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Fetal Alcohol Spectrum Disorder in Northeastern Ontario: A Descriptive Examination of Who is Assessed, Who Receives a Diagnosis, and Who Does Not

Trouble du spectre de l'alcoolisation fœtale dans le Nord-Est de l'Ontario : un examen descriptif des personnes évaluées, des personnes qui reçoivent un diagnostic et de celles qui ne le reçoivent pas

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Abstract

As part of a larger project that provides unique insight into the profile of Canadians assessed for Fetal Alcohol Spectrum Disorder (FASD) across various diagnostic clinics, the purpose of the current study was to highlight who presents for FASD assessment in Northeastern Ontario, and the related diagnostic outcomes between those who are diagnosed and those who are not. A total of 326 children and youth were included in the overall sample of individuals assessed at the only diagnostic service in the Northeastern Ontario region in Sudbury, Ontario. Specific comparisons between those diagnosed with FASD and those not diagnosed were further explored. Results indicated that functional difficulties, including both neurodevelopmental and mental health impairments, were evident in all individuals, regardless of an FASD diagnosis. However, for individuals who received a diagnosis of FASD, greater mental health concerns and neurodevelopmental impairment beyond what is necessary to receive a diagnosis were noted.

While impairment at the clinical level (i.e., 2 or more standard deviations below the mean, as per Canadian FASD Diagnostic Guideline) was lower in those who did not receive a diagnosis, difficulties pertaining to behaviour and mental health were identified. Overall, the results support a multiservice need among those prenatally exposed to alcohol in the region. The findings are discussed in relation to the existing *literature on the common outcomes associated with prenatal alcohol exposure, and FASD more specifically. Limitations and implications are also discussed.*

Résumé

Dans le cadre d'un projet plus vaste qui fournit un aperçu unique du profil des Canadiens évalués pour l'ensemble des troubles du spectre de l'alcoolisation fœtale (TSAF) dans diverses cliniques de diagnostic, l'objectif de la présente étude était de dresser le portrait des individus qui se présentent pour l'évaluation du TSAF dans le Nord-Est de l'Ontario, et de présenter plus précisément le profil de ceux reçoivent ou non un diagnostic. Au total, 326 enfants et jeunes ont été inclus dans l'échantillon global de personnes évaluées au seul service de diagnostic de la région du Nord-Est de l'Ontario, à Sudbury. Des comparaisons spécifiques entre les personnes ayant reçu ou non un diagnostic de TSAF ont été effectuées. Les résultats démontrent que les difficultés fonctionnelles, y compris les troubles neurodéveloppementaux et de santé mentale, étaient évidentes chez tous les individus, sans égard à la présence d'un diagnostic de TSAF. Cependant, pour les personnes ayant reçu un diagnostic de TSAF, des préoccupations concernant la santé mentale et les troubles neurodéveloppementaux allant au-delà de ce qui est nécessaire pour recevoir un diagnostic ont été notées. Bien que les déficits cliniquement significatifs (c.-à-d., au moins 2 écarts-types en-deçà de la moyenne, selon les lignes directrices canadiennes pour le diagnostic du TSAF) était moins présents chez les personnes n'ayant pas reçu de diagnostic, des difficultés liées au comportement et à la santé mentale ont été identifiées. Dans l'ensemble, les résultats soulignent un besoin multiservice chez les personnes exposées à l'alcool avant la naissance pour cette région de l'Ontario. Les résultats sont discutés en lien avec la littérature actuelle portant sur les conséquences couramment associées à l'exposition prénatale à l'alcool et sur le TSAF plus particulièrement. Les limites et les implications sont également discutées.

Mots-clés : trouble du spectre de l'alcoolisation fœtale, exposition prénatale à l'alcool, Nord-Est ontarien, évaluation, diagnostic, santé mentale.

Introduction

While there is a growing body of research on the typical patterns of deficits and common challenges associated with Fetal Alcohol Spectrum Disorder (FASD), little research has examined diagnostic outcomes in a Canadian sample, and to our knowledge, no research has considered them in Northeastern Ontario specifically. An earlier study conducted in Northern Ontario examining parenting stress among families of children with FASD identified a significant need for services, specialized supports and increased public knowledge surrounding the disorder (Watson et al., 2013). Furthermore, the authors of a 2015 *Northern Policy Institute* report revealed that individuals living in Northern Ontario face specific challenges in terms of accessing health care services, a lack of culturally appropriate care, as well as increased mental health concerns, as a result of both geographical and economic disparities (Al-Hamad & O'Gorman, 2015). These challenges, along with the established difficulties individuals with FASD and their families face, as well as a lack of research for FASD in Northeastern Ontario, suggest the need for attention in this area.

The aim of the current study was to establish a descriptive overview and profile of individuals who were assessed for FASD in the Northeastern region and to further compare the diagnostic outcomes between individuals diagnosed with FASD and those who did not receive a diagnosis. This information may prove beneficial in addressing the specific services, supports, and interventions that are needed to support those prenatally exposed to alcohol in Northeastern Ontario.

Common Outcomes Associated with FASD and Prenatal Alcohol Exposure

A consistent finding throughout the FASD literature is that the emotional, social, and familial impacts of FASD are profound (e.g., Popova et al., 2015; Reid & Moritz, 2019). At the individual level, both cognitive and behavioural impairments have been shown to significantly impede the success, fulfillment, and general wellbeing of those with FASD (e.g., Domeij et al., 2018; Stade et al., 2006). Most notably, structural damage caused by prenatal alcohol exposure (PAE), which often impairs essential areas of an individual's brain, severely compromises an individual's capacity to effectively plan and control behaviour (Mattson et al., 2011; Rasmussen et al., 2011). Consequently, abilities such as decision-making, organizing, inhibition, and the use of working memory can be difficult and, in some cases, unmanageable for individuals with FASD (Flannigan et al., 2019). Deficits in executive and adaptive skill functioning in individuals with FASD are particularly problematic and have been shown to have significant repercussions on skills in daily living (e.g., personal hygiene), socialization (e.g., the ability to cooperate with others), and communication (e.g., the ability to understand and use words; Mukherjee et al., 2019).

Individuals with FASD have impairment in several neuropsychological areas, with the specific areas of deficit being unique to each individual and thus creating variation in the presentation of the disorder (Ali et al., 2018; Carr et al., 2010). Mental health conditions commonly also co-exist within this population and further complicate the individual's everyday functioning and potential treatment (Pei et al., 2011; Popova et al., 2016; Weyrauch et al., 2017). Considering the widespread impairment, individuals with FASD require comprehensive and consistent support and guidance throughout their lives to provide them with direction, advice, structure, and to aid in their decision-making (Brown et al., 2019). Families often fulfill this mediating role, and have been found to experience significant and unique stress related to worry, daily demands, and the lack of understanding and awareness of their family member's difficulties (Brown et al., 2019; Reid & Moritz, 2019).

Researchers have shown that individuals prenatally exposed to alcohol who do not meet diagnostic criteria for FASD may still experience difficulties similar to those who are diagnosed (e.g., Kully-Martens et al., 2011). One meta-analysis examining differences in behaviour outcomes between children with PAE and those diagnosed with FASD found that PAE alone was associated with poor behaviour ratings (Tsang et al., 2016). Likewise, the authors of earlier studies demonstrated that compared to controls, children and youth with PAE had lowered general intelligence (Mattson et al., 2011), executive functioning deficits (McGee et al., 2008), difficulties with learning and memory (Mattson & Roebuck, 2002), as well as increased rates of psychopathology (Mattson & Riley, 2000). Together, these findings highlight the importance of addressing the particular areas of service need and their availability for individuals prenatally exposed to alcohol who do not meet diagnostic criteria, but who present with difficulties.

FASD in Northeastern Ontario

Though the prevalence of FASD in Northeastern Ontario is largely unknown, past research has reported increased rates in communities with a similar geography to Northeastern Ontario (Tough et al., 2008). It has also been identified that health care providers practicing in rural parts of Ontario report greater exposure to patients with FASD compared to those practicing in urban locations (Coons, Clement et al., 2017).

In 2011, the first ever FASD diagnostic clinic in Northeastern Ontario was established in Sudbury, Ontario, which services children and youth under the age of 18. Prior to the clinic's establishment, families often had to travel long distances or teleconference with health professionals to access an FASD diagnosis (Watson et al., 2013). As of March 2020, 255 individuals were on the waitlist to be assessed at the Sudbury Clinic and the average wait time was estimated to be between 12 to 18 months. The Sudbury FASD multidisciplinary team assesses each individual in line with the Canadian FASD Diagnostic Guideline (Cook et al., 2016) and provides referrals to available services and supports in the region when appropriate. Furthermore, a practice at the Sudbury FASD Diagnostic Clinic, similar to other clinics in Canada, is that confirmation of PAE is confirmed by means of a reliable source for each referral prior to FASD assessment. This protocol allows for greater certainty that the deficits and difficulties individuals present with, and thus those depicted in the current study, are a result of PAE.

Methods

The current study is part of a Canada wide project examining the patterns of difficulties, challenges, and needs of individuals assessed for FASD in Canada. In collaboration with the Canada FASD Research Network (CanFASD) National FASD Database project (Cook et al., 2021), a retrospective chart review and secondary data analysis of children and youth who have been assessed for FASD at the Sudbury FASD Diagnostic Clinic in Northeastern Ontario was conducted. The Canadian National FASD Database is a national, ongoing repository of FASD assessment-related information currently provided by 26 participating FASD diagnostic clinics across the country, representing seven provinces and territories (Cook et al., 2021). While exploring national trends across the country can be of significant value to understanding the shared similarities and challenges among individuals with FASD across the lifespan, the investigation of regional trends can also be of value, given the unique contexts and circumstances within which different diagnostic clinics operate. For example, this specific project came about via community-based discussions between researchers at Laurentian University and individuals working at the Sudbury FASD Diagnostic Clinic who were interested in participating in the National FASD Database Project. These community partners also wanted to investigate the priorities, opportunities, and challenges of their own clinic and how it compared to other clinics across the country. By focusing on one clinic in a particular setting, we are able to explore the similarities and differences with the findings discussed by other researchers investigating the full national sample of individuals assessed for FASD (see, for example, Burns et al., 2021; Flannigan et al., 2022; McLachlan et al., 2020; Temple et al. 2019), as well as to generate specific recommendations for individuals in Northeastern Ontario.

Data collection. For each individual, diagnostic information collected at the time of referral, as well as upon completion of the FASD diagnostic assessment, was transferred to the online National FASD Database through the secure web base format REDCap (Harris et al., 2009), hosted at the University of Alberta. After all accessible charts were reviewed and Database records were submitted, a request for data from specific database items was sent by the principal investigator of this study (JB) to CanFASD to permit access to the Northeastern Ontario data. Requested Database items provided information on demographics, referral reasons including presenting issues and concerns, as well as assessment and diagnostic outcomes. Ethical approval for the current study was obtained through the Laurentian University Research Ethics Board, Ontario, Canada (REB #6014984), which follows Tri-Council recommendations for research with human participants.

Participants. A total of 326 children and youth assessed for FASD at the Sudbury FASD Diagnostic clinic were included in the descriptive profile of the Northeastern Ontario population who presented for an FASD assessment. A total of 34 individuals who received an "at risk" designation were removed from the sample due to the small sample size, which did not allow for statistical comparisons to be accurately made. As well, for many of these individuals there was missing and incomplete data. The remaining 292 children and youth were grouped by their diagnosis (i.e., FASD or No FASD) and were compared. A full summary of the total sample demographics, compared by diagnosis, is displayed in Table 1.

Table 1

Participant Demographic Characteristics Grouped and Total Sample

Demographic Characteristic	FASD	No FASD	FASD/No FASD Grouped	Total Sample
Gender				
Male *n* (%)	83 (65.9)	96 (57.8)	179 (54.9)	203 (62.3)
Female *n* (%)	43 (34.1)	70 (42.2)	113 (34.7)	123 (37.7)
Average age	*11.29	*10.16	10.7	10.24
Age variability *n* (%)				
0-5 years	6 (4.8)	16 (9.6)	22 (6.7)	32 (9.8)
6-12 years	72 (57.1)	101 (60.9)	173 (53.1)	196 (60.1)
13-17 years	48 (38.1)	49 (29.5)	97 (29.8)	98 (30.1)
Total *n* (%)	126 (38.7)	166 (50.9)	292 (89.6)	326 (100)

Note: Total Sample is reflective of all participants including those with an at risk designation who were not included in either comparative groups. *Denotes a significant difference in age between groups.

Data analysis. Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 24. Descriptive analyses (N = 326) were run to create an overall profile of who was assessed for FASD in Northeastern Ontario using all National FASD Database items requested (i.e., referral source, ethnicity and gender, current living situation, reasons for referral, impaired neurodevelopmental domains, intelligence quotient scores, current issues being experienced, co-occurring mental health conditions, other factors being experienced). Chi-square analyses and independent samples *t*-tests were then performed to examine differences in diagnostic outcomes between those diagnosed with FASD and those who did not receive a diagnosis (N = 292). For more information regarding the specific variables available in the National FASD Database, please refer to the DataForm Data Dictionary Codebook available on the CanFASD website (CanFASD Research Network Dataform Project, 2020).

Results

Table 2 presents information about who presented for an FASD assessment (N = 326), description of the individuals' living situation, as well as reason for referral. Mental health concerns are also fully described for the overall sample (n = 326) as well as for individuals with FASD and no FASD diagnosis (N= 292). The 34 individuals who received an at risk designation were intentionally included in the overall sample to offer a full demographic profile.

Table 2

The Profiles of Individuals Assessed for FASD at the Sudbury FASD Diagnostic Clinic

Database Item	Level of Endorsement n (%)		
	Overall Sample	FASD	No FASD
	N = 326	N = 126	N = 166
Referral Source			
Social Services	135 (41.4)	55 (43.7)	67 (40.4)
Medical Professional	111 (34.0)	36 (28.6)	57 (34.3)
Family	64 (19.6)	29 (23.0)	32 (19.3)
Education System	8 (2.5)	2 (1.6)	6 (3.6)
Legal System	6 (1.8)	3 (2.4)	3 (1.8)
Other	2 (.6)	1 (.8)	1 (.6)
Living Situation			

Foster Care	82 (25.2)	32 (25.4)	46 (27.7)
Adopted	78 (23.9)	32 (25.4)	38 (22.9)
Other Family Members	78 (23.9)	23 (18.3)	42 (25.3)
Biological Parents	74 (22.7)	32 (25.4)	33 (19.9)
Group Home	6 (1.8)	3 (2.4)	3 (1.8)
In Custody	4 (1.2)	3 (2.4)	1 (.6)
Other (Independent etc.)	4 (1.2)	1 (.8)	3 (1.8)
Reasons for Referral			
Behavioural Issues	276 (84.7)	106 (84.1)	139 (83.7)
Learning Difficulties	157 (48.2)	*81 (64.3)	*64 (38.6)
Social Skills Difficulties	156 (47.9)	*52 (41.3)	*90 (54.2)
Other (Eligibility for Supports, Follow up etc.)	81 (24.8)	40 (31.8)	34 (20.5)
Self-Regulation Difficulty	78 (23.9)	33 (26.2)	36 (21.7)
Adaptive Living Problems	61 (18.7)	31 (24.6)	29 (17.5)
Developmental Delays	40 (12.3)	*22 (17.5)	*13 (7.8)
Difficulties with the Law	34 (10.4)	18 (14.3)	16 (9.6)
Mental Health Concerns			
Average Mental Health Concerns *M* (SD)	1.00 (1.52)	*2.00 (1.62)	*1.11 (1.37)
Range of Mental Health Concerns	0 – 7	0 – 7	0 – 6
Attention Deficit Hyperactivity Disorder	170 (52.1)	79 (62.7)	77 (46.4)
Oppositional Defiant Disorder	50 (15.3)	*17 (13.5)	*27 (16.3)
Suicide Ideation/Suicide Attempt	50 (15.3)	*29 (23.0)	*21 (12.7)
Intellectual Disability	48 (14.7)	*46 (36.5)	*2 (1.2)
Anxiety Disorder	26 (8.0)	13 (10.3)	9 (5.4)

Conduct Disorder	24 (7.4)	*19 (15.1)	*3 (1.8)
Attachment Disorder	21 (6.4)	10 (7.9)	9 (5.4)
Post-Traumatic Stress Disorder	20 (6.1)	*6 (4.8)	*11 (6.6)
Mood Disorder	18 (5.5)	8 (6.3)	9 (5.4)
Autism Spectrum Disorder	12 (3.7)	9 (7.1)	3 (1.8)
Substance Abuse	9 (2.8)	3 (2.4)	5 (3.0)

Note: For each case in the sample, more than one reason for referral and mental health concern could be selected.
*Statistically significant difference between groups.

Of particular importance to the aims of the study are documenting the mental health diagnoses of the individuals presenting for diagnosis (i.e., the overall sample of 326 individuals). The number of reported mental health concerns (see diagnoses listed in Table 2) in the sample varied (N = 326; range of diagnoses = 0 – 7), with participants presenting, on average, with 1 (*SD* = 1.5) mental health concern. Within this overall sample, 27.3% of children and youth had one reported mental health concern, 37.8% had two or more reported mental health concerns, and 33.4% had no identified mental health concerns. In 1.5% of cases, information regarding mental health concerns was not reported. When examining areas of neurodevelopmental impairment, as per the Canadian FASD Diagnostic Guideline, individuals on average were significantly impaired in two neurodevelopmental domains. Areas most commonly impaired included language, academic achievement, and cognition. The full demographic profile of individuals who were assessed for FASD in Northeastern Ontario is displayed in Table 2. The following sections focus on the sample of 292 individuals who received a diagnosis of FASD (N = 126) and those who did not (N = 166).

Demographic and Referral Differences

Chi-square analyses were performed to examine demographic differences between individuals who received a diagnosis of FASD and those who did not. Individuals with FASD did not differ from individuals without FASD by ethnicity or gender (p_s > .05). However, results of an independent samples *t*-test revealed a statistically significant difference between groups for age, *t*(290) = 2.565, *p* = .011. Individuals who received an FASD diagnosis (*M* = 11.29, *SD* = 3.61) were older than those who did not receive a diagnosis (*M* = 10.16, *SD* = 3.77). When comparing individuals' current living situation, no significant differences were found between groups (*p* > .05). A separate chi-square analysis was performed to determine whether groups differed based on the source of referral, and results revealed no significant differences (*p* > .05). Additional chi-square analyses were run to determine if groups differed by reasons for referral (e.g., behavioural concerns). The results indicated that a significantly greater proportion of individuals with FASD (64.3%) were referred for learning difficulties compared to those with No FASD (38.6%) [x^2 (1, n = 292) = 18.97, *p* = < .001]. Individuals diagnosed with FASD (17.5%) were also more likely to be referred for developmental delays compared to individuals with No FASD (7.8%) [x^2 (1, n

= 292) = 6.29, *p* = .012]. In contrast, significantly more individuals without FASD (54.2%) were referred because of social skills difficulties than individuals with FASD (41.3%) [x^2 (1, n = 292) = 4.80, *p* = .028]. Groups did not significantly differ (all p_s > .05) for all other referral reasons, which are outlined in Table 2.

Mental Health Differences

An independent samples *t*-test was run to determine whether a difference existed in the total number of co-occurring mental health diagnoses between individuals with FASD and those without FASD. Results revealed a statistically significant difference between groups, *t*(287) = 4.884, *p* = .028, indicating that individuals diagnosed with FASD (*M* = 2.00, *SD* = 1.62, range 0 – 7) had a greater number of mental health concerns than those without FASD (*M* = 1.11, *SD* = 1.37, range 0 – 6). Of the children and youth diagnosed with FASD (n = 126), 15.9% had no reported mental health concerns, 31.7% had one reported mental health concern, 17.5% had two reported concerns, and 33.4% had three or more reported mental health concerns. In 1.5% of cases, information on mental health concerns was not reported. Among the children and youth not diagnosed with FASD (n = 166), 44.6% had no reported mental health concerns, 25.3% had one mental health concern, while 29.5% had two or more reported mental health concerns. In .6% of cases, information regarding mental health concerns was not reported.

Chi-square analyses were then performed to examine differences between individuals with FASD and individuals without FASD for specific mental health concerns. Individuals with FASD (15.1%) made up a significantly greater proportion of those diagnosed with Conduct Disorder (CD) compared to their counterparts (1.8%) [x^2 (1, n = 45) = 4.87, *p* = .027]. Conversely, a statistically significant result was also found for ODD [x^2 (1, n = 48) = 5.61, *p* = .018], indicating that more individuals without FASD (16.3%) had a diagnosis of ODD compared to individuals with FASD (13.5%). In an effort to further explore whether these diagnoses differed by the gender or age of the children and youth in the sample, separate chi-square analyses were performed. Results indicated no significant differences between age and gender for both the diagnosis of CD and ODD (all p_s >.05).

A statistically significant finding was reported between diagnostic groups for suicidal ideation and or attempt [x^2 (1, n = 106) = 7.16, *p* = .007]. Results revealed that a greater number of individuals diagnosed with FASD (23.0%) had past suicidal ideation or a suicide attempt compared to individuals with No FASD (12.7%). Findings also showed that significantly more individuals without FASD (6.6%) had a comorbid diagnosis of Post-Traumatic Stress Disorder (PTSD) than individuals with FASD (4.8%) [x^2 (1, n = 22) = 6.47, *p* = .011]. Additional analyses revealed no significant differences (all p_s > .05) between groups for all other mental health concerns. A summary of these mental health findings is reported in Table 2, with the respective sample sizes.

Differences in Impairment Across Neurodevelopmental Domains

The total number of impaired neurodevelopmental domains between groups was compared using an independent samples *t*- test, and a significant result was found, *t*(289) = 50. 15, *p* = < .001. Findings indicated that individuals who received a diagnosis of FASD (*M* = 4.53, *SD* = 1.53) had a greater degree of neurodevelopmental impairment compared to those with No FASD (*M* = .78, *SD* = .78). Of the children and youth diagnosed with FASD (n = 126), 27.8% were significantly impaired in three neurodevelopmental domains, and 71.4% were impaired in four or more domains. Among those not diagnosed (n = 166), 43.4% had no significant neurodevelopmental impairment, 34.9% were significantly impaired in one neurodevelopmental domain, and 21.7% had significant impairment in two domains. Table 3 summarizes the findings of separate chi-square analyses comparing individuals with FASD and their counterparts for each of the 10 neurodevelopmental domains included in the Canadian FASD Diagnostic Guideline (Cook et al., 2016).

Table 3

Group Differences Across Neurodevelopmental Domains

Neurodevelopmental Domain	FASD % Impaired (n)	No FASD % Impaired (n)	p value	Cramers V
Motor Skills	46.3 (123)	7.3 (164)	< .001	.452
Neuroanatomy	19.7 (122)	2.4 (165)	< .001	.287
Language	76.6 (124)	11.9 (159)	< .001	.654
Academic	75.5 (110)	26.7 (120)	< .001	.487
Cognition	67.5 (123)	3.9 (155)	< .001	.677
Memory	48.2 (112)	1.9 (159)	< .001	.560
Executive Function	38.9 (95)	3.8 (105)	< .001	.435
Affect Regulation	10.7 (121)	8.4 (154)	.517	.039
Attention	50.5 (103)	14.1 (142)	< .001	.394
Adaptive Behaviour/Social	69.4 (98)	11.3 (151)	< .001	.599

Discussion

The purpose of this study was to provide a profile and descriptive overview of individuals who were assessed for FASD in the Northeastern region. Furthermore, we aimed to compare the diagnostic outcomes between individuals diagnosed with FASD and those who did not receive a diagnosis. The overall findings of the current study convey that regardless of an FASD related diagnosis, children and youth with PAE in Northeastern Ontario presented with a variety of functional difficulties and challenges. Likewise, for several of the diagnostic outcomes, no significant differences were reported between groups, which supports the need to consider participants who did not meet diagnostic criteria. While results for the overall sample as well as group comparisons were reported, only main findings for each diagnostic outcome are discussed here.

Demographics

The average age at which participants in the sample accessed the diagnostic service (approximately 10 years old) is somewhat concerning when considering existing literature that indicates that an early diagnosis before the age of 6 is most commonly correlated with better life outcomes among this population (e.g., Streissguth et al., 2004). This specific finding may speak to broader issues within the community such as a lack of education and awareness of FASD or limited diagnostic capacity. When discussing FASD diagnosis, one must also always consider the stigma attached with this disorder, and thus nonjudgmental and supportive awareness of the disorder as well as the assessment process is essential. Importantly, early diagnosis and participation in FASD targeted treatment have also been found to lessen caregiver distress (Zarnegar et al., 2016), with existing research demonstrating this need in Northern Ontario (Watson et al., 2013).

Sources of Referral

The finding that the majority of participants in the current study were referred for FASD assessment by social service agencies is not surprising given the proportion of participants living in either foster or adoptive care. Therefore, it is possible that concerns regarding the atypical development and behaviours of children with FASD are acknowledged and acted upon more frequently by foster and adoptive families. For example, researchers have previously identified that non-biological families who are often unaware of the child’s PAE are likely to seek multiple health care services in an attempt to better understand their child’s challenges (Rowbottom et al., 2010).

Furthermore, while almost half of the participants in the current study were living with either their biological parent(s) or with other family members, less than 20% of referrals were made by families. This finding potentially speaks to an additional need for community prevention and educational approaches in an effort to strengthen referrals from these sources. Both biological and adoptive families may not present for an FASD diagnosis due to the stigma surrounding FASD. Drawing upon recent research on effective FASD prevention and education methods, sharing the diagnostic information collected in the current study through the use of non-stigmatizing, community-based educational programming or in direct work with women of child-bearing age and their families may be beneficial (Choate et al., 2019). Future information is also warranted in addressing why families may be reluctant to initiate the FASD diagnostic process.

Results of the current study also demonstrated that medical professionals in the region are playing an active role in the referral process. This finding is promising and contradicts past research that identified a lack of exposure and education for FASD among Northern Ontario medical school students (Coons, Watson et al., 2017), as well as a heavy reliance on non-reliable sources for FASD education by medical professionals practicing in rural locations in Ontario

(Coons, Clement et al., 2017). Although our findings seem promising, results also indicated that medical professionals, along with the other referral sources, referred individuals who received a diagnosis of FASD and those who did not at a similar rate. Given the expected level of expertise for medical professionals, these findings may indicate a need for continued ongoing, specialized education regarding FASD to aid in a greater number of valid referrals, as well as for enhanced screening and recognition of the symptoms of FASD.

Reasons for Referral

When considering the reasons participants were referred for an FASD assessment, a significant number of individuals were experiencing behavioural concerns (84.7%). Problematic behaviour is a common concern among this population, with a separate study of children and youth reporting this concern in 90% of their sample (Reid et al., 2017). The degree of problematic behaviours in the current study can be further supported by the proportion of individuals who were removed from school, had difficulties with the law, and those reported to have been justice-involved. Concerningly, poor behavioural outcomes have been found to persist and intensify with age for individuals with PAE (Spohr et al., 2007), thus highlighting the importance of early, as well as ongoing, intervention. Although our sample focused specifically on children and youth assessed for FASD, our findings are similar to those highlighting the significant and substantial needs of individuals with FASD in Canada (McLachlan et al., 2020). McLachlan et al. (2020) identified that among adolescents, transition-aged youth, and adults with FASD in the National FASD Database, many presented with high rates of adverse outcomes including independent living support needs, alcohol and substance use, employment challenges, legal problems with offending, and school disruption.

Apart from the behavioural difficulties affecting all participants similarly, findings indicated that individuals with FASD were more likely to be referred for learning difficulties. It has been argued that for individuals with FASD, deficits in areas such as attention, executive functioning, and memory, which together interact to foster effective learning, commonly interfere with one’s academic achievement (Millians, 2015). Additional research has suggested that language deficits may limit one’s ability to follow classroom directions and discussions, which can have additional implications on learning (Millar et al., 2017). Furthermore, teachers often report difficulties in understanding diagnostic evaluations for students with FASD, a lack of school-specific information and strategies, and that in-service trainings for FASD fail to address the specific challenges and needs that may arise in the classroom (Pei et al., 2013; Ryan & Ferguson, 2006). Thus, ongoing, relevant, and appropriate training for Northeastern Ontario educators may be especially useful, as teachers who report having more experience on the job also report being able to work with students with FASD more effectively (Ryan & Ferguson, 2006). Research surveying educators in the region may also prove beneficial in identifying existing gaps in training amongst educators, and to inform future educational training practices.

Mental Health

Mental health concerns were also present among both groups of participants, though a greater number of co-occurring diagnoses were reported among individuals with FASD compared to those without FASD. Consequently, our findings support significant rates of mental health concerns in children and youth with FASD, with 82.5% of our sample with FASD having presented with mental health concerns. Overall, ADHD was the most frequently reported mental health concern among both groups, a finding which is reflected throughout the literature (Pei et al., 2011), including among a specialized national sample of individuals in the National FASD Database (Flannigan et al., 2022). When considering the current study's findings, it is important to highlight the significant overlap in symptoms between FASD and ADHD (Rasmussen et al., 2010), which has been argued to lead to the potential misdiagnosing of disorders (Graham et al., 2013). The presence of both FASD and ADHD has also been associated with greater and more severe behavioural symptoms compared to alcohol exposure without ADHD (Ware et al., 2013). Together, these findings help stress the importance of accurate diagnosing to ensure appropriate treatment, while supporting the argument that effective management of ADHD symptoms in those prenatally exposed to alcohol requires a tailored treatment approach (Young et al., 2016).

When considering other externalizing disorders, a greater proportion of participants without FASD had a diagnosis of ODD, while more individuals with FASD presented with a diagnosis of CD. Consistent with the literature, both ODD and CD are described as common outcomes of PAE (Easey et al., 2019). Taking into account the potential implications on the individual, both diagnoses indicate significant disruptions in mood and behaviour, with behaviours being of a more severe nature in CD (American Psychiatric Association [APA], 2013). These findings make sense in light of the behavioural concerns evident in the overall sample. The finding that CD was reported more in individuals diagnosed with FASD can be supported by research connecting neurocognitive deficits, specifically executive functioning impairments, with an increased vulnerability of engagement in high risk and criminal behaviours typical of CD (Wyper & Pei, 2016). Though FASD and CD share many of the same features, such as a lack of social judgement and impaired cause and effect reasoning, the presence of both disorders has been shown to further increase one's vulnerability to high risk behaviours and the severity of these outcomes (Wyper & Pei, 2016). Considering the combined implications of FASD and CD suggests that the timely and accurate recognition, diagnosis, and intervention of ODD among individuals with PAE is crucial, as it is an established potential precursor to the development of CD in both general and clinical populations (APA, 2013).

An important mental health finding was that a significantly greater proportion of individuals with FASD had a reported attempted suicide and/or suicidal ideation compared to those not diagnosed. Specifically, 15.3% of our sample of children and youth reported a suicide attempt and/or suicidal ideation, compared to 11.9% among children aged 6 to 12 and 34.7% among youth aged 13 to 17 recently published in a national sample of individuals from the National FASD Database (Flannigan et al., 2022). Previous researchers have suggested that neuropsychological, mental health, and environmental factors that are often present in individuals with FASD elevate their risk for suicidal thoughts and behaviours (Flannigan et al., 2022; Wyper & Pei, 2016). For example, in one study with a similar age demographic to the current study, suicide attempts were prevalent in 3% of children and 12% of youth (Huggins et al., 2008). More recently, suicidal ideation has been reported in 32.5% of adolescents with FASD, with 13% having required medical intervention after making a serious suicide attempt (O'Connor et al., 2019). Notably, among adolescents with FASD, psychosocial stressors, such as the number of living placements, as well as comorbid mental health conditions, both identified factors in the current study, were risk factors for suicidal ideation (O'Connor et al., 2019).

Neurodevelopmental Impairment

As expected, and in line with the Canadian Diagnostic Guideline for FASD (Cook et al., 2016), neurodevelopmental impairment was higher in those diagnosed compared to those who did not receive a diagnosis. Notably, while three areas of clinical impairment are needed to meet diagnostic criteria, 71.4% of the children and youth who received a diagnosis in this sample had four or more impaired domains, suggesting significant functional difficulty. Among areas of functioning, language, academic achievement, and cognition were the most common domains impaired, respectively. These domains are commonly reported as areas of difficulty among children and youth with FASD and indicate areas of high demand for service (Reid et al., 2017). The dispersed level of endorsement across all 10 neurodevelopmental domains for individuals who received a diagnosis also further supports the known widespread impairment among this population, and thus, the multitude of services required (Paley & O'Connor, 2011).

Limitations and Considerations

While the current study allowed for a plethora of information to be identified for the first time about children and youth who have been prenatally exposed to alcohol in Northeastern Ontario, there are a number of limitations to be discussed. Most notably, the sample is strictly representative of children and youth under the age of 18 who have accessed the diagnostic service in Northeastern Ontario. Therefore, the findings cannot be generalized to the broader FASD population in Northern Ontario, though research on this population as a whole is scarce. It is possible that the profiles ascertained in the current study are reflective of children and youth who had more identifiable challenges and deficits, which could have precipitated the initial referral for an FASD assessment. However, given the scope of the larger CanFASD National Database project, it is possible to explore overall trends among youth and adults with FASD using other participating Northern Ontario clinic data, as well as Canadian data more generally (e.g., McLachlan et al., 2020; Temple et al., 2019).

Additionally, while use of the Database allowed for a comprehensive and reliable means for collecting and comparing data, information collected was thus limited to what could be extracted from the Database. Most variables chosen for this study provided specific responses to choose from, which did not allow additional and at times meaningful information to be ascertained. For example, when selecting areas of neurodevelopmental impairment, no information regarding the degree of impairment was gathered. Domains that may have been approaching the range for clinical impairment could therefore not be determined. Likewise, for individuals who did not receive a diagnosis of FASD, it is unknown how their level of functioning compared to the threshold for a diagnosis.

Lastly, an identified limitation in the current study was the inability to effectively capture areas of strength among participants. The inclusion of such information in research with the FASD population is important and has been argued to be a pivotal way in shifting the focus and subsequent views of individuals with FASD from a strictly deficit-based perspective (Flannigan et al., 2018). The collection of information informing areas of strength and potential among individuals with FASD can also be particularly beneficial when incorporated into intervention methods to facilitate successful outcomes.

Conclusion

The results of the current study demonstrate a need to support children and youth prenatally exposed to alcohol in Northeastern Ontario, through a variety of informed services and support options. The findings further highlight the importance of not limiting such services to those with a confirmed diagnosis of FASD, and having services widely available, with a particular demand existing within the region's social service agencies. Most notably, behavioural and school-based interventions are needed, while social skills training and mental health supports are also justified.

Education regarding PAE and the typical manifestations of FASD that is relevant and meaningful to professionals and service providers, such as medical practitioners and school educators, is also warranted. Fostering a greater awareness of FASD among professionals in the region may also help to lessen the age at which children and youth are currently being referred for assessment in Northeastern Ontario, and to facilitate early diagnosis and intervention. Lastly, the findings indicate the need for mental health professionals in the region to appropriately screen individuals who have confirmed or possible PAE for mental health concerns, with appropriate attention being given to suicide risk. Future research that delineates the specific difficulties and degree of impairment found in the current study could be particularly beneficial in tailoring existing, or informing new, evidence-based interventions for this unique population in the region.

Key messages from this article

People with disabilities: You deserve to have services and supports available to you that appropriately acknowledge your disability and address your specific needs.

Professionals: Professionals and service providers need to be educated on the implications of prenatal alcohol exposure and are encouraged to screen for this potential in their practices.

Policy Makers**:** There is a demand to service and support individuals with prenatal alcohol exposure and those with FASD through multiple service sectors within the Northeastern Ontario region.

Messages clés de cet article

Personnes ayant une incapacité **:** Vous méritez d’avoir accès à des services et du soutien qui reconnaissent de manière appropriée votre incapacité et qui répondent à vos besoins spécifiques.

Professionnels **:** Les professionnels et les prestataires de services doivent être formés au sujet des implications de l'exposition prénatale à l'alcool et sont encouragés à dépister celles-ci dans leurs pratiques.

Décideurs **:** Il existe une demande de services et de soutien pour les personnes ayant une exposition prénatale à l'alcool et celles ayant un TSAF par l'intermédiaire de plusieurs secteurs de services dans la région du Nord-Est de l'Ontario.

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