

Prevalence of Fetal Alcohol Spectrum Disorder among High-Risk Children and Adolescents in a Correctional Facility

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ABSTRACT: **Background:** Fetal alcohol spectrum disorder (FASD) may be under-recognized and under-diagnosed in Israel. Fewer than 10 FASD diagnoses were reported between 1998 and 2007; however, several hundred diagnoses have been made since. Furthermore, less than 10% of surveyed Israeli pediatricians reported adequate knowledge of FASD.

Objectives: To determine the prevalence of suspected FASD, to establish a database as a starting point for epidemiological studies, and to develop FASD awareness for health, social, and educational services.

Methods: A chart review was conducted at an educational facility for children and adolescents with behavioral and learning challenges. The following information was extracted: adoption status, history of alcohol/drug abuse in the biological mother, medical diagnoses, medication use, and information regarding impairment in 14 published neurobehavioral categories. Subjects were classified as: category 1 (highly likely FASD) – impairment in three or more neurobehavioral categories and evidence of maternal alcohol abuse was available; category 2 (possible FASD) – impairment in three or more neurobehavioral categories and evidence to support maternal substance abuse (type/time unspecified); and category 3 (unconfirmed likelihood of FASD) – impairment in three or more neurobehavioral categories and no information regarding the biological family.

Results: Of 237 files analyzed, 38 subjects (16%) had suspected FASD: 10 subjects (4%) in category 1, 5 (2%) in category 2 and 23 (10%) in category 3. Twenty-seven subjects with suspected FASD (69%) had been adopted.

Conclusions: This study is the most comprehensive review of FASD among Israeli children and adolescents in a population with learning and behavior challenges.

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KEY WORDS: adoption, alcohol-related neurodevelopmental disorder (ARND), fetal alcohol spectrum disorder (FASD), prenatal alcohol exposure (PAE), Israeli population

Fetal alcohol spectrum disorder (FASD) is an umbrella term describing several medical conditions caused by prenatal alcohol exposure (PAE). The condition includes fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). More recently, the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) included FASD in their classification systems for neurodevelopmental disorders (NDD) associated with PAE (315.8) and NDD not otherwise specified (315.9) [1]. Individuals affected by FASD often display characteristics such as attention deficit, hyperactivity, aggressiveness, poor judgment, and speech and language difficulties. Early detection of FASD and early intervention is the most critical factor for avoiding adverse outcomes [2-5].

The incidence of FASD can be difficult to estimate. General population figures may underestimate the frequency of FAS. High-risk populations have a higher prevalence of FASD but the rate varies by geographic region. The results of several active case studies suggest an alarming pervasiveness, making FASD the leading cause of NDD worldwide. In a recent meta-analysis, the global prevalence of alcohol use during pregnancy was estimated at 9.8%. FAS was estimated to occur in 14.6 per 10,000 births in the general population. In addition, one in every 67 women who consumed alcohol during pregnancy would deliver a child with FAS, which translates to about 119,000 children born with FAS in the world every year [6]. The prevalence ratio of FAS to FASD is estimated at 1:9 or 1:10, indicating that FAS is only the tip of the iceberg [2].

In Israel, similar to many other countries, FASD is under-recognized and underdiagnosed. In a recent survey of geneticists and developmental pediatricians, less than 10% report they have sufficient knowledge and resources to diagnose and manage FASD [7]. Thus, misdiagnosis is likely a challenge for specialists and primary care providers. Fewer than 10 FASD diagnoses were reported in Israel between 1998 and 2007; however, to the best of our knowledge, there have been

several hundred additional diagnoses since then [8]. In Israel, adopted children, particularly those from Eastern Europe, may be at higher risk of FASD [8].

More than 1 in 1000 Israeli children are estimated to be at risk, and 15% of children assessed prior to adoption in 2011 were diagnosed with FASD or were at risk for the condition [9]. In Israel, drinking alcohol during pregnancy has not been a focus of health education initiatives. In 2012, of approximately 4000 women surveyed in hospital maternity wards, 14% reported alcohol consumption during pregnancy [10]. Understanding the prevalence of FASD in Israel among high-risk populations and of PAE in the general population is fundamental to the future of program organization and healthcare planning.

Three major methods have been used to estimate the prevalence of FASD: surveillance and record reviews, clinic-based studies, and active case ascertainment methods. The objective of the present study was to estimate the prevalence of FASD in high-risk populations in Israel based on a record review of children and adolescents.

PATIENTS AND METHODS

We conducted a detailed chart review at Bnei Arazim, a correctional facility for children and adolescents with neurobehavioral and learning challenges in central Israel. Bnei Arazim treats patients with severe psychiatric morbidities who have been hospitalized for long periods in psychiatric facilities without improvement in their status. These individuals have been diagnosed with severe conduct disorders, attention deficit hyperactivity disorders, learning disabilities, and other psychiatric disorders and special needs. They cannot return to their homes and families due to the inability of the family to cope with their difficult status. We selected our study population for a number of reasons. First, Bnei Arazim is a government-funded public center that admits patients from all regions of Israel. Second, the facility represents high-risk individuals with difficulties commonly seen in FASD, providing a high-risk, targeted population.

The study was approved by the Assuta Research Ethics Committee in Tel Aviv. The first author and a parent advocacy leader conducted the chart review. Charts contained medical, educational, social service, and psychological records. A pediatric psychiatrist responsible for the care of these children shared the required information with the researchers. All personal identifying information was removed. A password-protected database was created, and the following information was extracted from the files: history of alcohol/drug abuse by the biological mother, medical diagnoses, medication use, adoption status, and information regarding impairment in 14 published neurobehavioral categories using standardized psychological and psychiatric developmental tools. The cat-

egories included motor skills, neuroanatomy/neurophysiology, cognition, language, academic achievement, memory, attention, executive function, impulse control, hyperactivity, affect regulation, adaptive behavior, social skills, and social communication [3].

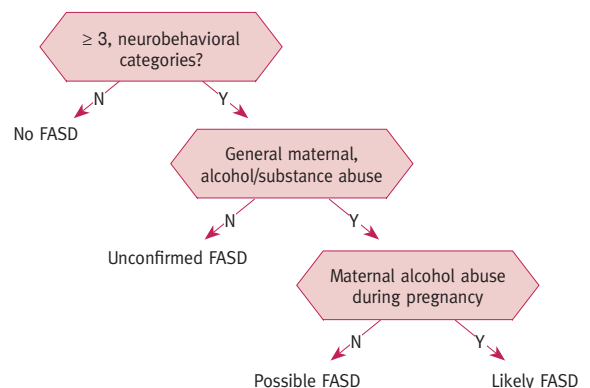
Participants were grouped into three categories [Figure 1].

- **Category 1:** Neurodevelopmental disorder associated with history of prenatal alcohol exposure
 - Likely FASD: impairment in three or more neurobehavioral categories was present and evidence was available to support prenatal alcohol exposure, early life adversity (ELA) and/or chronic maternal alcohol use disorder
- **Category 2:** Neurodevelopmental disorder associated with maternal substance use disorder (MSUD) and ELA
 - Possible FASD: impairment in three or more neurobehavioral categories was present and evidence was available to support maternal substance abuse (type/time unspecified)
- **Category 3:** Neurodevelopmental disorder not otherwise specified and ELA
 - Unconfirmed likelihood of FASD: impairment in three or more neurobehavioral categories was present in the absence of information regarding the biological family [Figure 1].

RESULTS

The majority of the children and adolescents who attended this correctional facility did so due to serious encounters with the law. In total, 237 files were analyzed and no case was excluded. Evidence was available for 10 participants regarding PAE. For five, there was information suggestive of PAE because their

Figure 1. Flowchart representing criteria for three categories of suspected FASD: likely FASD, possible FASD, and unconfirmed FASD



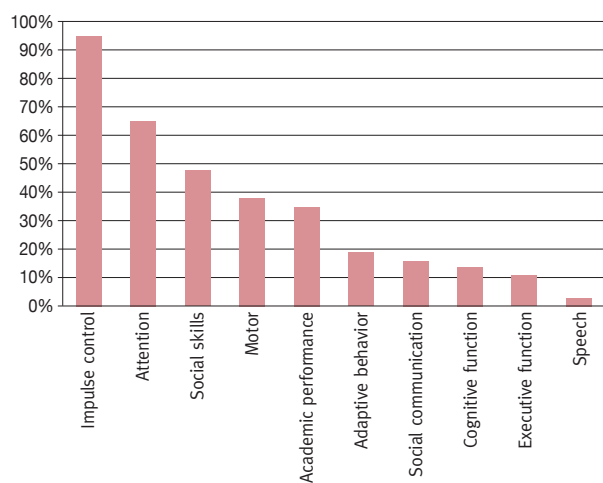
FASD = fetal alcohol spectrum disorder

biological mothers abused drugs and other substances, but the prenatal period was not specified. For 23, there was no specific information regarding maternal alcohol use but the family history and collateral information available to the investigators suggested the child was at high risk of PAE, in addition to both ELA and a similar neurodevelopmental phenotype. Hence, based on our categories, a total of 38 children and adolescents (16%) were suspected of a FASD diagnosis because they met the DSM-V criteria for neurodevelopmental disorders (315.8 or 315.9) [1]. Of these participants, 42% were female and 58% were male. Ten participants (4%) met the definitions of category 1, five (2%) met the criteria in category 2, and 23 (10%) were grouped into category 3. Children across all categories were 9.5–16 years of age at admission to the facility (mean age 13.5 years).

Twenty-seven of the 38 children and adolescents in all FASD categories (71%) were recorded as having been adopted. Ten were born in Eastern Europe (Russia, Romania, Lithuania, and Ukraine) and the remainder were born in Israel, Africa, South America, or North America, or the information was unavailable. The origins of the remaining 29% were unavailable, but indications showed that they were born to mothers who had more recently immigrated to Israel.

All of the children and adolescents suspected of FASD had at least four neurobehavioral deficits. Deficits in impulse control was the most common category (95%) of the participants, followed by deficits in social skills (48%), motor deficits (38%), low academic performance (35%), problems in acquiring adaptive behavior (19%), poor social communication (16%), issues in cognitive function (14%), difficulties with executive function (11%), and speech deficits (3%) [Figure 2]. Other neurobehavioral categories frequently used in formal diagnosis were not recorded in the files.

Figure 2. Percentage of children with suspected FASD and each of the listed neurodevelopmental deficits



FASD = fetal alcohol spectrum disorder

The children were referred from multiple sources, including social services, psychiatric hospitals, school psychologists/teachers, child protective services, the military, parents, court order, medical personnel, or prison staff. Fifteen of the children (39%) with suspected FASD were diagnosed with ADHD at a mean age of 8 years (range 4–17 years), 5 children (13%) were diagnosed with conduct disorder, and 2 children (5%) were diagnosed with generalized anxiety disorder. The mean age at diagnosis for the remaining conditions was 7 years.

DISCUSSION

This study suggests that the prevalence of FASD may be as high as 16% of the population of children enrolled at Bnei Arazim, an education and behavior correctional facility in central Israel. This finding is more than 30 times the estimated prevalence in the general population of school-aged children [11].

Adopted children have been previously identified as a high-risk group for FASD in Israel and abroad, particularly when the adoptee was born in Eastern Europe [9,12]. Our findings support this conclusion and emphasize the need to develop services for families whose children may be at risk for FASD. Currently, a child up to 7 years of age who has been diagnosed with FASD can receive services, such as occupational and speech therapy, from the Ministry of Education, and they are eligible for a disability pension from the National Insurance Institute. However, these services are limited: the former by age since FASD may not be diagnosed until age 7 years or later, and the latter due to a shortage of qualified pediatricians and other health professionals needed for medical assessment. Of note, 31% of the children with suspected FASD in our study population were not adopted and were conceived by Israeli mothers. Recent data suggest that alcohol consumption during pregnancy is a public health concern in Israel. The alarming prevalence of PAE worldwide, including Israel, is of concern for both women and their children. Its eradication has been identified by the United Nations in its list of sustainable development goals (SDG # 1,3,4,5,8,10) for 2030 [13].

Although our study provides a rough estimate of the prevalence of FASD in a high-risk population of children enrolled at a learning and behavior correctional facility, our figure of 16% suspected FASD coincides with a recent study concerning Israeli children eligible for adoption. Our findings also showed that 16% were at risk for or diagnosed with FASD [9]. To the best of our knowledge, none of the children in our study had a past diagnosis of FASD. There is a high likelihood that under-diagnosis and misdiagnosis of this condition is commonplace in Israel. In addition, the children with suspected FASD from our study population had been previously diagnosed with other conditions such as ADHD, conduct disorder, and general anxiety disorder at a mean of 7 years of age. This finding coincides with the mean age at

diagnosis of FASD, further suggesting that this population may be underdiagnosed or misdiagnosed [14].

Our study was limited to a retrospective chart review. Inherent in this type of study is a high variability in the quality and type of data available from each subject. For FASD specifically, this problem is accentuated by the lack of information about PAE.

For the diagnosis of FASD, documented PAE is imperative. Specifically, for ARND, ARBD, and neurodevelopmental PAE, these diagnoses can only be made with evidence of PAE. For some children in our study, clear evidence regarding PAE was available with a detailed medical and social history of the child's biological family. For other children, there was no explicit information about the pregnancy or even the child's biological family. In the latter cases, the diagnosis of unconfirmed FASD was made by clinical observations, timeline of events, and evidence suggesting childhood neglect.

Further work is needed to determine the prevalence of FASD in Israel. Our study is based on a review of records; hence, clinic-based and active case studies are needed. In addition, some of the participants evaluated in this study were young adults at the time of data collection, possibly representing a previous adoption cohort, and not a current one.

Our study provides a starting point for a comprehensive assessment of FASD epidemiology in Israel. Special education in Israel continues up to the age of 21 years. If children are enrolled in special education programs, such as those available at Bnei Arazim, they continue to be treated into their adolescent years. In addition, health services that focus on child development play an important role in the health system. In the case of Bnei Arazim, there is close collaboration between the facility and other community, medical, and educational services to ensure favorable continuity after the child is released from the facility. Further detailed studies are required and should begin in high-risk settings such as psychiatric hospitals, juvenile prisons, and correctional facilities, as well as at medical facilities and during adoption services. Understanding FASD epidemiology is the first step in determining how to allocate resources and services for this community. Furthermore, strategies to support women with a history trauma, domestic violence, mental health concerns, and addiction issues are needed in

addition to concurrent education about the effect of PAE and other environmental exposure prior to pregnancy recognition.

CONCLUSIONS

With early intervention and intervention, the concerns of PAE and FASD can be addressed and services and programs for this population can be developed and implemented.

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References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5[®]). Washington, DC: American Psychiatric Association, 2013.
2. Chudley AE, Conry J, Cook JL, Looock C, Rosales T, LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ* 2005; 172 (5): S1-21.
3. Cook J, Green C, Lilley C, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016; 188 (3): 191-7.
4. Sokol RJ, Delaney-Black VNB. Fetal alcohol spectrum disorder. *JAMA* 2003; 290 (22): 2996-9.
5. Stratton K, Howe C, Battaglia FC. Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. Washington, DC: National Academy Press, 1996.
6. Peadon E, Rhys-Jones B, Bower C, Elliott EJ. Systematic review of interventions for children with fetal alcohol spectrum disorders. *BMC Ped* 2009; 9 (35): e1471-2431.
7. Senecky Y, Inbar D, Diamond G, Basel-Vanagaite L, Rigler S, Chodick G. Fetal alcohol spectrum disorder in Israel. *IMAJ* 2009; 11 (10): 619-22.
8. Koren G. Adopted children from the former Soviet Union: are they at risk of fetal alcohol spectrum disorder? *Can Fam Physician* 2013; 59 (10): 1063-4.
9. Tenenbaum A, Hertz P, Dor T, Castiel Y, Sapir A, Wexler ID. Fetal alcohol spectrum disorder in Israel: increased prevalence in an at-risk population. *IMAJ* 2011; 13 (12): 725-9.
10. Neumark Y. Alcohol consumption in Israel: a public health and medical problem. *IMAJ* 2012; 14 (5): 315-17.
11. May PA, Gossage JP, Kalberg WO, et al. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Devel Disabil Res* 2009; 15 (3): 176-92.
12. Landgren M, Svensson L, Strömmland K, Grönlund MA. Prenatal alcohol exposure and neurodevelopmental disorders in children adopted from Eastern Europe. *Pediatrics* 2010; 125 (5): e1178-85.
13. United Nations. Sustainable Development Goals. 2016: [Available from <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>]. [Accessed 10 December 2017].
14. Astley S. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol* 2010; 17: e132.

“The most difficult thing is the decision to act, the rest is merely tenacity. The fears are paper tigers. You can do anything you decide to do. You can act to change and control your life; and the procedure, the process is its own reward”

Amelia Earhart (1897–1937), American aviation pioneer, the first female aviator to fly solo across the Atlantic Ocean, and author

“When you counsel someone, you should appear to be reminding him of something he had forgotten, not of the light he was unable to see”

Baltasar Gracian (1601–1658), Spanish Jesuit, writer and philosopher