may offer some protection against ethanol-induced *neuroapoptosis*.³⁷ The benefits of prenatal and postnatal treatment with neuroprotective *peptides* in mitigating the effects of PAE on brain development have also been reported.³⁸⁻⁴⁰ Studies have also documented the protective effects of various nutrients, including folate, selenium, vitamin C, zinc and choline.⁴¹⁻⁴⁵ Other research has demonstrated some positive effects of neonatal handling, postnatal environment enrichment and rehabilitative training on rats and mice with perinatal alcohol exposure.⁴⁶ For example, voluntary exercise has been found to improve spatial memory among alcohol-exposed rats,⁴⁷ whereas introducing complex motor training during the postnatal period effectively remediated the motor deficits of alcohol-exposed rats.⁴⁸

2. Programs for mothers with substance abuse problems

Treatment programs for mothers with substance abuse problems have been one route to early intervention for young children with FASD, either by providing direct services for children or by connecting mothers to services in their community. The program New Choices provides services for mothers with substance abuse problems and their children aged 0 to 5 years, including addiction counseling, parent education and counseling, peer support and enrichment programs

for children.⁴⁹ A preliminary evaluation found that mothers demonstrated improvements in depressive symptoms and empathy for their children, and children exhibited improvements in social development.⁵⁰ In Seattle's Birth to Three Program,⁵¹ paraprofessionals work with mothers with alcohol and substance use problems to connect them with appropriate services and to facilitate their ability to provide a safe caregiving environment for their children, but do not provide direct intervention services for the children. While positive effects have been found for mothers, at a three-year follow-up, no significant differences were found between the treatment and control group children on a measure of developmental functioning.⁵² Such findings suggest there may be limited effects of this type of intervention on child outcomes, particularly if direct early intervention is not provided to the child.

3. Parent-focused intervention

While not focusing exclusively on very young children with FASD, some studies have nonetheless included younger children in their samples.⁵³ One promising approach, Families Moving Forward (FMF),⁵⁴ provides supportive behavioural consultation to promote parental self-efficacy and reduce child behaviour problems in families raising children aged 4 to 11 years with FASD. Caregivers who participated in the FMF group reported greater improvements in parenting efficacy and greater reductions in child behaviour problems, compared to caregivers in the community standard of care group.⁵³

4. Cognitive and educational interventions

A small number of cognitive and educational interventions for FASD have also included young children in their samples. Children aged 3 to 10 years with FASD who participated in a socio-cognitive habilitation program in mathematics in addition to receiving educational support showed greater gains on mathematics outcome measures compared to those who received educational support only,⁵⁵ and these gains were maintained six months later.⁵⁶ To address impairments in working memory, Loomes and colleagues developed an intervention to promote the use of rehearsal strategies among children aged 4 to 11 years with FASD.⁵⁷ Children in the experimental condition demonstrated significant improvement in their scores on a digit span task across three sessions whereas the control group showed no such improvement.

5. Adaptive skills training

Individuals with FASD show deficits across multiple domains of adaptive functioning, including

communication, socialization, and personal and community skills.⁵⁸ To address the lack of safety awareness often seen in children with FASD, a computer-based intervention was designed to increase fire and street safety skills in children aged 4 to 10 years old with FASD. Children receiving the intervention demonstrated significantly greater gains in safety-related knowledge and appropriate behavioural responses in comparison to the control group.⁵⁹ Targeting impairments in social functioning, an evidence-based, manualized, parent-assisted social skills intervention, Children's Friendship Training (CFT),⁶⁰ was adapted for use with 6- to 12-year-old children with FASD. Compared to children in the control group, those who received CFT showed significantly greater improvement in their knowledge of appropriate social behaviour and were rated by their parents as having better social skills and fewer behaviour problems following treatment, and these gains were maintained at a three month follow-up.⁶¹

6. Pharmacological interventions

Young children are increasingly likely to receive pharmacological interventions to address behaviour problems,⁶² and given their increased risk for behaviour problems, children with FASD are likely to receive such interventions. Community and clinic-based surveys indicate that stimulants are commonly used in children with FASD.⁶³ Despite their common use, research on the efficacy of these medications for FASD has been limited by small samples or has entailed retrospective chart reviews rather than large-scale, double-blind, randomized controlled trials. Studies including children with FASD as young as 3 years old reveal a mixed pattern of findings, with some suggestion that symptoms of inattention may be less responsive to stimulants than hyperactive symptoms.^{64,65} Additionally, children with FASD may be especially vulnerable to negative side effects,⁶⁶ or may experience atypical reactions to medications.⁶³ Until more systematic studies have been done examining both the benefits and potential adverse effects of pharmacological regimens with this population, it is important to use caution in prescribing medications for children with FASD, particularly young children whose still-developing brains have already been impacted by PAE.

Research Gaps

Several lines of inquiry are ripe for further investigation. What are the most effective strategies for identifying young children impacted by PAE so that they may be directed towards appropriate interventions as early as possible? There also remains a need for long-term follow-up studies to examine whether early intervention programs are robust enough to reduce the emergence of

secondary disabilities later in life. Future studies might also investigate whether children with FASD can benefit from adaptations of existing early intervention programs,⁶⁷ including those that aim to promote more positive parent-child relationships, such as Right From the Start⁶⁸ or Attachment Biobehavioral Catch-Up,⁶⁹ as well as those designed to better equip parents to care for high risk children in foster care, such as Multidimensional Treatment Foster Care Program for Preschoolers.⁷⁰ Identifying moderators of treatment outcomes may allow programs to be tailored for certain subgroups. For example, early interventions may need to be adapted in different ways depending on the family context (i.e., birth families vs. adoptive/foster families).

Conclusions

Previous research has demonstrated that PAE can significantly compromise an infant's early development, particularly their capacity for self-regulation, which in turn may place them well on course for negative developmental trajectories. Deficits in self-regulation may confer further vulnerability by compromising early parent-child relationships (and potentially jeopardizing stable placements), impairing a child's ability to manage stressful situations, and interfering with their mastery of developmentally-appropriate tasks. Encouragingly, a small but growing number of studies have demonstrated with both animals and humans that early intervention can at least partially remediate some of the primary deficits associated with PAE. Such approaches are promising as they may also have the potential to mitigate some of the serious adverse outcomes often seen in individuals with FASD later in life. However, there remains much work to be done in order to identify affected children as early as possible and to develop a comprehensive continuum of services for these children and their families.

Implications for Parents, Services and Policy

1. Continued efforts must be made to improve training of professionals who work with young children, such as pediatricians, pediatric nurses, child welfare workers, daycare providers, preschool teachers and early childhood mental health consultants. Such training should include a better understanding of the full range of effects that may be associated with PAE, the importance of asking about and documenting a history of prenatal exposure to not only illicit substances but to alcohol as well, and the importance of early intervention for this population.
2. Better collaboration across different systems of care (e.g., hospitals, child welfare, regional centers, Early Start and Head Start programs) is critical to track and coordinate services for

children with FASD. Improved collaboration can help ensure that these children do not slip through the cracks and are directed towards effective interventions.

3. It is critical that intervention for children with FASD involves the entire family system in order to enhance the daily functioning and quality of life for these children and to better prepare and support their parents and caregivers. However, many mental health agencies are precluded from providing integrated services for children and parents by funding requirements.⁷¹ Amending such policies would likely facilitate better parent-child relationships, and promote more stable and nurturing caregiving environments for these vulnerable children.

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