

Stakeholder Perspectives on Risk Factors and Opportunities for Suicide Prevention among Individuals
with Fetal Alcohol Spectrum Disorder (FASD)

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Executive Summary

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Executive Summary

The complexity of Fetal Alcohol Spectrum Disorder (FASD) and related biopsychosocial challenges of the disability can exacerbate vulnerability to suicidality in this population. Individuals with Prenatal Alcohol Exposure (PAE) and/or FASD experience significant mental health concerns and youth with FASD in particular are at higher risk of *suicidality* (i.e., ideations, attempts, and deaths) than those without FASD. Individuals with FASD need lifelong support. Current gaps in our knowledge and understanding about the experience of suicidality among individuals with FASD presents significant barriers to effective risk assessment, intervention, and prevention approaches in this population. There are limited mental health services available to individuals with FASD and their caregivers. There is no consistent suicide response strategy for this population and the problem is dealt with on a case-by-case basis for children and youth in care with a focus on the particular mental health problems experienced by the individual. It is recognized that children, youth, and young adults with FASD often have mental health problems and that these concerns are exacerbated in the transition to adolescence and into adulthood.

This research focused on stakeholders' perspectives on FASD and suicidality and was conducted in Alberta, Canada. Our findings provide perspectives on the experiences of caregivers, professionals, and young adults living with FASD. This project was informed by independent, but interconnected, research activities. First, this research included a scoping literature review of published research and relevant grey literature. Second, we completed a secondary data analysis on suicidality and associated factors using records from Canada's National FASD Database ("DataForm"), a national repository of clinical information gathered from FASD assessment and diagnostic clinics across Canada. The DataForm analysis provided information on rates of suicidal ideation/attempts among 796 participants and examined the associations between suicidal ideation/attempts and select demographic and biopsychosocial factors in this group. Lastly, focus groups and individual interviews were conducted with caregivers ($n = 6$), frontline service providers and other FASD and mental health professionals ($n = 14$), researchers ($n = 9$), and a group of young adults with FASD ($n = 4$). N-Vivo was utilized to conduct an analysis of these focus groups and interviews. Caregiver interviews were also accompanied by an online survey ($n = 23$) that characterized the demographics, clinical needs, and adverse life events of children and youth (7-24 years) with PAE/FASD who experience suicidality. Responses to the online survey also captured detailed information about past and present experiences of suicidality in this population. In this summary we highlight the key findings of this research, provide recommendations for policy, practice, and research, and note suggestions for future research.

Rationale for the Research

FASD and suicidality is an under-researched topic and an under-reported problem. Suicidality is increasingly being recognized as a concern in the FASD population (e.g., Huggins et al., 2008; O'Connor et al., 2019; Thanh & Jonsson, 2016). Individuals living with FASD experience a higher risk of suicidality than the general population (Flannigan et al., in press; O'Connor et al., 2019). Research on the topic of FASD and suicide is extremely limited and very few studies currently address this topic in the literature (e.g., O'Connor et al., 2019; Brownell et al., 2019; Burns et al., 2020; Temple et al., 2019). This research was focused on deepening our understanding of this phenomenon, underpinned by the Alberta Youth Suicide Intervention Strategy - *Building Strength, Inspiring Hope* Report (2019) - a plan for youth suicide prevention. Suicide is an issue that affects everyone, and it is not well understood in relation to FASD or disability.

Despite the apparent increased risk of suicidality among individuals with PAE and FASD (and young people, in particular), relatively little is known about *why* suicidality occurs in this population. There is some emerging evidence that individuals with FASD may exhibit suicide risk factors that align with risks in the general population, such as co-occurring mental health and substance use issues, lack of social support, and a history of trauma or abuse (Huggins et al., 2008; O'Connor et al., 2019; Temple et al., 2019), as well as risk factors inherent to their diagnosis, such as impulsivity and deficits in executive functioning (Temple et al., 2019; Mela, 2021). Adverse life experiences may also contribute to suicidality in this population, as individuals with FASD experience high rates of caregiver disruption, ongoing stress and victimization, and substantial difficulties in daily living (Flannigan et al., in press; McLachlan et al., 2020; Price et al., 2017; Mela, 2021). Hodas and Brocius (2016) identify FASD as a genuine public health problem and recognize 'system induced trauma', indicating that the actions of service systems in responding to FASD can cause trauma to families. Critical problems identified in service systems include the dismissal of concerns raised by families, youth not being listened to, assumptions that negative behaviours are intentional, families being refused counselling services indicating individuals with FASD do not benefit from counselling, and that the severity of concerns of families are often not taken seriously. Jonsson (2019) points out the concern that despite a substantial knowledge base of the problems and concerns for individuals with FASD, care and interventions for this population require resources and FASD "receives substantially less attention and funding for research than many other diseases and disabilities"(p. 162), highlighting the need for a focus on prevention.

Research Activities and Findings

1. **Scoping review of available literature** relative to youth suicide and FASD included both published research and grey literature.
Findings: 27 studies were included and tell us suicide risk is higher for individuals with FASD in comparison to the general population.
2. **Secondary data analysis of the National FASD Database** known as DataForm with the Canada FASD Research Network examined mental health diagnoses and suicidal ideation/attempts across Canada.
Findings: There were 796 participant files reviewed and 25.9% were reported to experience suicidality. Key risk factors included substance use, history of trauma, and impaired affect regulation.
3. **Caregiver Survey** with 23 families focused on life events, sleep habits, and a suicide severity scale.
Findings: Children and youth with FASD and co-occurring suicidality experienced a range of *health conditions*, as well as high rates of *neurodevelopmental conditions* including ADHD, learning disorders, and depression. 78% of children/youth were taking medications and 44% of children had serious sleep problems. Caregivers report barriers to accessing supports including a lack of services or long waitlists. Over a one-month period, 43.5% of children and youth experienced suicidal ideation.
4. **Qualitative Research Interviews and Focus Groups** were conducted with stakeholder groups including professionals providing direct service, caregivers involved in the care of children/youth and young adults with FASD, FASD researchers, and a small group of adults living with FASD.
Findings:
 - Caregivers have serious concerns about the risk of suicide for youth with FASD and identify that even a minor crisis can precipitate talk of wanting to die. Youth with FASD do not always comprehend the finality of suicide. Youth who express suicidal thoughts are often experiencing emotional pain that they want to stop. Caregivers are often on high alert in caring for youth with FASD as the risk of suicide is real.

- Caregivers (n = 23) reported suicidal ideation over the period of one month in the population aged 7-24 (23 children, youth and young adults) in terms of expressing wanting to be dead (passive) (82.6%) or active thoughts of killing self (55%). This population had many adverse experiences, and the need was identified to engage in intervention activities such as supporting self-regulation, working with trauma experiences, and focusing on adaptive coping strategies. The need also exists to provide supports in school, to promote self-worth, and to build self-esteem. It is also critical to recognize the tremendous stress that suicidal ideation creates in families and to provide additional supports such as counselling and respite.
- Professionals are deeply concerned about the risk of suicide in this population including high-risk drug use that can contribute to death. In some cases, individuals with FASD are refusing to take Naloxone kits from their support workers while engaged in high-risk drug use. The concern is that this is being used as a means of suicide.
- All stakeholders identified gaps in counselling and intervention supports for this population and highlighted the need for training on FASD on the frontlines. Professionals indicated the risk of suicide as a result of mental health problems is problematic and requires intensive supports including access to counselling.
- Adults with FASD informed us that daily experiences of sensory overload and anxiety are real, and, at times, they do not know how to make things better on their own. The participating adults all had a history of growing up in care and recognized the impact of this experience. They did not want their disability dismissed because it was not easily visible to others, often indicating that this makes life harder. They valued counselling and supports from people who understood FASD and focused on their strengths and hopes for the future.
- There are misconceptions about the mental health needs of individuals with FASD as expressed by caregivers and professionals. For example, it was identified by some participants that some mental health services in Alberta have taken the position that individuals with FASD do not benefit from counselling or their needs are too complex to provide support. Individuals with FASD who participated in this research told us of the benefit of engaging in mental health counseling. A lack of access to mental health support is simply unacceptable given the high risk of this population to suicidality as identified in this research. It is unfathomable that caregivers would not be able to access the very services designed to promote mental health in families. Full access to these services is essential from a disability and human rights position and any concerns can be addressed through FASD training, support, knowledge, and education .

Summary

Individuals with FASD are resilient and bring unique perspectives into the world, yet the world does not understand this disability well. FASD and suicidality is problematic, and concerns start at a young age, and often, can be linked to adverse childhood experiences. The biopsychosocial challenges of FASD contribute to mental health problems for those with FASD across environments. The need exists to promote mental health and reduce adverse outcomes associated with FASD. The voices of caregivers were profound in terms of the challenges they face on a daily basis, particularly for those with active suicidal ideation. The perceptions of individuals around the meaning of suicide and death do not necessarily equate with a desire to die, nor is there a good understanding of the finality of death. Rather, “suicide talk” is often driven by painful psychosocial/emotional experiences from which the young person wants to escape. Children, youth and adults with FASD experience high rates of adversity and trauma - all contributing factors to mental health problems leading to risk of suicide. Taken together, the results of this work provide further evidence for the increased risk of suicidality among this population and further our understanding of the complexity of suicidality among individuals with FASD. Focused intervention plans and protocols for those with FASD at risk of suicide need to be developed.

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