Ten-year experience of fetal alcohol spectrum disorder; diagnostic and resource challenges in Indigenous children

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Abstract

Background:

Although fetal alcohol spectrum disorder (FASD) can have a disproportionate impact in some Indigenous communities, there is a paucity of literature on its epidemiology.

Objective:

To characterize the epidemiology of Indigenous individuals under the age of 18 years who were diagnosed with FASD at Anishnawbe Health Toronto over a 10-year period.

Methods:

Children who were assessed at Anishnawbe Health Toronto from 2002 to 2012 and met the 2005 criteria for FASD were included. The multidisciplinary team assessed neurodevelopmental abnormalities, FASD facial features and growth parameters and enquired about maternal alcohol consumption, current custody and involvement with the criminal justice system.

Results:

Forty-nine children were diagnosed with FASD. None of these had full fetal alcohol syndrome (FAS); 12 were diagnosed as partial FAS and 37 with alcohol-related neurodevelopmental disorder (ARND). Thirty-five were male and the median age at diagnosis was 9 years. Nineteen were wards of children's services, and 8 were living with adoptive parents. All children had

abnormalities in psychometric testing. Other issues included: behavioural issues (80%); learning disabilities (63%); attention deficit hyperactivity disorder (43%); developmental delay (14%); involvement with the criminal justice system (12%) and alcohol abuse (10%). The morbidity and impairment for ARND was higher on almost every measurement compared with partial FAS.

Conclusions:

FASD is a preventable cause of lifelong significant morbidity to Indigenous children with a high proportion of children needing foster-care services and involvement with the criminal justice system at an early age. Although ARND is difficult to diagnose, it can result in significant morbidity. Additional resources for culturally sensitive primary prevention and early diagnosis of FASD for Indigenous families are required.

Keywords: *Alcohol-related neurodevelopmental disorder, Diagnosis, Fetal Alcohol Spectrum Disorder, First Nations; Indigenous.*
Topic: alcohol abuse, primary prevention ,fetal alcohol syndrome, alcohol drinking, attention-deficit/hyperactivity disorder, patient care team, psychometrics, behavior, learning disabilities ,facial features ,developmental delay , foster care ,adult attention deficit hyperactivity disorder , community , interdisciplinary treatment approach , adoptive parent , neurobehavioral disorder associated with prenatal alcohol exposure , cultural sensitivity
Issue Section: Original Article

Fetal alcohol spectrum disorder (FASD) is the spectrum of conditions including the structural anomalies, behavioural and neurocognitive abnormalities that are associated with fetal exposure to alcohol (1). There are no national Canadian statistics currently available on this disorder. The diagnosis of FASD may be missed, this leading to under representation of its prevalence. Despite these limitations, the prevalence of FASD has been estimated as 1% or approximately 330 000 in Canada (2).

FASD is a highly preventable condition found in all socioeconomic groups but has disproportionately affected some Indigenous communities (3,4). Although fewer Inuit and Cree women residing in Northern Quebec drank alcohol compared with the general population, those who drank consumed higher quantities (5). While there are Indigenous communities where alcohol is restricted, First Nations women have a 10-fold increase risk of death due to alcohol and drugs than their non-Indigenous counterparts (6). Higher rates of alcohol use often translate into increased rates of FASD (7). Although Indigenous communities are heterogeneous for risk, alarming FASD statistics have been reported in some Canadian Indigenous communities, such as 190 per 1000 live births in a community in British Columbia [where 22 of 116 children less than 18 years of age were diagnosed with FASD (3)] and there were 55–101 cases per 1000 live births on a Manitoba First Nations reserve (4). Intergenerational trauma from the

residential school system and other colonial policies have contributed to widespread alcohol and other substance abuse in some communities and individuals; however, not all individuals who had these exposures abuse alcohol (8). This problem is not limited to Canada. The prevalence of fetal alcohol syndrome (FAS) in the USA has been reported as 1%–3% per 100 live births and FASD as 9.1 per 1000 live births (9) with rates higher for American Indians/Alaska native compared with other racial groups (7); the risk is attributed to poverty and historical trauma such as residential schools (10) rather than race.

As FASD is a preventable cause of brain damage, with lifelong social and behavioural implications, prevention, identification and amelioration of the impact of FASD are of high priority, especially in under-researched populations such as urban Indigenous children. The objective of this report is to characterize the epidemiology of Indigenous individuals under the age of 18 years who were diagnosed with FASD at Anishnawbe Health Toronto (AHT) over a 10-year period (2002–2012) and to discuss some of the diagnostic and resource challenges for FASD in Indigenous children.

METHODS

AHT is a community health centre located in downtown Toronto, Canada. Its mission is to provide comprehensive health to the Indigenous community in Toronto. This review assesses all cases of FASD diagnosed at AHT, in individuals under 18 years of age, between 2002 and 2012. Patients were referred to AHT for FASD assessment by family physicians, social workers, schools, parents or relatives. The diagnoses of FASD were based on the 2005 Canadian guidelines (9) for full FAS, partial FAS, and alcohol-related neurodevelopmental disorder (ARND). The diagnosis of FASD is complex and requires a comprehensive history, physical and neurobehavioural assessment by a multidisciplinary team (9). The multidisciplinary team involved in the assessment included general practitioners or a paediatrician, psychologists, social workers, traditional healers and a FASD support worker who acts as a navigator for the family.

The assessment included questions about demographics including age at assessment and sex. Current custody was also recorded. For the diagnosis, the following were sought 1) details of maternal alcohol consumption in pregnancy, 2) evidence of classical facial features associated with FAS, 3) growth parameter deficiencies prenatally and postnatal and 4) evidence of neurodevelopmental abnormalities.

Cases diagnosed as full FAS (with or without confirmation of maternal alcohol exposure) had abnormalities in the following three domains: facial dysmorphic features, growth abnormalities and neurocognitive defects (1). Those diagnosed as partial FAS (with or without confirmation of maternal alcohol exposure) displayed some typical facial dysmorphic features with abnormalities in at least one other domain (i.e., growth and neurocognitive). ARND children had a history of documented alcohol exposure and displayed the characteristic patterns of behavioural or neurocognitive abnormalities such as markedly impaired executive functioning but lacked the classical facial dysmorphic features or growth abnormalities (9).

A review of the exposure to alcohol in pregnancy was conducted through interviews with the biological mother, review of medical or social service records. Maternal alcohol consumption was described by the

trimester (first, second or throughout pregnancy). The frequency was categorized as occasional, binge (periods of excessive drinking usually more than four drinks in a 2-hour period), regular (two or more drinks most days of the week), chronic (long-term heavy use with dependency) and a combination of binge and regular drinking.

Growth parameters included the birth weight and height and weight recorded at the assessment. A child was considered to have a growth deficiency if he/she was less than the fifth percentile on any parameter. Although there are many dysmorphic features associated with classical FAS (1), in keeping with the 2005 Canadian guidelines, it was restricted to short palpebral fissures, smooth philtrum and thin upper lip (9). Facial features were graded according to a Likert scale with a range of 1 to 4, where 1 = no features of classical FAS, 2 = one feature, 3 = two features and 4 = all facial features of FAS.

A clinical psychologist conducted psychometric testing. Neurobehavioural assessment was conducted across eight domains: hard and soft neurological signs; brain structure (head circumference, abnormalities on magnetic resonance imaging); cognition; expressive and receptive communication; academic achievement; memory; executive functioning and abstract reasoning; attention deficit and hyperactivity; adaptive behaviour; social skills and communication. A domain was considered abnormal if 2 standard deviations below the mean or based on significant dysfunction taking into consideration age, socioeconomic and environmental factors. Outcomes were categorized on a Likert scale: 1 = no structural or functional evidence of impairment, 2 = dysfunction in less than 3 domains, 3 = dysfunction across three or more domains, 4 = across three or more domains with structural or neurological abnormalities. Behavioural issues such as involvement with the criminal justice system were documented. Cases were categorized as either 1) full FAS, 2) partial FAS, 3) ARND, 4) insufficient evidence to make a diagnosis, or 5) no evidence of FASD. In this report, we describe the cases that met the criteria of FASD (categories 1–3) through descriptive epidemiology.

RESULTS

There were 80 individuals assessed for FASD during the study period. The diagnosis demographics and prenatal exposures are listed in Table 1. There was no evidence of FASD in six (8%) and in 25 patients (31%) there was not sufficient evidence to diagnose the disorder. Forty-nine children (61%) were diagnosed with FASD. None of these had full FAS; 12 were diagnosed as partial FAS and 37 were diagnosed with ARND. Thirty-five of 49 (71%) patients with FASD were male. The median age for all categories was 9 years.

Table 1.

Demographics and pregnancy exposure for Indigenous children with FASD assessed at Anishnawbe Health, Toronto, 2002–2012

	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Demographics			
Male	35 (71)	10 (83)	25 (68)
Median age in years (range)	9 (0–18)	9 (6–17)	9 (0–18)
Source of information			
Mother	30 (61)	9 (75)	21 (57)
Father	5 (10)	1 (8)	4 (11)
Close relative	9 (18)	2 (17)	7 (19)
Children's Aid Society	5 (10)	0	5 (14)
Currently residing with			
Mother	6 (12)	1 (8)	5 (14)
Father	6 (12)	2 (17)	4 (11)
Both parents	1 (2)	1 (8)	0
Adoptive parents	9 (18)	1 (8)	8 (22)

	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Other relatives	8 (16)	2 (17)	6 (16.2)
Children's Aid Society	19 (39)	5 (42)	14 (38)
Pregnancy exposure and delivery			
Timing of drinking			
First trimester drinking	36 (74)	8 (67)	28 (76)
Second trimester drinking	1 (2)	1 (9)	0
Drinking all through pregnancy	2 (4)	1 (9)	1 (3)
Unavailable	10 (20)	2 (17)	8 (22)
Frequency of drinking			
Occasional only	2 (4)	0	2 (5)
Regular only	14 (29)	2 (17)	12 (32)
Binge only	2 (4)	1 (9)	1 (3)
Combined pattern (binge and regular)	15 (31)	6 (50)	9 (24)

	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Known to be chronic alcohol abuser	16 (33)	3 (25)	13 (35)
Other known drugs usage			
Crack	7 (14)	0	7 (19)
Cocaine	10 (20)	1 (8)	9 (24)
Marijuana	20 (41)	5 (42)	15 (41)
Birth weight in kilogram			
3.2 or over	26 (53)	4 (33)	22 (60)
2.5–3.1	14 (29)	6 (50)	8 (22)
Less than 2.5kg	5 (10)	1 (8)	4 (11)
Unknown	4 (8)	1 (8)	3 (8)
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ARND alcohol-related neurodevelopmental disorder; FAS fetal alcohol syndrome; FASD fetal alcohol spectrum disorder

Of the 49 children who had a diagnosis within FASD, 19 (39%) were wards of the Children's Aid Society or in foster care, 8 (18%) were living with adoptive parents, 13 (26%) with one or both parents and 8 (16%) with other relatives. Although it was possible to confirm prenatal alcohol exposure, as many of these children lived in foster homes, the duration or amount of prenatal alcohol consumed could not always be specified. Sixteen (27%) of the mothers were not aware of being pregnant in their first trimester and two (4%) drank throughout pregnancy. Drinking patterns of the mothers and information on concomitant drug use of crack, cocaine and marijuana where available are documented in Table 1.

The diagnosis and behavioural issues are listed in Table 2. Moderate-to-severe classical FAS facial features were documented in two-thirds of children but not in ARND children (by definition). All children had abnormalities in psychometric testing, with 44 demonstrating impairment in two to three domains whereas five had impairment in more than three domains (all with ARND). A significant proportion had issues such as learning disabilities and behavioural problems (both observed in more than half of cases);

developmental delay, attention deficit hyperactivity disorder (ADHD), alcohol abuse and involvement with the justice system were also observed. There was a higher percentage of disabilities in the ARND than the partial FAS group in all categories except developmental delay.

Table 2.

Growth, physical features and behaviour assessment and issues for Indigenous children with FASD

	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Physical assessment			
Facial features			
No abnormality	13 (27)	1 (8)	29 (97)
Mild abnormality	21 (43)	3 (25)	1 (3)
Moderate abnormality	14 (29)	7 (58)	0
Severe abnormality	1 (2)	1 (8)	0
Growth parameters at assessment visit			
Height below fifth percentile	2 (4)	2 (17)	0
Weight below fifth percentile	3 (6)	2 (17)	1 (3)
Neurobehavioural testing			

	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Abnormalities in 2–3 domains	44 (90)	12 (100)	32 (86)
Abnormalities in greater than three domains	5 (10)	0	5 (14)
Other brain dysfunction			
Learning disability	31 (63)	6 (50)	25 (68)
Developmental delay	7 (14)	4 (33)	3 (8)
ADHD	21 (43)	3 (25)	18 (49)
Behaviour problems	39 (80)	9 (75)	30 (81)
Other issues			
Alcohol abuse	5 (10)	1 (8)	4 (11)
Involvement with criminal justice	6 (12)	2 (17)	4 (11)
	Total, n=49	Partial FAS, n = 12	ARND, n= 37
Physical assessment			

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DISCUSSION

This is the first study describing Indigenous children with FASD presenting at an urban Indigenous health centre in Canada. The key finding in our series was that the morbidity and impairment for ARND was higher on almost every measurement compared with partial FAS. Without the classical facial features of FASD, children with ARND remain an invisible group and are harder to diagnose, especially without the history of prenatal alcohol exposure, whereas the neurobehavioural disability is just as prominent (11).

FAS is the leading preventable cause of neurodevelopmental disabilities among Canadian children and youth (12) and has substantial individual and societal costs. Stade et al. (13) described children with FASD as having lower health-related quality of life than children with physical disabilities or those who lived with the sequelae of childhood cancer. Societal burden for FASD is immense due to the lost productivity, excess medical and educational expenses, and costs to the foster care and criminal justice system (12). In 1998, the excess cost of FASD was estimated to be $4 billion in the USA (14). The annual costs of managing FASD per affected person less than 21 years of age in Canada was estimated to be

$350,000 in 2006 (13). A 2014 total cost estimate was updated to $9.7 billion a year with 40% being related to the justice system, 21% health care, 17%, education, 13% social services and 9% to others (15).

In our study, a high proportion of cases were living in foster homes. A case control study of American Indian children with FAS demonstrated that a disproportionate number were placed in foster homes (16). This is likely due to a combination of the inability of the biological mother to care for her child and the serious life-long problems in adapting to independent living (12). FASD is frequently associated with ADHD (17) and sleep disturbance (18) which compounds learning difficulties. Deficits in executive functioning, such as organizing, difficulty learning from mistakes and a lack of inhibition can lead to life-long problems adapting and functioning in society (12). In addition, there are high rates of secondary disabilities that develop as a consequence of FASD such as depression, panic disorders and maladaptive behaviour such as antisocial and delinquent behaviour, impulsivity, bullying, destructive behaviour or self-harm (12). In one surveillance of 473 individuals with FASD, 94% had mental health problems identified as secondary disabilities such as depression, ADHD and panic disorders (19).

In this study, 12% of the children were already involved with the justice system, despite a median age of 9 years. Many Indigenous children with FASD will become involved with the justice system in their teen and later years. Often they are disadvantaged when dealing with apprehending officers due to disabilities in various aspects of their cognitive functions. In British Columbia, 60% of adults (>12 years of age) diagnosed with FASD had been involved with the justice system (20). Given the relative lack of diagnostic resources in Indigenous communities, we postulate that a considerable number of Indigenous offenders with FASD have never been diagnosed as having this disorder. Increased diagnostic resources for FASD in the correctional system may allow a greater emphasis on rehabilitation and support.

One of the most important factors for reducing secondary disabilities and improving the long-term outcome of FASD is an early diagnosis (before the age of six) (11). Delay in diagnosis may increase the risk of secondary disabilities such as poor school experiences, inappropriate sexual behaviour, alcohol and drug abuse, and incarceration and retention in the justice system. An early diagnosis of FASD might ameliorate the risks of serious criminal behaviour. In addition, it can lead to increased independence, and greater access to services, especially during the school years. Other measures which could improve the long-term outcome of FASD include enhanced substance abuse programs and programs designed to improve life skills and usability.

As FASD is a major public health issue in Canada, efforts must be made to reduce the risk of alcohol exposure to a fetus in pregnancy. Primary prevention (to protect the fetus against alcohol before pregnancy) or secondary prevention (to reduce the amount of alcohol consumed in a pregnant woman) measures need to be enhanced in communities with high rates of FASD. Early detection of pregnancy provides more opportunities for abstinence. Alcohol abuse in pregnancy is often reinforced by social and economic factors and can be difficult to change; it often requires multiple strategies to minimize the risk of alcohol exposure to the fetus (21). Culturally and linguistically appropriate media campaigns targeting American Indian women of child-bearing age on FASD appeared to decrease their drinking behaviour (22). There have been successful programs among American Indians including individual case

management (21,23). Identification and intervention for women with a previous child with FASD is a high priority to prevent future children with FASD (24).

The diagnosis of FASD is complex for numerous reasons, and ARND likely remains difficult to diagnose and continues to be underdiagnosed. Currently the Canadian guidelines suggest a multidisciplinary approach to the assessment of FASD. Assessment of FASD requires a knowledgeable and experienced team of health professionals consisting of a paediatrician, psychologist, social worker and when necessary, an audiologist, speech and language pathologists and an occupational therapist. Inclusion of a traditional healer or elder as part of the team is highly recommended. Indigenous traditional healers help foster a cultural connection, interpret meaning of FASD in cultural context to both parents and children and provide lifestyle and vocational guidance.

Currently, most Indigenous communities do not have the diagnostic resources for FASD. The FASD TOOL KIT for Aboriginal Families is one resource for frontline workers and families for those affected with FASD (25); however, a comprehensive list of resources for FASD Indigenous communities is not available. Further research on the presentation of FASD in Indigenous communities, the barriers for diagnosis and availability of support services are needed. The development of Regional Diagnostic Assessment Facility would be beneficial for Indigenous populations with small populations. Partnerships with communities and governmental agencies should work toward identifying and addressing the gap in diagnosis and service.

LIMITATIONS

The sample size of this study was low, and because of referral bias, this report may represent some of the more severe cases of FASD; it is not clear if the results from this study can be generalized to other urban Indigenous populations. In addition, as many of the children with FASD are in foster care, the maternal history of alcohol consumption is often not available; further contributing to the likelihood that some of the suspected cases may not have been identified. Recent revisions to the diagnosis of FASD in 2016 have removed the growth restrictions and generally reduced the threshold for diagnosis; this may have resulted in additional children being identified if reapplied to this population (2).

CONCLUSION

FASD is a preventable cause of lifelong significant morbidity to Indigenous children and their caregivers, with a high proportion of children needing foster-care services and being involved with the justice system at an early age. Additional resources for prevention, diagnosis and accommodation for Indigenous communities are required to start addressing this complex issue. The number of regional diagnostic assessment facilities for FASD sensitive to Indigenous cultural safety needs to be increased.

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Conflict of Interest

The authors have no conflicts of interest to declare.

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