



SHORT AND LONG TERM IMPACTS AND IMPLICATIONS OF FETAL ALCOHOL SYNDROME DISORDERS ON COGNITIVE DEVELOPMENT IN CHILDHOOD

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ABSTRACT

Fetal alcohol syndrome disorders (FASD) represent a collection of disorders with which a child is born, due to maternal consumption of alcohol during pregnancy. Known as an invisible disability, its prevalence is difficult to capture, in part due to societal stigma and the lack of physical markers contributing to diagnostic difficulty. In Canada, FASD prevalence is estimated to be around 4%. The symptoms experienced by a child with FASD are typically classified into two categories: primary disabilities to describe functional deficits since birth as a result of the impact of alcohol on the brain; and secondary disabilities that occur later in life as a result of a child's environment and primary disabilities. The impacts of FASD will affect each child differently in both the types and severity of disabilities. A major challenge faced by children and youth with FASD is receiving adequate mental health support, as well as evidence-informed practices involved in improving behavioural and cognitive functioning. COVID-19 has dramatically affected both children with FASD and their caregivers, likely exacerbating existing challenges. With increased rates of alcohol consumption and other mediating factors, experts are concerned about rising FASD rates during the pandemic.

Each condition has an individual set of diagnostic criteria based on particular symptoms.[1-2] For example, FAS is diagnosed in the presence of central nervous system abnormalities, facial abnormalities, and growth deficit, while alcohol-related birth defects is diagnosed in the presence of problems with organ formation and function. [1]

The signs and symptoms of FASD are commonly categorized into primary and secondary disabilities.1 Primary disabilities are those that are present at birth and are a direct consequence of the underlying damage caused by prenatal exposure to alcohol. Signs and symptoms may include physical defects and/or intellectual or cognitive disabilities. On the other hand, secondary disabilities describe symptoms that are not present at birth but occur later in life as a result of the primary disabilities associated with FASD. It is important to note, however, that the severity of FASD varies from individual to individual.[1] In 2018, the Canada Fetal Alcohol Spectrum Disorder Research Network estimated that the prevalence of FASD in Canada was around 4%.[3] Similarly, a 2019 study deduced a 2-3% prevalence rate in the Greater Toronto Area, Ontario.[4] However, many individuals do not manifest the physical symptoms associated with FASD; thus, the true prevalence of FASD remains unknown due to the inherent difficulty in diagnosing FASD without obvious physical symptoms.[5]

INTRODUCTION

Fetal alcohol syndrome disorders (FASD) represent a collection of disorders that afflict children due to maternal consumption of alcohol during pregnancy. This umbrella term encompasses a range of conditions associated with fetal alcohol exposure such as fetal alcohol syndrome, fetal alcohol effects, partial fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder, and alcohol-related birth defects.

Although efforts have been made to address the impacts and implications that FASD has on the cognitive development of children, additional research must be conducted to develop a holistic understanding of these challenges so that more effective diagnoses, interventions, and support can be implemented. Moreover, given the negative repercussions the COVID-19 pandemic has had on many, there is limited research on how the COVID-19 pandemic has affected this vulnerable group.

Therefore, the research question of this review is: what are the short-term and long-term impacts and implications of FASD on a child's cognitive development? This will allow us to identify what is needed to support the challenges that stem from this domain.

Our review followed a non-systematic approach and both a web search and electronic database search were performed to find published literature that shed light on this topic. The results from the literature are presented below.

IMPACT ON COGNITIVE DEVELOPMENT

I. Primary Disabilities

Primary disabilities refer to functional deficits that occur due to the impact of alcohol on neurological development, causing the dysfunction of a child's central nervous system.[6] Primary disabilities in children with FASD will impact each child differently, varying in deficit area (e.g., physical, mental, behavioural, learning disabilities) and severity.[6] Examples of primary disabilities include impairment in memory, attention, cognition, language, executive function, and adaptive function.[7] Children with FASD may also frequently engage with maladaptive behaviour, such as impulsivity, bullying, dishonesty, sexual inappropriacy and physical aggression.[6] The aforementioned primary disabilities can then, in turn, lead children with FASD to become engaged with the justice system from a young age.[7] In fact, Passamore et al. determined that youth with FASD are 19 times more likely to be incarcerated compared to their typically developing peers.[7] Moreover, reports indicate deficits in adaptive and executive functioning are most significant in individuals with FASD. Adaptive functioning refers to the skills required by an individual in order for them to live independently. Executive functioning by contrast refers to higher-order cognitive processes such as interference control, working memory, and cognitive flexibility that help us facilitate our everyday lives and goal planning.[6,8]

In the past, FASD diagnosis revolved primarily around the detection of physical features attributed to FASD. However, its diagnosis was limiting as many children with prenatal alcohol exposure suffer from FASD-related neurobehavioural consequences, despite not having recognizable physical features associated with the disorder.[6] This can be demonstrated from the results of a 14-year longitudinal study conducted by Streissguth et al. that explored the difficulties associated with FASD diagnosis. It was found that by the time individuals had reached 14 years of age, the effects of alcohol exposure (e.g. physical, cognitive symptoms, primary disabilities) were no longer detectable by blinded clinical examinations.[9]

Additionally, Streissguth et al. explored the neurocognitive consequences of children with prenatal maternal alcohol exposure by documenting neurobehavioural deficits, growth and alcohol-related physical anomalies for around 500 infants from birth onwards. Responses relating to central nervous system dysfunction were documented throughout the participants' lives. On the date of birth, central nervous system-related responses of increased head turning to the left, tremulousness, hand-to-face movements and time spent with eyes open, as well as decreased bodily activity were documented. Other markers of central nervous system dysfunction include longer latency to suck, as well as lower sucking pressure. At four years of age, children with prenatal exposure to alcohol were seen to have decreased attention, poorer fine and gross motor function, longer latency to correct errors, as well as decreased intelligence quotients. By 14 years of age, prenatal alcohol exposure in children was found to be related to decreased attention, memory, phonological process and mathematical skills.[9]

II. Secondary Disabilities

Secondary disabilities are disabilities with which an individual is not born, but occur later in life as a result of the primary disabilities associated with FASD. Unlike primary disabilities, however, secondary disabilities can be improved or prevented through better understanding and appropriate interventions.[10] Secondary disabilities increase the complexity of care and result in social and economic costs to society.[11] In particular, people with FASD are at an increased risk for the secondary disabilities of mental health problems and behavioural disorders.[10,12] In a study of 473 individuals with FASD, 94% of participants experienced mental health and behavioural problems.[10] Among co-morbid mental health issues faced by individuals with FASD, the most common ones are attention problems, such as attention-deficit/hyperactivity disorder, conduct disorder, alcohol or drug dependence, depression, and anxiety.

Children with FASD are also at an increased risk of disrupted school experience (e.g., being suspended, expelled, or dropping out of school), legal issues (e.g., encounters with police, authorities, or the judicial system), showing inappropriate sexual behaviour (e.g., unwanted advances and inappropriate touching), alcohol and drug problems, and confinement (e.g., inpatient treatment for mental health and alcohol/drug problems and incarceration for crime), employment problems, and dependent living. These secondary disabilities are often caused by inadequate support systems; therefore, family dynamics and system-level factors can serve as either protective factors or contribute to exacerbating the expression of secondary disabilities. Risk factors include exposure to violence (sexual and/or physical abuse) and late diagnosis. In the same study conducted by Streissguth et al., those exposed to violence were four times as likely to exhibit inappropriate sexual behaviour.

Protective factors include an early diagnosis, eligibility for services, living in a stable home with nurturing parents, and protection from violence.[10] Therefore, to mitigate the impact of these secondary disabilities, it is imperative that support at home, school, and the healthcare system is strengthened beginning in childhood.[12]

CHALLENGES AND SUPPORT AVAILABLE

Primary disabilities refer to central nervous system dysfunction but diagnosis based on physical features attributed to FASD is limiting and ineffective as demonstrated in the study conducted by Streissguth et al. Secondary disabilities occur later in life and are often caused by inadequate support systems. Therefore, protective and risk factors can improve or prevent secondary disabilities.

Furthermore, studies by Kully-Martens et al. and Keightley et al. focused on pilot programs for children and youth with FASD in Canada.[13-14] Kully-Martens et al.'s study replicated and extended the math interactive learning experience (MILE) program for children (n=28) in Canada.[3,5] Impairments in mathematics have been shown to be of great significance for individuals with FASD.[3] The specific cognitive functioning differences that underlie mathematical impairments for children with FASD include slower processing speed, decreased specific processing efficiency, working memory deficits, difficulty in understanding quantitative concepts and problem solving, and difficulty with visual-spatial processing.[13] The MILE program consists of five one hour one-on-one sessions conducted in a school setting with no direct involvement from caretakers, and considers the strengths and weaknesses of each individual child.[13] The results of the MILE program was shown to be effective at improving math achievement among children with FASD. It is promising that with limited time of five hours, there were significant improvements to the mathematical achievements of the children who received the MILE intervention. The study by Keightley et al. investigated the use of a theatre-based intervention for Indigenous youth in Canada with FASD.[14] The participants (n=3) met five days a week for four hours over a span of four weeks. At the end of the intervention, the authors noted three major findings: (1) a sense of self-confidence garnered through self-expression; (2) an environment in which the participants felt that their individual cognitive issues were supported; and (3) a sense of cohesion and community amongst participants. This intervention was shown to be successful in supporting the cognitive skills of self-expression, social development, and community building in youth with FASD. Overall, there does not appear to be many articles exploring the cognitive abilities for children and youth exposed to alcohol prenatally within the Canadian context.

DISCUSSION

I. Impact of COVID-19

The COVID-19 pandemic has dramatically impacted the routines and day-to-day life for all families, especially children with FASD and their caregivers. Some concerns that caregivers have expressed include: 1) the disruption of services for themselves and their child, and 2) the impact social isolation has on their child's mental health.[15]

Firstly, even prior to the pandemic, 30% of Canadians who care for someone with a disability felt that the support(s) they received were inadequate.¹⁶ The pandemic has only increased these unmet needs due to the cancellation of healthcare appointments, reduced support services available during this time, and other barriers to receiving care.[16]

Secondly, Canadian parents of children with disabilities have been found to be experiencing a higher level of stress throughout the pandemic when compared to parents of children without disabilities. Statistics Canada conducted a crowdsourcing survey in June 2020, where over 32,000 parents responded about how the pandemic has impacted parenting.[17] The results revealed that while many parents reported being "concerned" about their children, parents of children with disabilities were "very" or "extremely concerned". For example, 70% of parents of children with disabilities were very or extremely concerned about their child's screen time. In contrast, these concerns were at a lower rate of 60% among parents of children without disabilities. Likewise, 60% of parents of children with disabilities were notably concerned about their child feeling lonely or isolated, compared to 50% in other parents. However, the most significant difference was how parents perceived their child's school performance and mental health. Among parents of children without disabilities, 36% and 43% reported being very or extremely concerned for their child's learning and mental health, respectively. These figures increased to 58% and 60% for concerns of learning and mental health among parents of children with disabilities.

Moreover, the COVID-19 pandemic has increased mental health challenges for children with FASD. With many schools transitioning to remote online learning or a hybrid model, students with FASD have significantly less time with their teachers, who then, cannot fully understand their needs. Furthermore, increased social isolation has resulted in feelings of boredom, restlessness, and nervousness.[15] These feelings, compounded with pandemic stress and the lack of accessible support services, have exacerbated mental health challenges. Thus, many children and their caregivers are being left with unmet needs.

Consequently, 76% of Canadian parents of children with

disabilities reported feeling very or extremely concerned about managing their child's behaviour, stress, anxiety, and emotions.[17]

Lastly, experts in the field are also worried that the rates of FASD may rise during the COVID-19 pandemic due to increased alcohol consumption. The Canadian Centre on Substance Use and Addiction revealed that 20% of Canadians have increased their alcohol consumption during the pandemic due to the lack of routine, boredom, stress, and loneliness. Furthermore, women have been found to consume more drinks than recommended per day according to Canada's Low Risk Alcohol Drinking Guidelines.[15] Additionally, intimate partner violence, a risk factor for FASD, as it may increase maternal alcohol consumption, has increased during the pandemic. Lockdown and stay-at-home measures have increased safety concerns among women who live with controlling or coercive partners, and it has been found that the number of calls to women's support services has significantly risen during this time.[18] With both the rise in alcohol consumption and intimate partner violence, there may be a potential increase in alcohol-exposed pregnancies.[18] Strategies that can help prevent FASD during the pandemic are inclusion of FASD education and prevention in public health messaging, provision of free contraceptives, and collaboration among healthcare providers for substance use and intimate partner violence to provide holistic care to women at risk of substance use during pregnancy.[18-19]

Hence, it is clear that the COVID-19 pandemic has impacted FASD in a number of facets, including the disruption of support services for children with FASD and their caregivers, the impact of social isolation on the mental health of children with FASD, and the potential increase in FASD prevalence in the near future.[12,15]

II. Current Research Gaps & Future Developments

Given the short-and long-term implications on a child's cognitive development, alongside the complexities of FASD, over 90% of individuals diagnosed with this disorder are estimated to experience mental health challenges.[20] Despite the prevalence of such poor implications, little research has investigated the impact of interventions that address these persistent challenges for youth with FASD. In fact, a recent systematic review conducted in 2020 aimed at exploring the effectiveness of mental health and substance use interventions, revealed that only three out of 10,000 screened studies assessed their efficacy in FASD individuals.[20] The need for these future developments are imperative during this time, given the impacts of COVID-19 in exacerbating mental health challenges for these individuals.

Thus, future research is warranted to investigate the effectiveness of such interventions in FASD youth

specifically. Apart from the poor mental health outcomes that many children with FASD experience, many other repercussions associated with the primary and secondary disabilities of FASD also exist. While their implications have been well-established, again, there is limited research on specific behavioural and cognitive strategies that may improve cognitive functioning. Developing a deeper understanding of the effectiveness of these strategies is critical to the implementation of intervention programs that can improve the physiological, psychosocial and physical health outcomes amongst youth with FASD.[21] Moreover, pharmacological interventions are often prescribed to manage the behavioural issues associated in children with FASD. However, if specific brain receptors that these medications act on are altered by prenatal alcohol exposure, then they may be ineffective.[6] Thus, future research should be aimed at developing a deeper understanding of the various changes that FASD can cause at a cellular level in order to facilitate more effective pharmacological interventions for youth with FASD.[22]

Given the rising concerns of caregivers, especially during the COVID-19 pandemic, it is pertinent that stronger support services are put in place. The 2015 Ontario provincial roundtable report on FASD found very little to no immediate crisis support or services outside of business hours.[23] Furthermore, participants of this roundtable report also called for more funding for services so that families and caregivers have increased access to supports that would assist them in coping with their mental health challenges as well. Finally, support currently exists in silos. As such, streamlining resources for children with FASD and their caregivers will be essential to reduce barriers in accessing information about these programs. For example, participants recommended establishing a one-stop 24/7 source where they could obtain the most updated information about FASD services, such as a national website or toll-free number.

By improving the current research gaps and enhancing support services, caregivers and children with FASD will be more cared for, thus leading to better outcomes with the child's cognitive and overall health development. Stakeholders, such as governmental jurisdictions, are beginning to see these gaps and take action for the future. For example, the Ontario government is investing \$10.1 million in annual funding towards FASD programs and services and diagnostic services for people impacted by FASD.[24] This funding will go towards expanding FASD diagnostic services through new clinics and programs.



CONCLUSION

ASD is a collection of disorders that result in a child due to alcohol consumption during pregnancy, with its signs and symptoms mainly presenting as primary and secondary disabilities. Primary disabilities refer to functional deficits that directly reflect the underlying central nervous damage caused by prenatal exposure to alcohol. On the other hand, secondary disabilities are those that manifest later in life as a result of the primary disabilities associated with FASD. Secondary disabilities are often linked to or exacerbated by the experiences of children with FASD in school and family, especially with regards to the support they receive or stressors they are exposed to.

Caregivers' concern for the impact of FASD primary and secondary disabilities on their child, particularly mental health challenges, has increased significantly during the COVID-19 pandemic.[22] These concerns stem from the disruption of support services for their child and themselves, as well as the impact of social isolation on their child's mental health.[22-23] Additionally, experts are concerned that the rates of FASD may be rising due to heightened alcohol consumption during the pandemic.¹⁶ Therefore, the COVID-19 pandemic has created an urgent need for improved support services for children and caregivers affected by FASD, as well as enhanced FASD prevention strategies for the general public.

Finally, future directions in the field should also aim to address current research gaps and subsequently improve understanding of and treatments for FASD. Areas for future research include: exploring the specific impacts of FASD brain function and how behavioural and cognitive therapies can address it; mechanisms by which pharmacological interventions can improve cognitive functioning; and impact of mental health and substance use interventions for children with FASD.[6,20-21]

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