

CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

Early Interventions for Youth Affected by Prenatal Alcohol Exposure:
A Review of Current Literature

A graduate project submitted in partial fulfillment of the requirements

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By

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in collaboration with

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Abstract

Early Interventions for Youth Affected by Prenatal Alcohol Exposure:

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Master of Social Work

Purpose: The purpose of this research is to examine the early interventions for youth affected by Prenatal Alcohol Exposure (PAE). This review of the literature will seek to gain an understanding of the present research on early interventions for youth who are affected by prenatal exposure as well as identify the gaps remaining in the research.

Method: The method used to find the research material was through the California State University, Northridge, library research search engine.

Results: Fetal alcohol spectrum disorders (FASDs), caused by PAE, cause permanent conditions and are the number one cause of preventable birth defects and developmental disabilities. Five percent of the nation's children are born with Fetal Alcohol Spectrum Disorders (FASDs), due to prenatal alcohol exposure (PAE) which can cause developmental delays and learning disabilities. Attention span, memory, language, reasoning, judgment and decision making may all be affected by this spectrum disorder. Affected individuals have difficulty managing their day-to-day lives. Left unaddressed or untreated, many will have long-term issues, including mental health and addiction issues, lack of employment, incarceration, and other safety concerns. Individuals diagnosed with fetal alcohol spectrum disorders may need lifelong support, but the disorder is often misunderstood, say advocates. Access to effective early interventions -which improve

the outlook for affected individuals- is dependent upon early detection and intervention.

Research shows that with early diagnosis and effective interventions, “specific symptoms are manageable and affected individuals’ life outcomes can be improved.” (Nash & Davies, 2009, p.595)

A review of the literature shows barriers to receiving appropriate interventions. One such barrier to receiving appropriate interventions is early diagnosis. Another is training of providers such as pediatricians, teachers and occupational therapists. Another barrier is access to services, as these individual’s needs are not recognized by typical screenings for services at Regional Centers. Lastly, evidence based interventions for students with FASD have not yet been widely implemented.

Five Evidence Based neurodevelopmental interventions warrant further attention. Thereafter, four key needs exist to effectively reach this population: 1) awareness of FASD in the general population 2) establishment of evidence-based interventions 3) education and training within populations of providers, such as pediatricians, teachers, and occupational therapists to proliferate such trainings, and 4) making trainings available to relevant individuals and caregivers. In the spirit of Not About Us Without Us, in this quest for knowledge, representation of individuals with prenatal alcohol exposure and their caregivers should be considered vital, as these two groups have been on the front lines. In many cases, they have been so with no central information or training ground.

Introduction

Fetal alcohol spectrum disorders (FASDs) are the number one cause of preventable birth defects and developmental disabilities; they can cause developmental delays and learning disabilities (Bakhireva et al, 2018). Five percent of the nation's children are born with Fetal Alcohol Spectrum Disorders (FASDs), due to Prenatal Alcohol Exposure (PAE). The prevalence of FASDs is "similar to that of other developmental disabilities like Down Syndrome and Autism" (Nash & Davies, 2009, p.594), although more prevalent than Autism. Research indicates that our understanding of the deficits and disturbances associated with FASDs is far from complete, however, there are consistent findings indicating these are serious, lifelong disabilities-especially when these disabilities result from central nervous system damage. Symptoms due to damage to the Central Nervous System can include the following:

...microcephaly, focal neurological deficits, known MRI abnormalities, cognitive/developmental/behavioral problems. To meet the FAS diagnostic criteria, structural (microcephaly and/or abnormality on neuroimaging), neurological (seizure or abnormality on neurological exam), OR functional abnormalities must be documented. [Functional = (1) Global cognitive deficits or significant developmental delay in a child too young for an IQ assessment (e.g., IQ or developmental quotient below 3rd percentile) OR (2) Deficits (below 16th percentile) in THREE or more specific functional domains, e.g., cognitive, academic, executive function, attention, memory, adaptive, motor, language, social skills, etc. (American Academy of Pediatrics, n.d, n.p.)

FASDs can cause structural malformations, learning disabilities, hyperactivity, cognitive

confusion, difficulty understanding the consequences of actions, poor social function, memory impairment, and disrupted education for some (Blackburn et al, 2010). As is the case with all developmental disabilities, access to effective early interventions is a protective factor that improves the potential outlook for those with an FASD (Bakhireva et al, 2018).

One major barrier to receiving appropriate interventions is early and accurate diagnosis. For a variety of reasons, FASDs are often not identified or are misidentified. Birth Mother stigma/fear of stigma, inconsistent caregivers, financial instability or lack of effective provider training to recognize the symptoms limit the opportunity for effective intervention. Children with FASDs are often simply thought to be defiant and impulsive (Jones et al 2006). Their symptoms are interpreted as “behaviors,” which often set children up for negative labeling-and therefore, negative outcomes (Jones et al 2006). Because they have a role in tracking developmental milestones over time, pediatricians are positioned well to aid in early identification of risk factors and assessment for FASDs (Hanlon et al, 2015). “Pediatric providers need to be able to identify patients with FASD” (Chasnoff, 2015, p. 264). Early recognition and intervention is vital because “specific symptoms are manageable and affected individuals’ life outcomes can be improved” (Nash & Davies, 2009, p.594). Yet, pediatric board examinations focus little on FASDs, with only one question regarding the spectrum disorder on the test: related to diagnosing the classic signs of FAS facial features (AAP, n.d).

These features are: smooth philtrum, thin vermilion and small palpebral fissures (AAP, n.d). Relying on this information is incongruous with the research, which shows that those facial features are only exhibited when the mother drank during the time period between 9-17 days gestation in utero (AAP, n.d). This practice is flawed:

If the mother drinks alcohol very early in pregnancy when the fetus' face is forming — around 17 days after conception, which is before most women know they are pregnant — the child may develop facial features that can be used to diagnose fetal alcohol syndrome: The space between their upper lip and nose is smooth, for instance, rather than grooved; their heads are small for their age; and their eye openings -- the distance between the inner and outer edge of the eyes -- tend to be shorter than normal, said Charness, also chief of staff at the Veterans Affairs Boston Healthcare System. (Weintraub, 2018, n.p)

Therefore, solely relying on these facial features as a diagnostic criteria overlooks most affected youth, and leaves many vulnerable.

Systems are not set up to support the needs of children with FASDs. Even with a diagnosis of FASD or an alcohol-related neurodevelopmental disorder (ARND) at an early age, patients are often “ineligible for special services because their intellectual abilities often fall within the average range of intelligence” (Kohlberg & Buckley, 2007, p .279). In Los Angeles County, FASDs are not one of the five qualifying conditions covered by the Regional Center.

Another barrier to successful early interventions is training for providers. Not only are pediatricians limited in their knowledge, as already mentioned, but elementary school teachers and other providers, such as Speech Language Therapists and Occupational Therapists require uniform understanding of the potential symptomology and interventions for individuals affected by PAE. Due to the complexity of FASDs and the highly individualized needs of those affected by this spectrum disorder, educators require specialized training to meet the needs of students with FASD (Blackburn et al 2010). Furthermore, behavior modification techniques employed by most educators are often ineffective when used on students with FASDs (Malbin, 2007). There

is an identified need for “service delivery in the form of targeted therapeutic interventions that directly address the needs of this student population” (Cleversey, Brown & Kapasi, 2018, p.1160).

Methods

The articles used in the literature review were found using California State University, Northridge's, online library search resource. The keywords that were used to find the articles were: fetal alcohol spectrum disorder, fetal alcohol, fetal alcohol syndrome, prenatal alcohol exposure, trauma in utero, evidence-based fetal alcohol, fetal exposure, effective interventions for alcohol exposure, pediatrician training, pediatrician training FASD, pediatrician training FAS, pediatrician fetal alcohol, teacher training, teacher training FASD, teacher training FAS, teacher fetal alcohol, statistics, fetal alcohol outcomes, FAS outcomes, FASD outcomes, fetal alcohol interventions, FAS interventions, FASD interventions, FAS resources, Fetal Alcohol resources, FASD resources support groups, FAS specialists, FASD specialists, FASD interventions and Fetal Alcohol specialists.

Results

The CDC provided federal funding to develop systematic, specific, and scientifically evaluated neurodevelopmental interventions (Brems, 2010). Bertrand provides a brief overview of the general intervention framework developed for individuals with FASDs and the methods and general findings of five specific intervention research studies conducted. These studies provided scientifically validated interventions that can address their children's needs and can be presented to schools, social services and mental health providers when seeking accommodation or support.

The first intervention studied was Project Bruin Buddies, which is a social skills training program to improve peer friendships for children with fetal alcohol spectrum disorders, sponsored by UCLA (Bertrand, 2009).

This study was designed to examine the effects of parent-assisted children's friendship training (CFT) (Frankel & Myatt, 2003) compared with the effect of delayed treatment control (DTC) on the social skills of children with a history of prenatal alcohol exposure, and to examine the maintenance of social skills gained over a 3-month period. (Bertrand 2009, p.989)

Bruin Buddies has "shown to improve peer interactions, social skills, and parent understanding of FASD-related disabilities" (AAP, n.d, n.p). The second intervention is a "sociocognitive habilitation using the math interactive learning experience (MILE) program" (Bertrand, 2009, p.991). The program for alcohol-affected children "provided learning strategies to compensate for core alcohol-related neurodevelopmental deficits" (Bertrand, 2009, p.991) and was developed to support learning math . The program included "intensive, short-term individual

instruction of each child, as well as training for the child's caregivers and teachers. The goal was to provide a consistent method of instruction of mathematical concepts across therapeutic, home, and school environments" (Bertrand, 2009, p.992). This program demonstrates "the effectiveness of adaptive materials and tutoring methods to improve math knowledge and skills in children with FASDs" (AAP, n.d). The third study, a neurocognitive habilitation program from the Children's Research Triangle 4 "was developed to be a systematic intervention strategy for children in the child welfare system that had a diagnosis of FAS or ARND" (Bertrand, 2009, p.994).

The program provided education and support to enhance the families' capabilities to care for the children, and focuses on improving the children's executive functioning, a central deficit for children with FASDs (Mattson et al., 1998; Rasmussen, 2005). The intervention strategies developed for the program focused on the concept that children would be best equipped to improve their executive functioning deficits if they were better able to self-regulate. (Bertrand, 2009, p.994)

The fourth study was from the University of Oklahoma Health Sciences Center. They used parent-child interaction therapy which uses an:

application of an evidence-based treatment to reduce behavior problems among children with fetal spectrum disorders and families moving forward, a behavioral consultation intervention to improve outcomes for families raising children with fetal alcohol spectrum disorders...The aim of the study was to evaluate two group-based interventions for children with FASDs) that would reduce (a) behavior problems among children with FASDs and (b) decrease parenting stress among caregivers. One treatment used a group

adaptation of an evidenced-based behavioral parent training treatment, Parent-Child Interaction Therapy (PCIT) (Eyberg & Boggs, 1998) that provided both parents and children with a live, coached practice of behavioral parenting skills. The other was a parent-only Parenting Support and Management (PSM) program that comprised components from other effective behavioral programs. (Bertrand, 2009, p. 997)

The fifth and final study was conducted by the University of Washington. The program was called, Families Moving Forward and studied:

a behavioral consultation intervention to improve outcomes for families raising children with fetal alcohol spectrum disorders. The overall goal of this study was to evaluate an intervention designed to improve caregiver self-efficacy, meet family needs, and reduce child problem behaviors. The specific aims of the study were: (a) to create a feasible, specialized behavioral consultation intervention – the Families Moving Forward (FMF) Program – for caregivers raising children with FASDs, based in part on positive behavior support techniques, and (b) to assess the efficacy of the FMF intervention, when compared with the community standard of care, using a randomized control trial design. (Bertrand, 2009, p.1000)

Families Moving Forward is a “consultation intervention that combines a positive behavior support approach with motivational interviewing and other scientifically validated treatment techniques” (AAP, n.d, n.p).

Previously, information and strategies for interventions specific to individuals with FASDs have been gleaned from those used with people with other disabilities and from the practical wisdom gained by parents and clinicians through trial and error or shared through

informal networks. Although informative to a limited degree, “such evolving treatments have been implemented without systematic or scientific evaluation” (Bertrand, 2009, p.1003). Only recently have they been demonstrated to be effective for this specific application (AAP, n.d). The Language to Literacy program can be utilized within the classroom to assist with developing literacy and “to improve receptive and expressive language skills” (AAP, n.d, n.p) which often are not in sync with one another. USFA Kids is another evidenced based intervention which teaches safety to children affected by PAE via computer (AAP, n.d).

Despite the recent gains, the need for further research is acknowledged within the existing literature “Research on evidence based interventions for students with FASD is a growing field” (Cleversey, Brown & Kapasi, 2018, p.1159).

Caregivers might not know about specific modalities that have been found to be effective and may instead rely on experts in the field for direction in this area. However, he notes, these caregivers possess unique insights into the development of their children and the efficacy of interventions (Cleversey, Brown & Kapasi, 2018).

Discussion

Findings

The findings suggest that the scientifically based interventions on individuals with FASDs are often focused on parent or family involvement. One of the reasons for the involvement is to help the client and family successfully apply the teachings of the interventions outside of the structured environment.

Creating real change for individuals--both children and adults--affected by prenatal alcohol exposure is a social justice issue. Dr. Carl Bell, a Chicago psychiatrist who aims to draw attention to the issue of PAE and FASDs for years says, "It's reprehensible that this could be going on this long and nobody bothered to see it" (Weintraub, 2018, n.p). He continues, "Homelessness, drug addiction, violence, suicide, school failure, unemployment, being victimized in childhood. All of those things are connected to this" (Weintraub, 2018, n.p). Bell continues, "It's all over prison, foster care, special education," he said. "It's heart-breaking, that's what it is" (Weintraub, 2018, n.p).

Dr. Carl Bell, is also noted his increasing concerns about the impacts of FASDs on Chicago's South Side due to a 2015 study. The study performed an, "examination of 611 children who came to the Jackson Park Hospital's Family Medicine Clinic on Chicago's South Side, roughly 40 percent met the criteria for a fetal alcohol spectrum disorder." (Weintraub, 2018, n.p). One study published in the Journal of the American Medical Association, found that children from all racial and socioeconomic backgrounds were equally likely to have fetal alcohol hfg disorders (Centers for Disease Control and Prevention, 2013). Another study, completed in

2011, found that women from high-income households were more likely to binge drink than women with lower incomes -- and thus put their children at higher risk (CDC, 2013).

Limitations

The limitation in the research is that the majority of the research is done in controlled settings and has not been tested in institutionalized settings. Because no evidence based practices exist, protocols cannot be uniformly rolled out, measured and tracked over time. Information on interventions is often anecdotal and education about existing interventions is spotty-as is the access to said interventions. Additionally, because this is a spectrum disorder, no two affected individuals will likely present with the exact same symptomatology. Lastly, because of social justice issues related to race, education, economics and access to health care, individuals with prenatal alcohol are not always identified and treated. "Intervention research is always a challenge with inherent weaknesses."(Bertrand, 2009, p.1003)

Future Research

Future research needs to be done in the way of creating and connecting programs and interventions with resource centers, schools and disenfranchised communities that normally don't have access to resources. It is hoped that interventions which already exist will positively impact academic success, diminishing secondary and tertiary effects and, therefore, helping us reach for a more equitable and socially just society system for all people.

Conclusion

Early interventions which have the potential to improve the outlook for affected individuals is dependent upon early detection and intervention. Research shows that

“specific symptoms are manageable and affected individuals’ life outcomes can be improved” (Nash & Davies, 2009, p 594). A review of the literature shows a need for further research on recommended interventions and widespread dissemination of findings and development of best practices for providers and caregivers who may potentially encounter with youth affected by PAE.

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Appendix

ADDENDUM – Early Interventions for Youth Affected by Prenatal Alcohol Exposure

Early Interventions for Youth Affected by Prenatal Alcohol Exposure is a joint graduate project between Rachel Romanski and Lesly Mejia. This document will explain the division of responsibilities between the two parties.

Rachel Romanski is responsible for all the following tasks/document sections:

- Researching scientifically based interventions for individuals and families who have experience with FASD, completing the first part of the “Results” section.
- Completing the “Future Research” section by analyzing the current studies and identifying studies that have not been completed.
- Formatting the “Methods” section by gathering all methods used to complete the literature review.
- Researching barriers to receiving early interventions for individuals and families who have experience with FASDs.

Lesly Mejia is responsible for all the following tasks/document sections:

- Researching limitations for studies on FASDs, completing the first part of the section “Limitations”.
- Analyzing the research gathered on FASDs interventions, completing the “Findings” section.
- Gathering the basic introductory facts and research on FASDs, completing the “Introduction” section.

- Formatting the title page.

Both parties shared responsibilities for the following tasks/document sections:

- Gathering references, completing the section “References”.
- Formatting the signature page.
- Formatting the Table of Contents.
- Completing the “Conclusion” section by analyzing the gathered research on the literature.

Rachel Romanski	Date	Lesly Mejia	Date
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