

COVID-19 Pandemic Challenges for Families of Children and Youth impacted by Fetal Alcohol Spectrum Disorder

Les défis liés à la pandémie COVID-19 pour les familles d'enfants et de jeunes touchés par le trouble du spectre de l'alcoolisation fœtale

Author Information

Maude Champagne,¹
Rachel Willis,²
James Reynolds¹

¹Centre for Neuroscience Studies,
Queen's University, Kingston ON Canada

²Queen's University, Kingston ON
Canada

Correspondence:

20mc17@queensu.ca

Keywords

fetal alcohol spectrum disorder,
FASD,
Dangerous behaviours,
pandemic,
mental health

Abstract

Research has consistently shown that parents of children with fetal alcohol spectrum disorder (FASD) experience greater levels of stress, severely impacting their quality of life. Since the beginning of the COVID-19 pandemic, there has been a growing concern about increased challenges experienced by these families. A mixed-methods approach was used to address our research questions. An anonymous online survey (n = 17) along with semi-structured interviews (n = 10) conducted over the time period of October and November 2020 were used to explore the needs and challenges of families of children and youth with FASD during the pandemic. Interview transcripts were coded and analyzed using interpretative phenomenological analysis. The most striking finding for caregivers was an increased occurrence of their children's challenging behaviours, including aggression. Previous mental health issues of children were reported as being exacerbated due to the disruption in services, loss of routines and structures. Several parents reported being diagnosed with post-traumatic stress disorder as a result of caring for their children. Placement instability, mental health issues in the child, siblings and parents were all amplified. This study underscores the need for increased mental health support for individuals with FASD and their families, including safe and accessible respite options and interventions to respond to dangerous behaviours and aggression both during the pandemic and post-pandemic.

Résumé

Les études ont démontré de façon constante que les parents d'enfants ayant un trouble du spectre de l'alcoolisation fœtale (TSAF) vivent davantage de stress, ce qui affecte sévèrement leur qualité de vie. Depuis le début de la pandémie COVID-19, les défis accrus auxquels sont confrontées leurs familles sont de plus en plus inquiétants. Un devis mixte a été utilisé pour répondre à nos questions de recherche. Un sondage en ligne anonyme ($n = 17$) accompagné d'entrevues semi-structurées ($n = 10$) menées au cours de la période d'octobre à novembre 2020 ont été utilisées pour explorer les besoins et les défis des familles d'enfants et de jeunes ayant un TSAF pendant la pandémie. Les transcriptions des entretiens ont été codées et analysées à l'aide d'une analyse phénoménologique interprétative. Le constat le plus frappant pour les donneurs de soins était une fréquence accrue des comportements problématiques de leurs enfants, y compris l'agressivité. Les problèmes de santé mentale antérieurs des enfants se sont avérés être exacerbés à cause de l'interruption des services, de la perte des routines et des structures. Plusieurs parents ont déclaré avoir reçu un diagnostic de trouble de stress post-traumatique en raison de la prise en charge des soins de leurs enfants. L'instabilité du placement ainsi que les problèmes de santé mentale chez l'enfant, la fratrie et les parents ont tous été amplifiés. Cette étude souligne la nécessité d'un soutien accru en matière de santé mentale pour les personnes ayant un TSAF et leurs familles, y compris des options de répit ainsi que des interventions sécuritaires et accessibles pour répondre aux comportements dangereux et à l'agressivité, tant pendant la pandémie qu'après celle-ci.

Mots-clés : Trouble du spectre de l'alcoolisation fœtale, TSAF, comportements dangereux, pandémie, santé mentale

Introduction

Fetal alcohol spectrum disorder (FASD) is a medical diagnosis and a lifelong condition describing a range of neurodevelopmental and physical impairments due to prenatal alcohol exposure (PAE) (Cook et al., 2015; Rasmussen et al., 2008). Individuals with FASD present with impairment in several domains of brain function, such as memory, attention, emotion regulation, and executive and adaptive functioning skills (Cook et al., 2015). FASD has been estimated to occur with a prevalence of about 4% in the Canadian general population (Popova et al., 2019).

Rates of mental health disorders among individuals with FASD are as high as 94% (Anderson et al., 2018). Among children, brain injury due to prenatal alcohol exposure leads to difficulty in emotional regulation, and the diagnosis of FASD is associated with high rates of externalizing behaviours (Lange et al., 2017). Externalizing behaviours can include actions that are harmful to others, such as aggression, or to the person themselves, such as substance use (Kauten & Barry, 2020). In a Canadian study on challenging behaviours of children with FASD between 6 to 12 years, externalizing and disruptive behaviours were identified as the most difficult situation for parents to manage (Green et al., 2014).

Research has consistently shown that the stress that parents of children with FASD experience severely impacts their well-being (Bobbitt et al., 2016; Watson et al., 2013), including an increased incidence of mental and physical health problems, financial and relationship difficulties and career challenges (Green et al., 2014). Whereas difficulties experienced by these families were already challenging and generally unsupported prior to the pandemic, COVID-19 increased the frequency and severity of these challenges, including minimal access to respite, increased feelings of anxiety in both children and caregivers, and extreme reactions (CanFASD, 2020). Researchers examining the impact of the pandemic on families raising children reported much higher concerns expressed by parents about their child's mental health and well-being compared with parents of children without disabilities (Arim et al., 2020). Individuals with FASD are more susceptible to stress (Hellemans et al., 2010) and thrive on structure, routine and predictability, elements that have been disrupted by public health measures. These concerns have led many community organizations to seek partnerships with researchers to better understand the needs of their clients during this crisis. The present research study was conducted in collaboration with a community-based agency in Ontario, Canada that delivers services and supports for individuals with disabilities, including a specialized program for FASD. The specific aims were to:

- Assess the needs of caregivers of children and youth with FASD during the pandemic;
- Make recommendations to adapt services to the needs identified; and
- Assess the accessibility and satisfaction of virtual support groups and virtual family support services.

This manuscript is focused on the experiences of families raising children and youth with FASD during the pandemic, and the needs identified.

Methods

Study Design

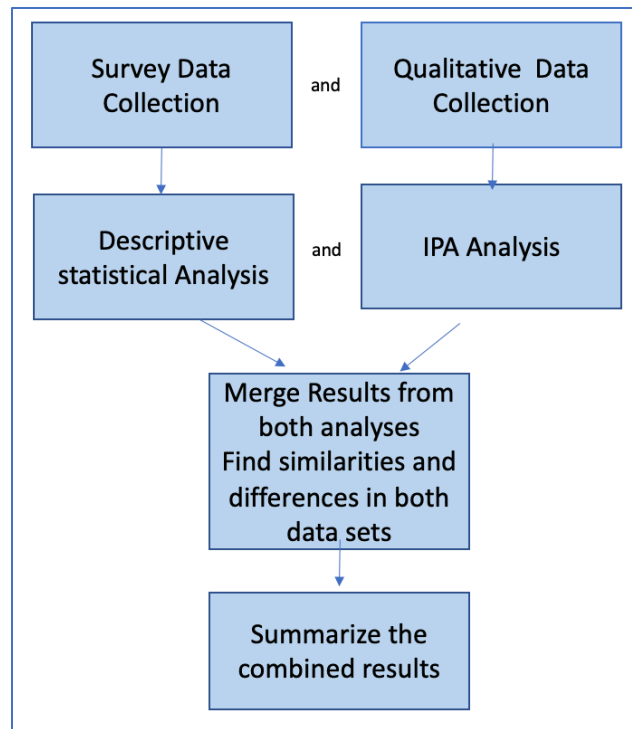
Protocols and procedures for this research study were reviewed and approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board which is in line with the Canadian Tri-Council Recommendations for Research with Human Participants (REB: 6030302). A mixed-method research design was chosen to allow for more clients to participate because they could choose to (i) only complete the short survey or, (ii) the survey and the semi-structure interview, or (iii) the interview alone. While the survey focused on gaining information from a larger group, it was also essential to obtain comprehensive information from families through interviews. Questions from both the survey and qualitative interviews were determined in collaboration with the community agency and the research team based on client feedback since the beginning of the pandemic.

Data Collection and Analysis

An email invitation to complete the survey and to participate in a qualitative interview was sent to all current caregivers accessing a specialized FASD support program by the community agency partner (approximately 70 clients). Quantitative and qualitative data were collected over the time period of October and November 2020. Data were analyzed using a convergent parallel

design (Creswell, 2014). The results from the survey and the interviews were analyzed separately and subsequently integrated (Figure 1).

Figure 1: Convergent Parallel Design Flowchart



Survey

Clients could follow a link provided in the email invitation to complete the survey via Qualtrics. Since the survey was anonymous, the authors didn't know if participants in the interviews also completed the survey. The survey questions were primarily focused on the services provided by the community agency such as which program they were accessing, if they preferred online and other aspects of service provision, followed by questions on well-being. This manuscript reports specifically on the well-being aspects of the survey. Parents were asked to rate their depression and anxiety symptoms, feeling of boredom/loneliness and perceived level of social support on a scale (increased, about the same, and decreased). Quantitative statistics were gathered and analyzed using Qualtrics Software.

Interviews

For the qualitative interviews, informed consent was obtained using a verbal consent script. Questions were focused on service needs and adaptations required, but questions on the participant's experience were also asked such as "Please describe how COVID-19 has impacted your family?" and "Are there any support services your family would need in relation to your child with FASD?" Participants are identified with pseudonyms in this manuscript. The audio

recordings of the qualitative interviews were destroyed after all transcripts were transferred to a secure online database. The ten semi-structured interviews lasted between 35 to 65 minutes and were conducted by MC and RW using the encrypted version of Zoom. The transcription was done by a professional transcriber. All transcripts were subsequently coded and analyzed using NVivo analysis software by both MC and RW. Interpretative phenomenological analysis (IPA) was used to perform the interview analysis. In qualitative studies, this approach aims at understanding the point of view of the participants and is concerned with understanding the meaning attached to their experience (Smith et al., 2009) When studying issues that may be difficult to disclose such as aggression from child to parent, IPA allows the researcher to interpret participant's inner processes such as their mental states and emotions (Smith et al., 2009), which is key to our work as we seek to understand the mental health needs and challenges of parents. Transcripts were read multiple times by MC and RW; both individually coded the first three interviews and then reviewed and compared the codes. All remaining interviews were coded by both coders and codes were reviewed several times. Any discrepancy was discussed and resolved through consensus. Codes that were unique to one participant and not shared by other participants were excluded or integrated into other themes. Codes were transformed into themes and a table with themes, subthemes, pseudonyms and quotes was created. NVivo was used to conduct several comparative analyses to find similarities and divergence between participants as suggested by Smith (2009).

Participants

Survey. The online survey was completed by 17 parents with a total of 21 children/youth.

Interviews. The ten parents who participated in the qualitative interviews were adoptive families either through international adoption, the Canadian child-welfare system, or kinship (Tables 1 and 2) An email invitation to complete the survey and to participate in a qualitative interview was sent to all current caregivers accessing a specialized FASD support program by the community agency partner (approximately 70 clients). The community agency serves primarily adoptive or foster families, hence the lack of participation from biological families. There were two single-parent households (1 male and 1 female) and the remaining 8 parents were in a heterosexual relationship. Half of the families were living in a rural environment ($n = 5$). Parents were between 40-69 years old and had high levels of education. The children of the participants for which they were receiving FASD support services ($n = 14$) were between 6 and 24 years old and 5 were females. While parents identified the mental health diagnoses of their children, only 2 out of 10 reported a formal diagnosis of post-traumatic stress disorder (PTSD) for their child: others spoke of the trauma their child experienced before the adoption. Several children were identified as *strongly suspected* FASD due to a lack of prenatal history; still, there was enough evidence of prenatal alcohol exposure and neurodevelopmental challenges for them to be eligible for the FASD program of this community-based agency.

Table 1
Parent Participant Demographics (Interviews)

Characteristics	Total Sample (N = 10)
Parent gender	
Male	1
Female	9
Parent age	
40-49	4
50-59	3
60-69	3
Years in a couple	
10-19	3
20-29	2
30+	2
Relationship status	
Heterosexual	7
Homosexual	0
Highest level of education completed	
High school	0
College/diploma	2
University/ degree	6
Professional/graduate school	2
Approximate family income	
\$50,000 - \$99,999	2
\$100,000 - \$149,999	1
\$150,000 - \$199,999	3
≥\$200,000	1
Not specified	3
Living environment	
Urban	5
Rural	5
Total number of children in family	
1	2
2	6
≥3	2
Number of children receiving/have received support from a FASD worker	
1	7
2	2
3	1

Table 2
Demographics of Children and Youth of Parent Participants (Interviews)

Characteristics	Total Sample, (N = 14)
Parent/child relationship	
Adoptive	12
Kinship placement	2
Support from FASD worker	
Previously	2
Currently	12
FASD diagnosis	
Yes	6
Strongly Suspected	7
At risk	1
Child age	
5-9	3
10-14	3
15-19	7
20-25	1

Other mental health diagnoses	
ADHD	7
Anxiety	6
- Separation anxiety	2
Trauma	2
Reactive Attachment Disorder	2
Oppositional Defiant Disorder	2
Autism Spectrum Disorder	2
Other*	7

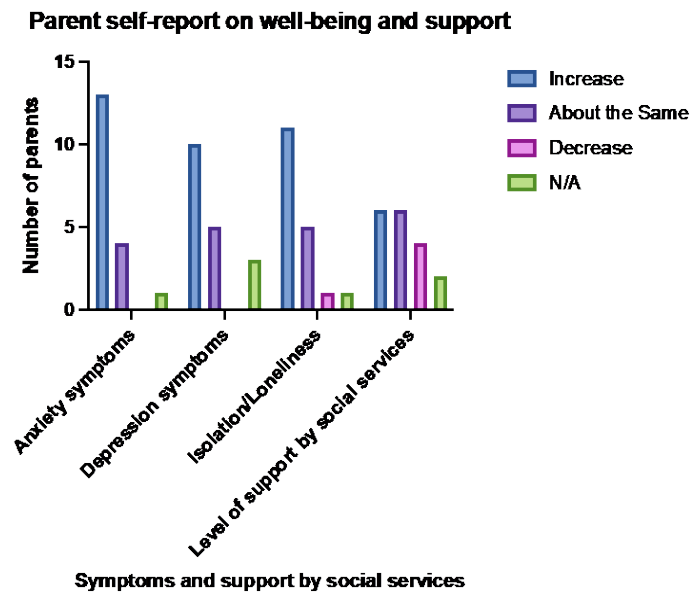
*Other mental health diagnoses include intellectual disability (n=1), learning disability (n=1), depression (n=1), sleep disorder (n=1), sensory processing disorder (n=1), disruptive mood dysregulation disorder (n=1), developmental delay (n=1)

Results

Survey Results

Parents self-reported on several elements regarding their well-being (Figure 2); 72% reported an increase in anxiety symptoms, 56% in depression symptoms and 61% in loneliness and isolation. The perceived level of support received by social services was varied with a 33% increase, 33% about the same and a 22% decrease.

Figure 2



Parents reported on their children’s well-being (Figure 3); 58% had an increase in anxiety symptoms, 57% in isolation and loneliness. Depression symptoms were noted to be increased for 33% or being about the same for 33%. However, 29% of parents rated depression symptoms as not applicable to their child. Parents also reported on their child’s challenging behaviour, which increased for 50% of them and stayed about the same for 38 % of them (Figure 4). Dangerous behaviours increased for 38% of them, stayed the same for 38% and were not applicable for 17% of the children as reported by the parents.

Figure 3

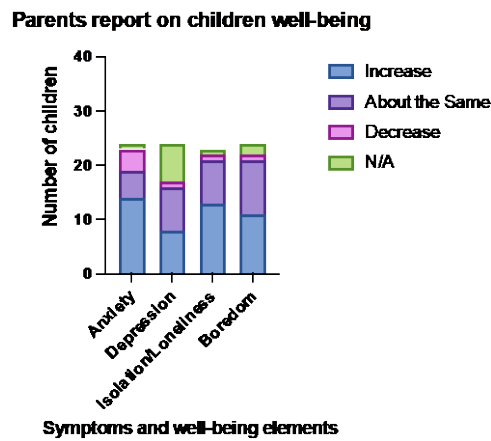
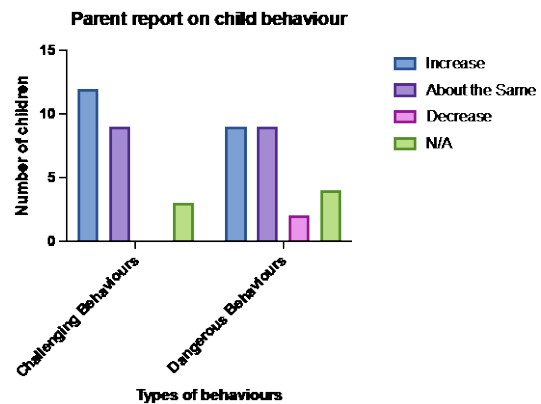


Figure 4



Interview Results

Table 3

Themes from Interviews

Main themes	Subthemes
Child challenging and dangerous behaviours	Safety concerns
Child mental health	Stability and predictability Developmental Regression Attachment issues/trauma history
Parent mental health	Needs are overlooked No break from the child Parental trauma
Placement instability	Vulnerability factors

Children’s Challenging and Dangerous Behaviours

Results from the interview revealed that the greatest concerns of parents related to an increase in problematic behaviours during the pandemic. The authors separated these concerning behaviours into two categories: challenging behaviours and dangerous behaviours. Challenging behaviours were described as constant bugging, not following instructions, not sitting still when required, and speaking loudly. Dangerous behaviours were described as aggressive behaviours that posed a threat to the safety of another individual or to themselves and included instances such as biting, kicking, destroying objects, hitting, self-harm and unsafe sexual behaviours. Families described

these problematic behaviours at length, and these accounted for 1/3 of the coding references related to family members. In interviews, families described the oppositional behaviours they faced daily and the exacerbation of the constant disruptions to their work. Parents described situations where they and their other children were at risk such as being attacked with a knife or hit with hard objects on the head. Some described feeling like a prisoner in their own home, having to live with their abuser. Parents were very distressed for themselves but also quite worried by the self-directed harmful behaviours displayed by their children and extremely worried for the safety of all family members.

And I guess it's, you know, most recently it's the anger and the violence, that frankly, that has been a problem. -Tyler

We were dealing with child-on-parent aggression and violence and I just felt like I was a prisoner in my own home, you know, forced to live with my abuser because my abuser is my son, and so I just...I was so afraid and nervous all the time that, you know, basically the next hit or kick. - Christina

Children's Mental Health

Several of the families participating in this study had multiple children presenting with a history of trauma and prenatal alcohol exposure. Parents were worried these situations were re-traumatizing their children. Parents mentioned essential components to support these children's mental health are predictability, routine and structure; elements severely impacted by the pandemic.

You had this kid who was already imploding a little bit, and then you take away all the structures, all the supports, all the predictability, everything just went...got worse, behaviours got worse, the violence and aggression got worse, his mental health just tanked and nothing was working. -Nicole

Since all the children were also adopted, attachment difficulties were also an aggravating factor mentioned by parents. For this population, parental proximity may be experienced as threatening. The lockdown created a situation in which children and parents had no break from each other:

I would say that for a child that has an attachment disorder, being at home with the family without relief from that...and without the ability to like decompress, is just an extremely loaded situation. And many children with attachment disorders respond in violent ways to their triggers and a lockdown is a... can be of frightening and life-threatening event for a family. – Jillian

Parents also reported developmental regression in their children in several domains such as sleeping, eating as well as extreme separation anxiety. A parent reported having the impression that their pre-teens were back to acting like a toddler. According to several participants, it appears that the stress induced by the pandemic led to behaviours stemming from past trauma resurfacing.

Parent Mental Health. Having to cope with all these problematic behaviours was highly stressful for parents and affected their mental health. Many reported having to access mental health support for themselves because of the challenging nature of their caregiving experience. A

concerning finding was that two parents reported being diagnosed with post-traumatic stress disorder (PTSD) as a result of caring for their child.

I'm trying not to have this fear and I'm trying to let it go and I actually had a counselor helping me with it, because in all honesty, caring for Nadia has created mental abuse for me and I have PTSD. And sometimes I feel that that's overlooked, right?-Nancy

While some parents were receiving mental health support, some felt that their needs in this regard were often overlooked. Parents were dealing with safety issues and mental health concerns, they reported being exhausted by having to provide constant supervision due to the nature of the behaviours displayed by their children.

No Break From the Child

Respite is essential and quite difficult to access for families impacted by FASD, but the pandemic made this need even more challenging to fulfill according to these parents. Public health measures related to social distancing as well as lockdown placed families in a situation where they had to face these difficulties in isolation. Many parents were themselves at higher risk of complications related to COVID-19 due to their age, disability or pre-existing health issues which complicated the decision and the opportunity to access safe respite.

Placement Instability

Among families interviewed, three of them reported having their adoption placement at risk of breakdown, including one whose child was no longer living in the home at the time of the interview. A noteworthy finding was that the three families considering a placement for their child had the highest reported frequencies of dangerous behaviours. This may reflect that increasing dangerous behaviours can lead to placement instability. A common factor in these three families was also their rural living environment; a challenge mentioned by them in accessing critical services for their family.

Vulnerability Factors

A comparative analysis was conducted using NVivo to capture the main differences mentioned by a participant reporting doing well versus a participant reporting not being sure if they could keep the child in their home due to the severity of the crisis. Several factors appeared to differentiate the participant doing well from the participant in crisis; child-centered factors included the child's attachment difficulties and mental health issues leading to dangerous behaviours, whereas family-centered factors included caregiver's mental health concerns, living in a rural environment and being a single parent. It seems likely that child- and family-centered factors interact to contribute to the severity of the crisis.

Discussion

When considering these results, it is crucial to situate the dangerous behaviours displayed by the children and youth into perspective. These behaviours are stemming from prenatal alcohol exposure and for some, experiences of early adversity leading to struggles with emotional regulation, executive functioning deficits, and sensory processing difficulties (Lange et al., 2017). In the context of this study, the public health measures and stress related to the pandemic seem to have aggravated already difficult behaviours and family relationships. Understanding the roots and aggravating factors of these behaviours is crucial to inform the development of interventions suitable to the needs of these families. Interventions rooted in behaviour modification (e.g., rewards and consequences-based programs) should be avoided while approaches taking into account the neurodevelopmental impact of prenatal alcohol exposure and for some children, adverse childhood experiences, should be preferred (Petrenko et al., 2015).

In the Canadian scientific literature, we have yet to recognize the severity of the aggression some families impacted by FASD are experiencing. The stigma that already surrounds FASD in addition to the stigma associated with aggression displayed by children with a neurodevelopmental disorder towards their family members may have contributed to the reticence of acknowledging the gravity of the issue in some families (Aspler et al., 2021). Without wanting to further stigmatize children with FASD, we need to acknowledge this issue and address this need to prevent adverse outcomes. It is also important to mention that not all children with FASD will display aggression. In adoption literature, the main cause of adoption disruption is aggressive behaviours (Palacios et al., 2018). This factor was also seen in the current study; families reporting the highest level of aggression were also facing the greatest possibility of not being able to keep the child in their home. It is imperative to respond to this issue since a nurturing and stable home is the main protective factor against secondary adverse outcomes associated with FASD (e.g., homelessness, substance abuse, incarceration) (Rasmussen et al., 2012).

Furthermore, the literature currently doesn't capture or define accurately the whole spectrum of challenging behaviours. In our study, we used two categories to capture the differences between these behaviours (challenging versus dangerous). Similarly, when other authors refer to behaviours in the context of FASD, the spectrum of severity and consequences is not typically captured. In the current study, we had parents describing the full range of behaviours such as being oppositional or talking back, as well as behaviours that were physically harmful such as hitting, kicking, and pushing. We also had behaviours that parents described as life-threatening such as being run after with a knife or being hospitalized from receiving a blow to the head from a hard object. However, these descriptions may not fully portray the intensity of the experience of parents of children who use aggression towards them. Tremblay (2020) described the experience of adoptive parents of children with developmental trauma who displayed aggression as *filiation trauma*, impacting all aspects of their lives. Some parents who participated in the current study reported being traumatized by their parenting experiences. Many of the participants reported requiring mental health treatment for themselves, something many of our participants also said was overlooked by the current social services system. Nonetheless, children's resilience and attachment are deeply associated with the mental health of caregivers, hence the importance of supporting both child and caregivers (Mensah & Kiernan, 2010).

Limitations and Future Directions

The small sample size of the survey and the interviews as well as the lack of official diagnosis call for caution when interpreting the results in the broader context of families raising children with FASD. Another limitation regarding the study sample is that all children were adopted. This may be seen as an aggravating factor if we consider the possible attachment difficulties and trauma history that it may involve. However, adoptive families may not face the same stigma as biological families when accessing FASD services and they may also have more resources to support their children (Bell et al., 2016). A recommendation to develop ways to reach out to biological families was provided to the partner organization as it could reasonably be expected that biological families are experiencing a similar or even higher level of distress during the pandemic.

Conclusion

COVID-19 has increased the need for mental health services for all family members impacted by FASD. Supporting families during post pandemic, respite is also an essential component of caring for children and youth with disabilities and should be safely made available during and post-pandemic on a regular basis. The results of this study also highlight an urgent need for further research on interventions for aggression and its impact on family functioning and parental trauma.

Key Messages From This Article

People with disabilities. You deserve to receive adequate services for your mental health and your caregivers' mental health so you can live your best life.

Professionals. Interventions must be put in place to respond to the dangerous behaviours and aggression of some children and youth with FASD. It is important to understand that these behaviours stem from their brain-based disabilities and are at times compounded by a trauma history.

Policymakers. Build awareness on FASD for first responders and how to support these individuals and their caregivers during crisis situation. Resources for FASD-informed respite options that are accessible and safe during the COVID-19 pandemic as well as post-pandemic are crucial. Mental health capacity for both individuals with FASD and their support network has to be increased.

Messages clés de cet article

Personnes ayant une incapacité. Vous méritez de recevoir des services adéquats pour votre santé mentale et celle de vos soignants afin que vous puissiez vivre votre meilleure vie.

Professionnels. Des interventions doivent être mises en place pour répondre aux comportements dangereux et à l'agressivité de certains enfants et jeunes ayant un TSAF. Il est important de comprendre que ces comportements découlent de leurs incapacités d'origine cérébrale et sont parfois aggravés par des antécédents de trauma.

Décideurs. Sensibilisez les premiers répondants au TSAF et à la façon de soutenir ces personnes et leurs donneurs de soins en situation de crise. Des ressources pour des options de répit tenant compte du TSAF qui sont accessibles et sécuritaires durant la pandémie COVID-19 ainsi qu'après la pandémie sont cruciales. La capacité de soutien du réseau en matière de santé mentale tant pour les individus avec un TSAF que leurs proches doit être accrue.

Acknowledgements

The authors would like to thank the community-based agency, Mitacs and Kids Brain Health Network for funding this study and want to express their gratitude to families who generously participated in this study.

References

- Anderson, T., Mela, M., & Stewart, M. (2018). The implementation of the 2012 mental health strategy for Canada through the lens of FASD. *Canadian Journal of Community Mental Health, 36* (4), 69-81. <https://doi.org/10.7870/cjcmh-2017-031>
- Arim, R., Findlay L., & Kohen, D. (2020, August 27). StatCan Covid-19: Data to insights for a better Canada. The impact of the COVID-19 pandemic on Canadian families of children with disabilities. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/45-28-0001/2020001/article/00066-eng.htm>
- Aspler, J., Bogossian, A., & Racine, E. (2021). “It’s ignorant stereotypes”: Key stakeholder perspectives on stereotypes associated with fetal alcohol spectrum disorder, alcohol, and pregnancy. *Journal of Intellectual & Developmental Disability, 47*(1), 53-64. <https://doi.org/10.3109/13668250.2020.1865649>
- Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., Reynolds, J. N., & Racine, E. (2016). It’s a Shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics, 9*(1), 65-77. <https://doi.org/10.1093/phe/phv012>
- Bobbitt, S. A., Baugh, L. A., Andrew, G. H., Cook, J. L., Green, C. R., Pei, J. R., & Rasmussen, C. R. (2016). Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder. *Research in developmental disabilities, 55*, 100-113.
- CanFASD. Canadian FASD Research Network. (n.d.). <https://canfasd.ca/>
<https://canfasd.ca/2020/08/07/life-with-covid-19-from-a-caregivers-perspective/>
- Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Conry, J. L., LeBlanc, N., Looock, C. A., Lutke, J., Mallon, B. F., McFarlane, A. A., Temple, V. K., Rosales, T., Canada Fetal Alcohol Spectrum Disorder Research Network. (2015). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal, 188*(3),191-197. <https://doi.org/10.1503/cmaj.141593>
- Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (4th ed.). Thousand Oaks, CA: Sage.
- Green, C., Roane, J., Hewitt, A., Muhajarine, N., Mushquash, C., Sourander, A., Lingley-Pottie, P., McGrath, P., & Reynolds, J. N. (2014). Frequent behavioural challenges in children with fetal alcohol spectrum disorder: A needs-based assessment reported by caregivers and clinicians. *Journal of Population Therapeutics Clinical Pharmacology, 21*(3), e405-e420. <https://jptcp.com/index.php/jptcp/article/view/591>
- Hellemans, K. G., Sliwowska, J. H., Verma, P., & Weinberg, J. (2010). Prenatal alcohol exposure: Fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience & Biobehavioral Reviews, 34*(6),791-807. <https://doi.org/10.1016/j.neubiorev.2009.06.004>
- Kauten, R., & Barry, C. T. (2020) Externalizing behaviour. In V. Zeigler-Hill & T. K. Shackelford (Eds.) *Encyclopedia of personality and individual differences*. Springer.
- Lange, S., Rehm, J., Anagnostou, E., & Popova, S. (2017). Prevalence of externalizing disorders and autism spectrum disorders among children with fetal alcohol spectrum disorder:

- Systematic review and meta-analysis. *Biochemistry and Cell Biology*, 96(2), 241-251. <https://doi.org/10.1139/bcb-2017-0014>
- Mensah, F. K., & Kiernan, K. E. (2010). Parents' mental health and children's cognitive and social development. *Social Psychiatry and Psychiatric Epidemiology*, 45(11), 1023-1035. <https://doi.org/10.1007/s00127-009-0137-y>
- Palacios, J., Rolock, N., Selwyn, J., & Barbosa-Ducharme, M. (2018). Adoption breakdown: Concept, research, and implications. *Research on Social Work Practice*, 29(2), 130-142. <https://doi.org/10.1177/1049731518783852>
- Petrenko, C. L. (2015). Positive behavioral interventions and family support for fetal alcohol spectrum disorders. *Current Developmental Disorders Reports*, 2(3), 199-209. <https://doi.org/10.1007/s40474-015-0052-8>
- Popova, S., Lange, S., Poznyak, V., Chudley, A. E., Shield, K. D., Reynolds, J. N., Murray, M., & Rehm, J. (2019). Population-based prevalence of fetal alcohol spectrum disorder in Canada. *BMC Public Health*, 19, 845. <https://doi.org/10.1186/s12889-019-7213-3>
- Rasmussen, C., Andrew, G., Zwaigenbaum, L., & Tough, S. (2008). Neurobehavioural outcomes of children with fetal alcohol spectrum disorders: A Canadian perspective. *Paediatrics and Child Health*, 13(3), 185-191.
- Rasmussen, C., Kully-Martens, K., Cui, Y., Tough, S., & Zwaigenbaum, L. (2012, June 1). Risk and protective factors for secondary disabilities among children with fetal alcohol spectrum disorders. 35th Annual Scientific Meeting of the Research-Society-on-Alcoholism (RSA) Conference. McMaster University.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis. Theory, method and research.* SAGE Publications Inc.
- Tremblay, K. (2020). *Du trauma secondaire au trauma de filiation : l'expérience de parents adoptifs d'un enfant présentant un trauma complexe [Mémoire de maîtrise inédit].* Université du Québec Outaouais.
- Watson, S. L., Coons, K. D., & Hayes, S. A. (2013) Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability*, 38(2), 95-104. <https://doi.org/10.3109/13668250.2013.788136>