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Exploring Canadian Public Perceptions of Fetal Alcohol Spectrum Disorder

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Abstract

With a national prevalence of 4%, fetal alcohol spectrum disorder (FASD) is a leading developmental disability in Canada. FASD has lifelong effects on cognitive, emotional, behavioral, social, and physical health. Despite its significant prevalence, FASD is poorly understood and highly stigmatized, which can exacerbate challenges and limit access to supports. This study explored knowledge of FASD among 372 Canadian adults to identify common knowledge gaps and misconceptions. Participants were recruited through the Angus Reid Forum for a larger study on FASD and other neurodevelopmental disorders. In the current study, we analyzed responses to one open-ended question which asked participants to report what they know about FASD. Using qualitative content analysis, five categories emerged from the data: (1) general knowledge, (2) causes, (3) perceived impacts, (4) nature of FASD and (5) stigmatizing attitudes. The results suggest a wide range of knowledge and awareness. While some participants had a strong understanding, some were not aware of FASD, and others believed misconceptions and held stigmatizing beliefs. Participants who had direct experiences with individuals with FASD had a more accurate understanding. The findings suggest the need for targeted education campaigns to address misconceptions, reduce stigma, and promote a more informed understanding of FASD.

Lay Abstract

In Canada, experts believe that at least 4% of the population has fetal alcohol spectrum disorder (FASD), making it one of the most common developmental disabilities in Canada. FASD impacts an individual's cognition, emotions, behavior, social interactions, and physical health. Despite its significant prevalence, FASD is highly misunderstood. In addition, individuals with FASD are often judged and stigmatized. This can exacerbate the challenges they experience and limit access to supports, as well as lead to feelings of social isolation. In this study, we explored how Canadian adults perceive FASD, including what they know, what misconceptions are held, and what stigmatizing attitudes or beliefs exist. In an online survey, 372 Canadian adults were asked to share what they know about FASD. Their responses were carefully analyzed and split into five categories: general knowledge, causes, perceived impacts, the nature of FASD, and stigmatizing attitudes. There was a wide range of knowledge among participants, with some knowing little to nothing about FASD and others demonstrating a strong understanding. Participants who have had direct experiences with individuals with FASD in personal or professional ways had a more accurate understanding and even challenged some common misconceptions in their responses. The results of our study highlight a clear need for more education and resources to be made available to the public, which emphasize both the strengths and challenges of individuals with FASD, target existing misconceptions, work to reduce stigma, and create a more supportive environment for individuals and families impacted by FASD.

Keywords

fetal alcohol spectrum disorder, FASD, perceptions, misconceptions, stigma

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Fetal alcohol spectrum disorder (FASD) is a diagnostic term referring to the diverse range of impacts experienced by individuals prenatally exposed to alcohol (Cook et al., 2016). The resulting challenges vary in presence and severity between individuals but may impact cognitive, emotional, behavioral, social, and physical health. Common challenges include impairments in memory, attention, communication, emotion regulation, social skills, and motor skills (Bell et al., 2016; Cook et al., 2016; McCormack et al., 2022). These challenges may present in various contexts, including academics, mental health, and interpersonal relationships (Bell et al., 2016; McCormack et al., 2022). With a conservative estimated prevalence of 4% nationally, FASD is a leading developmental disability in Canada (Flannigan et al., 2018b). FASD is more prevalent than autism (2.0%), cerebral palsy (0.2%), Down syndrome (0.1%), and Tourette's syndrome (0.1%) combined (Flannigan et al., 2018b; Public Health Agency of Canada, 2022), yet it remains highly misunderstood. Additionally, up to 90% of individuals with FASD have comorbid mental or physical health conditions (Popova et al., 2016).

Early detection and interventions have been found to significantly improve health and social outcomes for individuals with FASD, which may allow them to lead happy and meaningful lives (Government of Canada, 2023; Pei et al., 2019). However, despite its prevalence and significant impacts, supports and interventions for individuals with FASD remain quite limited (Pepper et al., 2019; Petrenko et al., 2019). This scarcity of resources may stem from a lack of knowledge and awareness of FASD and high levels of stigmatization of individuals with FASD and prenatal alcohol exposure (PAE; Bell et al., 2016).

Public Knowledge of FASD

The characteristics of FASD are generally poorly understood, even among clinicians and other professionals, causing it to sometimes be referred to as an "invisible" condition (Coons et al., 2017; Luong et al., 2023; McCormack et al., 2022). A report from Luong et al. (2023) found that only 80% of pregnant persons were being screened for alcohol consumption by their physicians, and of those who screened positive, only 16% were being encouraged to reduce or discontinue their consumption. Furthermore, in a survey of 834 Canadian healthcare professionals, which included pediatricians, psychiatrists, family physicians, and obstetricians, 57% felt unqualified to diagnose FASD, and 28% felt it was beyond the scope of their practice (Coons et al., 2017). Moreover, McCormack et al. (2022) reported that knowledge and training on FASD are generally poor among professionals in health, education, justice, and social services.

Through consultation with an advisory board composed of academics, clinicians, researchers, frontline mental health service providers, and individuals with lived experience, the Canada FASD Research Network (n.d.a) identified several misconceptions they have recognized are held by the public about FASD; one is the belief that sentinel facial features (i.e. small eye openings, a thin upper lip, and a smooth philtrum) are primary identifiers. In reality, these features are only present in a small minority of individuals (Cook et al., 2016). Another misconception is that individuals with FASD have low intelligence; however, intelligence quotient (IQ) scores among individuals with FASD are often within a normal range and can vary from having a diagnosed intellectual developmental disorder to an above-average IQ (Public Health Agency of Canada, 2005). Additionally, while a misconception exists that FASD only impacts certain communities or groups (e.g. child welfare, Indigenous communities, justice/correctional populations), FASD is seen across all social, ethnic, cultural, and sociodemographic backgrounds where alcohol is consumed (Canada FASD Research Network, n.d.a).

Stigma Toward FASD

FASD is highly stigmatized, and multiple stereotypes exist that perpetuate that stigma (Aspler et al., 2022; Bell et al., 2016). One prevalent and harmful stereotype about persons with FASD is the tendency to attribute certain life trajectories to people with FASD, including challenges with substance use, involvement with the justice system, and experiencing homelessness (Aspler et al., 2022; Bell et al., 2016). Another harmful stereotype held by the public is the idea that individuals with FASD are incapable of learning from mistakes, adopting helpful strategies, or living on their own (Aspler et al., 2022). If these negative beliefs are internalized, they can turn into self-stigma, which can possibly cause shame and social isolation, and create barriers to seeking support and achieving goals (Volkow et al., 2021). Public endorsement of stereotypes and stigmatizing attitudes creates a risk of a "self-fulfilling prophecy," where individuals internalize the belief that they are destined for certain life trajectories, causing them to lose hope for their future and, in turn, act in ways that align with the societal expectations imposed upon them (Aspler et al., 2022).

Notably, societal responses to individuals with FASD shift significantly with age. In a critical sociological analysis, Dej (2011) demonstrates that children with FASD are often viewed as innocent victims who deserve treatment and support (Dej, 2011). However, as individuals age and continue to exhibit behaviors consistent with the challenges of FASD, they are increasingly viewed through a lens of personal responsibility rather than as individuals who require, and deserve, accommodations and supports. Dej (2011) demonstrates how the criminal justice system particularly reinforces this shift, reframing the FASD identity as a criminalized or deviant one in adulthood. This shift in societal responses aligns with the Attribution Model of

Stigma (Weiner, 1995), which posits that people hold more negative attitudes when they perceive someone as personally responsible for their situation. Given the lifelong nature of FASD and the permanent impairments caused by PAE, adults should be met with the same compassion as children. Still, adults with FASD continue to be perceived in a much more negative light and face significant stigmatization (Dej, 2011).

While there are limited studies on this topic, previous qualitative research has examined the perceived stigma felt by adults with FASD, specifically those navigating parenting and employment (Hargrove et al., 2024; Rutman & Van Bibber, 2010). Participants often felt misunderstood and judged based on their diagnosis, leading to unfair assumptions and negative perceptions. For instance, some felt that their condition unfairly branded them as “bad people” and expressed frustration with being defined only by their diagnosis, rather than being recognized for their strengths and achievements (Rutman & Van Bibber, 2010). In addition, individuals with FASD reported not disclosing their diagnosis, believing they would not have been hired if their employer were aware (Hargrove et al., 2024). In a similar qualitative investigation examining the experiences of youth with FASD, the overarching theme of “feeling different” emerged as a central construct encompassing their day-to-day lives (Stade et al., 2011). Such perceived stigma can negatively impact self-esteem, create barriers to seeking support, and contribute to feelings of social isolation (Volkow et al., 2021).

Research has suggested that the stigmatization of individuals with FASD extends beyond the individual themselves, impacting both adoptive and biological caregivers, as well as other loved ones (Bell et al., 2016; Corrigan et al., 2017; Wilson et al., 2023). In line with the Attribution Model of Stigma (Weiner, 1995), birthing parents of individuals with FASD are often blamed and stigmatized for their child’s condition (Corrigan et al., 2017). This stigma is driven by the narrative that FASD is “100% preventable” and that alcohol consumption during pregnancy is always intentional. However, it is important to note that FASD is not entirely preventable. Alcohol consumption during pregnancy is often unintentional due to factors like unplanned pregnancies and the normalization of alcohol consumption, especially during child-bearing years (Black et al., 2015; Health Canada, 2021); as such, alcohol consumption frequently occurs prior to pregnancy awareness (McCormack et al., 2017). Moreover, some birthing parents may not be able to completely abstain from alcohol for several reasons, such as alcohol use disorders, trauma, and coping with abuse (Meurk et al., 2014; Morton Ninomiya et al., 2023). Nevertheless, FASD has historically been framed as a moral failing of the birthing parent (Corrigan et al., 2017; Dej, 2011). This stigmatization may prevent the disclosure of PAE and create barriers to early interventions and diagnoses (Bell et al., 2016; Morrison et al., 2020). Notably, while individuals with FASD and their families frequently report feeling unsupported by professionals, findings from a scoping review indicate that professionals themselves are aware of, and frustrated by, their limited knowledge, training, and preparedness to provide adequate support (Wilson et al., 2023).

The Current Study

In 2005, the Public Health Agency of Canada launched a Framework for Action to improve support for individuals with FASD, emphasizing the need for awareness, compassion, respect, and support for individuals and their families (Public Health Agency of Canada, 2005). Despite this call to action, there is little empirical research assessing public knowledge and misconceptions about FASD. In a 2006 study, phone interviews revealed that 14% of 3622 Canadians had never heard of FASD (Environics Research Group, 2006). Of the participants who had, most associated it with PAE and cognitive challenges. A secondary analysis of two PolicyWise surveys by Choate et al. (2019) revealed that as of 2017, 15.1% of men and 5.5% of women in Alberta reported having no knowledge of FASD, though awareness had improved slightly since their 2011 survey. While these studies highlight the need for increased public awareness, they offer little insight into specific attitudes or misconceptions. As such, the current study expanded the literature by exploring the Canadian general public’s knowledge and perceptions of FASD. The findings may identify prevalent stereotypes and misinformation, allowing future awareness and education efforts to strategically target these knowledge gaps and misconceptions.

Methods

Research Design

The current study is part of a larger survey study that used an experimental vignette design to compare levels of stigma from the general Canadian public based on the diagnostic labels of FASD, attention-deficit hyperactivity disorder (ADHD), and autism. The larger study also assessed how including personal strengths of individuals with FASD impacted overall stigmatizing attitudes. The larger survey took approximately 10–20 min to complete. These results will be reported elsewhere. The study was funded by the Memorial University of Newfoundland Multidisciplinary Fund, and ethics approval was received from the Memorial University of Newfoundland Interdisciplinary Committee on Ethics in Human Research. Participants provided written informed consent to participate and have their data anonymously published. Responses to an open-ended question within the larger survey, which asked them to

Table 1. Participant Demographic Characteristics.

Demographic Variable	*N* (Valid Percent)
Province	
Alberta	39 (10.5)
British Columbia	41 (11.0)
Manitoba	17 (4.6)
New Brunswick	7 (1.9)
Newfoundland and Labrador	9 (2.4)
Nova Scotia	12 (3.2)
Ontario	162 (43.5)
Prince Edward Island	1 (0.3)
Quebec	72 (19.4)
Saskatchewan	10 (2.7)
Yukon	2 (0.5)
Gender	
Man	162 (43.5)
Woman	200 (53.8)
Nonbinary	3 (0.8)
Prefer not to say	3 (0.8)
Unsure	3 (0.8)
A gender not listed here	1 (0.3)
Race	
Black	2 (0.5)
East Asian	7 (1.9)
Hispanic/Latino/a/x	1 (0.3)
Indigenous	13 (3.5))
Middle Eastern	1 (0.3))
Other—please specify:	10 (2.7))
South Asian	7 (1.9))
Southeast Asian	8 (2.2)
White/Caucasian	323 (86.8)
Education	
Completed college	71 (19.1)
Completed graduate/professional degree	86 (23.1)
Completed high school	28 (7.5)
Completed undergraduate degree	92 (24.7)
Some college	38 (10.2)
Some graduate/professional degree	25 (6.7)
Some high school	8 (2.2)
Some undergraduate degree	24 (6.5)
Employment	
Yes	249 (67.3))
No	113 (30.5)
Prefer not to say	8 (2.2)
FASD heard of it	
Yes	303 (81.7)
No	55 (14.8)
Unsure	13 (3.5)
FASD diagnosis self	
Yes	0 (0.0)
No	371 (99.7)
Prefer not to say	1 (0.3)
FASD diagnosis other	
Yes	26 (7.0)
No	344 (92.5)
Prefer not to say	2 (0.5)
Demographic variable	*M* (*SD*)
Age	46.63 (16.15)

Note. FASD: fetal alcohol spectrum disorder.
The sample included 372 participants. Numbers may vary by question due to missing data.

describe what they knew about FASD, formed the dataset for the current study.

Participants

Canadian adults aged 18 years or older of the general public were recruited through the Angus Reid Forum, an established online research panel that provided access to Canadian residents who have registered to participate in surveys for compensation, with a request that participants be representative of the Canadian population. Of the 505 participants in the larger study, 415 responded to the open-ended question. After removing 14 duplicate responses and excluding 27 poor-quality responses (i.e. responses were incomplete, nonsensical, or did not apply to the question asked), the final sample consisted of 372 participants for the current study. Participant characteristics are in Table 1.

Materials

Qualitative data were collected through an open-ended survey question: "Please write anything you knew about people who have FASD (i.e. people who were exposed to alcohol in the womb) prior to participating in this study." Fifty-two French responses were translated to English verbatim by a bilingual translator from outside of the research team who was compensated for their time (Regmi et al., 2010). A bilingual member of the research team (I.M.) checked the translations for accuracy and found no discrepancies.

Data Analysis

The data were analyzed using conventional qualitative content analysis (Hsieh & Shannon, 2005), an inductive approach which allows codes and categories to emerge from the data. This approach is appropriate for descriptive research with limited existing literature (Vears & Gillam, 2022). Data were manually analyzed in Microsoft Excel by two graduate students (I.M. and M.D) and an undergraduate student (O.B.) who had relevant qualitative research experience or coursework. The coding was then reviewed by A.P., a criminologist and associate professor in sociology. All of the authors involved in coding were White, middle-class women. I.M. and A.P. have a combination of personal and professional experiences with individuals with FASD that have been deeply meaningful. These personal attributes and direct experiences may have impacted how the coders initially read and interpreted the responses. However, every effort was made to ensure this did not impact the coding process. For example, coding occurred independently and was then reviewed as a group in an effort to limit the amount of personal biases that impacted the coding.

The coders familiarized themselves with the data by reading through it in its entirety, then performed line-by-line coding and identified keywords in the data. After completing the initial coding, the coders shared their findings, discussed differences, and resolved discrepancies as a group. Once a consensus was reached on initial codes, a codebook was developed, and the data were recoded according to the new criteria. During secondary coding, related codes were grouped into broader categories and arranged into subcategories using an iterative, collaborative process. Intercoder reliability was ensured by using multiple coders, at least one with relevant experience with qualitative analysis, applying the same analysis framework across coders, developing a codebook, and resolving differences through discussion and consensus (Cofie et al., 2022).

Results

The findings of the current study are presented under five categories: (1) general knowledge of FASD, (2) causes of FASD, (3) perceived impacts, (4) nature of FASD, and (5) stigmatizing attitudes.

General Knowledge of FASD

Participants' knowledge varied based on personal and professional backgrounds. On one end of the spectrum, participants had very limited knowledge or awareness of FASD. Some participants reported having never heard of the condition or knowing "nothing," and others had very little knowledge: "I had heard of it as a disorder, but that was the extent of my knowledge" (ID278).

Participants also shared professional experiences that informed their knowledge and understanding of FASD. These included professionals in education (e.g. teachers, principals, teachers' assistants), nursing, child protective services, law enforcement, Special Olympics, and mental health and social service settings (e.g. psychologists, counselors, emergency shelter staff).

> I am a nurse and work with FASD patients on the regular. I see a lot of addiction with substance use and alcohol use disorder, other mental health comorbidities. FASD patients seem to have a higher [incidence] of unhoused individuals. As patients I have often encountered impulsive behavior, aggression, impatience, anger issues. This is not every patient. Most patients seem very aware and knowledgeable about how their FASD can impact their life and behaviour. (ID226)

Other participants' knowledge was informed by personal experiences, such as growing up with individuals with FASD, having friends with FASD, knowing classmates of their children who have FASD, friend's children, and personally adopting children with FASD. One adoptive parent said:

> I've adopted 3 children with confirmed or suspected FASD. I am aware of a lot of information. Prenatal exposure sucks,

> facial features are not the key diagnosis. FASD means lifelong impairment, but doesn't mean they can't thrive with support. (ID147)

Causes of FASD

Many participants discussed the etiology of FASD. Most were able to accurately identify PAE as the cause, while others indicated a belief that birthing parents had to be "drinking alcohol in excess" (ID346) or "an alcoholic while pregnant" (ID204) for FASD to develop. Some participants inaccurately identified other substances as the cause, with one saying FASD affects "children born to both alcoholic and drug addicted mothers" (ID273). Others incorrectly suggested FASD is hereditary, claiming it is "usually passed on by generation" (ID154).

Perceived Impacts

Participants reported impacts they understood to be associated with FASD among a variety of domains, including cognitive, emotional, behavioral, social, and physical health.

Perceived Cognitive Impacts

Participants reported their understanding of cognitive impacts, including general impact on cognitive functioning, learning difficulties and disabilities, impulsivity, hyperactivity, sensory sensitivities, and trouble with language and communication. They also noted challenges with executive functioning, such as issues with attention, memory, planning, and problem-solving. Participants described trouble understanding consequences, distinguishing right from wrong, and making good decisions, with one participant saying: "Hard time making decisions, impulsive, difficulty learning" (ID112). Participants also noted intellectual impacts, such as intellectual disabilities and low IQ, and developmental impairments related to brain and speech development.

Perceived Emotional Impacts. Participants reported the belief that FASD can impair emotional health, reporting difficulties with emotion regulation, "strong fluctuating emotions and frustrations" (ID175), being "quick to anger" (ID193), irritability, and impatience. Participants also reported that FASD is often comorbid with other conditions, and some named anxiety and depression as examples.

Perceived Behavioral Impacts. Participants identified behaviors that they understood to be typical of individuals with FASD. These included being disruptive, obsessive, aggressive, unpredictable, having difficulty following rules and listening to authority, and engaging in self-destructive behaviors. Participants also believed individuals with FASD are likely to have substance and alcohol use disorders. Conversely, some believed that individuals with FASD would have to abstain from alcohol and other substances due to intolerance; with one noting: "Both people I know can not even drink a sip of alcohol or they get sick" (ID105), while another stating they are "doomed to abstain from drugs and alcohol themselves for life" (ID273).

Perceived Social Impacts. Participants reported social impacts that they believed were associated with FASD. These included difficulty with social skills, fitting in, understanding social norms, forming meaningful relationships and secure attachments, recognizing manipulation and being easily taken advantage of. Participants also noted challenges in school, financial skills such as budgeting, and life skills, with one saying they are "lacking in life skills" (ID120), and another saying they have "trouble with basic tasks" (ID 280). Participants also linked FASD with overrepresentation in the justice system and unhoused population, as well as employment struggles. For example, one participant recognized many of the social impacts with the statement: "People with FASD are more likely to face issues with housing, being able to get and keep a job, schooling, socialization, and can have run-ins with law enforcement" (ID386).

Perceived Physical Impacts. Participants reported the physical impacts associated with FASD. Some participants spoke of "physical impairments" broadly, while others mentioned short-term (e.g. premature births, low birth weight) and long-term (e.g. coordination, physical growth) physical differences.

Participants also noted sentinel facial features. Although most participants described this phenomenon more broadly, with comments like "distinctive facial features" (ID 205), some knew the specific details, with one stating: "They also suffer from physical abnormalities such as a thin upper lip, flat midface, and a smooth divot below their nose" (ID123). Some recognized that not all individuals with FASD would have visible facial feature differences, but many did not identify this. A few participants indicated a belief that FASD could be fatal, with comments such as "often causing birth defects, complications, or death" (ID148) and "can have a shorter life expectancy" (ID104).

Nature of FASD

Some participants responded by describing the nature of FASD. Some participants indicated that it is a spectrum condition whereby individuals are impacted to varying degrees. Some participants indicated that it is lifelong; however, of those who mentioned age or developmental stage, the overwhelming majority focused on characteristics in infancy and childhood, and very few spoke of characteristics in adulthood. One participant even said that they had "no idea that the effects last into adulthood" (ID219).

Participants shared insights on diagnoses. First, many recognized that FASD is likely significantly underdiagnosed. Participants also indicated that individuals with FASD were likely to have comorbid diagnoses, such as ADHD, substance use disorders, learning disabilities, anxiety disorders, and other neurodiversities. Other participants compared FASD to autism, Down syndrome, ADHD, and the impacts of prenatal oxygen-deprivation. Finally, one participant also spoke about social inequities that surround FASD diagnoses:

> Given the same symptoms, poorer and/or indigenous children are more likely to be diagnosed with FASD while more affluent/ white children are more likely to be diagnosed with ASD or ADHD. (ID218)

Some participants spoke about the social challenges associated with FASD. Namely, participants indicated that individuals with FASD are often misunderstood and highly stigmatized:

> They experience frustration, criticism, rejection–which of course leads to behaviours-acting out in teen years, alcohol drug use, difficulty with the law … they are NOT UNDERSTOOD and they are STIGMATIZED. (ID86)

Participants often emphasized that individuals with FASD require and can benefit greatly from supports. Some offered broad statements, such as needing "additional assistance in life" (ID175) and "help with day to day tasks" (ID344), while others specified areas like needing "assistance with academics" (ID12), employment, and housing. One participant noted that parents also benefit from supports: "I know that raising a child with an [FASD] diagnosis is difficult and parents benefit from as many supports as possible" (ID197). Others highlighted the positive impact of support, stating: "Early diagnosis and intervention, along with appropriate support services, can help individuals with fetal alcohol disorders reach their full potential" (ID144), and "FASD means lifelong impairment, but doesn't mean they can't thrive with support" (ID147). Finally, a few noted some strengths of individuals with FASD, including kindness, humor, and talent, with one participant describing them as "loving, kind individuals with a sense of humor" (ID183).

Stigmatizing Attitudes

Some participant responses represented stigmatizing attitudes and beliefs. Some participants assigned blame to the birthing parent with statements like, "FASD is completely preventable if pregnant women abstain from alcohol" (ID144). Some participants portrayed individuals with FASD as dangerous, asserting, "They are unpredictable and dangerous to normal people" (ID158). Others suggested that individuals with FASD had limited morals and judgment: "They often have no conscience, very volatile and unpredictable with violent behaviours" (ID15). Additionally, some responses used deficit-based language, using terms such as "suffer" and "afflicted" when discussing those with FASD.

Finally, some participants also reported sociodemographic factors that they believed made someone more likely to have FASD, such as low socioeconomic status, Indigeneity, and being born to a single parent: "They often come from lower income families or single moms" (ID379); "The people I have heard of were children of indigenous mothers" (ID363).

Discussion

Fueled by the notion that FASD is regularly misunderstood but finding scarce empirical evidence within a general population, the current study aimed to delineate the Canadian public's knowledge and perceptions of FASD. Participants' responses to an open-ended survey question revealed varying levels of awareness and knowledge of FASD. The results provided insight into perceptions of the causes, impacts, and nature of FASD, while also highlighting incidences of stereotyping and stigmatization. This study provides the first comprehensive insight into how the Canadian general public conceptualizes FASD and offers valuable guidance for future efforts to raise awareness and address stigmatizing attitudes.

In terms of overall knowledge or awareness of FASD, responses ranged from having never heard of the condition to sharing deeply personal experiences. Some participants had little to no knowledge of FASD, while others reported stereotypical (e.g. knew of facial features but nothing else) and stigmatizing beliefs. These results were in line with previous findings, highlighting an overall lack of awareness (Choate et al., 2019; Environics Research Group, 2006). Some participants who reported stigmatizing views reported learning about FASD through questionable knowledge sources, such as the media, which tend to portray stigmatizing perceptions of FASD (Eguiagaray et al., 2016). Conversely, those with personal or professional experiences (e.g. through friends, family, school, or work) provided factual information and often challenged pervasive misconceptions. These findings suggest that direct exposure to individuals with FASD may increase awareness and reduce stigma, while media-driven misinformation reinforces negative stereotypes. This aligns with research on contact interventions, which highlight the benefit that simply having contact with individuals with mental health conditions may have on reducing public stigma (Morgan et al., 2018; Reinke et al., 2004).

Participant responses often included discussion about the cause of FASD. This may be reflective of the fact that FASD has a clear cause (i.e. PAE; Cook et al., 2016) and public discourse has often focused on blaming the birthing parent (Corrigan et al., 2017), but other information, such as its impacts, may not be well understood by the public (Choate et al., 2019). While many correctly identified PAE as the cause (Cook et al., 2016), some participants held unsubstantiated beliefs or assumptions about the necessary amount of alcohol consumption or attributed the cause to substance use, both with and without alcohol consumption. The idea that the birthing parent must consume alcohol in line with someone with an alcohol use disorder is harmful and inaccurate, as it may indicate a belief that infrequent consumption of alcohol in small amounts is safe during pregnancy, despite there being no known safe amount (Graves et al., 2020). Further, this finding may reflect a false belief that FASD only results from frequent or deliberate alcohol consumption during pregnancy. Importantly, many cases occur from consumption before pregnancy awareness (McCormack et al., 2017). Similarly, the idea that FASD is caused by the consumption of other substances is also inaccurate—FASD is only caused by PAE, though other substances have their own risks (Cook et al., 2017). A final suggested "cause" of FASD was heritability (i.e. the idea that FASD could be passed down to children), despite no evidence supporting this claim (Gemma et al., 2007). However, this finding could possibly be interpreted as participants recognizing that alcohol consumption may be more prevalent in individuals with multi and intergenerational trauma, leading to an increased incidence of FASD in these contexts. Overall, these responses highlight the need for educational campaigns to accurately convey the cause of FASD and target prevailing misconceptions.

Next, participants identified potential domains impacted by FASD, including cognitive, emotional, behavioral, social, and physical impacts. Many participants in our study were able to accurately identify several of the areas that can be impacted by FASD. There was, however, a pattern that emerged where participants' understanding primarily reflected the highest needs end of the spectrum, ultimately representing a misunderstanding of the spectral nature of FASD. Further, participants seemed to inappropriately presume that such impacts suggest a poor life trajectory, inability to care for oneself, or inability to live fulfilling lives. This deficit-focused perspective reinforces stigma and can create barriers to treatment and support-seeking, highlighting the need for education that emphasizes the capabilities, strengths, and potential of those with FASD (Choate & Badry, 2019).

Some participants noted accurate perceptions about the nature of FASD, namely that it is a lifelong, spectral, underdiagnosed condition that is often comorbid with other mental health diagnoses. However, when considering the data as a whole, it may suggest that some participants did not have a strong understanding of the nature of FASD. The overwhelming majority of participants who indicated a developmental stage in their response spoke about the characteristics in infancy and childhood. Some participants stated that they were unaware that the impacts lasted into adulthood, and very few participants spoke about characteristics explicitly within the context of adulthood, suggesting an overall unawareness that individuals continue to be impacted beyond childhood. The societal impact of this misconception may be evidenced by the fact that services for adults with FASD are quite scarce (Pei et al., 2016). Therefore, increasing public awareness of the fact that the impacts of FASD continue into adulthood may result in increased implementation of diagnostic resources and helpful services for adults, as well as encourage adults with FASD to seek supports. This is an especially important target as the appropriate supports can greatly improve adults' lives and enhance their personal understanding of themselves (Temple et al., 2021).

Of the participants who discussed FASD in adulthood, many highlighted highly negative outcomes, such as involvement in the justice system, housing instability, and difficulty maintaining employment. This aligns with the Attribution Model of Stigma (Weiner, 1995), which suggests that adults with FASD would be viewed as more responsible for their outcomes and thus face greater stigma. To counter this, it is crucial to increase awareness that the impacts of FASD continue throughout the entire life course in order to foster an increased sense of compassion and promote the allocation of supports for adults with FASD.

In conjunction with the tendency to describe highly negative outcomes, participants also endorsed various stigmatizing beliefs. For instance, some participant responses blamed birthing parents and used very negative language toward them. FASD has historically been framed as a "maternal problem," and public messaging has often shamed birthing parents (Corrigan et al., 2017); however, there are a number of factors that need to be considered. Birthing parents may be consuming alcohol prior to pregnancy awareness or may be unaware of the risks and potential impact of PAE (McCormack et al., 2017), especially given that some trusted sources (e.g. physicians, midwives) are telling birthing parents that some alcohol consumption during pregnancy is acceptable, or are not effectively counseling about the potential risks (Crawford-Williams et al., 2015; Luong et al., 2023). Additionally, having an alcohol use disorder or experiencing abuse or trauma may contribute to alcohol consumption during pregnancy (Morton Ninomiya et al., 2023; Popova et al., 2022). Stating that FASD is "100% preventable" is an oversimplification and can contribute to the stigmatization of birthing parents who have consumed alcohol while pregnant (Canada FASD Research Network, 2023). We must call upon families, support systems, healthcare teams, and communities to work together to support birthing parents, rather than placing blame on individuals.

Some participants attributed the development of FASD to certain sociodemographic and ethnic groups, namely low-income or single-parent families, and Indigenous Peoples. While some studies suggest a higher prevalence in special subpopulations, specifically in child welfare and justice populations (Popova et al., 2019), these findings must be interpreted with special considerations in mind (Flannigan et al., 2018a). For example, the majority of children assessed for FASD do not live with their biological parents (Astley, 2010), and many people have their first opportunity to be assessed within justice settings (Pei et al., 2018). In addition, access to diagnostic teams across Canada is quite limited, which also calls these findings into question (Popova et al., 2024). The belief that there is a higher prevalence in Indigenous communities is particularly questionable, as there is little high-quality evidence to support this (Flannigan et al., 2018a). Furthermore, in Canada, Indigenous communities and advocates have made special efforts to increase diagnostic access, thereby increasing the number of individuals assessed and subsequently diagnosed with FASD. Thus, when studies report a higher prevalence, it cannot necessarily be concluded that there is a higher incidence; rather, it reflects greater diagnostic attention in this population (Flannigan et al., 2018a). Moreover, the belief that FASD is an "Indigenous problem" must be critically examined as it fails to acknowledge the profound impacts of settler colonialism on Indigenous Peoples, including the use of alcohol as a means of control (Yousefi & Chaufan, 2022). Further, it is crucial to recognize that the continued surveillance, marginalization, and stigmatization of Indigenous Peoples may reinforce this lasting misconception (Flannigan et al., 2018a). While improved diagnostic access for Indigenous communities is a positive development, without strong evidence to confirm a higher incidence in these communities compared to the general population, perpetuating this discourse risks reinforcing harmful stereotypes and may lead to devastating consequences for Indigenous individuals and communities.

Another stigmatizing belief reported by participants in our sample is the idea that individuals with FASD are dangerous, unpredictable, and lacking morality. Unfortunately, such harmful perceptions of dangerousness are common for those with mental health conditions (Jorm et al., 2012) and can easily lead to prejudice and discrimination (Corrigan & Kosyluk, 2014). Other participants questioned the capacity of individuals with FASD to complete basic tasks, live independently, and deal with stressful situations; such beliefs can also be detrimental. For example, some service providers who hold negative beliefs about their capacity and ability to benefit from support services will restrict individuals with FASD from participating in their (Aspler et al., 2022). This is particularly harmful because, as some participants in our sample recognized, individuals with FASD can benefit greatly from specialized support services across multiple domains, such as education, employment, and mental health services (Pei et al., 2019). These stereotype-driven discriminatory behaviors impact employment, housing, and access to supports and contribute to overpolicing and overrepresentation in the justice system.

Finally, many participants adopted a deficit-based approach to understanding and conceptualizing FASD, which was evidenced through using language like "suffer from" and "afflicted with," as well as negative and callous language, both toward individuals with FASD and their birthing parents. Deficit-based language reinforces stigma and shame and creates barriers to support-seeking (Bell et al., 2016; Choate & Badry, 2019). Shifting to a strengths-based, person-first approach that emphasizes potential is one way to promote a more holistic understanding and potentially reduce stigma (Flannigan et al., 2021; Shogren et al., 2006). The Canada FASD Research Network (n.d.b) recommends using terms like "individuals with" or "impacted by" FASD, instead of using words like "afflicted," "suffering," or "damaged." Individuals with FASD have many strengths, which were recognized by some participants in our sample, such as being kind, loving, and talented individuals (Flannigan et al., 2021). Recognizing strengths and meeting people with compassion, empathy, and a willingness to help is also critical to reducing stigma.

Limitations and Future Directions

It is important to note several limitations to the interpretation of these findings. The design was a self-report survey, which may not have fully captured participants' attitudes due to social desirability bias. However, the survey was anonymous, which may have helped reduce some of this bias. Many responses had an overall negative and stigmatizing tone, which suggests either that social desirability bias was limited, or, alternatively, that the findings could have been even more negative without such bias. Furthermore, the sample consisted only of individuals living in Canada and was predominantly made up of White (86.6%) participants. As such, our results should only be interpreted within this context. Additionally, there was an underrepresentation of participants from the territories (0.5% from the Yukon and none from other territories), which could have skewed the results. Finally, participant data came from a larger study with additional items, possibly exposing participants to a fatigue effect. Future research on public perceptions of FASD is needed and should keep the limitations of the current study in mind.

As for future directions, it is essential that educational and social media campaigns are utilized to contest harmful misconceptions and challenge stigmatizing attitudes. Given that some participants indicated that their knowledge of FASD came from media sources, future research should investigate these outlets to determine whether portrayals of FASD are accurate and nonstigmatizing, as past research suggests media representations often are not (Eguiagaray et al., 2016). Public school systems also offer an excellent option for educating youth. Incorporating accurate information about the risks of alcohol consumption during pregnancy before students reach child-bearing age may provide the future generation with knowledge to make safe decisions. School curricula can also promote a balanced narrative about people's strengths and challenges and spread up-to-date, factual information regarding FASD.

Given that Canada is considered a global leader in FASD research and advocacy, evidenced by the development of dedicated national and provincial research networks and community organizations, national diagnostic guidelines, and specialized clinics (Pei et al., 2017), our methodology and findings could provide useful insights for similar studies internationally. While our results revealed that some participants accurately identified FASD characteristics and recognized strengths and support needs, the identified misconceptions and knowledge gaps highlight areas for targeted education. Other countries developing FASD awareness programs could benefit from these insights when designing educational campaigns aimed at addressing public misconceptions and reducing stigma.

Conclusion

The current study provided valuable insights into the Canadian public's knowledge, perceptions, and attitudes toward FASD. Our results indicate that individuals in our study had a wide range of awareness and knowledge about FASD. While some participants demonstrated a strong understanding of the potential impacts, nature, strengths, and needs of individuals with FASD, many participants had little to no knowledge, responded with stereotypes or stigmatizing views, reported the most severe possible impacts, or believed common misconceptions. Therefore, it is clear that public education is essential for enhancing understanding and awareness, with the aim of dismantling stereotypes and promoting an informed, inclusive understanding of FASD in Canada.

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Ethical Statement

This study received ethical approval from the Memorial University of Newfoundland Interdisciplinary Committee on Ethics in Human Research (ICEHR No. 20240859) on 10 November 2023. All participants provided written informed consent before participating in the study.

Author Contributions

IDM, BBH, and TGJA contributed equally to this work. Significant contributions and revisions were made by MKD, OCB, SG, AMFP, and NH.

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Data Availability Statement

The deidentified data are available from the corresponding author upon reasonable request and with the permission of the Interdisciplinary Committee on Ethics in Human Research.

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