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Interventions for Children With Fetal Alcohol Syndrome: A Systematic Review

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Interventions for Children With Fetal Alcohol Syndrome: A Systematic Review

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
In Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe lifelong effects that can occur when an unborn baby is exposed to alcohol (Wilson, 2013). FASD is a worldwide issue and affects individuals of all races and socioeconomic statuses. It is irreversible, however, if diagnosed early, individuals can receive interventions to help improve their quality of life.

A systematic literature review was conducted to address the research question, what research-based interventions are available for children with fetal alcohol syndrome. Based on inclusion and exclusion criteria, thirteen articles were analyzed. The articles included in the study address interventions in areas such as behavioral interventions, social skills, educational interventions and safety skills.

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Interventions for Children With Fetal Alcohol Syndrome: A Systematic Review

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe lifelong effects that can occur when an unborn baby is exposed to alcohol (Wilson, 2013). “Based on the best available data, it can be estimated that 2-5% of children in the United States have an FASD” (NOFAS, 2016, p.1). However, not all individuals exposed to alcohol before birth will be affected by FASD.

Diagnoses surrounding Fetal Alcohol Spectrum Disorders include Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, Alcohol-Related Neurodevelopmental Disorder, Alcohol-Related Birth Defects, and Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (MOFAS, 2015b). Of these diagnoses, FAS is considered to be the most severe. Although it is hard to establish an exact number, “FASD affects an estimated 40,000 infants each year—more than Spina Bifida, Down Syndrome, and Muscular Dystrophy combined” (NOFAS, 2014, p.1)

Fetal Alcohol Syndrome impacts society in many ways, including financially. In the United States, the economic cost for FAS is nearly four billion dollars each year (CDC, 2015a). According to the CDC (2015a), “The lifetime cost for one individual with FAS in 2002 was estimated to be \$2 million”. Additionally, the cost can be much higher with more severe cases and those with greater needs.

Much of the research surrounding Fetal Alcohol Spectrum Disorders focuses on prevention with pregnant mothers, detailing the risks of drinking when pregnant, while also offering brief intervention programs to those who are thought to be at-risk. Although these prevention methods and interventions are important, more information is needed, especially evidence-based interventions for individuals with Fetal Alcohol Syndrome.

The purpose of this study is to identify what research-based interventions are available for children with Fetal Alcohol Spectrum Disorder and to bring to light the need for further research.

Literature Review

Diagnosis

According to MOFAS, “1 in 10 pregnant women report using alcohol” (2015a, p. 1). Although the number of mothers who drink while pregnant in the United States is quite high, the number of children who get diagnosed with FAS is much lower. Throughout the literature, a common theme identified is that there is no safe limit or level of alcohol consumed during pregnancy (Landgraf, Nothacker, Kopp, & Heinen, 2013). In addition to alcohol consumption, “...there are a series of other factors, including psychological, social and biological factors, which are presented as potentials risk factors for the occurrence and severity of FAS” (Esper & Furtado, 2014, p. 886).

Diagnosing an individual with Fetal Alcohol Syndrome can be difficult, however, there are specific diagnostic criteria to be followed. To be diagnosed with FAS, an individual needs to have one or more growth abnormalities. This may include “pre- or postnatal growth deficit”, which includes weight, height and body mass index (Dörrie, Föcker, Freunsch, & Hebebrand, 2014). An FAS diagnosis must also include “...all three characteristic facial abnormalities—short palpebral fissure length, a thin upper lip, and a smooth philtrum” (Landgraf et al., 2013, p. 703). “They must also have at least one diagnosed structural or functional abnormality of the central nervous system” (Landgraf et al., 2013, p. 703). This could include “microcephaly, intellectual disability, psychiatric conditions, language, motor, memory disorders” (Dörrie et al., 2014, p.864). There does not need to be confirmation of prenatal alcohol exposure for an individual to be diagnosed with FAS (Dörrie et al., 2014, p. 864).

Diagnostic Challenges

There is a need for greater attention and education for professionals who work, and interact with individuals with Fetal Alcohol Syndrome. In addition, there is a need for greater access to diagnostic services (Burd, 2006). Research conducted in Germany found that "...many people with FAS in Germany go undiagnosed, although they display the typical signs, and thus fail to receive appropriate help" (Landgraf et al., 2013, p. 708).

Throughout much of the research, a strong emphasis was placed on the importance of early diagnosis and early intervention. Often literature focuses on the worst-case scenarios; however, individuals affected by Fetal Alcohol Syndrome can still function successfully in society if given proper support. Some protective factors include "involvement in special education and social services, stable and nurturing environment and absence of violence" (CDC, 2015b).

Secondary Disabilities

A reoccurring theme throughout much of the literature involved secondary disabilities experienced by individuals with FASD. "Secondary disabilities are those that are not present at birth but occur as a result of the primary disabilities and can presumably be prevented or lessened by better understanding and appropriate interventions" (Nulman, Ickowicz, Koren, & Knittel-Keren, 2007). This can include mental health issues, troubles in school, problems with the law, inappropriate sexual behaviors and problems with drugs and alcohol.

In particular, they have reported that of those diagnosed with FAS, over 90% have mental health problems, 60% have been expelled from school, 60% have been in trouble with the law, 50% have been or are in jail, 50% have engaged in

inappropriate sexual activity, and 30% have alcohol or drug problems (Pei & Rinaldi, 2004, p.131).

Much of the literature made specific reference to ADHD, which is the most common “...reported mental health diagnosis in individuals with prenatal alcohol exposure” (Peadon & Elliott, 2010, p. 510).

Maternal Risk Factors

Maternal risk factors were discussed throughout the literature; however, there were some inconsistencies in identifying who drinks while pregnant. In regards to demographics, “Prenatal alcohol use appears to be highest among women who are older than 30 years, have less than a high school education, or are not married” (Meschke, Hellerstedt, Holl, & Meesselt, 2008, p. 443). Conversely, according to MOFAS, “These women are more likely to be: single, college educated, employed, middle to upper income” (2015a, p.1). Nonetheless, alcohol is consumed by women from all backgrounds, regardless of race or socioeconomic status, which puts their child at risk of being born with an FASD.

Many of the articles focused on certain population within the United States. Native Americans and Alaskan Natives were often examined throughout the literature. Articles also made reference to studies conducted in South Africa, which has a high FASD prevalence rate.

Timing

Many articles made reference to the timing of alcohol consumption during pregnancy and the impact it had on the baby. “Because fetal development continues right up to the end of the pregnancy term, there may be no safe time for a pregnant women to

consume alcohol, however drinking around the time of conception is perhaps most dangerous” (Niccols, 1994, p.96). With this in mind, articles also discussed other crucial developmental periods that occur throughout each trimester, reinforcing the statement that there is no known safe time to consume alcohol while pregnant.

This study aims to identify what research-based interventions are available for children with Fetal Alcohol Syndrome. It also seeks to identify if there is evidence to support the effectiveness of each of these intervention types.

Conceptual Framework

The data collected in this study was analyzed using evidence-based practice as a conceptual framework. Evidence-based practice is “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research” (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p.71). This integrative model is essential to the proposed research question, focusing specifically on literature, and interventions that are backed up with research. It guides the study, providing support to the research question, and is also adaptable to studies focused on a variety of disciplines.

Methods

The researcher conducted a systematic literature review due to the limited specific research-based information available surrounding interventions for children with Fetal Alcohol Spectrum Disorders. To conduct a systematic review, the researcher identified, assessed and synthesized the information available to this topic (The Campbell Collaboration, n.d.). For the purpose of this study, “intervention” and “program” will be used interchangeably.

Search Strategies

The data collection process occurred during the months of December 2015 and January 2016. The St. Thomas online databases, PsychInfo and SocIndex, were utilized throughout the data collection process. Articles were also requested through the Interlibrary Loan System when articles from the databases were not readily available. Articles were obtained using seven specific search terms. These include “Fetal Alcohol Syndrome”, “Intervention”, “Program”, “Children”, “Youth”, “Adolescent”, and “Maternal Alcohol Use.” These search terms were used in several combinations to collect the most available research. This is shown in Table 1.

Table 1.

Search Terms Combinations Used During Data Collection

Fetal Alcohol Syndrome	Intervention	Children
Fetal Alcohol Syndrome	Intervention	Youth
Fetal Alcohol Syndrome	Intervention	Adolescent
Fetal Alcohol Syndrome	Program	Children
Fetal Alcohol Syndrome	Program	Youth
Fetal Alcohol Syndrome	Program	Adolescent
Fetal Alcohol Syndrome	Intervention	Maternal Alcohol Use
Fetal Alcohol Syndrome	Program	Maternal Alcohol Use

Selection Criteria

Since this research is targeted towards research-based articles, peer reviewed journals were collected. Dissertations and thesis papers were excluded from this study. Due to time constraints, only journal articles were included in this study, ruling out books.

Inclusion. This study was not targeted towards one specific area, such as independent living skills or school-based interventions, but instead, remained open to identify a variety of intervention settings. The research collected was targeted towards children, from birth up to 18 years of age, and must have been diagnosed with a Fetal Alcohol Spectrum Disorder, specifically Fetal Alcohol Syndrome. Studies were targeted towards human interventions, and written within the last ten years.

Exclusion. This study focused specifically on Fetal Alcohol Syndrome, and excluded studies solely involving other diagnoses on the Fetal Alcohol Spectrum, such as pFAS, ARND, or ARBD. Research focused on adults was excluded from this study, as well as individuals with dual diagnoses. Articles that involved multiple substance use during pregnancy were excluded, along with studies that involved animal interventions. Abstracts were not included nor were books, dissertations or thesis papers.

Data Collection Process

Through the data collection process, 498 articles were collected and only thirteen articles met selection criteria. Reasons why articles were ruled out included lack of specific interventions, lack of FASD diagnosis, and date of publication. The majority of the articles collected were from the United States and Canada, along with many studies

conducted in South Africa. Two articles could not be acquired due to language barriers.

The data collection process is summarized in Figure 1.

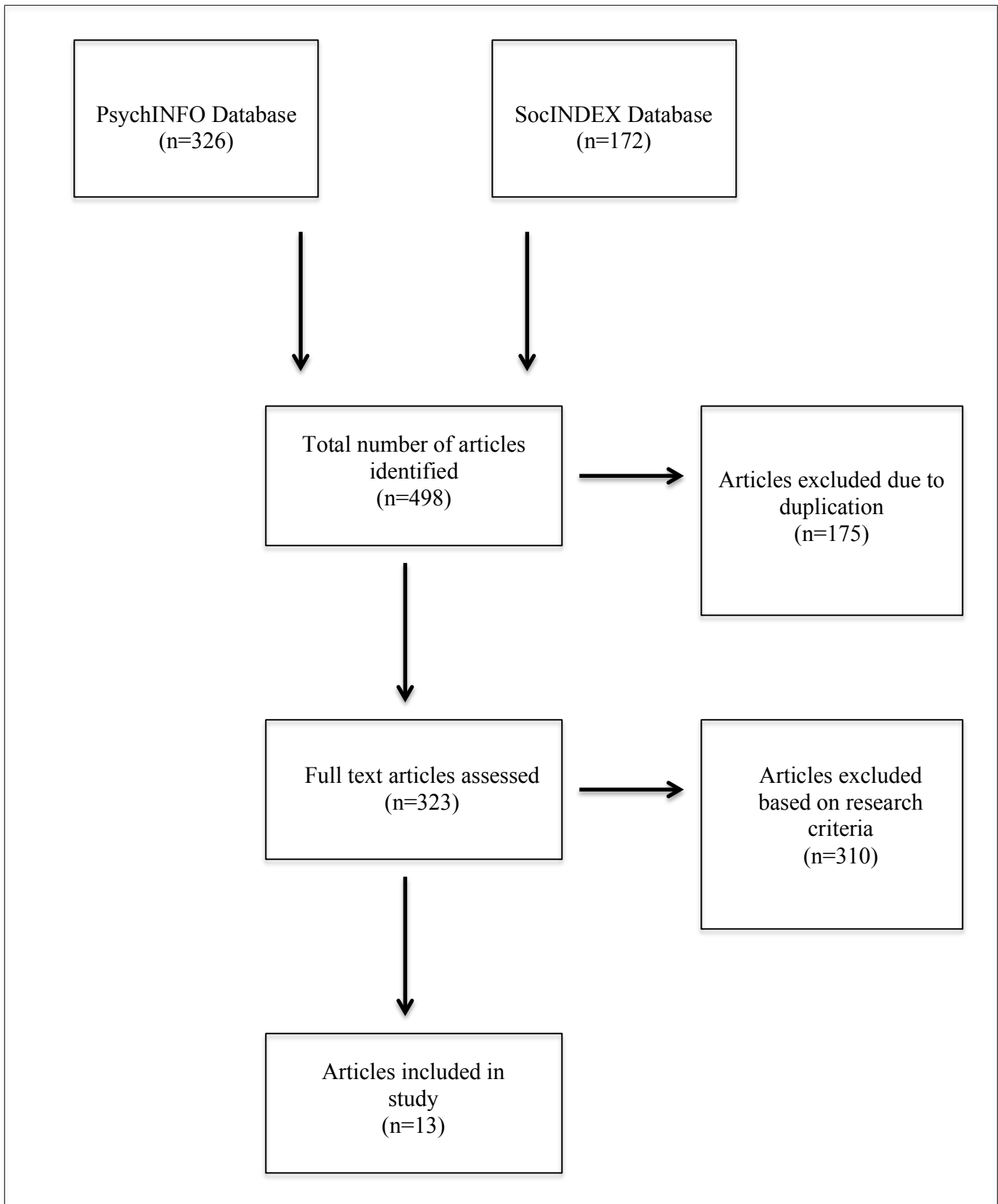


Figure 1. Flow Diagram of Data Collection Process

Findings

From the research collected, only thirteen articles were included in this study, with many fitting into categories surrounding safety skills, behavioral interventions, educational interventions and social skills. Six articles provided a brief overview of interventions, while seven articles discussed specific programs. Table 2 provides a list of included articles.

Safety Skills

Of the articles collected, four discussed an intervention surrounding safety skills for children with Fetal Alcohol Spectrum Disorders, specifically fire safety. All four articles made reference to a study conducted in the United States by Padgett, Strickland and Coles, which aimed to identify the effectiveness of a virtual reality computer game as an intervention for children with FASD to learn safety skills. The participants were 32 children, ages four to seven years, with a diagnosis of FAS or pFAS. The length of the program was one week, meeting only two times.

Virtual reality computer game. The intervention discussed throughout the articles was a virtual reality (VR) computer game, which aims to increase safety awareness. Throughout the VR computer game, children received instructions by an animated character using incremental steps, which align with United States Firearm Administration guidelines (Paley & O'Connor, 2011, p. 71). These steps include, "...recognizing a fire danger in the home, leaving the home immediately by the shortest safe route, and waiting at a preassigned meeting place outside the home" (Padgett, Strickland & Coles, 2006, p.66). The intervention presented was modified to specifically target children with FASD, an intervention originally formatted for children with Autism.

Modifications include, "...more verbal instructions, background music, and to provide more visual cues...to accommodate the typical verbal strengths and visual-spatial and fine motor weaknesses of children with FAS" (Padgett et al., 2006, p.67). The game can be played through the use of multiple technology accessories, such as a headset, body trackers, joystick, keyboard or a mouse (Padgett et al., 2006, p.66).

The intervention is composed of three levels that increase in difficulty, requiring more independent thinking and problem solving as the child progresses throughout the game. "The three levels in each condition were (a) animated guide led, yellow arrows indicated the correct path out of the house; (b) animated guide led, no arrows; and (c) no guide, no arrows" (Padgett et al., 2006, p. 67). Positive reinforcements are given to children when they complete the task correctly by the animated character, while the examiner remains quiet throughout the training, providing no assistance to the child. "If the child attempts a dangerous motion, such as walking into a fire, the screen goes black, the danger is explained, and the child is placed back at the game's beginning" (Padgett et al., 2006, p. 67).

Behavioral Interventions

One article identified GoFAR as a behavioral intervention for children with Fetal Alcohol Spectrum Disorders. GoFAR utilizes the strategy, FAR, Focus and plan, Act, and Reflect.

Using this technique, children learn to control their attention and approach problems thoughtfully by developing a plan rather than responding in a hurried and impulsive manner. Children then perform the plan and reflect back on what

worked or did not work during problem-solving (Coles, Kable, Taddeo & Strickland, 2015, p. 2225).

Although only one article made reference to the program GoFAR, the metacognitive technique, FAR, has been implemented into numerous interventions for children with FASD.

Coles, Kable, Taddeo and Strickland conducted a study, in the United States, to evaluate the overall effectiveness of the GoFAR program. Thirty children, aged five to ten years, participated in the study, and also had a diagnosis of FAS, pFAS or those who had “significant levels of alcohol-related physical features” (Coles et al., 2015, p.2225). Participants were assigned to one of three groups: GoFAR, FACELAND, a game designed to understand feelings, or Control group, which received no interventions. The program was broken down into three interventions and span over a ten week period. The intervention was modified to place emphasis on increasing self-regulation and decreasing disruptive behaviors, specifically in relation to the child’s home life.

GoFAR. The GoFAR program consists of three interventions, a computer game that teaches children the FAR strategy, parent training therapy sessions, and Behavioral Analog Therapy (BAT) (Coles et al., 2015). The first component, the computer game, was invented by do2learn.com. During this stage, FAR strategy was introduced to the child by Miles, the space alien, and his cat, Junior. There are five levels throughout the game, allowing the child to practice the FAR methodology while also acquiring positive reinforcement. During the parent training therapy sessions, information was provided “...for the parent to teach them to facilitate their child’s behavioral regulation skills” (Coles et al, 2015, p.2225). This occurred simultaneously with the computer game

intervention, over the course of five weeks. The BAT sessions concluded the intervention, extending the intervention over another five weeks, by assisting both the child and parent in how to utilize the FAR technique, when disruptive behaviors occur related to FASD, in their everyday lives (Coles et al, 2015). Homework assignments were also included throughout this portion of the intervention.

Mathematic Skills

Five articles discussed Math Interactive Learning Experience (MILE) as an intervention for children with FASD to improve math skills. “The MILE program rests on the theory that there are basic cognitive functions supporting mathematical cognitions, which impact academic achievement and adaptive functioning skills” (Kable, Coles & Taddeo, 2007, p.1428). The program was developed in the United States, and involved 56 children, aged three to ten years, with a diagnosis of FAS or partial FAS. Due to caregiver’s participation within the intervention, and also to determine the effectiveness of the program, “...children were required to have been with their current caregiver for at least 6 months before enrollment and projected to remain with this caregiver for the next 6 months” (Kable et al., 2007, p.1427). The duration of the program was six weeks.

Math Interactive Learning Experience. MILE consists of three key components: caregiver education, support for learning readiness and math interventions specifically targeted towards children with FASD. The first component involved caregiver training, throughout two workshops, surrounding topics such as background information about FAS, tools to help caregivers gain support and methods to manage children’s behaviors. The second component involves learning readiness, which is “...defined as preparing the child’s physical and social environment and behavioral

functioning to support optimal learning” (Kable, Taddeo, Strickland & Coles, 2015, p. 2). This provided a baseline within the program. The intervention concluded with the math intervention, in which participants were assigned to the math intervention group or control group (Paley & O’Connor, 2011).

Multiple strategies were implemented throughout the program including the incorporation of FAR as “...a metacognitive tool for regulating attentional focus and mental effort while engaging in mathematical problem-solving” (Kable et al., 2015, p.2). Additional strategies that were utilized and targeted towards children with FASD include, “...a slower pace of instruction, interactive learning experiences, and feedback regarding patterns of errors and mediation to improve integration of the math concepts” (Kable et al., 2015, p. 2).

Social Skills

Of the articles collected, nine made reference to a group-based intervention for children with FASD to learn social skills. The intervention, Children’s Friendship Training (CFT), was developed by Fred Frankel and Robert Myatt. The study involved 100 children, ages six to twelve years of age, with an FASD. CFT was 12 sessions, each lasting 90 minutes. This took place over a 12-week period.

Children’s Friendship Training. “CFT teaches children how to interact with peers, how to enter a group of children already playing, how to arrange and handle in-home play dates, and how to avoid and resolve conflicts” (Brown, Connor, & Adler, 2012, p. 782). Throughout the intervention, the parents play a key role. “A central component of CFT is parental assistance to children in establishing social networks and in practicing newly learned skills” (Schonfeld, Paley, Frankel, & O’Connor, 2009,

p.432). The parents also attend separate sessions to learn how to best help their children at home regarding the skills being taught. “These skills were taught in a small group setting through instruction on simple rules of social behavior; modeling, rehearsal, and performance feedback during treatment sessions; rehearsal at home; homework assignments; and coaching by parents during play between children” (Schonfeld et al, 2009, p. 432). This reinforces the importance of practicing learned skills both during sessions and at home.

Intervention Effectiveness.

To determine the effectiveness of each of the interventions, a pretest and posttest were given. In addition, many interventions separated children into control groups to evaluate the effectiveness. A follow-up assessment was conducted after children received treatment, ranging from one week to six months later to assess how much information was retained.

Table 2.*Articles Utilized Throughout the Study*

Author (s)	Title of Article	Intervention
Brown, Connor & Adler (2012)	Conduct-Disordered Adolescents with Fetal Alcohol Spectrum Disorder	Brief overview of available interventions
Chandrasena, Mukherjee & Turk (2009)	Fetal Alcohol Spectrum Disorders: An Overview of Interventions for Affected Individuals	Brief overview of available interventions
Clark (2012)	Adolescents Affected by Fetal Alcohol Spectrum Disorder (FASD) and Behavior	Brief overview of available interventions
Coles, Kable, Taddeo & Strickland (2015)	A Metacognitive Strategy for Reducing Disruptive Behavior in Children with Fetal Alcohol Spectrum Disorders: GoFAR Pilot	GoFAR (Behavioral Skills)
Coriale, Fiorentino, Lauro, Marchitelli, Scalse, Fiore, Maviglia & Ceccanti (2013)	Fetal Alcohol Spectrum Disorder (FASD): Neurobehavioral Profile, Indications for Diagnosis and Treatment	Brief overview of available interventions
Davis, Desrocher & Moore (2010)	Fetal Alcohol Spectrum Disorder: A Review of Neurodevelopmental Findings and Interventions	Brief overview of available interventions
Kable, Taddeo, Strickland & Coles (2015)	Community translation of the Math Interactive Learning Experience Program for children with FASD	Math Interactive Learning Experience (Math Skills)
Kable, Coles & Taddeo (2007)	Socio-cognitive Habilitation Using the Math Interactive Learning Experience Program for Alcohol- Affected Children	Math Interactive Learning Experience (Math Skills)

Kodituwakku (2009)	A Neurodevelopmental Framework for the Development of Interventions for Children With Fetal Alcohol Spectrum Disorders	Brief overview of available interventions
Laugeson, Paley, Schonfeld, Carpenter, Frankel & O'Connor (2008)	Adaptation of the Children's Friendship Training Program for Children with Fetal Alcohol Spectrum Disorders	Children's Friendship Training (Social Skills)
Padgett, Strickland & Coles (2006)	Case Study: Using a Virtual Reality Computer Game to Teach Fire Safety Skills to Children Diagnosed with Fetal Alcohol Syndrome	Virtual Reality Computer Game (Safety Skills)
Paley & O'Connor (2011)	Behavioral Interventions for Children and Adolescents With Fetal Alcohol Spectrum Disorders	Brief overview of available interventions
Schonfeld, Paley, Frankel & O'Connor (2009)	Behavioral Regulation as a Predictor of Response to Children's Friendship Training in Children With Fetal Alcohol Spectrum Disorders	Children's Friendship Training (Social Skills)

Discussion

Throughout the data collection process and analysis, many trends were observed within the literature, including the origins of the articles. The majority of the literature came from the United States and Canada. However, many studies were conducted in South Africa, which has the highest prevalence of Fetal Alcohol Spectrum Disorders.

Overarching strategies occurred throughout the literature, specifically the need for interventions to have structure. However, articles indicated that it was not that simple. It was stated numerous times that there needs to be a balance within interventions to ensure that it does not become too controlling. For example, the GoFAR intervention was very structured, but provided children with a few selective choices, such as allowing the child to pick the game background.

A reoccurring theme throughout the literature was the number of interventions that were modified to fit the needs of individuals with Fetal Alcohol Spectrum Disorders. The majority of interventions were an adaptation from another diagnosis, such as Autism. This can be extremely beneficial as it provides an opportunity to target an intervention on specific children's needs, making it more client-focused. This would be valuable considering all of the biological and environmental factors that often affect individuals with FASD.

It was surprising to learn that there were so many modalities to how interventions are presented. The incorporation of video games into interventions was fascinating. It allows individuals to learn at their own pace and on their own time. Considering the amount of time individuals spend playing video games, it seems clever to make it a learning experience and an opportunity for growth.

It was also evident that a strong emphasis has been placed on the importance of family throughout Fetal Alcohol Spectrum Disorder interventions. Many of the articles highlighted the importance and role of the family, as it relates to a child with FASD. It appeared as though many of the interventions would not be possible if the work was not continued at home, making caregivers a key element throughout many interventions. Possibilities for future studies may identify interventions specific towards children who lack family support or those who do not have a consistent caregiver.

Limitations

Due to the limited timeframe for this research project, only two online databases were used throughout the data collection process. The goal of this study was to identify what information was available regarding interventions for children with FASD, however, it could be beneficial in future studies to be more specific and to conduct a more in depth study on specific skills.

Much of the literature stated that the interventions were effective based on follow up sessions with the participants, however, little is know about how these interventions affect individuals as they continue to grow and age. Considering diagnosis is fairly new, it implies for greater research, looking at more of a long-term effect rather than short term.

Even with the search terms targeted towards interventions for children with Fetal Alcohol Syndrome, so much literature involved prevention efforts. Although this is important, interventions are still needed to address the needs of individuals with FASD. It is important to strive to become more informed, educate others, and continue to look for ways to help individuals affected by FASD live happy and fulfilling lives.

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